## 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.

# 28 April 2014 Edition | Issue #355



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to <u>Specialist Publications</u> and 'Factors associated with feelings of reward during ongoing family palliative caregiving' (p.7), in *Progress in Palliative Care*.

## Canada

Life after death: The last info gap

THE GLOBE & MAIL | Online - 21 April 2014 - What's intriguing is the extent to which people haven't given up on the possibility that life continues after death. What's startling is the extent to which they believe that individuals who have died are continuing to follow what is taking place in their lives and - even more - continuing to be in contact. What's puzzling is that this belief persists despite a substantive decline in religious beliefs and behaviour. Belief in life after death has remained steady for some time now. In Canada, for example, about 50% of adults say they believe in life after death, about 30% are uncertain and just 20% rule out the possibility altogether. Those figures are virtually unchanged from 1975. Over the years, we have had a sense that many people who attend funerals don't really think "this is it" - be they religious or not. Our surveys confirmed the hunch. Close to 40% of Canadians say that they "definitely" or "possibly" will see people again who have died. Some 30% say they don't know, and only about 30% have actually closed the door on the possibility, including just one in two of those who have "no religion." <a href="http://www.theglobeandmail.com/globe-debate/life-after-death-the-last-info-gap/article18059665/">http://www.theglobeandmail.com/globe-debate/life-after-death-the-last-info-gap/article18059665/</a>

Noted in Media Watch, 15 July 2013, #314 (p.9):

JOURNALS OF GERONTOLOGY (Series B) | Online – 29 June 2013 – 'Do afterlife beliefs affect psychological adjustment to late-life spousal loss?' Beliefs in an afterlife may be maladaptive for coping with late-life spousal loss, particularly if one is uncertain about its existence or holds a pessimistic view of what the afterlife entails. Findings are broadly consistent with recent work suggesting that "continuing bonds" with the decedent may not be adaptive for older bereaved spouses. <a href="http://psychsocgerontology.oxfordjournals.org/content/69B/1/103">http://psychsocgerontology.oxfordjournals.org/content/69B/1/103</a>

Noted in Media Watch, 28 March 2011, #194 (p.9):

■ JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 14 March 2011 –'Perspectives on death and an afterlife in relation to quality of life, depression, and hopelessness in cancer patients without evidence of disease and advanced cancer patients.' When there was no evidence of disease, negative emotions played the most important role, whereas in the advanced cancer situation, attitudes toward death and an afterlife ... became more prominent. <a href="http://www.jpsmjournal.com/article/S0885-3924(11)00013-3/abstract">http://www.jpsmjournal.com/article/S0885-3924(11)00013-3/abstract</a>

## U.S.A.

## Caregiving study to examine needs of Kentuckians

KENTUCKY | *The Harlan Daily Enterprise* – 23 April 2014 – The Legislative Research Commission [is] to conduct a study on family caregiving and long-term supports and services in Kentucky and deliver recommendations by December. This is a win for the 735,000 Kentuckians who are caregivers, providing an estimated 704 million hours of care at an estimated value of \$7.1 billion. The study will identify existing caregiver programs, polices and resources, develop new ways to help family members continue to provide necessary support for their loved one, interview family caregivers about their needs and wants and develop recommendations on enhancing support. <a href="http://www.harlandaily.com/news/announcements-local\_features/4545704/Caregiving-study-to-examine-needs-of-Kentuckians">http://www.harlandaily.com/news/announcements-local\_features/4545704/Caregiving-study-to-examine-needs-of-Kentuckians</a>

#### Talking about dying and death

## Fighting words are rarer among British doctors

THE NEW YORK TIMES | Online - 22 April 2014 - We talked here recently about the bellicose expressions often used in discussing the end of life<sup>1</sup> – the well-intended encouragement to "keep fighting," to declare someone a "fighter," to never "give up." And then, when someone dies, to describe him or her as having "lost the battle" with a disease. That post led me ... to researchers at Lancaster University in England, who have been analyzing the actual language patients, caregivers and health care professionals use to describe responses to disease. The Metaphor in Endof-Life Care Project<sup>2</sup> – developed by linguists, a palliative care specialist and a computer scientist has used specially developed software to comb through about 1.5 million words, gathered from interviews and from posts on health-related websites based in Britain. People working in health care there have been discussing military imagery for a decade, said Elena Semino, head of linguistics at the university. "There's a lot of awareness that battle metaphors can be very harmful to patients," she told me. "Professionals are conscious of the problems, and they're advised not to use them." Instead, British public health leaders and medical practitioners are more apt to talk about the end of life as a "journey" instead of a war, with "pathways" and "steps" instead of fights and weapons. http://newoldage.blogs.nytimes.com/2014/04/22/fighting-words-are-rare-amongbritish-doctors/? php=true& type=blogs&ref=health& r=0

