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.

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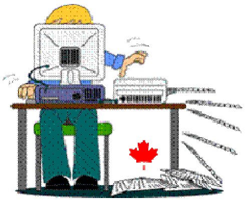


Compiled & Annotated by Barry R. Ashpole

24/7 palliative care: Scroll down to Specialist Publications and 'What challenges good palliative care provision out-of-hours? A qualitative interview study of out-of-hours general practitioners'(p.5), published in *BMJ Supportive & Palliative Care.*

Canada

Baby Joseph returns to Canada

ONTARIO | CBC News (Windsor) – 21 April 2011 – Joseph Maraachli, the terminally ill baby at the centre of a legal and ethical battle that led to his care in a U.S. hospital, returned to Canada. Canadian doctors had refused to perform a tracheotomy to prolong his life. But in March, the group Priests for Life flew him to a hospital in St. Louis, Missouri, where he received the procedure. In a joint statement ... by Cardinal Glennon Children's Medical Center and Windsor Regional Hospital, Joseph's doctors said he is responding well to the tracheotomy, and has been breathing on his own, without the aid of a ventilator, for more than a week. http://www.cbc.ca/news/health/story/2011/04/21/wdr-maraachli-returns-to-windsor.html

From Media Watch dated 21 March 2011:

- ONTARIO | *Vancouver Sun* (British Columbia) – 14 March 2011 – **'Baby Joseph to get tracheotomy by the end of the week: U.S. doctors.'** http://www.vancouversun.com/life/Baby+Joseph+tracheotomy+week/4435461/story.html

Canadian federal election 2 May 2011

2011 Election survey: Home/palliative care

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online report – 21 April 2011 – The Canadian Home Care Association estimates public outlays on home care in Canada are about $5.8 billion per year. There is no known estimate of private outlays for home care, although the Health Council of Canada has estimated that in the neighbourhood of 500,000 Canadians are tending ailing relatives. The level of private spending, though, has never been quantified. Some families spend on the order of thousands of dollars annually for medical supplies and equipment, while others shell out between $30,000-$60,000 per year to hire private services. One thing is certain, though – there is no sign that spending by Canadians on home care will abate any time in the near future. A slew of campaign promises ... might suggest that major support for families providing home care or major changes in ... policies, programs and strategies are in the offing.http://www.cmaj.ca/earlyreleases/21april11_home-palliative-care.dtl

N.B. Canada was rated 9th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Helping Ottawans find palliative care

ONTARIO | *Ottawa Citizen* – 21 April 2011 – A new hotline and website ... aims to help Ottawa residents find information and services about palliative care in the region. The hotline and website, created by the new Champlain Regional Hospice Palliative Care Program, are expected to make it faster and easier to navigate the maze of services for people with progressive, incurable or life-threatening illnesses. The website explains palliative care, describes the types of care available – whether in the home, in a hospice or at hospitals in the region – and provides links to outreach programs and day support programs. Users will be able to read about services and download referral forms. Medical professionals staffing the hotline will provide the same information and offer guidance to help callers understand the best options for their needs. http://www.ottawacitizen.com/health/Helping+Ottawans+find+palliative+care/4652509/story.html

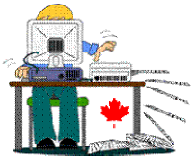
U.S.A.

New regulations threaten the future of hospice care

CONNECTICUT POST (Bridgeport) | Online OpEd – 22 April 2011 – Ever since 1974, when Connecticut Hospice Care opened its doors and became the first such institution in America, our state has been a nationally recognized leader in hospice care. But proposed new standards may set us on a dangerous path – one that threatens the high-quality delivery of this care here in Connecticut. Worse, it threatens to force terminally ill patients in our state to spend their last hours, days and weeks with unnecessary pain and without care. Under the new standards proposed by the Department of Public Health, hospice patients who have days, maybe hours to live would not see a doctor for 24 hours, versus the immediate medical assessment provided today. In-patient facilities would no longer be required to have a physician and pharmacist on-site. And tragically, the mandatory ratio of nurses to patients would be dramatically reduced. Less staff and fewer services means less aid, including less pain and symptom management, for patients at the end of life. With these new regulations, many could die in fear and agony without adequate medical and spiritual support. http://www.ctpost.com/default/article/New-regulations-threaten-the-future-of-hospice-1348909.php

