Media Watch...

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

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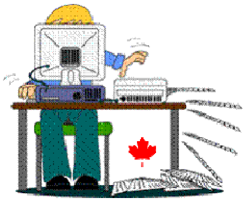


Compiled & Annotated by Barry R. Ashpole

In the last month of life: Scroll down to U.S.A. and 'At the end, a rush to the ER' (p.4), published in the *New York Times.*

Canada

The good, the bad and the ugly of palliative care...

ONTARIO | *Country Cottage Now* (Gravenhurst) – 8 June 2012 – Palliative care and the effectiveness of the health-care system in general can be vastly improved, said the famed Dr. Brian Goldman. The award-winning medical journalist, Toronto-area physician and CBC [Canadian Broadcasting Corporation] radio host of 'White Coat, Black Art' was ... guest speaker for the North Simcoe Muskoka Palliative Care Network during their annual general meeting... Speaking to a crowd of palliative care nurses, doctors and health-care professionals, the doctor held back no punches on this thoughts about the Canadian health-care system and how those in palliative care or seniors seem to get a shorter end of the stick. "Patients are being left behind, many of them right when they need help most," he said. "We have a culture that denies people become frail, as if to say our mission is to keep people not frail until some nanosecond when it all runs downhill and they keel over, rather than allowing people the grace to enjoy their lives despite frailty." "We just passed through an unprecedented period of health-care boom; we were spending more and more dollars and every time we had a problem we just spent more money," he explained. "You know those times are coming to an end. In fact, we're about to go back into a global recession and we, of course, have a big budget deficit in Ontario and a debt. We're going to have to pay the piper and how we do that is being played out in front of us. There's a real battle for the hearts and minds of Ontario right now," Goldman continued, adding the Ontario Medical Association and provincial government are currently in debate over how the system will change. "We're going to have to tackle some very serious issues and some people won't be happy with how we do that." http://www.cottagecountrynow.ca/community/health/article/1370792--the-good-the-bad-and-the-ugly-of-palliative-care-subject-of-talk

Specialist Publications

Of particular interest:

'Implementing the British Columbia practice support program in end of life care' (p.10), published by *BMJ Supportive & Palliative Care*.

Report card on provincial health systems notes spotty progress for home care

CANADIAN PRESS | Online report – 4 June 2012 – The latest report card on provincial health policy shows some improvement in offering home care and mental health services, but progress is spotty across the country. The Health Council of Canada's 2012 progress report[1] says the provinces are generally living up to their 2003 commitments to boost home care, increase the number of doctors and nurses, and develop indicators to show the public how well they are doing. But the report says progress [is] far from uniform across the country, and is underwhelming. "The accords have not brought about the large-scale change that was envisioned when they were created," the report says. The health council puts the blame on the vagueness of the 2003 agreements, and the emphasis on creating a common ground rather than pushing each jurisdiction toward improvement. Instead of working together to share and implement great ideas, each province has worked by itself to meet poorly defined goals, the report says. The council questions whether the provinces are on solid enough footing to proceed with a meaningful plan for the future. http://www.thespec.com/news/canada/article/737138--report-card-on-provincial-health-systems-notes-spotty-progress-for-home-care

Extract on end of life care from Health Council of Canada's report

Alberta, British Columbia, New Brunswick, Nova Scotia, Ontario, Prince Edward Island, and Saskatchewan met the [2003] commitment. In 2005, Ontario invested about $115 million in their end-of-life strategy, in large part to shift health care for persons in the last stages of their life from hospital to more appropriate settings. British Columbia also exceeded this accord commitment with their 2006 end-of-life strategy. In the remaining provinces and territories, there is not enough information available to measure progress on end-of-life home care.

1. 'Progress Report 2012: Health care renewal in Canada,' Health Council of Canada, June 2012. http://healthcouncilcanada.ca/tree/ProgressReport2012_FINAL_EN.pdf

N.B. The Health Council of Canada report makes mention of the federal government's Compassionate Care Benefit [see sidebar right]: "The compassionate care benefit is provided to employed caregivers of people who are seriously ill with a significant risk of death within 26 weeks, although it's not clear how well used the benefit is across the country. According to a 2011 evaluation,[1] most participants view the compassionate care benefit as an important support for family caregivers, although it is not being widely used and could be improved. Almost all jurisdictions met this commitment within a few years of the accords, with the exception of Alberta and the Northwest Territories. Some jurisdictions offered more than the standard eight weeks. Saskatchewan, for example, provides caregiver leave for up to 16 weeks."

1. 'Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care?' *BMC PUBLIC HEALTH*, published online 18 May 2011 (noted in Media Watch, 23 May 2011).http://www.biomedcentral.com/content/pdf/1471-2458-11-335.pdf

Cont.