- THE NEW YORK TIMES | Online 11 April 2014 'Wounded by the language of war.'
  When did the language we use to talk about death start to resemble a Pentagon briefing, full of
  military references and combat analogies? [Noted in Media Watch, 21 April 2014, #354 (p.5)]
  <a href="http://newoldage.blogs.nytimes.com/2014/04/11/wounded-by-the-language-of-war/?ref=health">http://newoldage.blogs.nytimes.com/2014/04/11/wounded-by-the-language-of-war/?ref=health</a>
- 2. Metaphor in End-of-Life Care Project, Lancaster University; http://ucrel.lancs.ac.uk/melc/



World Day 11 October 2014: Who Cares? We Do!

http://www.worldday.org/news/world-day-2014-who-cares-we-do/

## **Media Watch Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.12.

## Should doctors limit medical care to save money for "society"?

FORBES | Online - 21 April 2014 - Can your doctor serve two masters at once? That's the question American physicians are grappling with. The New York Times recently reported on a growing debate within the medical profession as to whether doctors should make treatment decisions in the best interests of their individual patients - or if they should limit care to save money for "society." This would represent a seismic shift in standard medical ethics. Traditionally, a doctor's primary ethical duty is to the patient. Patients literally put their lives in our hands, trusting that their physician will always act as their advocate. But with health care costs currently consuming 18% of the U.S. economy (and an enlarging share of government budgets), some doctors are openly calling for fellow physicians to limit their use of more expensive tests and therapies to save money for "the larger society." <a href="http://www.forbes.com/sites/paulhsieh/2014/04/21/should-doctors-limit-medical-care/">http://www.forbes.com/sites/paulhsieh/2014/04/21/should-doctors-limit-medical-care/</a>

## **Specialist Publications**

'Framing the issue of ageing and health care spending in Canada, the U.K. and the U.S.,' (p.7), in *Health Economics*, *Policy & Law*.

 'Cost of treatment may influence doctors,' The New York Times, 17 April 2014. http://www.nytimes.com/2014/04/18/business/treatment-cost-could-influence-doctors-advice.html?smid=tw-share

Noted in Media Watch, 25 February 2013, #294 (p.2):

• AMERICAN ACADEMY OF HOSPICE & PALLIATIVE MEDICINE | Online – Accessed 20 February 2013 – 'Five things palliative care physicians and their patients should question.' U.S. specialty societies representing more than 500,000 physicians developed lists of five things physicians and patients should question in recognition of the importance of physician and patient conversations to improve care and eliminate unnecessary tests and procedures. http://www.choosingwisely.org/wp-content/uploads/2013/02/AAHPM-5things-List Web.pdf

## From private ordeal to national fight: The case of Terri Schiavo

THE NEW YORK TIMES | Online – 20 April 2014 – To this day, the name Schiavo is virtually a synonym for epic questions about when life ends and who gets to make that determination. It would be nice to believe that since Ms. Schiavo's death nine years ago, America has found clear answers. Of course it has not, as is evident in Retro Report's exploration of the Schiavo case, the latest video documentary in a weekly series that examines major news stories from the past and their aftermath. <a href="http://www.nytimes.com/2014/04/21/us/from-private-ordeal-to-national-fight-the-case-of-terri-schiavo.html?hp&r=0">http://www.nytimes.com/2014/04/21/us/from-private-ordeal-to-national-fight-the-case-of-terri-schiavo.html?hp&r=0</a>

Noted in Media Watch, 13 September 2010, #166 (p.13):

JOURNAL OF MEDICAL ETHICS, 2010;36(9):571-573. 'How the public responded to the Schiavo controversy.' Opinions expressed in the letters [to the editor] sampled strongly supported the use of living wills and strongly condemned public attention to the case as well as political interventions. Letters tended to be against withdrawal of life support, proxy consent and associated procedures as well as against court decisions and legal procedures. In comparison with reports written by journalists, letters to editors contained fewer controversial claims about Schiavo's neurological condition and behavioural repertoire but similar loaded language to describe withdrawal of life support. http://jme.bmj.com/content/36/9/571.abstract