Iowa hospices inspected only once every 20 years

IOWA | *Desmoines Register* – 24 April 2011 – Hospice providers that care for hundreds of Iowans in the final stages of a terminal illness are now being inspected by the state on a schedule of one visit every 20 years. Patient advocates say that sort of inspection cycle "doesn't even pass the laugh test," and puts Iowans at risk of sub-standard care. It's one example of how Iowa is turning a blind eye to critical elements of the state's health care system. http://www.desmoinesregister.com/article/20110424/NEWS10/104240335/Iowa-hospices-inspected-only-once-every-20-years?Iowa%20Politics%20Insider



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

New bereavement policy for students who lose loved one

INDIANA | *Journal & Courier* (Lafayette) – 21 April 2011 – [Purdue] university has adopted a formal policy that spells out a standard formula for how long a student can be absent due to a family member's death. The policy was drafted by the Purdue Student Government and was approved by the faculty senate in March. It will be official in the fall. "Before this policy there was really no mandatory protection for students in the case of losing a loved one," said Brad Krites, a junior at Purdue and president of Purdue Student Government. He said most faculty members would be accommodating, but some would not comply with student requests. "There are always those few that make things difficult," he said. "We as a university should have student success and well-being at the forefront of everything we do." The length of the absence depends on the family member who died and the distance needed to travel. Most students will be allowed to miss one to three days of class to attend funerals of relatives or immediate family members. Under this new policy, students can petition to receive a leave of absence for the death of a friend or other family member not specified in the policy. More time also can be given if students have to travel long distances. http://www.jconline.com/article/20110418/LIFE08/104180307/New-bereavement-policy-students-who-lose-loved-one?odyssey=tab%7Ctopnews%7Ctext%7CFRONTPAGE

Specialist Publications

Of particular interest:

'Untaming grief? For palliative care physicians' (p.4), published in the *American Journal Hospice & Palliative Medicine.*

The case for rationing healthcare

CALIFORNIA | *Los Angeles Times* (OpEd) – 18 April 2011 – We want our doctors to go all-out for our loved ones and ourselves. But as voters and consumers, we send a different message. We pick politicians who promise to cut taxes, and we demand low-cost insurance. We're telling government and the healthcare industry to hold the line on healthcare costs, even if it means sacrificing clinical benefits. http://www.latimes.com/news/opinion/commentary/la-oe-bloche-rationing-20110418,0,6247911.story

Patients with do-not-resuscitate orders fare worse

REUTERS | Online report – 18 April 2011 – A new study could help people with a do-not-resuscitate order make better decisions about what surgeries they are willing to undergo.[1] About seven in 10 Americans die with such an order, which instructs healthcare workers not to use life-prolonging treatment if a patient's heart or breathing stops. But other situations that aren't necessarily covered in the do-not-resuscitate [DNR] ... orders may also be worth considering, researchers say. http://www.reuters.com/article/2011/04/18/us-do-not-resuscitate-idUSTRE73H6W620110418

1. 'High mortality in surgical patients with do-not-resuscitate orders,' *Archives of Surgery*, published online 18 April 2011. http://archsurg.ama-assn.org/cgi/content/short/archsurg.2011.69

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GEORGIA | *Savannah Morning News* – 20 April 2011 – **'Georgia judge rejects assisted suicide law challenge.'** A Georgia judge rejected a free-speech challenge to the state's law against assisted suicide, allowing a high-profile case to proceed against four members of a suicide group charged with helping a cancer-stricken man kill himself. http://savannahnow.com/latest-news/2011-04-20/ga-judge-rejects-assisted-suicide-law-challenge

