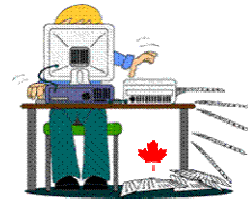


Media Watch...

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.

7 March 2011 Edition | Issue #191



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

Compiled & Annotated by Barry R. Ashpole

Care planning: Scroll down to [Specialist Publications](#) and 'The effect on surrogates of making treatment decisions for others' (p.6), published in *Annals of Internal Medicine*.

Canada

Hospital disclosure muddies baby case

ONTARIO | *London Free Press* – 1 March 2011 – If the parents of Baby Joseph want their son to die at home, all they have to do is ask, [said] officials at London Health Sciences Centre. The hospital's position, made public [27 February 2011] in a media release¹ ... came with a twist: Doctors are willing to take Joseph to his Windsor home, but once there, would remove him from a ventilator, an act observers say would lead to his death in a matter of minutes. The release may also serve to muddy negotiations between the lawyer representing the treating physician at the hospital and the lawyer representing the parents of Joseph Maraachli. While it's true the hospital has offered to take Baby Joseph home, that offer was made during confidential negotiations, [the Maraachli family's lawyer] Mark Handelman said. Such a surprise disclosure isn't going to sit well with the parents, he said. "(His parents) are hugely distraught by the whole of the process ... (Making public an offer made confidentiality) can't benefit negotiations and it could hurt it," Handelman said. <http://www.lfpress.com/news/london/2011/02/28/17440436.html>

1. **'London Health Sciences Centre launches public information campaign.'** While medical, legal and ethical support for the best interests of 'Baby Joseph' is widespread the public has a "right to know" the truth ... [to] form their opinions based on fact, not innuendo, speculation or untruths. <http://www.newswire.ca/en/releases/archive/February2011/27/c6400.html>

N.B. Noted in Media Watch dated 28 February 2011.

Hospital confronts social media uprising over care of dying baby

GLOBE & MAIL | Online article – 1 March 2011 – One of Canada's most prestigious medical institutions has made the bold decision to go public with details of a highly emotional tug-of-war over a dying infant in an attempt to defend itself against a slew of threats, condemnations and criticisms playing out in social media. The case highlights how the emerging influence of viral videos, online campaigns and social networks can quickly damage an organization and force even the most staid institutions to change their communications strategies. <http://www.theglobeandmail.com/news/national/ontario/hospital-confronts-social-media-uprising-over-care-of-dying-baby/article1925978/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *Calgary Herald* (OpEd) – 28 February 2011 – **'There's no reset button on state-sanctioned killing.'** Instead of trying to prompt a debate on euthanasia by killing his wife with an injection of lethal drugs, Nova Scotia resident Stefan Bolton should have bent an ear toward Quebec. He would have heard abundant reasons to stay his hand. He would also ... have witnessed growing coldness to the initial fervour for normalizing them as medical treatments. <http://www.calgaryherald.com/news/There+reset+button+state+sanctioned+killing/4357450/story.html>

From Media Watch dated 28 February 2011:

- NOVA SCOTIA | CBC News – 24 February 2011 – **'Man claims mercy killing of terminally ill wife.'** A Nova Scotia man admits to giving his terminally ill wife a deadly dose of drugs, according to a report that also says he turned himself in to police. He said he came forward because he wanted to spur a public debate about euthanasia. <http://www.cbc.ca/news/canada/nova-scotia/story/2011/02/24/ns-liverpool-euthanasia-claim.html>
- QUEBEC | *Laval News* – 28 February 2011 – **'Help should always precede assisted suicide says expert.'** While acknowledging that an open investigation of assisted suicide and euthanasia is useful to educate the public, [Brian] Mishara [director of the Centre for Research & Intervention on Suicide & Euthanasia at Université du Québec à Montréal] notes that the debate obscures the fact that quality palliative care for people at the end of their lives remains largely unavailable. <http://lavalnews.ca/article/CSSS-de-Laval-annual-suicide-prevention-conference-190406>

U.S.A.

