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

Distinguishing between preferred place of care and preferred place of death: Scroll down to <u>Specialist Publications</u> and 'Achieving the preferred place of care for hospitalized patients at the end of life' (p.11), published in *Palliative Medicine*.

Canada

Fear of ghosts spawns protest against ... hospice

BRITISH COLUMBIA | CTV News - 13 January 2011 – Asian condo owners at the University of B.C. are protesting plans to build a hospice nearby, saying they're afraid of plummeting property values – and ghosts. Janet Fan, who owns a unit in a high rise on campus, has started a petition against plans for a 15-bed hospice in the empty lot next door (see sidebar). "Eighty per cent of the residents in this building are Asian, and 100% of them are very upset," she told CTV News. Tan says the ... residents are wary of having the dying so close to home. "We believe that if the living and the dying are too close to each other, it will bring very bad fortune, as well as it will be harmful to the children. It's just something we were taught when we were little kids," she said. "Our parents would say things like that ghosts are associated with death and we were just very afraid of the whole death thing." The site was selected for the hospice after a fouryear review of 12 possible locations. A final decision on the hospice ... has now been delayed because of opposition to the project.http://www.ctvbc.ctv.ca/servlet/an/loc al/CTVNews/20110113/bc ubc hospice 11 0113/20110113?hub=BritishColumbiaHome

All Canadians should accept death in their backyard

GLOBE & MAIL | Online OpEd - 14 January 2011 –To say "not in my backyard" to a hospice is the worst imaginable form of Nimbyism [not in my back yard-ism], whether the underlying reason is the alleged "cultural sensitivities" of some Chinese Canadians or something else. It would surely be an unreasonable accommodation to banish the sick, the gasping, the frail, for the sake of someone's cultural values, taboos or superstitions. Ms. Fan and other opponents ask for a kind of legally sanctioned discrimination against a group that, to borrow from human-rights terminology, is "historically disadvantaged" and always will be. To permit such discrimination would be repugnant and ridiculous. It would be wrong, though, to assume the Chinese-Canadian community is homogeneous in its views on hospices, or on death and dying. http://www.theglobeandmail.com/news/opinions/e ditorials/all-canadians-should-accept-death-intheir-backyard/article1871293/

There's no manual for home death

GLOBE & MAIL | Online article – 10 January 2011 – It could be that death at home is a lot like a home birth – risky, unpredictable and subject to complications. Except, I suppose, that the challenge is saving the dignity of the old life rather than welcoming the new. My brother and I weren't strangers to home death. We had been caregivers for our father, who died of cancer when we were in our 20s. Still, I would have liked to be able to refer to a book I have yet to see in print that I imagined would be titled: The ABCs of Home Death. When I told ... [my mother's] ... doctor that she had chosen to die at home, he was skeptical and advised hospitalization. He wanted to test her heart, her kidneys, her blood. He prescribed a cocktail of pills, all encased in bubble packs. He wasn't sure how the morphine would affect her mentally. Above all, he refused to say how long she might live. http://www.theglobeandmail.com/life/facts-and-arguments/theres-no-manual-for-home-death/article1862122/

Of related interest:

■ NOVA SCOTIA | Halifax News (OpEd) – 13 January 2011 – 'When it comes to helping family caregivers, we can do better.' Today, 2.7 million Canadians provide care for seniors, and by 2017 it is estimated that the number of seniors with chronic conditions requiring home care services will increase by one-third. http://www.halifaxnewsnet.ca/Opinion/2011-01-13/article-2113801/When-it-comes-to-helping-family-caregivers-we-can-do-better/1

Specialist Publications

Of particular interest:

'Framework urges physicians to proceed with caution on palliative sedation' (p.8), published in the Canadian Medical Association Journal.

U.S.A.