## International

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

## End of life treatment for elderly under question

AUSTRALIA (New South Wales) | *The Sydney Morning Herald* (OpEd) – 24 April 2014 – Intensive care specialist Bob Wright ... [has] ... called for a national re-think on end-of-life treatment, questioning whether it was the "right thing" to expend time, energy and money on elderly people who are beyond medical help. Professor in aged care at the University of Sydney, Susan Kurrle, said the "biggest problem" is health practitioners failing to ask older people what they want. "A lot of elderly people are being treated inappropriately and that's a major cost to the health system." She said although three quarters of people in nursing homes have advanced care directives, only about 25% of Australians over 70 have put in place a plan for future care. "A surprising number of people don't want large amounts of intervention. They want quality care but they don't want heroics." A 2013 report published by the Australian Centre for Health Research found that more than 52% of Australians die in hospital, a figure that is increasing 0.6% annually for men and 1.2% for women. This is despite the fact that more than 90% would prefer to die at home. http://www.smh.com.au/national/health/end-of-life-treatment-for-elderly-under-question-20140423-374i7.html

 'Leadership and quality in end of life care Australia: Round table recommendations,' Australian Centre for Health Research, February 2013. <a href="http://www.scribd.com/doc/186171133/End-of-Life-Care-Leadership-and-quality-in-end-of-life-care-in-Australia">http://www.scribd.com/doc/186171133/End-of-Life-Care-Leadership-and-quality-in-end-of-life-care-in-Australia</a>

#### Of related interest:

AUSTRALIA (New South Wales) | The Sydney Morning Herald (OpEd) – 23 April 2014 – When prolonging life becomes too cruel and costly. For a decade we struggled to define futility, then we gave up. It became clear that everybody had a different idea of what was futile. Sometimes the family would insist that "everything possible" should be done, long after the doctors had concluded there would be no benefit. Just as often the doctors (usually specialists in their own organ system with little knowledge of the patient as a whole person) would insist technology could still prevail. The default setting became "do everything possible then we will attract the least criticism regardless of outcome." Quite rightly, this default is being questioned. <a href="http://www.smh.com.au/comment/when-prolonging-life-becomes-too-cruel-and-costly-20140423-zgy6e.html">http://www.smh.com.au/comment/when-prolonging-life-becomes-too-cruel-and-costly-20140423-zgy6e.html</a>

## Armenians struggle for the right to die without pain

ARMENIA | Eurasianet – 23 April 2014 – Although eligible patients are entitled to free, state-subsidized opioid painkillers, the process for acquiring them can prove so complicated and time-consuming that patients often die before they receive the medication. A lack of clear, time-efficient procedures is a big part of the problem. No law on palliative care exists. Under current practices, a medical commission and, then, local police officials must approve each morphine prescription. The medical commissions themselves are a cumbersome arrangement; since they comprise the patient's attending physician, the head of the local clinic or hospital where the patient is receiving treatment, as well as two other qualified doctors, it's not always easy to convene a commission in a timely manner and then get members to agree on a course of action. http://www.eurasianet.org/node/68300

#### 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>

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

## Warning over "unacceptable" lottery in care of the dying

U.K. | The Daily Telegraph - 23 April 2014 -Patients dying from dementia and heart disease are treated worse than cancer sufferers, the country's chief inspector of hospitals has warned as he announced a national review of end-of-life care. Professor Mike Richards said too many patients were being condemned to an "unacceptable" lottery in care, with "a huge number of inequalities" in standards of treatment - depending on where people live, which disease they develop, and where they spend their final days. The Care Quality Commission is to hold a national review amid increasing concern that too many patients are being denied the right pain relief, end up being treated without dignity, or end up dying in hospital despite clear wishes to die in their own homes. <a href="http://www.telegraph.co.uk/health/healthnews/10783345/Warning-over-unacceptable-lottery-in-care-of-the-dying.html">http://www.telegraph.co.uk/health/healthnews/10783345/Warning-over-unacceptable-lottery-in-care-of-the-dying.html</a>

#### **Specialist Publications**

'Demand for family caregivers will exceed supply by 2017, think tank predicts' (p.6), in British Medical Journal.

'Commission to probe end of life care' (p.10), in *Health Services Journal*.