End-of-life decisions can take a toll on surrogate decision-makers

CALIFORNIA | *Los Angeles Times* – 28 February 2011 – End-of-life medical decisions, such as whether to stop treatment or discontinue life support, are often difficult for friends or relatives of an incapacitated patient. The surrogate decision-maker may wonder what the patient would have wanted or may have to deal with other friends' or relatives' varying opinions. A study published [in the *Annals of Internal Medicine*] ... finds that some surrogate decision-makers suffer from the experience for months or years. Surrogate decision-making is common in hospitals. An average of 40% of hospitalized patients can't make decisions for themselves. That figure rises to 70% if the patient is elderly and 95% if the patient is critically ill according to ... [a] new study, from the National Institutes of Health. <http://www.latimes.com/health/boostershots/1a-heb-end-of-life-decisions-20110228,0,6043108.story>

Using psychology to help caregivers

PSYCHOLOGY TODAY | Online article – 1 March 2011 – Although family caregivers might become very well trained to care for the specific needs of their particular relative's condition, they are not medical experts. This means that if something goes wrong, they may not have the background to make the most informed decisions. And unlike healthcare workers who are paid to provide treatment, many family caregivers work in 24-hour shifts. The ... demands on their time and resources mean that family caregivers are at risk for experiencing ... "caregiver burden." <http://www.psychologytoday.com/blog/fulfillment-any-age/201103/using-psychology-help-caregivers>

N.B. Scroll down to [Specialist Publications](#) for an abstract of **'Systematic review: The effect on surrogates of making treatment decisions for others'** (p.6), published in the *Annals of Internal Medicine*.

Dignity Memorial Homeless Veterans Burial Program

Unclaimed bodies of vets get military burials

MICHIGAN | Associated Press – 28 February 2011 – The bodies of two unclaimed U.S. Army veterans held at the Wayne County morgue in Detroit will receive free military burials. Anthony Bullock and William Roland Jr. were to be laid to rest ... in Holly's Great Lakes National Cemetery as part of the Dignity Memorial Homeless Veterans Burial Program. Services will include flag presentation and gun salute. The program has provided nearly 1,000 free burials for homeless and indigent veterans in 35 cities since 2000. <http://www.armytimes.com/news/2011/02/ap-unclaimed-bodies-of-vets-get-military-burials-022811/>

From Media Watch dated 3 January 2011:

- NEW YORK | *Little Falls Times* – 31 December 2010 – '**Honor Guard provides funeral services state-wide.**' The New York Army National Guard's 130 Honor Guard members helped more than 10,000 families bid a dignified farewell to their veterans at funerals in 2010. The ten New York Military Forces Honor Guard offices ... performed honors at an average of 900 funerals each month. <http://www.littlefallstimes.com/newsnow/x1599385960/NY-Honor-Guard-provides-funeral-services-statewide>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *HUFFINGTON POST* | Online OpEd – 5 March 2011 – '**Signs of hope in western states.**' The people's simple yearning for freedom and control at the end of life has been no match for the heavy-handed political power of long-established religious and medical lobbying institutions. http://www.huffingtonpost.com/barbara-coombs-lee/signs-of-hope-in-western-_b_831110.html

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.

International

Palliative care adds months to life

AUSTRALIA | *The Age* (Melbourne) – 3 March 2011 – Cancer patients wanting to live for as long as possible should receive palliative care sooner rather than later after research found it could prolong life more effectively than receiving treatment alone. In a finding that could dramatically change doctors' and patients' views of palliative care, the research also concluded that patients with lung cancer enjoyed much greater quality of life and fewer depressive symptoms if they were referred to palliative care soon after diagnosis rather than in the late stage of their disease. Melbourne cancer specialist Ian Haines said the study¹ ... represented a watershed moment for oncology because many people viewed palliative care as a default option for patients when all other avenues had been exhausted. <http://www.theage.com.au/national/palliative-care-adds-months-to-life-20110302-1bewh.html>

1. *NEW ENGLAND JOURNAL OF MEDICINE* | Online article – 18 August 2010 – **'Early palliative care for patients with metastatic non-small-cell lung cancer.'** As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life, but longer survival. <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>

N.B. Noted in Media Watch dated 23 August 2010.

Specialist Publications

Of particular interest:

'Measuring the net benefits of hospice and palliative care: A composite measure for multiple audiences – palliative net benefit' (p.11), an editorial published in the *Journal of Palliative Medicine*.