Noted in past issues of Media Watch:

'The workplace perspective on supporting family caregivers at end of life: Evaluating...,' *Community, Work & Family*, 26 March 2012. http://www.tandfonline.com/doi/abs/10.1080/13668803.2012.664891

'Family caregivers' ideal expectations of Canada's Compassionate Care Benefit,' *Health & Social Care in the Community*, 15 September 2011.http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2011.01028.x/abstract

'Protect caregivers from financial ruin,' a Maytree Policy in Focus (Canada), March 2010. http://maytree.com/policyPDF/MaytreePolicyInFocusIssue11.pdf

'The uncompassionate elements of the Compassionate Care Benefits program...,' *Global Health Promotion*, 2010;17(1):50-59. http://ped.sagepub.com/content/17/1/50.short

'Evaluating Canada's Compassionate Care Benefit: The Perspective of Family Caregivers,' McMaster University (Canada), 2010. http://www.coag.uvic.ca/eolcare/documents/CCB%20evaluation%20final%20report%20-%20English.pdf

- *THE NATIONAL POST* | Online article – 5 June 2012 – **'Giving too much: 'Compassion fatigue' is a real health risk for long-term caregivers.'** Are you taking care of a family member or friend who is ill or needs assistance? If the condition is temporary with an expected quick recovery, then your caregiving responsibilities will be short-term. If the condition is more serious or even terminal, then you run the risk of being pushed to the limits over time, leaving you feeling overwhelmed and challenged both mentally and physically. http://life.nationalpost.com/2012/06/05/giving-too-much-compassion-fatigue-a-real-risk-for-caregivers/

U.S.A.

The good and the bad of cancer care in California

THE CALIFORNIA REPORT | Online report – 7 June 2012 – More than a million Californians are living with cancer, and a new report from the California HealthCare Foundation (CHCF) takes a look at how the disease has affected the population over time. The report found persistent disparities across race. The survey also looked at end of life care and cancer. CHCF took up the general issue of end-of-life care earlier in the year with a survey.[1] The report showed that while 70% of Californians want to die at home, only 32% actually do so. Most Californians die in a hospital or nursing home. http://blogs.kqed.org/stateofhealth/2012/06/07/the-good-and-the-bad-of-cancer-care-in-california/?utm_source=rss&utm_medium=rss&utm_campaign=the-good-and-the-bad-of-cancer-care-in-california

1. 'Final Chapter: Californians' Attitudes and Experiences with Death and Dying,' California Healthcare Foundation, February 2012 (noted in Media Watch, 23 February 2012). http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/F/PDF%20FinalChapterDeathDying.pdf

New law would create online database for end-of-life wishes

MICHIGAN | WNEM-TV (Saginaw) – 7 June 2012 – The Michigan Senate ... unanimously passed a measure to create a website for state residents that would allow loved ones and health care providers to know their end-of-life wishes. If the bill becomes law, Michigan residents will be the first to have these instructions accessible no matter where they travel in the country. "I expect Michigan to become the national model for states across the country for legislation establishing these important websites," said [Sen. Jim] Marleau, chair of the Senate Committee on Health Policy. Senate Bill 723 would create the Peace of Mind Registry, a secure database providing health care providers access to a patient's advance directives. Advance directives are legal documents allowing individuals to specify patient advocates, religious preferences, and other decisions about end-of-life care ahead of time. http://www.wnem.com/story/18728823/new-law-would-create-online-database-for-end-of-life-wishes

Last Moment Robot: 'End of life detected'

CNET | Online report – 5 June 2012 – Imagine drawing your final breath in the sole company of a talking machine: "I am here to comfort you. You are not alone, you are with me." As a woman lies on a mattress on the floor, a small white machine attached to her outstretched right arm offers the following words: "I am the Last Moment Robot. I am here to help you and guide you through your last moment on Earth. I am sorry that your family and friends can't be with you right now, but don't be afraid. I am here to comfort you. You are not alone, you are with me. Your family and friends love you very much, they will remember you after you are gone." Jarred by the notion of someone dying in the company of a machine instead of loved ones (or at least other humans)? That's partly the point. The image "reveals the cruelty of life, lack of human support/social connections," [says] Dan Chen, who created the robot. "On the other hand, the robot becomes something that you can trust/depend on. It could give you the 'placebo effect' of comfort." http://news.cnet.com/8301-17938_105-57447109-1/last-moment-robot-end-of-life-detected/

At the end, a rush to the ER

NEW YORK TIMES | Online report – 5 June 2012 – What elderly person wants to spend time in an emergency room? They're so chaotic and uncomfortable that several hospitals have opened calmer, more specialized emergency units particularly designed for their oldest patients. But how much more distressing is an ER visit for someone who's within weeks of dying? Dr. Alexander Smith, a palliative care specialist and researcher at the University of California, San Francisco [UCSF], can recite a long list of reasons that spending hours in emergency rooms doesn't make sense for people so close to death. "The emergency department isn't set up for palliative or end-of-life care," he said in an interview ... [see sidebar right]. "The attitude of people in emergency medicine is to diagnose and fix, not provide comfort." They're trained to act; do-not resuscitate orders or patients' distaste for aggressive procedures prevent them from acting. ER staff also are usually meeting their patients for the first time and are unfamiliar with their histories, goals and preferences. Add that frail and frightened patients can wait most of a day to be examined, to undergo tests, to get the results. Also add: "stretchers, cold rooms and a guy in the next bed screaming," Dr. Smith said. Sadly, though, in a large national study[1] ... half the older adults who died had gone to an emergency room during the last month of their lives, and the ER visit had led most of them straight to a hospital bed. http://newoldage.blogs.nytimes.com/2012/06/05/at-the-end-a-rush-to-the-e-r/