International

Dying patient? Don't dial 999 if they're old

U.K. | *Daily Express* – 24 April 2011 – A health trust has been condemned after it advised care home staff not to call an ambulance automatically if an elderly resident was dying. Officials issued the instructions for old people who have "do not resuscitate" notes placed on their files by their GP after consultations with relatives. A care home organisation has attacked the order, saying it put pressure on employees who were not trained to make a medical judgment about whether somebody was dying or not. http://www.express.co.uk/posts/view/242564/Dying-patient-Don-t-dial-999-if-they-re-old

N.B. In the U.K. '999' is the equivalent of '911' in North America for emergency services.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- RUSSIA | RIA Novosti (Moscow) – 21 April 2011 – **'Russian healthcare bill would formally ban euthanasia.'** The Russian government submitted a bill to the lower house of parliament ... that would officially ban euthanasia, pre-empting any attempt to introduce the practice into Russian law. The main purpose of the healthcare protection bill is to review medical assistance standards drawn up in 1993. There has been some discussion in Russia of the merits of euthanasia, and [a] bill to allow patients suffering from incurable diseases to be euthanized at their own request was blocked in 2007. http://en.rian.ru/russia/20110421/163634966.html

Corrections & Clarifications

A report published in the U.K.'s *Daily Mail*, noted in last week's Media Watch (18 April 2011, #197), was headlined **'Assisted suicide set to be legalized in Swiss old peoples' homes.'** The proposed law applies only to the Canton of Vaud.

Specialist Publications

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

Untaming grief? For palliative care physicians

AMERICAN JOURNAL HOSPICE & PALLIATIVE MEDICINE | Online article – 19 April 2011 – Little doubt (if any) remains as to the assured importance of physicians possessing praxis regarding psychosocial issues, including grief dynamics, in order to tend to dying and sorrowing people. It stands to reason then that palliative care physicians become knowledgeable enough about the phenomenon of grief. But imperative nuances must also be considered: what sort of knowledge on grief, as well as how much of such knowledge, is enough? This article poses topical queries on the importance of the palliative care physician exercising a deliberate agenda to persistently refine one's personal framework or beliefs regarding grief. In doing so, it is proposed physicians will engender improved self-knowledge, which will serve to better poise themselves toward being with and purposefully encountering aggrieved others. http://ajh.sagepub.com/content/early/2011/04/19/1049909111406705.abstract

Forgotten grievers: An exploration of the grief experiences of bereaved grandparents

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2011;17(4):170-176. The small body of literature generally claims that grandparents experience 'double pain,' meaning that they concurrently experience feelings of loss for their grandchild and pain associated with their own child's grief. However, this study found that grandparents experience 'cumulative pain.' http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=83356;article=IJPN_17_4_170_176

What challenges good palliative care provision out-of-hours? A qualitative interview study of out-of-hours general practitioners

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – 20 April 2011 – Out-of-hours doctors [i.e., participants in this study] were not confident about their palliative care knowledge and expressed a wish for more education. Lack of familiarity with patients requiring acute palliative care, compared with the closer bonds formed within the in-hours general practice setting, was perceived as troublesome and problematic, and lack of follow-up was felt to be a major factor. There was a clearly expressed fear of killing or harming patients with the strong drugs used in palliative care. Opiophobia, especially when faced with patients who were seen only once, affected prescribing decisions. http://spcare.bmj.com/content/early/2011/04/21/bmjspcare-2011-000015.abstract

From Media Watch dated 31 May 2010:

- *PALLIATIVE MEDICINE* | Online article – 25 May 2010 – **"Oh God, not a palliative': Out-of-hours general practitioners within the domain of palliative care.'** This project explored factors influencing confidence in dealing with symptom control and palliative care provision outside regular working hours. http://pmj.sagepub.com/cgi/content/abstract/0269216310368580v1

Of related interest:

- *AMERICAN MEDICAL NEWS* | Online report – 25 April 2011 – **'House call practice attracts $11.5 million investment.'** With house calls becoming more common – and better paying – at least one medical practice that specializes in this area has attracted investor interest. http://www.ama-assn.org/amednews/2011/04/25/bisb0425.htm

Media Watch: Editorial Practice

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

Distribution

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

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Comparing clinician ratings of the quality of palliative care in the intensive care unit