#### Of related interest:

U.K. | The Guardian – 24 April 2014 – 'U-turn over human rights protection for home care.' People receiving state-funded care in their own homes will now be given additional protection by the Human Rights Act, ministers have conceded following pressure from the Liberal Democrat side of the government. <a href="http://www.theguardian.com/society/2014/apr/24/uturn-human-rights-home-care">http://www.theguardian.com/society/2014/apr/24/uturn-human-rights-home-care</a>

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

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

Raising the bar for the care of seriously ill patients: Results of a national survey to define essential palliative care competencies for medical students and residents

ACADEMIC MEDICINE | Online – 23 April 2014 – Given the shortage of palliative care specialists to ensure quality of care for patients with serious, life-threatening illness, generalist-level palliative care competencies need to be defined and taught. This survey ... defines comprehensive and essential palliative care competencies for medical students and internal/family medicine residents that are specific, measurable, and can be used to report educational outcomes; provide a sequence for palliative care curricula in undergraduate and graduate medical education; and, highlight the importance of educating medical trainees in communication and pain management. <a href="http://journals.lww.com/academicmedicine/Abstract/publishahead/Raising">http://journals.lww.com/academicmedicine/Abstract/publishahead/Raising</a> the Bar for the Care of Seriously III.99091.aspx

Noted in Media Watch, 9 December 2013, #335 (p.11):

- JOURNAL OF PALLIATIVE CARE & MEDICINE | Online Accessed 5 December 2013 'Learning and teaching palliative care: Can we do better?' Twenty years ago, James and MacLeod identified a number of aspects of palliative care education that were problematic. http://www.omicsgroup.org/journals/Learning-and-Teaching-Palliative-Care-Can-We-Do-Better-2165-7386.1000e124.pdf
  - 1. 'The problematic nature of education in palliative care,' *Journal of Palliative Care*, 1993;9(4):5-10. <a href="http://www.ncbi.nlm.nih.gov/pubmed/7510805">http://www.ncbi.nlm.nih.gov/pubmed/7510805</a>

Cont.

Noted in Media Watch, 16 July 2012, #262 (p.10):

- HEALTH LEADERS | Online 13 July 2012 'Palliative care challenged by physician shortage.' While there is about one cardiologist for every 71 people experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative care physician for every 1,200 people living with a serious or life-threatening illness. http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage
  - 'Estimate of current hospice and palliative medicine physician workforce shortage,' Journal of Pain & Symptom Management, 2012;40(6):899-911 [Noted in Media Watch, 13 December 2010, #179 (p.9)] <a href="http://www.jpsmjournal.com/article/S0885-3924(10)00602-0/abstract">http://www.jpsmjournal.com/article/S0885-3924(10)00602-0/abstract</a>

## Psychosocial interventions for patients with advanced cancer and their families

AMERICAN JOURNAL OF LIFESTYLE MEDICINE | Online – 17 April 2014 – The aim of this narrative review is to describe published interventions that have attempted to improve the quality of life of advanced cancer patients and their family caregivers (e.g., spouses, partners, and other family members) and to describe some of the challenges that make it difficult to implement such programs in clinical settings. Toward that end, the added value that family-based psychosocial interventions can bring to advanced cancer care is described. The literature on family-based interventions in advanced cancer is reviewed, and different theoretical approaches and outcomes highlighted ... followed by a description of some of the health system barriers to supportive family care in advanced cancer care ... [and] ... a synthesis of research findings and proposes directions for future research. http://ajl.sagepub.com/content/early/2014/04/16/1559827614530966.abstract

#### Of related interest:

- AUSTRALIAN JOURNAL OF GRIEF & BEREAVEMENT, 2014;17(1):10-13. 'How do patients with advanced cancer cope with an uncertain disease trajectory?: Implications for grief counselling.' This paper describes strategies patients [i.e., study participants] use to cope with the uncertain trajectory of their disease. They coped ... through avoidance, maintaining a normal life, comparing themselves favourably to others in a similar situation, and remaining positive. Participants indicated that they did not wish referral for psychological support. <a href="http://search.informit.com.au/documentSummary;dn=234561658804087;res=IELHEA">http://search.informit.com.au/documentSummary;dn=234561658804087;res=IELHEA</a>
- JOURNAL OF RELIGION, SPIRITUALITY & AGING, 2014;26(2-3):173-185. "Every time you deal with a death you think, 'one day' ... ": The emotional and spiritual effects of dealing with aging, dying, and death for staff in a residential aged care facility.' This ... study aimed to learn more about the emotional and spiritual costs and/or benefits for staff in [Australian residential aged care facilities] this context. Data ... suggested frequent encounters with death and old age had affected many participants' attitudes to life and death. While some saw it as an incentive to "enjoy the day," there was also evidence of existential anxiety and fear of aging. <a href="http://www.tandfonline.com/doi/abs/10.1080/15528030.2013.855965#.U1Z131VdX8k">http://www.tandfonline.com/doi/abs/10.1080/15528030.2013.855965#.U1Z131VdX8k</a>