Report calls for action to stem Alzheimer's deluge

MINNESOTA | *Star-Tribune* (Minneapolis-St. Paul) – 13 January 2011 – The number of Minnesotans with Alzheimer's disease and other forms of dementia will swell from 88,000 now to 198,000 in the next 30 years, with the prospect that state coffers, families and employers could be overwhelmed by the stress and costs of care, according to a report that will be delivered to the Legislature. Fear of the disease and ignorance about treating symptoms have kept many Minnesotans from getting help until caregivers are exhausted and in chaos, advocates say. The result ... is a heavy drain on personal and state finances as patients are placed sooner than necessary in nursing homes and families are battered by the unrelenting stress of caregiving. http://www.startribune.com/lifestyle/health/113427524.html?elr=KArks7PYDiaK7DUHPYDiaK7DUiD3aPc: Yyc:aUoD3aPc: 27EQU

From Media Watch dated 11 January 2010:

- CANADA | National Post 5 January 2010 'Preparing for a deluge of dementia.' Nearly a half million Canadians ... currently suffer from some form of dementia, such as Alzheimer's disease. Thirty years from now, as baby boomers age and live longer than any previous generation, that figure will rise to over 1.1 million, according to a new study by the Alzheimer Society of Canada. http://network.nationalpost.com/np/blogs/fullcomment/archive/2010/01/05/national-post-editorial-board-preparing-for-a-deluge-of-dementia.aspx
 - Rising Tide: The Impact of Dementia on Canadian Society, Alzheimer Society of Canada, 2010. http://www.alzheimer.ca/english/rising_tide/rising_tide_report.htm

U.S. nursing home closings hit poor neighborhoods hardest: Study

BLOOMBERG BUSINESS WEEK | Online report – 10 January 2011 – Widespread nursing home closures over the past decade have resulted in a 5% drop in available nursing home beds across the U.S., with poor, urban neighborhoods hardest hit, new research reveals. The country's minority population is aging at a steeper rate compared with the white population, said study lead author Zhanlian Feng, an assistant professor of community health in the Center for Gerontology & Health Care Research at Brown University [Providence, Rhode Island]. And so the potential need for long-term care is rising fastest in minority communities, even as nursing home closings are happening more often in their areas. This disproportionate impact of nursing home closings on minority and low-income communities will have all sorts of implications in terms of access and quality of care issues. http://www.businessweek.com/lifestyle/content/healthday/648664.html

ARCHIVES OF INTERNAL MEDICINE | Online article – 10 January 2011 – 'Geographic concentration and correlates of nursing home closures: 1999-2008.' Nursing home closures are geographically concentrated in minority and poor communities. Since nursing home use among the minority elderly population is growing while it is declining among whites, these findings suggest that disparities in access will increase. http://archinte.ama-assn.org/cgi/content/full/archinternmed.2010.492

Of related interest:

ARCHIVES OF INTERNAL MEDICINE | Online article – 10 January 2011 – 'Medicare expenditures among nursing home residents with advanced dementia.' Medicare expenditures among nursing home residents with advanced dementia vary substantially. Hospitalizations and hospice account for most spending. http://archinte.ama-assn.org/cgi/content/short/archinternmed.2010.478

Era of Indiana online death registry begins

INDIANA | Evansville Courier-Press – 10 January 2011 – Families now should be able to obtain death certificates necessary to collect on life insurance policies and pensions and complete burial arrangements faster thanks to Indiana's new electronic system that makes it easier for local officials to complete death records. However, doctors, funeral directors and coroners could face criminal charges and a \$1,000 fine for failure to complete information in the Indiana Death Registry System in a timely manner. http://www.courierpress.com/news/2011/jan/10/era-of-online-death-registry-begins-doctors-at/

Assisted (or facilitated) death

Representative sample of recent news media coverage:

MONTANA | KRTV News (Grand Falls) – 12 January 2011 – 'Montana lawmaker sponsors bill to address "aid in dying."' State Senator Anders Blewett ... introduced a bill ... in the Montana Legislature which would allow terminally ill patients to choose aid in dying. Blewett says the bill is in response to the Montana Supreme Court ruling in Baxter v. Montana. http://www.krtv.com/news/mt-lawmaker-sponsors-bill-to-address-aid-in-dying-/

From Media Watch dated 8 November 2010:

■ THE HASTINGS REPORT, 2010;40(6):15-17. 'Baxter and the return of physician-assisted suicide.'
Physician-assisted suicide is legal in Oregon and Washington. Until very recently, it has been illegal in every other state, and claims to its being a federal constitutional right were rejected by the U.S. Supreme Court a dozen years ago in the Glucksberg and Quill decisions. But a recent development in Montana has altered the landscape somewhat. On December 31 of last year, the Montana Supreme Court decided Baxter v. Montana, a case that most observers thought would clarify the status of physician-assisted suicide under Montana's constitution. The court, it turns out, decided not to do that – not now, at least. http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=4956

International

Hospices facing widespread cuts in funding

U.K. | Eulogy - 13 January 2011 - A nationwide survey last month found that around 30% of hospices in the U.K. have suffered cuts in their statutory funding in 2010. Despite an extra £150m in state funding being injected into hospice and palliative care in 2010-2011 by means of the End of Life Care Strategy, hospices across the country are losing out. The survey. conducted by Help the Hospices and The National Council for Palliative Care. examined the funds being made available to over 100 adult palliative care providers in England. A third of these providers reported that they were aware of cuts already impacting upon local palliative services. With an ageing population, an increase in demand for their services in the near future seems set to put further strain on the palliative and hospice care sectors, already stretched as they are. Jonathan Ellis, director of public policy and parliamentary affairs at Help the Hospices, commented: "This survey reinforces the need for a fair and transparent system of funding for hospices that recognises the true value of the care hospices provide to people facing the end of life, and their friends and family. It is concerning that nearly 30% of hospices surveyed have already had their statutory funding cut this year and it is frustrating that in many areas the extra funding allocated to hospice and palliative care is still not getting through to frontline services." http://www.eulogymagazine.co.uk/article/late

http://www.eulogymagazine.co.uk/article/late -news/detail/id/75

From Media Watch dated 6 December 2010:

U.K. | BBC News – 2 December 2010 – 'Review says National Health Service must ensure good palliative care.'
The NHS [National Health Service] in England has failed to take responsibility for ensuring good end-of-life care, according to an independent review.¹
The paper highlights some organisations that are doing "excellent" work. But it says funding and services have developed ad hoc. The report says this

(Cont. next column)

variation has had damaging consequences. "The 'postcode lottery' within palliative care means that patients with the same diagnosis in different geographical locations can expect very different levels of service," it states. The review says although most people say they would like to be cared for and die in their own home or care home, the proportion who achieve this is "very small." http://www.bbc.co.uk/news/health-11902757

 Palliative Care Funding Review Interim Report, December 2010. http://www.palliativecarefunding.org.uk/l nterimReport.pdf

Improvements to continue in end-of-life care

U.K. | Courier Press (Isle of Wight) - 12 January 2011 - Significant progress has been made to improve end-of-life care services on the Island. health chiefs have said. Following an NHS [National Health Service] consultation with patients and relatives, which revealed too many people were dying in hospital when they would have preferred to be cared for at home, steps were taken to develop new services. In 2009, there were 1,648 deaths on the Island, of which 49% were at St Mary's Hospital, 21% at residential or nursing homes, 17% at home, 9% at the Earl Mountbatten Hospice, and 9% elsewhere. But a patient survey revealed around 66% of patients would prefer to die at home while only 9% wanted to die in hospital. Since the publication of the Isle of Wight End-of-Life Care Strategy in September 2009, a specialist palliative care team has been developed at St Mary's and new end-of-life care equipment has been bought to enable people to remain in their own homes. End-of-life care beds and an end-oflife care garden have been established at the Island's prison, and a unified Do Not Attempt Cardiopulmonary Resuscitation policy has been adopted.http://www.iwcp.co.uk/news/news/improv ements-to-continue-in-endoflife-care-36672.aspx

Specialist Publications

Of particular interest:

'Why do health professionals refer individual patients to specialist day hospice care?' (p.10), published in the *Journal of Palliative Medicine*.