Welsh Conservatives debate on palliative care

U.K. (WALES) | BBC News – 2 March 2011 – The Welsh Conservatives called on the assembly government to increase funding and support for hospices, and to develop outreach palliative services. The government formed a Palliative Care Implementation Board in 2007 ...[that] ...wrote a report making a number of recommendations on how to improve palliative care services. Some of those recommendations were to increase Clinical Nurse Specialist capacity, and funding to develop 7 day working and the establishment of a 24-hour service consultant advice to health care professionals for adult and paediatric services. Minister for Health & Social Services Edwina Hart AM [Assembly Member] noted that central funding in 2010-2011 increased from £4 million to £6.888 million. http://news.bbc.co.uk/democracylive/hi/wales/newsid_8167000/8167442.stm

New post-mortem method developed

U.K. | BBC News – 1 March 2011 – A non-surgical autopsy technique which could remove the need to open up the body to determine a cause of death has been developed. It involves a scanner and a small incision in the neck and has so far been shown to be 80% accurate in determining the cause of death. Conventional post-mortem examinations require cutting open the body so the vital organs can be inspected. The method has been developed by the University of Leicester. <http://www.bbc.co.uk/news/science-environment-12616550>

Extract from BBC News

The conventional autopsy process can be distressing for the family and is opposed by some communities on religious grounds.

Quality of end-of-life care

'Dispatches: Secret NHS Diaries' told a harrowing but necessary story

U.K. | *Metro* (London) – 28 February 2011 – [National Health Service] NHS-bashing is something of a national sport these days – everyone seems to have a damning tale of waiting lists or superbugs and medical teams come under constant criticism. In the wake of government cuts, such attacks can seem slightly unfair, but tonight's Dispatches told a story that needed to be heard. This simple and sensitive film used secret filming to follow three terminally ill patients and the NHS care they received. Just the very concept of terminal illness is upsetting enough, but watching it unfold in front of your eyes is nothing short of distressing. Factor in the appalling way in which the NHS appears to deal with it and this Dispatches film was just heartbreaking. There were harrowing scenes as the subjects deteriorated before our eyes, while doctors and nurses reacted to them apparently without compassion. <http://www.metro.co.uk/tv/reviews/856845-dispatches-secret-nhs-diaries-told-a-harrowing-but-necessary-story>

1. Channel 4: 'Dispatches: Secret NHS Diaries'
<http://www.channel4.com/programmes/dispatches/4od#3168786>

From Media Watch dated 21 February 2011:

- U.K. | *Daily Telegraph* – 14 February 2011 – **'National Health Service shamed over callous treatment of elderly.'** The damning [Health Service Ombudsman] report warns that extra money will not help the National Health Service meet required standards of care and that more problems are likely as the population ages.¹ <http://www.telegraph.co.uk/health/healthnews/8324569/NHS-shamed-over-callous-treatment-of-elderly.html>
 1. *Care and Compassion?* Parliamentary & Health Service Ombudsman, February 2011.
<http://www.ombudsman.org.uk/about-us/media-centre/press-releases/2011/?a=6666>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- INDIA | *Med Guru* – 7 March 2011 – **'Mercy killing: Supreme Court turns down Aruna's death wish.'** India's Supreme Court has rejected a petition for the mercy killing of Aruna Shanbaug, a nurse who has been in a vegetative state since 1973.
<http://www.themedguru.com/20110307/newsfeature/mercy-killing-sc-turns-down-arunas-death-wish-86143930.html>
 - INDIA | *Times of India* – 4 March 2011 – **'Docs divided over euthanasia.'** Attorney general G E Vahanvati said in the Supreme Court that euthanasia is an un-Indian practice. He said that western parameters seldom applied to Indian culture. "We do not lead our terminally ill parents or kids to death. Who decides if one should live or die?" <http://timesofindia.indiatimes.com/city/mumbai/Docs-divided-over-euthanasia/articleshow/7623562.cms>
- AUSTRALIA (NEW SOUTH WALES) | *Sydney Morning Herald* – 7 March 2011 – **'Australia may get euthanasia clinic.'** Plans for Australia's first euthanasia clinic are likely to go ahead, Exit International director Dr. Philip Nitschke says. "There is a need for a service to provide end of life expertise for those considering using the new legislation. This is a specialist area where few doctors have expertise," Dr. Nitschke said. <http://news.smh.com.au/breaking-news-national/australia-may-get-euthanasia-clinic-20110307-1bjq5.html>
- SWISSINFO.CH | Online report – 28 February 2011 – **'Mental illness tests assisted suicide norms.'** A television documentary following the path to assisted suicide taken by a man suffering from bipolar disorder has focused debate on the practice for the mentally ill. 'Tod nach Plan' (Death by Plan) ... was echoed by the almost simultaneous screening of a documentary on Swiss-French television depicting a French writer with a non-mortal illness who travelled to Zurich to end her life. http://www.swissinfo.ch/eng/swiss_news/Mental_illness_tests_assisted_suicide_norms.html?cid=29585264