Noted in past issues of Media Watch:

'Why do palliative care patients present to the emergency department? Avoidable or unavoidable?' *American Journal of Hospice & Palliative Care*, 23 May 2012. http://ajh.sagepub.com/content/early/2012/05/18/1049909112447285.abstract

'Practically speaking: Emergency medicine and the palliative care movement,' *Emergency Medicine Australasia*, 2012;24(1):4-6. http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01531.x/full

'Palliative care in the emergency department: An oxymoron or just good medicine?' *Emergency Medicine Australasia*, 2012;24(1):102-104. http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01505.x/abstract

'Does palliative care have a future in the emergency department?' *Journal of Pain & Symptom Management*, 2012;43(1):1-9. http://www.jpsmjournal.com/article/S0885-3924(11)00272-7/abstract

'IPAL-EM launches to improve palliative care in emergency medicine,' Center to Advance Palliative Care, 10 October 2011. http://www.eurekalert.org/pub_releases/2011-11/tmsh-ilt110411.php

'The palliative care model for emergency department patients with advanced illness,' *Journal of Palliative Medicine*, 18 July 2011. http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0011

1. 'Half of older Americans seen in emergency department in last month of life: Most admitted to hospital, and many die there,' *Health Affairs*, 2012;31(6):1277-1285. http://content.healthaffairs.org/content/31/6/1277.abstract

Of related interest:

- *EMERGENCY MEDICINE NEWS*, 2012;34(6):3-19. **'Viewpoint: Palliative care belongs in the ED.'** No abstract available. http://journals.lww.com/em-news/Citation/2012/06000/Viewpoint__Palliative_Care_Belongs_in_the_ED.14.aspx

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2012;8(2):120-134. **'Palliative social work in the emergency department.'** As increasing numbers of palliative and emergency medicine departments partner to both improve ED care for patients with life-threatening illness and initiate palliative care consults earlier in hospitalizations, palliative and ED social workers have an opportunity to join their physician and nurse colleagues who are making inroads in this important and growing area. http://www.tandfonline.com/doi/abs/10.1080/15524256.2012.685427

Hospitals add palliative teams at feverish pace

ASSOCIATED PRESS | Online report – 4 June 2012 – In 2000, there were 658 palliative programs in hospitals, according to the Center to Advance Palliative Care... By 2009, about 63% of hospitals had palliative teams, with a total of 1,568 programs recorded. The field is expected to continue growing as awareness and acceptance spreads, just in time to help baby boomers – the 78 million Americans born between 1946 and 1964 – as they move toward old age and begin developing more serious and life-threatening illnesses. Though the programs and their scope vary widely, a common scenario might look like this: A patient is diagnosed with lung cancer, and a palliative care team's assistance is enlisted from the start, working alongside oncologists and other specialists. The palliative team may include doctors and nurses as well as a social worker and chaplain. Together, they coordinate care among the many medical professionals, have long consults with the patients and their families to answer questions, and may preventively prescribe medications for likely side effects of treatment, from pain to constipation to nausea. The palliative team has a clear vision of the patients' goals and personal philosophies and, depending on these factors, might help steer them away from treatments that are determined to be more painful than they're worth. http://www.federalnewsradio.com/317/2889888/Hospitals-add-palliative-teams-at-feverish-pace-

Specialist Publications

Of particular interest:

'U.S. hospice industry experienced considerable turbulence from changes in ownership, growth, and shift to for-profit status,' (p.11), published in *Health Affairs*.

Futile cancer drugs are costing the U.S. a fortune

THE FISCAL TIMES | Online article – 4 June 2012 – Next time you hear someone use the phrase "death panels," ask them if they're aware of a study of terminally ill lung cancer patients[1] ... [that] ... showed that those who chose palliative care and hospice lived three months longer and had a better quality of life, with fewer side effects, than those who opted for aggressive treatment. If those same people talk about the need to control government spending on health care, you might point them to the 2007 study by the National Hospice & Palliative Care Organization, which claimed Medicare saved over $2,300 for every patient who opted for palliative and hospice care when diagnosed with a terminal illness. Yet fewer than 40% of U.S. cancer patients who eventually died from the disease used hospice or palliative care services in 2007, which in two out of three cases were delivered in the person's home or nursing home. A third of the patients didn't get the referral for hospice services until a week before their deaths, and the median length of time in hospice was just three weeks. http://www.thefiscaltimes.com/Articles/2012/06/04/Futile-Cancer-Drugs-Are-Costing-the-US-a-Fortune.aspx#page1