#### Elder care in the U.K.

#### Demand for family caregivers will exceed supply by 2017, think tank predicts

BRITISH MEDICAL JOURNAL | Online – 25 April 2014 – The number of elderly people in England who need care will outstrip the number of adult children who are able to provide it for the first time in 2017 and will grow steeply after that, a think tank has predicted. Without concerted action to tackle this "family care gap," pressure on hospital emergency departments and inpatient beds is likely to increase as more older people slip into crisis without the day care they need, it warns. By 2017 England will have 20,000 elderly people who need more than 20 hours a week of care (intense care) but no family member to care for them, the report from the Institute for Public Policy Research has said. http://www.bmj.com/content/348/bmj.g2938

 The Generation Strain: Collective Solutions to Care in an Ageing Society, Institute for Public Policy Research, April 2014. <a href="http://www.ippr.org/assets/media/publications/pdf/generation-strain">http://www.ippr.org/assets/media/publications/pdf/generation-strain</a> Apr2014.pdf

#### Of related interest:

■ PROGRESS IN PALLIATIVE CARE | Online – 17 April 2014 – 'Factors associated with feelings of reward during ongoing family palliative caregiving.' Of the few studies that have paid attention to feelings of reward in family palliative caregiving, most are retrospective and examine the experiences of bereaved family caregivers. Although feeling rewarded has been described as an influence that may facilitate the way family caregivers handle the caregiving situation, no study has sought to identify the factors associated with feelings of reward... <a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9240892&fulltextType=RA&fileId=S1478951514000145">http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9240892&fulltextType=RA&fileId=S1478951514000145</a>

Noted in Media Watch, 3 June 2013, #308 (p.8):

PSYCHO-ONCOLOGY | Online – 28 May 2013 – 'The positive aspects of caregiving for cancer patients: A critical review of the literature and directions for future research.' A total of 35 articles were identified. Findings revealed spousal caregivers ... experienced various positive aspects of caregiving, such as an enhanced relationship with the carereceiver, the feeling of being rewarded, a sense of personal growth, and a perception of personal satisfaction. <a href="http://onlinelibrary.wiley.com/doi/10.1002/pon.3311/abstract">http://onlinelibrary.wiley.com/doi/10.1002/pon.3311/abstract</a>

## Understanding community engagement in end-of-life care: Developing conceptual clarity

CRITICAL PUBLIC HEALTH | Online – 16 April 2014 – Public health approaches to end-of-life care have received increased literature, policy and practice focus. These recognise the significance of community engagement activities and their contribution to end-of-life care. In the U.K., community engagement is a priority for the majority of hospices. Nevertheless, there exists some ambiguity about the range of different practice that exists under this heading, the principles underpinning it, and the outcomes for the work. This paper presents a definition and a conceptual model of community engagement for end-of-life care services and the communities they serve. <a href="http://www.tandfonline.com/doi/abs/10.1080/09581596.2014.909582?queryID=%24%7BresultBean.gueryID%7D">http://www.tandfonline.com/doi/abs/10.1080/09581596.2014.909582?queryID=%24%7BresultBean.gueryID%7D</a>

Noted in Media Watch, 6 January 2014, #339 (p.5):

■ BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 January 2014 – 'End-of-life conversations and care: An asset-based model for community engagement.' Public awareness work regarding palliative and end-of-life care is increasingly promoted within national strategies for palliative care. Different approaches to undertaking this work are being used, often based upon broader educational principles, but little is known about how to undertake such initiatives in a way that equally engages both the health and social care sector and the local communities. http://spcare.bmj.com/content/early/2014/01/02/bmjspcare-2013-000516.abstract