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

Researching the end-of-life in old age: Cultural, ethical and methodological issues

AGEING & SOCIETY, 2011;31(3):386-407. Cross-cultural studies and studies in which cultural factors were of prime interest were selected with a view to examining the concept of a "good death" in old age. It discusses the evidence of cultural similarities and differences and the impact of social and cultural change on ideas concerning a good death. It identifies ... influences and pressures on end-of-life care for older people and discusses the significance of communication and the roles of families and service providers. The paper identifies substantive and methodological lessons for researchers ... and suggests ways in which the impact of research might be enhanced. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8193130&ulltextType=RA&fileId=S0144686X10000966>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 4 March 2011 – '**Research priorities associated with family caregivers in palliative care: International perspectives.**' The results of this study reinforce the findings of systematic reviews that have demonstrated a need for the evolution of intervention development focused on improving family caregiver support. However, there are other key areas that also warrant comprehensive attention, including marginalized family caregivers and strategies to assist health professionals to identify family caregivers who have significant psychosocial issues. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0345>

The effect on surrogates of making treatment decisions for others

ANNALS OF INTERNAL MEDICINE | Online article – 28 February 2011 – Forty studies, 29 using qualitative and 11 using quantitative methods, provided data on 2,854 surrogates, more than one half of whom were family members of the patient. Most surrogates were surveyed several months to years after making treatment decisions, the majority of which were end-of-life decisions. The quantitative studies found that at least one third of surrogates experienced a negative emotional burden as the result of making treatment decisions. The qualitative studies reported that many or most surrogates experienced negative emotional burden. The negative effects on surrogates were often substantial and typically lasted months or, in some cases, years. The most common negative effects cited by surrogates were stress, guilt over the decisions they made, and doubt

regarding whether they had made the right decisions. Nine of the 40 studies ... reported beneficial effects on a few surrogates, the most common of which were supporting the patient and feeling a sense of satisfaction. Knowing which treatment is consistent with the patient's preferences was frequently cited as reducing the negative effect on surrogates. <http://www.annals.org/content/154/5/336.abstract?sid=f6073a72-011f-4649-a4bb-1a4fa9e1f04e>

Extract from *Annals of Internal Medicine*

Making treatment decisions has a negative emotional effect on at least one third of surrogates, which is often substantial and typically lasts months (or sometimes years).

Of related interest:

- *ELDER LAW ATTORNEY* (New York State Bar Association), 2011;21(1):32-39. '**Hospice and palliative care in New York: Changing landscape for patients, families and providers in health decision making.**' In New York State, the integrated approach that has already begun to the implementation of the FHCDA [Family Health Care Decisions Act], the PCIA [Palliative Care Information Act] and the MOLST [Medical Orders for Life-Sustaining Treatment] program aligning patient goals with policy goals, systems objectives and professional training will facilitate adjustments to these changes at all levels. <http://www.redlig.com/Dec10-nysba.pdf#page=32>

Cont.