1. 'Early palliative care for patients with metastatic non–small cell lung cancer,' *New England Journal of Medicine*, 9 August 2010 (noted in Media Watch, 23 August 2012). http://www.nejm.org/doi/full/10.1056/NEJMoa1000678#t=articleTop
2. 'Comparing hospice and non-hospice patient survival among patients who die within a three-year window,' *Journal of Pain & Symptom Management*, 2007;33(3):238-246. http://www.nhpco.org/files/public/JPSM/march-2007-article.pdf

Media Watch posted on Palliative Care Network-e Website

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

International

Red Cross slams 'false economy' as home care cuts crisis puts elderly in danger

U.K. | *Daily Mirror* – 10 June 2012 – Cuts to home care are putting the elderly and vulnerable at risk, the British Red Cross warns today. Isolation among older people is increasing, leading to more accidents plus pressure on hospital beds and National Health Service funds, it says. The charity commissioned a survey which found almost nine out of 10 GPs said patients were at risk due to cuts to home care. http://www.mirror.co.uk/news/uk-news/red-cross-slams-false-economy-872264

More woes for cancer patients

AFRICA (ZIMBABWE) | *NewsDay* – 9 June 2012 – The Bulawayo Island Hospice – a palliative care centre for cancer patients – has stopped, with immediate effect, enrolling additional cancer-treatment beneficiaries due to financial constraints. Island Hospice administrator Anita Dick said the institution was meant to cater for, and effectively manage terminal illnesses, "but due to financial constraints, the centre was failing to offer services hence the need to immediately stop enrolments." http://www.newsday.co.zw/article/2012-06-09-more-woes-for-cancer-patients/

Living wills Bill debated in Dáil

IRISH TIMES | Online report – 8 June 2012 – A Bill to allow for "living wills" was debated in the Dáil [the lower house of the Irish Parliament] and passed the second stage. If enacted, the Bill would allow people to set out the level of treatment they wish to have should they become terminally ill or incapacitated and unable communicate. The Advanced Healthcare Decisions Bill has the support of Government and passed the second stage in the Dáil when introduced by Dr. [Liam] Twomey [Fine Gael Teachta Dála (member of the lower house)]. It will next go before the health committee. http://www.irishtimes.com/newspaper/breaking/2012/0608/breaking16.html

National Consultation

CPR 'may cause harm' to dying patients

IRISH TIMES | Online report – 7 June 2012 – It is important for medical practitioners to identify patients for whom "do not attempt resuscitation" (DNAR) orders would be appropriate to prevent a "lack of dignity in otherwise inevitable deaths," a public meeting heard. Dr. Deirdre Madden, a senior lecturer in law at University College Cork and chairwoman of the National Consent Advisory Group,[1] said that cardiopulmonary resuscitation (CPR) was not originally intended for terminally ill patients, but was now commonly used to treat any patient who had a cardiac arrest. "In many cases where it is used it will not work, it will not be effective or successful, it may indeed cause harm to patients," she said. Dr. Madden, who urged those present to take part in an ongoing national consultation process on DNAR orders..., said DNARs as envisaged under the policy document referred just to resuscitation and did not affect patients receiving other forms of treatment. http://www.irishtimes.com/newspaper/ireland/2012/0607/1224317443712.html

Specialist Publications

Of particular interest:

'Evaluating the effectiveness of CPR for in-hospital cardiac arrest,' (p.7), published in the *American Journal of Hospice & Palliative Medicine*.

1. 'Do Not Attempt Resuscitation,' National Consent Policy, National Consent Advisory Group, June 2012.http://www.hse.ie/eng/about/Who/qualityandpatientsafety/hsestandardsandguidance/National_Consent_Advisory_Group/ncag4.pdf

How having terminal cancer has made me a better doctor: The inspirational diary of a hospital registrar transformed into desperately-ill patient

U.K. | *Daily Mail* – 5 June 2012 – Last July, aged just 29, Dr. Kate Granger was diagnosed with terminal cancer. The treatment has been arduous and unsuccessful so Kate ... has taken the brave decision to stop and, with just months to live, has returned to her job as a hospital registrar at Pinderfields Hospital, Wakefield. During her treatment, she's kept this inspiring diary... http://www.dailymail.co.uk/health/article-2154683/How-having-terminal-cancer-better-doctor.html

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- DENMARK | *The Copenhagen Post* – 8 June 2012 – **''Differences of opinion' over assisted suicide emerging in ethical panel.'** After coming out decisively against active suicide twice previously in the past 25 years, parliament's independent panel of ethics experts now appears to be divided on the issue. The panel, Etisk Råd, which is responsible for advising parliament on ethical issues related to health and biotechnology, reopened discussion about active suicide during its monthly meeting in May, and in contrast to 1997 and 2003, members reportedly had "differences of opinion" during discussions. http://cphpost.dk/news/national/%E2%80%98differences-opinion%E2%80%99-over-assisted-suicide-emerging-ethical-panel