## Framing the issue of ageing and health care spending in Canada, the U.K. and the U.S.

HEALTH ECONOMICS, POLICY & LAW | Online – 23 April 2014 – Direct claims about intergenerational equity are infrequent among the articles coded, but articles in the U.S. were more likely than those in Canada and the U.K. to claim that of high health care spending on older people takes resources away from younger people. In Canada a larger percentage of articles in the authors' sample either claimed high health care spending is crowding out other types of government expenditure. Almost no articles in the U.S. challenged the view population ageing causes health care spending, whereas in both Canada and the U.K. a small, but steady stream of articles challenged the idea that population ageing is to blame for health care spending increases. <a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9243514&fulltextType=RA&fileId=S1744133114000115">http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9243514&fulltextType=RA&fileId=S1744133114000115</a>

Cont.

#### Of related interest:

■ HEALTH ECONOMICS, POLICY & LAW | Online – 23 April 2014 – 'The political economy of rationing health care in England and the U.S.: the "accidental logics" of political settlements.' This article argues that rationing is designed into the English National Health Service and designed out of U.S. Medicare. The authors compare rationing for the elderly in the U.S. and in England for acute care, care at the end of life, and chronic care. <a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9243518&fulltextTy">http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9243518&fulltextTy pe=RA&fileId=S1744133114000127</a>

# The social determinants of health and justice and the aging in prison crisis: A call for human rights action

INTERNATIONAL JOURNAL OF SOCIAL WORK | Online – 14 April 2014 – The rapid growth of the incarceration of aging people in prison across the globe is particularly problematic in the U.S., which has the largest incarceration rate per capita. This paper examines the aging in prison crisis through the lens of the social determinants of health, well-being, and justice. Case studies and promising practices are reviewed to assist in a coordinated human rights based response to address the aging in prison crisis at the grassroots, national, and international levels. file:///C:/Users/Barry/Downloads/4914-19738-2-PB.pdf

#### Extract from International Journal of Social Work article

Currently, international correctional systems are grappling with how to provide the health related services to large numbers of aging people in prison, especially those aged 65 and older. Most correctional systems are unprepared and under resourced to provide specialized services and long-term care or palliative and end-of-life care.

**N.B.** The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of articles, reports, etc., on this critically important public health issues noted in the weekly report in recent years is available online at the Palliative Care Community Network website: <a href="http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons">http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons</a>

## Palliative care for the older person: Cloak or cover-up?

JOURNAL OF RELIGION, SPIRITUALITY & AGING, 2014;26(2-3):186-200. Care of older people with incurable illness provides fertile ground for palliative care... True palliation means to cover the person and their family with a protective cloak of care including personalised attention to thoroughly assessed physical, spiritual, psychological and emotional needs. Health professionals, chaplains and volunteers are encouraged to enter each person's unique story in their journey towards death. When the cloak is ill-fitting it becomes a mere cover-up; opportunities for care missed.http://www.tandfonline.com/doi/abs/10.1080/15528030.2013.867425?queryID=%24%7Br esultBean.queryID%7D#.U1Z3clVdX8k

#### Barry R. Ashpole

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

## Advance directives in the context of uncertain prognosis for residents of nursing homes

OPEN JOURNAL OF NURSING, 2014;4(4):321-329. This report documents the findings of a study focused on the advanced directives of 182 residents of three LTC facilities in southern Ontario, Canada. Although almost all had a completed advance directive within 3 months of death, most did not have a palliative designation or directive until a few days before they died. Each facility's written Progress Notes revealed staff members usually sought additional confirmation of care preferences from residents' substitute decision-makers within a few days of the death. It was thus common for advance directives to change from a more interventionist approach to the least interventionist approach near death. This change indicates that the meaning and significance of advance care planning and resulting advance directives must be considered in light of the processes and temporal factors involved in their completion and use within this distinct population. The relational nature of advance care planning and concern about ageism as a factor for withholding or withdrawing life support for LTC residents are considered as possible explanatory factors. These findings and their implications are described in relation to end-of-life care policies and practices in LTC facilities. file:///C:/Users/Barry/Downloads/OJN 2014041814345992%20(1).pdf

Noted in Media Watch, 21 April 2014, #354 (p.12):

■ PALLIATIVE CARE: RESEARCH & TREATMENT, 2014;8:1-6. 'Examining do-not-resuscitate orders among newly admitted residents of long-term care facilities.' This study is important to the current literature because it is the first to examine DNR orders among LTC residents in Canada using administrative data. It is distinctive because it used a comprehensive instrument to examine multiple domains. In summary, findings show 70% of LTC residents in Ontario have recorded DNR orders and that future research needs to examine rates of compliance. http://www.la-press.com/palliative-care-research-and-treatment-journal-j86

Cont. next page.