- *JOURNAL OF MEDICAL ETHICS* | Online article – 27 February 2011 – '**Advance directives and older people: Ethical challenges in the promotion of advance directives in New Zealand.**' This paper considers some of the specific challenges that need to be addressed if the promotion of advance directives are to improve outcomes of patient treatment and care near the end of life. Caution should be exercised in promoting advance directives to older people, especially in light of several factors: ageist attitudes and stereotypes towards them, challenges in the primary healthcare setting, and the way in which advance directives are currently focused and formulated. <http://jme.bmj.com/content/early/2011/02/25/jme.2010.039701.abstract>

N.B. New Zealand rated 3rd 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 death of a patient: A model for reflection in GP training

BMC FAMILY PRACTICE | Online article – 3 March 2011 – The Dutch government has chosen a policy of strengthening palliative care in order to enable patients to die at home according to their preference. In order to facilitate this care by GPs, the authors wanted to know how to support them in their training. They examined the ways in which the death of a patient influences the doctor both at a professional and at a personal level. Forty-three themes emerged from the interviews and focus group. They fell into three groups: professional values and experiences, personal values and experiences, and the opinions of the GPs as to what constitutes a good death. The authors constructed a model of the doctor-patient relationship on the basis of these findings. This model enables GP trainees [in] identifying the unique character of the doctor-patient relationship as well as its reciprocity when the two were confronted by the patient's impending death. <http://www.biomedcentral.com/content/pdf/1471-2296-12-8.pdf>

Of related interest:

- *CANCER* | Online article – 1 March 2011 – '**Hematology/oncology fellows' training in palliative care: A national study.**' Palliative care is recognized as integral to the practice of oncology, yet many oncologists report inadequate training in critical palliative care domains, such as symptom management, psychosocial care, and communication skills. The authors of this report sought to assess the quantity and quality of palliative care education within oncology fellowships. [Respondents to a survey] rated the quality of palliative care education as inferior to overall oncology training and may benefit from more teaching on pain management, psychosocial care, and communication skills. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.25952/abstract>

Media Watch Online

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

Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/Resources/Usefullinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation Services: <http://www.hpconnection.ca/newsletter/inthenews.html>

Ontario | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm>
(Scroll down to 'Newsletters/Media Updates')

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/search/?tag=Media+Watch>

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

The perspectives of clinical staff and bereaved informal care-givers on the use of continuous sedation until death for cancer patients

BMC PALLIATIVE CARE | Online article – 4 March 2011 – A significant minority of dying people experience refractory symptoms or extreme distress unresponsive to conventional therapies. In such circumstances, sedation may be used to decrease or remove consciousness until death occurs. This practice is described in a variety of ways, including: 'palliative sedation,' 'terminal sedation,' 'continuous deep sedation until death,' 'proportionate sedation' or 'palliative sedation to unconsciousness.' Surveys show large unexplained variation in incidence of sedation at the end of life across countries and care settings and there are ethical concerns about the use, intentions, risks and significance of the practice in palliative care. There are also questions about how to explain international variation in the use of the practice. This protocol relates to the UNBIASED (UK Netherlands Belgium International Sedation) Study. The aims are

to explore decision-making surrounding the application of continuous sedation until death in contemporary clinical practice, and to understand the experiences of clinical staff and decedents' informal caregivers of the use of continuous sedation until death and their perceptions of its contribution to the dying process.

<http://www.biomedcentral.com/content/pdf/1472-684x-10-5.pdf>

Extract from *BMC Palliative Care*

To the authors' knowledge, this is one of the few studies which seek to take a qualitative perspective on clinical decision making surrounding the use of continuous sedation until death and the only one which includes the perspectives of nurses, physicians, as well as bereaved informal care-givers.

Of related interest:

- *AMERICAN JOURNAL OF HEALTH SYSTEM-PHARMACY*, 2011;68(6):523-527. **'Developing policy, standard orders, and quality-assurance monitoring for palliative sedation therapy.'** Development of policy, standard orders, and quality-assurance monitoring for PST [palliative sedation therapy] required a formal multidisciplinary process. A process-improvement process is critical to defining institutional policy, educational goals, and outcome metrics for PST. <http://www.ajhp.org/content/68/6/523.abstract>

From Media Watch dated 14 February 2011:

- *PHILOSOPHY, ETHICS & HUMANITIES IN MEDICINE* | Online article – 8 February 2011 – **'The ethical and legal aspects of palliative sedation in severely brain injured patients: A French perspective.'** The issue of palliative sedation deserves particular attention in adults with serious brain injuries and in neonates with severe and irreversible brain lesions, who are unable to express pain or to state their wishes. In France, treatment limitation decisions for these patients are left to the physicians. <http://www.peh-med.com/content/pdf/1747-5341-6-4.pdf>

N.B. Articles, editorials, guidelines by professional bodies, etc., on the issue of palliative sedation have been featured in many past issues of Media Watch. A sample listing appears in the weekly report dated 17 January 2011 (p.8).