- RUSSIA | RIA Novosti – 6 June 2012 – **'Third of Russians approve of euthanasia.'** The Russian populace is evenly split on euthanasia, with one-third approving of the practice, one-third thinking it unacceptable and most of the rest are unaware of the concept, according to a new poll published by state-run Public Opinion Foundation. http://en.ria.ru/society/20120606/173881617.html

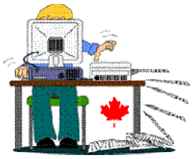
Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

Evaluating the effectiveness of CPR for in-hospital cardiac arrest

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 5 June 2012 – The true effectiveness of CPR [cardiopulmonary resuscitation] remains unknown as it presents significant challenges for evaluation and research. Many resuscitation practices are driven by non-quantitative reasoning and may not be evidence based. Several studies have been published on survival after in-hospital CPR. However, the reported survival rates from one hospital to another vary significantly due to a number of reasons such as type of hospital, presence of specialized cardiac units, patient demographics, differences in inclusion criteria, outcome definitions and so on. http://ajh.sagepub.com/content/early/2012/06/03/1049909112448522.abstract

From Media Watch, 5 March 2012:

- *ADVANCES IN PALLIATIVE MEDICINE*, 2011;10(3-4):89-94. **'CPR vs. DNR in the context of palliative care.'** This paper considers some of the issues surrounding ... cardiopulmonary resuscitation and arranging "do not resuscitate" orders for palliative care patients. http://www.advpm.eu/



Barry R. Ashpole

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

Increasing access

A qualitative study of homelessness and palliative care in a major urban center

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 5 June 2012 – Rates of morbidity and mortality are significantly higher in homeless populations. Homeless people experience many barriers to receive adequate palliative care [see sidebar right]. This qualitative study examines how a major urban city's palliative care resources can be improved to increase access and better serve the homeless. The findings ... suggest that in order to increase access and to serve the city's terminally ill homeless better, the following 4 areas must be addressed: 1) increasing positive interaction between the health care system and the homeless; 2) training staff to deal with the unique issues confronting the homeless; 3) providing patient-centered care; and, 4) diversifying the methods of delivery. http://ajh.sagepub.com/content/early/2012/06/03/1049909112448925.abstract

Noted in past issues of Media Watch:

'Homeless people need better palliative care...,' *Community Care* (U.K.), 24 May 2011. http://www.communitycare.co.uk/Articles/2011/05/24/116870/homeless-people-need-better-palliative-care-finds-charity.htm

'Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of...,' *Palliative Medicine*, 4 April 2011.http://pmj.sagepub.com/content/early/2011/03/30/0269216311402713.abstract

'End-of-life care for the homeless,' Canadian Healthcare Network, 9 November 2010. http://www.canadianhealthcarenetwork.ca/nurses/news/movers-shakers/monica-flinn-end-of-life-care-for-homeless-6956

'Effect of an end-of-life planning intervention on the completion of advance directives in homeless persons,' *Annals of Internal Medicine*, 2010; 153(2):76-84. http://www.annals.org/content/153/2/76.abstract

'A last kindness to the homeless,' *Kansas City Star* (Missouri, U.S.), 1 April 2009. http://www.kansascity.com/news/local/story/1119812.html

Practical guidelines for developing new palliative care services: Resource management

ANNALS OF ONCOLOGY, 2012;23(Suppl3):70-75. The data are relatively clear cut that palliative care improves quality of life and symptom control, improves quality of care by reducing aggressive but unsuccessful end of life care, and reduces costs. That should be an easy message to deliver to the public, health care administrators, payers, and governments. In fact, the arguments to develop palliative care services must be clear and concise, and make the clinical and financial case for the services that the palliative care team wants to deliver. The authors discuss some of the types of models including consult services, outpatient programs, and inpatient units; the important components; some easy to use screening tools; components of the consultation team; a model medical record that increases "prompts" to do best palliative care; and data to report to supervisors. http://annonc.oxfordjournals.org/content/23/suppl_3/70.abstract

Turkish community-based palliative care model: A unique design

ANNALS OF ONCOLOGY, 2012;23(Suppl3):76-78. An organized palliative care system was lacking in Turkey before 2010. One of the pillars of Turkish Cancer Control Programme is palliative care. The Pallia-Turk project in this respect has been implemented by the Ministry since 2010. The project is unique since it is population based and organized at the primary level. This means, the whole population [of 70 million] will have the quickest and easiest way for access to palliative care. http://annonc.oxfordjournals.org/content/23/suppl_3/76.abstract

> **N.B.** Turkey was rated 34th (of forty countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Under-diagnosis of pain by primary physicians and late referral to a palliative care team

BMC PALLIATIVE CARE | Online article – 7 June 2012 – [In this retrospective study] under-diagnosis of pain by primary physicians was associated with late referral to palliative care teams [PCTs]. Shortening the duration from admission to referral to PCTs, and increasing physicians' awareness of palliative care may improve pain management for cancer patients. http://www.biomedcentral.com/1472-684X/11/7/abstract