#### **Media Watch: Editorial Practice**

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

#### **Distribution**

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

## **Links to Sources**

- 1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
- 2. Links often remain active, however, for only a limited period of time.
- **3.** Access to a complete article, in some cases, may require a subscription or one-time charge.
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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:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 20 April 2014 'Assessing challenges in end-of-life conversations with patients utilizing a public safety-net health care system.' This study examined barriers to end-of-life care discussions as experienced by health care providers working in a public safety-net health care system where the majority of their patients were low-income and immigrant Latinos seeking medical treatment. <a href="http://aih.sagepub.com/content/early/2014/04/17/1049909114530550.abstract">http://aih.sagepub.com/content/early/2014/04/17/1049909114530550.abstract</a>
- ANNALS OF EMERGENCY MEDICINE | Online 17 April 2014 'Physician Orders for Life-Sustaining Treatment and emergency medicine: Ethical considerations, legal issues, and emerging trends.' Since its original development in Oregon in 1993, Physician Orders for Life-Sustaining Treatment (POLST) is quickly growing in popularity and prevalence as a method of communicating the end-of-life care preferences for the seriously ill and frail nationwide. <a href="http://www.annemergmed.com/article/S0196-0644(14)00220-0/abstract">http://www.annemergmed.com/article/S0196-0644(14)00220-0/abstract</a>

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

## Does ethnicity affect where people with cancer die? A population-based 10 year study

PLOS ONE | Online – 21 April 2014 – This is the first population-based U.K. study using death registration data to examine variations in place of death from cancer across different ethnic groups. The authors found that location of death varies according to decedents' country of birth. People who were born in Asia and Africa were significantly less likely than those from the U.K. or Ireland to die in a hospice. People born in the Caribbean were significantly less likely to die at home than those born in the U.K. Decedents born in Asia, Africa and the Caribbean were all significantly more likely than those from U.K. to die in a hospital. We do not know to what extent these variations are a result of differing preferences for place of death, which may be influenced by culture. Nor can we accurately identify which factors related to diagnosis, personal, environmental or service-related circumstances may prevent certain groups from accessing specialist palliative care. More detailed prospective studies are urgently required to understand this. <a href="http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0095052;jsessionid=F71A18CFA4FB13E3A49D82F3FA0E027A">http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0095052;jsessionid=F71A18CFA4FB13E3A49D82F3FA0E027A</a>

#### Of related interest:

■ HEALTH SERVICES JOURNAL | Online – 22 April 2014 – 'Commission to probe end of life care.' The Care Quality Commission is to launch an investigation into inequalities in end of life care. The review follows mounting evidence that particular groups experience poorer quality care at the end of life, and that the care they receive does not always meet their needs. <a href="http://www.hsj.co.uk/news/cqc-to-probe-end-of-life-care/5070115.article?blocktitle=News&contentID=8805">http://www.hsj.co.uk/news/cqc-to-probe-end-of-life-care/5070115.article?blocktitle=News&contentID=8805</a>

#### End-of-life care in India

# A study on knowledge, attitude, and practices regarding palliative care among doctors in Border Security Force

PROGRESS IN PALLIATIVE CARE | Online – Accessed 22 April 2014 – The lack of awareness is among the biggest challenges facing palliative care in India. Awareness is dismal, especially in North India. This study explores the knowledge, attitude, and awareness about palliative care among doctors serving in the Border Security Force: 75.5% of the doctors were not aware of the basic concept (only 38 could name a palliative centre); 46.5% did not know that pain is the fifth vital sign (only 3.7% believe the patient's own assessment of pain); 57% were unaware of the World Health Organization analgesic ladder; 83% would try cardio-pulmonary resuscitation on a gasping patient with an advanced, incurable illness; 54% think spirituality is linked with religion; and, 51.8% believe telling a patient about his illness depends on both the patient's and family's wishes. <a href="http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.00000000090">http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.00000000090</a>

Cont.