Informing severely ill patients: Needs, shortcomings and strategies for improvement

BREAST CARE, 2011;6(1):8-13. The patients' knowledge and understanding will support the coping process, improve comfort and enhance patient participation and autonomy. Since information needs are highly individual and vary throughout the course of the disease, an interactive approach of assessing the patients' needs and responding to them adequately is mandatory. In this article, the information needs of advanced cancer patients and their families are explained, shortcomings of the present information concepts are discussed, and an integrative approach to responding to patients' information needs throughout the care pathway is advocated. <http://content.karger.com/ProdukteDB/produkte.asp?Doi=324563>

Bringing palliative care to the homeless

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article (see sidebar) – 1 March 2011 – Canadian palliative care programs are generally created with the needs of mainstream society in mind. Though these systems attempt to accommodate everyone, the unique challenges of serving marginalized populations make this difficult. And there is perhaps no population more challenging to assist in dying than the homeless. Yet this population needs support more than most others, says Wendy Muckle, executive director of Ottawa Inner City Health ... that aims to help homeless people receive the same quality of health care as other Canadians. "With the homeless, I would argue that their need and right to have support through the end of life is even greater than the mainstream populations because of the suffering they have already experienced in their lives and the fact that their housing status would imply that they have poorer capacity to cope than others," Muckle writes. "However, to take the values of palliative care and apply them to the homeless is problematic as sometimes the values are not the same or the interpretation of the values is pretty different. The challenge to health providers is to suspend judgement and truly accept the right of the

homeless patient to define the end of life experience from their own values and perspective." http://www.cmaj.ca/earlyreleases/1mar11_bringing-palliative-care-to-the-homeless.dtl

This is the eleventh article in a series on end-of-life care (all of which were noted in Media Watch on being posted or published)

Part I: 'Preparing for the inevitable.'

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3704)

Part II: 'Advance directives: Obstacles in preparing for the worst.' (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3743)

Part III: 'End-of-life planning framework calls for fewer checklists, more conversation.'

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3746)

Part IV: 'Tools help patients tackle tough choices for end-of-life care.'

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3750)

Part V: 'National home care standards urged.'

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3731)

Part VI: 'Access to palliative care varies widely across Canada.' (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3763)

Part VII: 'Framework urges physicians to proceed with caution on palliative sedation.'

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3766)

Part VIII: 'Pocket-sized help for people with dementia.'

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3705)

Part IX: 'Grief therapy for those left behind.'

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3793)

Part X: 'Providing hospice in the womb.'

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3776)

From Media Watch dated 13 December 2010:

- U.K. | National End of Life Care Programme – 8 December 2010 – '**End of life care – achieving quality in hostels and for homeless people.**' *End of life care – achieving quality in hostels and for homeless people – a route to success* is designed to provide a practical guide to support hostel staff in ensuring that people nearing the end of their life receive high quality end-of-life care. http://www.endoflifecareforadults.nhs.uk/assets/downloads/RTS_Homeless_Final_20101208.pdf

From Media Watch dated 15 November 2010:

- CANADIAN HEALTHCARE NETWORK | Online article – 9 November 2010 – '**End-of-life care for homeless.**' It's a tough subject, even for people with stable housing and plenty of support: Where and how do they wish to be cared for as life draws to a close? But for homeless and marginalized people on the streets of Halifax, Nova Scotia, there's a good chance that, when their time comes, they may not have the opportunity to choose the kind of end-of-life care that they would prefer. <http://www.canadianhealthcarenetwork.ca/nurses/news/movers-shakers/monica-flinn-end-of-life-care-for-homeless-6956>