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article 0 7 June 2012 – **'Attitudes of health care professionals to opioid prescribing in end-of-life care: A qualitative focus group study.'** If international priorities on improving pain management ... are to be achieved, educational opportunities for generalists need to be enhanced, and effective interprofessional working models need to be developed so that pain management for patients at the end of life is optimized. http://www.jpsmjournal.com/article/S0885-3924(12)00138-8/abstract

Clinical care tracker

A new member of community specialist palliative care team

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – Accessed 5 June 2012 – The Clinical Care Tracker (CT) ... enhance[s] the quality and efficiency of services provided by the Community Specialist Palliative Care Team (CSPCT) at Marie Curie Hospice, Penarth. The CT is a registered nurse who works exclusively on the telephone, providing a point of contact for any patient or family on the CNS [Clinical Nurse Specialist] caseload and for clinicians and services involved in their care. http://spcare.bmj.com/content/2/2/6.2.abstract

Cont. p.10

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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3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Of related interest:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2012;14(5):365-373. **'"It's different in the home ..." The contextual challenges and rewards of providing palliative nursing care in community settings.'** Findings of this study reflect the unique geographical, physical, and social realities of palliative care nursing in community settings. The contextual challenges and rewards of working in community palliative nursing practice were reflected in four main themes: 1) who I am; 2) resigning myself to the system; 3) feeling valued and respected; and, 4) managing grief and loss. http://journals.lww.com/jhpn/Abstract/2012/07000/_It_s_Different_in_the_Home____The_Contextual.10.aspx

'They patiently heard what we had to say…this felt different to me': The palliative care needs and care experiences of advanced cancer patients and their families in Bangladesh

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – Accessed 5 June 2012 – The data fit well within the existing domains of palliative care, as respondents described the family-wide distress and impact of the disease, psychological, physical and social problems. However, the contextual experience of cancer in this setting revealed particular challenges, as respondents described anger, helplessness and mistrust towards existing (non-palliative) healthcare. Poor patient-doctor communication and unmet need for information contributed greatly to these poor experiences. By contrast, experience of palliative care was explained in radically different terms, with a clear shift in the nature of the interaction and resulting care, to bring effective communication and relief from suffering. http://spcare.bmj.com/content/2/2/145.short

Palliative care in Canada

Implementing the British Columbia practice support program in end of life care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – Accessed 5 June 2012 – The British Columbia (BC) Practice Support Program, supported by the General Practice Services Committee (a joint program of the BC Medical Association, the Ministry of Health), has been an effective strategy to change and influence the care being offered in GP offices throughout BC. This innovative program has engaged 2000 GPs ... in practice redesign since 2007 and now is providing a module to improve the identification, assessment and management of patients at the end of life, including redesign of office processes and procedures that need to be implemented to support a new approach. It integrates aspects of the Gold Standards Framework (U.K.), the BC Chronic disease management framework, the triple aim of the Institute for Health Care Improvement, with the norms and practices of hospice palliative care in Canada. Participants include GP champions as the teachers together with local palliative care providers, home care nurses, specialist physicians and general practitioners and their MOAs [medical office assistants]. There are 3 learning sessions interspersed with two action periods during which physicians are supported to implement changes in practice like a registry; flags to alert the physician to key changes; more collaborative practice and supports for advance care planning. The algorithm and the clinical support tools embedded in the algorithm have been well received and reinforce a best practice approach. http://spcare.bmj.com/content/2/2/179.2.short

World hospice & palliative care day October 13 2012
http://www.worldday.org/

Dignity-driven decision making: A compelling strategy for improving care for people with advanced illness

HEALTH AFFAIRS, 2012;31(6):1269-1276. The concept of dignity-driven decision making builds on previous efforts to define and develop patient- and family-centered care for people with advanced illness. More a framework than a rigid structure, the dignity-driven decision making model emphasizes the centrality of a collaborative process in which patients, most of whom are elderly; their families; and clinicians work together continuously to define the goals of care and how best to implement them. The early experiences of some organizations already practicing dignity-driven decision making in their care suggest that the model can improve patient care. Whether the system of care can produce enough savings to pay for its increased costs in the form of additional clinicians and managers is not yet known. Policy-driven actions, such as payment reform and closer alignment of quality incentives with the model's objectives, will be integral to further development and dissemination of the model. http://content.healthaffairs.org/content/31/6/1269

Of related interest:

- *ANNALS OF ONCOLOGY*, 2012;23(Suppl3):29-32. **'Palliative communications: Addressing chemotherapy in patients with advanced cancer.'** Patients with advanced cancers often endure chemotherapy late in their disease course leading to unnecessary adverse effects, loss of quality of life, and delay in hospice referral. http://annonc.oxfordjournals.org/content/23/suppl_3/29.abstract