Law allows withdrawal of life support

TAIWAN | *The China Post* (Taipei) – 11 January 2011 – Terminally ill and non-cognitive patients will have a third chance of ending their lives peacefully with a diagnosis from medical experts explaining an incurable condition and the consent of their closest family members, according to the latest amendment to the Hospice & Palliative Care Act ratified by the Legislative Yuan. The new rules ... mark an obvious change from the present situation in which life support for patients can be terminated only if families could prove that the patients had expressed their wish not to be resuscitated by extraordinary measures, including cardiopulmonary resuscitation. http://www.chinapost.com.tw/taiwan/national/national-news/2011/01/11/287158/Law-allows.htm

Proposal to rein in treatment for elderly 'horrifying'

U.K. (SCOTLAND) | *The Herald* (Glasgow) – 11 January 2011 – Proposals to rein in aggressive therapies and treatments for older people in the final stages of life have been compared to "euthanasia for the elderly" by one of Scotland's foremost patient advocates. Dr. Jean Turner said she had been horrified by suggestions put forward in *The Herald* ... by Professor Phil Hanlon, a former adviser to the Scottish Executive, that the elderly should be prescribed far fewer drugs and given fewer tests and procedures as they enter physical decline. Mr. Hanlon said he feared that unmitigated expansion of the NHS [National Health Service], combined with an eventual crash in funding, "would be bad for everyone" and that a shift in approach was needed to prevent the health service becoming unsustainable. http://www.heraldscotland.com/news/health/proposal-to-rein-in-treatment-for-elderly-horrifying-1.1079090?localLinksEnabled=false

U.K. (SCOTLAND) | The Herald (Glasgow) – 12 January 2011 – 'The elderly require honest information about what they can expect from the NHS.' It is unfortunate that ... [Prof. Hanlon's] well-considered views might now "struggle for air" between the Age Scotland and the assisted suicide lobbies. The edict emphasised by Age Scotland and supported by many in the profession that "the NHS must treat all equally, the rich and the poor, the young and the old" had the unintended consequence of cattle-herding octogenarians across Scotland to "direct to test" colonoscopies with scant regard for the distress caused to patients (and their carers) and the unknown mortality which may have resulted. http://www.heraldscotland.com/comment/herald-letters/letters-12-january-2011-1.1079418

N.B. Age Scotland is an advocacy group representing Scotland's elderly population.

The terrible price of cutbacks for palliative care patient Rebecca (4)

IRELAND | *Tribune* (Dublin) – 9 January 2011 – A terminally ill four-year-old girl is facing the loss of vital nursing support services due to government cutbacks which could mean she will be forced back into hospital rather than being cared for at home. This is despite that caring for her in hospital will cost the state significantly more than if she were to remain in the care of her parents. Rebecca Crowley, who is currently receiving palliative care from a combination of the HSE [Health Service Executive] and the Jack & Jill Foundation, has a brain disorder called lissencephaly and she requires round-the-clock care. Although the ... Foundation said it was able to provide homecare nursing services at a significantly cheaper cost than the HSE, it has had to withdraw such services for children such as Rebecca who are aged four and over due to a funding shortfall. The foundation has estimated that up to 100 children which it cares for could be forced to return to hospital, at a cost of more than €14m to the state, because the HSE has refused to bridge a funding gap for the charity of just €750,000. While the foundation has continued to provide two-nights-a-week care to Rebecca, it warned that its funding situation meant this could not continue indefinitely, and that the HSE was required to step in. http://www.tribune.ie/news/article/2011/jan/09/the-terrible-price-of-cutbacks-for-palliative-care/

There are few hospices and most hospitals turn away terminally ill patients

CHINA | The Straits Times (Singapore) - 8 January 2011 – Walking into the apartment, Dr. Lu Qi saw an elderly man rubbing his head over and over in distress. His right eye was hanging from its socket and a growth protruded from one ear. The retired professor, who had been suffering from nose cancer, could no longer speak and could barely see. But bloodied tears streamed down his cheeks when he was able to comprehend that a doctor had finally come to see him. As he fumbled to get off his seat to kowtow in gratitude to Dr. Lu, she sobbed as well. For Dr. Lu – a doctor of internal medicine for 37 years and a hospital administrator for another 15 years – that shocking, troubling scene was emblematic of China's current struggle to take care of its terminally ill. "I had never realised a patient with late-stage cancer would be waiting for death at home like that, with no dignity at all," Dr. Lu said, recalling the episode that took place last April. That convinced her to start a palliative care service at the community health centre in west Beijing's Deshengmen area where she works, offering needy or desperate patients solace in their final days. Her non-profit centre, set up in October to offer medical advice and prescriptions for terminally ill patients who are dying at home, is extremely rare in this vast and rapidly ageing country of 1.3 billion. http://admpreview.straitstimes.com:90/vgnext-