CRITICAL CARE MEDICINE, 2011;39(5):975-983. [In this multi-centre study involving thirteen hospitals] nurses rated nursing care significantly higher than physicians rated physician care in five domains. In addition, although nurses and physicians gave comparable ratings to palliative care delivered by nurses, nurses' and physicians' ratings of physician care were significantly different with nurse ratings of this care lower than physician ratings on all but one domain. The [multi-site] study supports the content validity of the ten overall rating items and supports the need for improvement in several aspects of palliative care, including spiritual support for families, emotional support for clinicians, and clinician education about palliative care in the intensive care unit.http://journals.lww.com/ccmjournal/Abstract/2011/05000/Comparing_clinician_ratings_of_the_quality_of.8.aspx

From Media Watch dated 4 April 2011:

- *JOURNAL OF INTENSIVE CARE MEDICINE* | Online article – 24 March 2011 – **'End of life care in ICU: A practical guide.'** The purpose of this manuscript is to provide a practical guide to end of management for all bedside practitioners. The manuscript outlines not all but some fundamentally important ethical concepts and provides helpful rules and steps on end-of-life management... http://jic.sagepub.com/content/early/2011/02/13/0885066610392697.abstract

N.B. Additional articles on the palliative care in the intensive care unit are noted in this issue of Media Watch.

Palliative care and withholding and withdrawing dialysis

DIALYSIS & TRANSPLANTATION, 2011;40(4):154-155. The aging dialysis population, with its decreasing functional status, the high mortality of end-stage renal disease (ESRD), and the rise of palliative medicine as a specialty have all served to promote the importance of end-of-life care for ESRD patients. Even though nephrologists have an increased understanding of the issues involved in ESRD end-of-life care, most individuals working in dialysis know of a case in which it felt as if "the dead were being dia-lyzed." An increased effort to focus on palliative care issues in ESRD, especially advance care planning, may serve to reduce the frequency of such cases. http://onlinelibrary.wiley.com/doi/10.1002/dat.20552/full

From Media Watch dated 11 April 2011:

- *NEW YORK TIMES* | Online article – 1 April 2011 – **'When ailments pile up, asking patients to rethink free dialysis.'** Kidney specialists are pushing doctors to be more forthright with elderly people who have other serious medical conditions, to tell the patients that even though they are entitled to dialysis, they may want to decline such treatment and enter a hospice instead. http://www.nytimes.com/2011/04/01/health/01dialysis.html?_r=1

Dying well: Factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland

JOURNAL OF CLINICAL NURSING | Online article – 21 April 2011 – People are living longer consequently acute and long-stay care setting will increasingly become places where older people die. This study identified the factors that influence the provision of good EoL [end of life] care for older people. Mobilising resources to ensure that these factors are considered is crucial to ensuring that regardless of where older people die in Ireland, they will receive the highest standard of care that nurses can provide. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2010.03628.x/abstract

N.B. Ireland was rated 4th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

The role of complementary indigenous Malay therapies: Perspectives from palliative care patients

JOURNAL OF COMPLEMENTARY & INTEGRATIVE MEDICINE, 2011;8(1):Article 16. Although the popularity of complementary indigenous Malay therapies (CIMT) in general healthcare is undeniable in the Malaysian context today, their usage within the palliative care scenarios remains unexplored. Our study was specifically embarked to determine CIMT's usage pattern, reasons, attitudes, beliefs, perceptions and health-related quality of life (HRQoL) differences (users vs. non-users) in a sample of hospice-based palliative patients in Selangor, Malaysia. From the 39 consenting patients 38.5% were users of CIMT. Dried medicinal roots, herbs and sea cucumber products were the most preferred types of CIMT (53.3%). The most common reason cited for usage was because these were "easier and simpler to be administered" (46.7%). Although users' attitudes, beliefs and perceptions were more favourable than the non-users, between 30-73% of users remained unsure or had no knowledge regarding CIMT. They also exhibited significantly poorer physical symptoms than the non-users, a probable motive for seeking CIMT in the first place. Despite the small sample size, the findings provided some insight into the role of CIMT especially with regard to usage trends and overall well-being among the terminally-ill, of which healthcare professionals should constantly be vigilant of amidst their routine care responsibilities. http://www.bepress.com/jcim/vol8/iss1/16/