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 4 June 2012 – **'Adaptive leadership: A novel approach for family decision making.'** This case report presents an exemplar family meeting in the ICU led by a palliative care specialist, with discussion about the strategies used to improve the capacity of the family to make a decision consistent with the patient's goals. http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0406

U.S. hospice industry experienced considerable turbulence from changes in ownership, growth, and shift to for-profit status

HEALTH AFFAIRS, 2012;31(6):1286-1293. The U.S. hospice industry ... has undergone substantial changes during the last decade. The magnitude of these changes has not been fully captured in previous studies or reports. In this longitudinal study of hospices active in Medicare during 1999-2009, the authors analyzed Provider of Services files to understand key shifts in the industry. They found evidence of substantial turbulence. One-fifth of Medicare-certified hospices active in 1999 had closed or withdrawn from the program by 2009, and more than 40% had experienced one or more changes in ownership. The most prominent trend was the shift in ownership type from non-profit to for-profit ownership. Four out of five Medicare-certified hospices that entered the marketplace between 2000 and 2009 were for-profit. Hospices also became larger, as the proportion with 100 or more full-time employees doubled to 5% from 1999 to 2009. Although each of the Census regions had more hospices in 2009 than in 1999, the geographic distribution of hospices in the country changed, with proportionally more in the South and West. The impact of all of these changes on cost and quality of hospice care, as well as patient access, remains a critical area for future research. http://content.healthaffairs.org/content/31/6/1286.abstract

From Media Watch, 16 April 2012:

- U.S. | *Palm Beach Post* (Florida) – 14 April 2012 – **'Hospice profits raise questions about Medicare volunteer rule.'** http://www.palmbeachpost.com/health/hospice-profits-raise-questions-about-medicare-volunteer-rule-2305341.html

From Media Watch, 6 February 2012:

- U.S. | *Connecticut Post* – 3 February 2012 – **'Should shareholder concerns govern end-of-life care?'** http://www.ctpost.com/news/article/Should-shareholder-concerns-govern-end-of-life-2999642.php

Cont.

- U.S. | *McKnight's Long-Term Care News & Assisted Living* | Online article – 2 February 2012 – **'Marketing by hospices to be focus of federal investigation.'** http://www.mcknights.com/marketing-by-hospices-to-be-focus-of-federal-investigation/article/225053/

From Media Watch, 30 January 2012:

- U.S. | *Palm Beach Post* (Florida) – 22 January 2012 – **'Take the profit out of dying.** http://www.palmbeachpost.com/opinion/editorials/take-the-profit-out-of-dying-2118554.html

Resources for Middle Eastern patients: Online resources for culturally and linguistically appropriate services in home healthcare and hospice, Part 3[1,2]

HOME HEALTHCARE NURSE | Online article – 1 June 2012 – As the population of patients [in the U.S.] for whom English is not their primary language grows, home care and hospice clinicians are challenged to provide culturally respectful and acceptable patient-centered care for cultures and languages unfamiliar to them. This article identifies resources for understanding the culture of Middle Eastern-born patients and appropriate patient education materials in most of the languages...http://journals.lww.com/homehealthcarenurseonline/Abstract/publishahead/Resources_for_Middle_Eastern_Patients__Online.99983.aspx

1. Resources for Spanish-speaking patients (Part 1), *Home Healthcare Nurse*, 2012;30(1):E1-E7. http://journals.lww.com/homehealthcarenurseonline/Abstract/2012/01000/Online_Resources_for_Culturally_and_Linguistically.17.aspx

2. Resources for Asian patients (Part 2), *Home Healthcare Nurse*, 2012;30(4):225-232. http://journals.lww.com/homehealthcarenurseonline/Fulltext/2012/04000/Online_Resources_for_Culturally_and_Linguistically.4.aspx

Of related interest:

- *ANNALS OF ONCOLOGY*, 2012;23(Suppl3):62-65. **'Cultural diversity: Family path through terminal illness.'** A family's experience with illness cannot be considered in isolation from the cultural milieu in which it occurs. http://annonc.oxfordjournals.org/content/23/suppl_3/62.abstract

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 7 June 2012 – **'Culture is a priority for research in end-of-life care in Europe: A research agenda.'** This first pan-European meeting compiled a research agenda, identifying key areas for future research focusing on culture, diversity, and their operationalization. http://www.jpsmjournal.com/article/S0885-3924(12)00149-2/abstract

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 4 June 2012 – **'Cultural competence in end-of-life care: Terms, definitions, and conceptual models from the British literature.'** The variety of terms, definitions, and models underpinning cultural competency approaches demonstrates a lack of conceptual clarity, and potentially complicates implementation. http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0526

Mapping children's palliative care around the world: An online survey of children's palliative care services and professionals' educational needs

JOURNAL OF PALLIATIVE MEDICINE, 2012;15(6):646-652. This study provides insight into who is providing CPC [children's palliative care] ... and highlights the multi-disciplinary nature of CPC. It raises questions about how we can best support colleagues in resource-limited settings. It suggests further study ... into the nature of regional demand for CPC, the best places to resource and provide CPC, the nature of professionals' training needs, the most effective ways to train and deliver CPC care, the best ways for professionals to support each other, and effective ways to share resources and knowledge... http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0405

Cont.