templating/v/index.jsp?vgnextoid=42f0a2570 f06d210VgnVCM100000430a0a0aRCRD&v gnextchannel=4e60758920e39010VgnVCM 1000000a35010aRCRD

 China rated 37th 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/QO D main final edition Jul12 toprint.pdf

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

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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.

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/

Assisted (or facilitated) death

Representative sample of recent news media coverage:

AUSTRALIA | ABC News – 12 January 2011 – 'A local Nationals MP supports debate on euthanasia despite opposing it.' The Australia Institute poll of almost 1300 people found 71% of Coalition voters said a doctor should be allowed to help someone with a terminal illness to end their life, if their suffering could not be relieved. The Nationals MP Michael McCormack said while he would welcome a national debate on euthanasia, he opposes assisted death. http://www.abc.net.au/news/stories/2011/01/12/3111070.htm

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

"These people are dying; we don't want to make them die faster."

Palliative care researchers tackle whether to stop statins for terminally ill

AMERICAN MEDICAL NEWS | Online article - 11 January 2011 - Research in palliative medicine is moving into determining what kinds of care can be withdrawn safely for patients near the end of life, say doctors behind a new research consortium. The Palliative Care Research Group, a coalition of nine organizations that its leaders say is the first of its kind, was formed in January 2010. The two leaders of the group, the Duke University School of Medicine and the University of Colorado School of Medicine, were awarded a \$7.1 million National Institute of Nursing Research grant. The money will fund the group's multisite clinical trial starting in 2011 to investigate the effect of stopping statins in 1,200 patients with terminal illnesses. "We're focused on doing the clinical research required to improve the evidence base for what we have, and what we do, in palliative care," said Amy P. Abernethy, MD, director of the Duke Cancer Care Research Program in North Carolina. "The consortium is intended to do the hard work of figuring out what works and what doesn't in the palliative care toolbox." Physicians are split, for example, on whether to stop prescribing statins and many other medications for chronic conditions when caring for patients with terminal illnesses. Patients' quality of life might be improved if they could be freed of nagging side effects such as the muscle pain often associated with cholesterollowering statins. But some doctors are concerned that actions intended to reduce polypharmacy could shorten survival times or lead to other adverse consequences, she said, http://www.amaassn.org/amednews/2011/01/10/prsb0111.htm

Literature review

End-of-life care conversations with heart failure patients

BRITISH JOURNAL OF GENERAL PRACTICE, 2011;61(582):e49-e62. Current models of end-of-life care (EOLC) have been largely developed for cancer and may not meet the needs of heart failure patients. Conversations focus largely on disease management; EOLC is rarely discussed. Some patients would welcome such conversations, but many do not realise the seriousness of their condition or do not wish to discuss end-of-life issues. Clinicians are unsure how to discuss the uncertain prognosis and risk of sudden death; fearing causing premature alarm and destroying hope, they wait for cues from patients before raising EOLC issues. The implications [of the findings of the literature review] for policy and practice are discussed: such conversations can be supportive if expressed as "hoping for the best but preparing for the worst."