Subjective definitions of problems and symptoms in palliative care

PALLIATIVE CARE: RESEARCH & TREATMENT | Online article – 17 April 2011 – Data from ... the Hospice & Palliative Care Evaluation (HOPE) from 1999 to 2001 demonstrated considerable variance in the incidence of patients' symptoms and problems between participating services. Staff members [i.e., participants in this study] rated pain, weakness, nausea/emesis as the most frequent physical symptoms; anxiety, depression and amentia as most frequent psychological symptoms; wound treatment, mobilisation and weakness as nursing problems and organisation of care settings, loneliness, demands of relatives the most common social needs. They used a wide range of definitions for cachexia, weakness and depression. Even though definitions differed widely, underlying concepts seemed to be compatible. http://www.la-press.com/subjective-definitions-of-problems-and-symptoms-in-palliative-care-article-a2595

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/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx

Ontario | HPC Consultation Services: http://www.hpcconnection.ca/newsletter/inthenews.html

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

U.S.A.

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

International

Global | Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/world/world/

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

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/news.htm

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BRITISH MEDICAL JOURNAL* | Online OpEds – 21 April 2011 – **'Should the law on assisted dying be changed?' No.** Patient safety is at the heart of good clinical governance: not having the confidence to seek medical intervention early poses a threat to the lives of all patients, regardless of impairment. http://www.bmj.com/content/342/bmj.d1883.extract **Yes.** The case for legalising assisted dying for people with terminal illness is easily stated. Unbearable suffering, prolonged by medical care, and inflicted on a dying patient who wishes to die, is unequivocally a bad thing. http://www.bmj.com/content/342/bmj.d2355.extract

Worth Repeating

Should doctors go to patients' funerals?

BRITISH MEDICAL JOURNAL | Online response by authors – 27 July 2007 – It was heartening to receive many positive and supportive responses to both the published editorial and to the subsequent interviews performed.[1] We were privileged to hear personal stories from patients' relatives as well as learning about a range of practices doctors were undertaking to convey a gesture of respect and support following the death of a patient. These responses were instructive to us as authors and have left us with a more complete answer to our question: 'Should doctors go to patients' funerals?' If possible and appropriate, yes. Should doctors have some method whereby they convey a gesture of acknowledgment, compassion and support? Absolutely. Dealing with the death of a patient is not something that appears to be a part of the medical school curriculum; however, it is a situation that we as doctors universally face. In terms of dealing with the external situation (personal coping with grief is a more complex issue) perhaps the only preparation that is necessary is an appreciation of how important our role can be following the death of a patient and some forethought as to what form that role may take. Attending the funeral is only one such option [see sidebar]. http://www.bmj.com/content/334/7607/1322.extract/reply#bmj_el_173383

Acceptable options:

1) Sending a condolence card or letter. This can be from the doctor with a personal message or thoughts appropriate to the particular patient or can be a collaborative effort with all the relevant staff adding their own personal message.

2) Having a practice meeting to 'de-brief' after the patients' death to ensure everyone is coping and what the practice response will be. Someone other than the doctor may wish to attend the funeral, someone in the practice team may be aware of a particular need within the family that others are unaware of, worries or issues around the death can be aired and from this forum a card or letter may be able to be signed or flowers sent.

3) A telephone call to the next-of-kin or close relative following the death can express sympathy, check on family support, determine if any follow up is required and may be able to resolve any misunderstandings regarding medical care or the circumstances of death.

4) Arranging a family conference in the weeks following the death to review the patient illness or circumstances of death, to help answer any lingering questions and to ascertain how everyone is coping.

1. **'Should doctors go to patients funerals?'** *British Medical Journal*, online editorial posted 21 June 2007. http://www.bmj.com/content/334/7607/1322.extract?sid=e4a82627-3087-43bf-8b0a-7f5877e00db8