Noted in Media Watch, 29 April 2013, #303 (p.14):

- MEDICAL JOURNAL ARMED FORCES INDIA, 2013;69(1);2-3. 'End of life care: Should we struggle on, or let go?' Numerous studies have found that the medical care of the dying to be unnecessarily prolonged, painful, expensive and emotionally burdensome to both patients and their families. <a href="http://medind.nic.in/maa/t13/i1/maat13i1p2.pdf">http://medind.nic.in/maa/t13/i1/maat13i1p2.pdf</a>
- MEDICAL JOURNAL ARMED FORCES INDIA, 2013;69(1):48-53. 'End of life issues in the intensive care units.' A structured discussion of end-of-life issues is a relatively new phenomenon in India. Personal beliefs, cultural and religious influences, peer, family and societal pressures affect decision making. http://www.mjafi.net/article/S0377-1237(12)00163-3/abstract

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- BMC MEDICAL ETHICS | Online 21 April 2014 'Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the [U.K.] Commission on Assisted Dying.' In May 2013 a new Assisted Dying Bill was tabled in the House of Lords and is currently scheduled for a second reading in May 2014.1 The Bill was informed by the report of the Commission on Assisted Dying which itself was informed by evidence presented by invited experts. This study aims to explore how the experts presenting evidence to the Commission on Assisted Dying conceptualised mental capacity for patients requesting assisted suicide and examine these concepts particularly in relation to the principles of the Mental Capacity Act 2005. There was agreement on the importance of mental capacity as a central safeguard in proposed assisted dying legislation. Concepts of mental capacity, however, were inconsistent. There was a tendency towards a conceptual and clinical shift toward a presumption of incapacity. This appeared to be based on the belief that assisted suicide should only be open to those with a high degree of mental capacity to make the decision. The "boundaries" around the definition of mental capacity appeared to be on a continuum between a circumscribed legal "cognitive" definition of capacity (in which most applicants would be found to have capacity unless significantly cognitively impaired) and a more inclusive definition which would take into account wider concepts such as autonomy, rationality, voluntariness and decision specific factors such as motivation for decision making. Ideas presented to the Commission on Assisted Dying about mental capacity as it relates to assisted suicide were inconsistent and in a number of cases at variance with the principles of the Mental Capacity Act 2005. http://www.biomedcentral.com/content/pdf/1472-6939-15-32.pdf
  - Assisted Dying Bill, May 2013. <a href="http://www.publications.parliament.uk/pa/bills/lbill/2013-2014/0024/2014024.pdf">http://www.publications.parliament.uk/pa/bills/lbill/2013-2014/0024/2014024.pdf</a>
  - The current legal status of assisted dying is inadequate and incoherent..., Commission on Assisted Dying, January 2012. [Noted in Media Watch, 9 January 2012, #235 (p.7)] <a href="http://www.demos.co.uk/files/CoAD">http://www.demos.co.uk/files/CoAD</a> - web.pdf?1325710486
  - PALLIATIVE & SUPPORTIVE CARE | Online 24 April 2014 'Verbalized desire for death or euthanasia in advanced cancer patients receiving palliative care.' Almost 10% of the population [i.e., study participants] receiving specific oncological palliative care made a DDC [desire-to-die comments] (7.3%) or EUC [desire-for-euthanasia comments] (2.5%). The worst well-being score was lower in the EUC group. The reasons for both a DDC and EUC were mainly non-physical. Emotional and spiritual issues should be identified and effectively addressed when responding to a DDS in terminally ill cancer patients. <a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9241844&fulltextType=RA&fileId=S1478951514000121">http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9241844&fulltextType=RA&fileId=S1478951514000121</a>

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## **Media Watch Online**

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <a href="http://hospicecare.com/about-iahpc/newsletter/2014/4/media-watch/">http://hospicecare.com/about-iahpc/newsletter/2014/4/media-watch/</a>

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

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

PALLIMED (Hospice & Palliative Medicine Blog): <a href="http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html">http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html</a> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

#### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <a href="http://centres.sg/updates/international-palliative-care-resource-center-media-watch/">http://centres.sg/updates/international-palliative-care-resource-center-media-watch/</a>

#### Australia

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

#### Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/inthenews.html

ONTARIO | Palliative Care Consultation Program (Oakville): <a href="http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/">http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/</a> [Scroll down to 'Additional Resources']

## Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <a href="http://www.eapcnet.eu/Themes/Organization/Links.aspx">http://www.eapcnet.eu/Themes/Organization/Links.aspx</a> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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

U.K. | Omega, the National Association for End-of-Life Care: <a href="http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c">http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c</a>

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