Improving access to pediatric palliative care

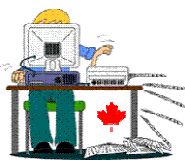
INTERNAL MEDICINE NEWS | Online article – 4 March 2011 – Stefan J. Friedrichsdorf has a list of "myths" about pediatric palliative care that he presents during lectures. Among them: that the death of a child in the U.S. is a rare event, that pediatric palliative care is just for children with cancer, and that care starts when treatment stops. In his lectures – and in his work every day at Children's Hospitals & Clinics of Minnesota, Minneapolis – Dr. Friedrichsdorf debunks these myths. The pain and palliative care program at Dr. Friedrichsdorf's institution is a relatively long-standing program, but pediatric palliative care is a new subspecialty and is still a relatively new area of pediatric care and of palliative medicine – one for which delivery models and educational pathways are still evolving, and one for which reimbursement is poor and regulatory barriers are challenging. More than 15,000 children and teens die in the United States each year from life-limiting diseases – and less than a quarter of them have cancer, according to data cited by Dr. Friedrichsdorf. Neuromuscular or neurodegenerative disorders cause a significant proportion of those deaths, followed by congenital or genetic disorders, cardiovascular disorders, and metabolic disorders. <http://www.internalmedicineneeds.com/news/oncology-hematology/single-article/improving-access-to-pediatric-palliative-care/c1d363a8fa.html>

Palliative care in advanced heart failure: An international review of the perspectives of recipients and health professionals on care provision

JOURNAL OF CARDIAC FAILURE, 2011;17(3):231-252. This systematic literature review aimed to collate qualitative and quantitative evidence on: 1) patients' perceived needs and experiences of care provision; and, 2) the perspectives and understanding of health professionals on care delivery. Advanced HF patients report little discussion with health professionals about their clinical status and sense a lack of timely support to accommodate their evolving needs. Health professionals report poor multidisciplinary communication and lack confidence both in diagnosing advanced HF and in communicating a poor prognosis to those affected, affecting the provision of good-quality coordinated care. [http://www.onlinejcf.com/article/S1071-9164\(10\)01144-9/abstract](http://www.onlinejcf.com/article/S1071-9164(10)01144-9/abstract)

Of related interest:

- *THE MEDICAL POST* | Online report – 3 March 2011 – '**Guidance lacking for palliative care of stroke patients.**' Not only stroke patients but their families have palliative-care needs that are often not being met. "There are very few guides in the medical literature for palliative treatment of dying stroke patients," said Dr. Dylan Blacquiere, a neurology resident at the University of Ottawa [Ontario, Canada]. <http://www.canadianhealthcarenetwork.ca/physicians/magazines/the-medical-post/march-8-2011/guidance-lacking-for-palliative-care-of-stroke-patients-14661>



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.

Measuring the net benefits of hospice and palliative care: A composite measure for multiple audiences – palliative net benefit

JOURNAL OF PALLIATIVE MEDICINE, 2011;14(3):264-265. As a sector, hospice and palliative care services have been poor at "selling" their benefits to funders and the community more broadly. As a sector, we need to do better, be smarter, and ensure we are delivering a handful of key messages on behalf of the people who benefit from our services. To date, no one single outcome measure has been developed that captures the net benefit of involving hospice or palliative care services. Yet funders are looking for reasons to justify the investment in these services (or, more frighteningly, to disinvest). The benefits from provision and receipt of palliative care should be captured from the four main stakeholders: patients, their caregivers, involved clinical staff, and the health system(s) through which that care is provided. Smith and colleagues explore the issues which are important to caregivers when reflecting back on the death of a loved one.¹ Although 14 domains were explored covering the last month of the person's life and one global rating was subsequently assessed, the data make things clear. First, there is wide variation even among bereaved family members about what constitutes quality care at the end of life. Second, the factors identified by caregivers may differ from those identified by patients and health professionals; such differences

have been reported before.² The important contribution by the work of Smith and associates is that it begins to quantify and to weight the relative importance of key aspects of care at the end of life by people who have experienced (as recipients of care themselves from hospice and palliative care services) and provided that care (as caregivers for people who are dying).
<http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2011.9722>

Building on community assets to improve palliative and end-of-Life care

JOURNAL OF SOCIAL WORK IN END OF LIFE & PALLIATIVE CARE, 2011; The authors describe the development of a multidisciplinary, interfaith, grassroots community group of professionals and laypersons who have created a replicable model to enhance palliative and end-of-life care. The Collaborative for Palliative Care leverages existing community assets and capacities within the health and social service programs of Westchester County, New York, resulting in a unique public-private partnership. It has played a critical role in changing the culture of care for residents of Westchester who are faced with the challenges of serious and terminal illness. <http://www.informaworld.com/smpp/content~db=all~content=a934225179~frm=abslink>

1. **'Can we make reports of end-of-life care quality more consumer-focused? Results of a nationwide quality measurement program,'** *Journal of Palliative Medicine*, 2011;14(3):301-307. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0321>

N.B. Noted in Media Watch dated 7 February 2011.