Of related interest:

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online article – Accessed 5 June 2012 – **'The importance of robust children's palliative care: Now and the future.'** Together for Short Lives [a charitable organization] is committed to collecting information from its members in order to support the development of services across the sector to meet the needs of children and young people with life-limiting conditions. Since 2009, Durham University Mapping Team has collaborated with Children's Hospices U.K. (Formerly ACT and Children's Hospices U.K.) in developing more efficient ways of collecting data. http://adc.bmj.com/content/97/Suppl_1/A169.3.abstract

- *CLINICAL NURSE SPECIALIST*, 2012;26(4):212-215. **'Pediatric palliative care communication: Resources for the clinical nurse specialist.'** The purpose of this article was to highlight the lack of communication skills pediatric practitioners have when delivering bad news and introducing pediatric palliative care to a family with a child with a life-limiting condition. Fortunately, innovative tools and guidelines have been appearing in recent literature, and the clinical nurse specialist has an opportunity to implement these communication tools by utilizing her core competencies. New advances are not being disseminated [however] to the pediatric healthcare practitioner population, leaving practitioners with inadequate education and preparation for implementing pediatric palliative care. http://journals.lww.com/cns-journal/Abstract/2012/07000/Pediatric_Palliative_Care_Communication__Resources.8.aspx

Media Watch Online

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

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx (Click on 'Current Issue' under 'Media Watch')

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

ONTARIO | Mississauga Halton Palliative Care Network: http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.palliativecareconsultation.ca/?q=mediawatch

U.S.A.

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

Europe

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

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

Asia

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

International

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

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

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

Taking care of the carers

NURSING REVIEW (Australia) | Online article – 5 June 2012 – Caring for patients at the end of life is emotionally demanding work but regular clinical supervision for nurses can help to buffer against stress. In 2010, the Northern Adelaide Palliative Care Service implemented an innovative and integrated model of care to meet the mental health needs of patients. The Specialist Mental Health Initiative in Palliative Care, funded through the Department of Health & Ageing Local Palliative Grants Program, sought to develop both knowledge and skills within the interdisciplinary community team as well as facilitating direct mental health support to the patient and their families. http://www.nursingreview.com.au/pages/section/article.php?s=Education&idArticle=23862

Of related interest:

- *QUALITY HEALTH RESEARCH* | Online article – 6 June 2012 – **'Stress variances among informal hospice caregivers.'** The authors' goal was to describe the variance in stressors for caregivers to establish evidence for the assessing caregivers for team interventions theoretical framework. http://qhr.sagepub.com/content/early/2012/06/04/1049732312448543.abstract
- *QUALITY HEALTH RESEARCH*, 2012;22(7):1007-1015. **'"It's like we're grasping at anything": Caregivers' education needs and preferred learning methods.'** Four categories of educational needs were identified [in this study]: a) respite; b) caregiving essentials; c) self-care; and, d) the emotional aspects of caregiving. http://qhr.sagepub.com/content/22/7/1007.abstract

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *CURRENT ONCOLOGY*, 2012;19(3):133-138. **'Pereira's attack on legalizing euthanasia or assisted suicide: Smoke and mirrors.'**[1,2] http://www.current-oncology.com/index.php/oncology/article/view/1063/913
    1. 'Legalizing euthanasia or assisted suicide: The illusion of safeguards and controls' *Current Oncology*, 2011;18(2):e38-e45 (noted in Media Watch, 11 April 2011). http://www.current-oncology.com/index.php/oncology/article/view/883/645
    2. 'Casting stones and casting aspersions: Let's not lose sight of the main issues in the euthanasia debate.' *Current Oncology*, 2012;19(3):139-142. http://www.current-oncology.com/index.php/oncology/article/view/1088/914
- *CURRENT ONCOLOGY*, 2012;19(3):143-154. **'Assisted death and the slippery slope – finding clarity amid advocacy, convergence, and complexity.'** The assisted-death regimes of the Netherlands, Belgium, Luxembourg, Switzerland, and the states of Washington and Oregon are discussed and examined with respect to the slippery slope analytical rubric. In addition to providing a preliminary explanation of how the slippery slope argument has been academically defined and constructed, the paper examines assisted-death models from the perspective of considering what might exist at the top and at the bottom of the slippery slope. It also explores the nature and scope of safeguards implemented to avoid slippage, and shows that what lies at the top and bottom of the slippery slope may be different from jurisdiction to jurisdiction. After identifying some of the recent concerns that have arisen within each of the jurisdictions (concerns that might be viewed by some as evidence of slide), the paper concludes by making note of certain critical issues in the current assisted-death debate that merit deeper examination. http://www.current-oncology.com/index.php/oncology/article/view/1095/915

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