2. **'Factors considered important at the end of life by patients, family, physicians, and other care Providers,'** *Journal of the American Medical Association*, 2000;284(19):2476-2482. <http://jama.ama-assn.org/content/284/19/2476.abstract>

[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/>

To medicalize mourning

THE MCGILL DAILY (University of McGill, Montreal, Quebec, Canada) | Online article – 3 March 2011 – Over the past 25 years in the Diagnostic & Statistical Manual of Mental Disorders (DSM) has expanded to allow room for a number of "new" disorders. Included in this growing group is "Complicated Grief," or "Prolonged Grief Disorder," which is being considered for a spot in the DSM-V, due out in 2013. While many psychiatrists believe that pathological grief has long deserved a place in diagnostic nomenclature, its potential inclusion as a mental disorder has great implications for how we understand and negotiate a fundamental human experience: the death of a loved one. <http://www.mcgilldaily.com/2011/03/to-medicalize-mourning/>

From Media Watch dated 7 February 2011:

- *DEPRESSION & ANXIETY*, 2011;28(2):103-117. **'Complicated grief and related bereavement issues for DSM-5.'**¹ Normally, grief does not need clinical intervention. This article focuses primarily on a discussion of possible inclusion of a new diagnosis and dimensional assessment of complicated grief. <http://onlinelibrary.wiley.com/doi/10.1002/da.20780/abstract>
 1. *Diagnostic & Statistical Manual of Mental Disorders IV*, American Psychiatric Association (due for publication May 2013).

From Media Watch dated 16 August 2010:

- *NEW YORK TIMES* | Online OpEd – 14 August 2010 – **'Good grief.'** A startling suggestion is buried in the fine print describing proposed changes for the fifth edition of the *Diagnostic & Statistical Manual of Mental Disorders* – perhaps better known as the DSM 5, the book that will set the new boundary between mental disorder and normality. If this suggestion is adopted, many people who experience completely normal grief could be mislabeled as having a psychiatric problem. http://www.nytimes.com/2010/08/15/opinion/15franceses.html?_r=1

From Media Watch dated 9 August 2010:

- NATIONAL PUBLIC RADIO (NPR) | Online report – 2 August 2010 – **'Is emotional pain necessary?'** Traditionally, the American Psychiatric Association's manual of mental disorders has warned doctors away from diagnosing major depression in people who have just lost a loved one. <http://www.npr.org/templates/story/story.php?storyId=128874986>

Worth Repeating

Attending to the pain of the dying: An agenda for science

JOURNAL OF MEDICINE AND THE PERSON, 2009;7(1):1-3. The medical treatment of the dying is almost invisible today, an embarrassing situation that can only get worse as the rest of medical science succeeds in allowing a greater fraction of the population live into old age with sufficient residual mental and physical capacity to understand their situation. For the sake of these lucky people ... medical science is obligated now to begin a research effort focused on making dying itself as brief, and as healthy, as possible. This is no joke: the hospice movement – not a product of scientific medicine but a reaction to it – has shown that a dying accompanied by a minimum of pain and a maximum of social interaction is healthier and better by far than the typical dying of today, accompanied as it is so often by prolonged agony and isolation. For most of my life ... I scrupulously avoided my own personal and professional responsibility to attend to the dying. It is not that I had no chances to make the connection between science and dying. I simply chose not to take them. In my own confusion, I lost sight of the fundamental truth that dying is as distant from death as any other stage in life is. <http://www.springerlink.com/content/c287743gp162472m/>

Barry R. Ashpole
Beamsville, Ontario CANADA

'phone: 905.563.0044
e-mail: barryashpole@bellnet.ca