Of related interest

■ JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 14 January 2011 – 'Is the patient's voice under-heard in family conferences in palliative care? A question from Sydney, Australia.' No abstract available. http://www.jpsmjournal.com/article/S0885-3924(10)00983-8/fulltext

Framework urges physicians to proceed with caution on palliative sedation

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article - 4 January 2011 Easily the most controversial tool in the palliative care arsenal, the practice of sedating patients near death to relieve intolerable and refractory suffering may also be the most widely misunderstood. Debate over the therapy's potential for misuse, confounded by a lack of clear or consistent quidance on its ethical and medically appropriate use, has misled the public and even some health professionals to view it as a covert form of euthanasia, says Dr. Larry Librach, director of the Temmy Latner Centre for Palliative Care at Mount Sinai Hospital in Toronto, Ontario. "In these days of budget cutbacks, people are suspicious we just want to speed up death to free up resources." Part of an expert team drafting a national framework to better define and guide the use of continuous palliative sedation therapy in Canada, Librach says confusion over when and how to administer the therapy has only served to feed those fears [see sidebar]. "Some physicians aren't aware of the indications to start treatment. they don't know how to conduct an appropriate assessment, so they make a wrong diagnosis, they don't consult the patient or their family and they end up sedating someone with months left to live," he explains. "Without clear guidance, physicians may also prescribe the wrong drugs to achieve sedation, such as opioids, or may not monitor the patient closely enough to ensure they're properly sedated. says Dr. Doreen Oneschuk, a palliative care physician at Grey Nuns Hospital in Edmonton, Alberta, and member of the team drafting the framework.

http://www.cmaj.ca/cgi/rapidpdf/cmaj.109-3766v1.pdf From Media Watch dated 3 January 2011:

PAIN MANAGEMENT, 2011;1(1):31-40. 'When there are no good choices: Illuminating the borderland between proportionate palliative sedation and palliative sedation to unconsciousness.'http://www.futuremedicine.com/doi/abs/10.2217/pmt.10.1?journalCode=pmt

From Media Watch dated 4 October 2010:

MAYO CLINIC PROCEEDINGS, 2010;85(10): 949-954. 'Ethical decision making with end-of-life care: Palliative sedation and withholding or withdrawing life-sustaining treatments.' http://www.mayoclinicproceedings.com/content/85/10/949

From Media Watch dated 20 September 2010:

BMC PALLIATIVE CARE | Online article – 13 September 2010 – 'European Association for Palliative (EAPC) Care framework for palliative sedation: An ethical discussion.' http://www.biomedcentral.com/content/pdf/1472-684x-9-20.pdf

From Media Watch dated 9 August 2010:

DER SCHMERZ | Online article – 28 July 2010 – 'Sedation in palliative medicine: Guidelines for the use of sedation in palliative care.' http://www.ncbi.nlm.nih.gov/pubmed/20661593

From Media Watch dated 17 May 2010:

[U.S.] NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online posting – 11 May 2010 – 'Statement and commentary on palliative sedation therapy to promote greater understanding.'http://www.nhpco.org/i4a/pages/index.cfm?pageid=5847

THE HASTINGS REPORT, 2010;40(3):32-38. 'Rethinking guidelines for the use of palliative sedation.' http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=4661

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.

The development of evidence-based European guidelines on the management of depression in palliative cancer care

EUROPEAN JOURNAL OF CANCER | Online article – 4 January 2011 – Depression is common in cancer patients, particularly those with advanced disease. It is associated with adverse outcomes such as increased pain, disability and poorer prognosis. The aim was to produce a European evidence-based clinical guideline on the management of depression in patients receiving palliative care to inform practice, establish policy, promote European consensus and ultimately improve patient outcomes. Recommendations were devised using the best available evidence. http://www.sciencedirect.com/science? ob=ArticleURL& udi=B6T68-51W4WDM-1& user=10& coverDate=01%2F04%2F2011& rdoc=1& fmt=high& orig=search& origin=search& sort=d& docanchor=&view=c& searchStrld=1608084607& rerunOrigin=scholar.google& acct=C000050221& version=1& urlVersion=0& userid=10&md5=87313b4a351a6b6a342ef4ba6364fe0&searchtype=a

U.K.'s National Institute of Health & Clinical Effectiveness

The real-life death panel, reformed

HASTINGS CENTER REPORT, 2011;41(1). The U.K.'s ... government has just begun the most sweeping overhaul of the National Health Service [NHS] since its inception. Under the reforms, 80% of the NHS budget will be handed over to about five hundred local consortia of primary care physicians, who will be empowered to make medical spending and allocation decisions for their patients. Every element of the NHS is being redesigned to increase competition and decentralize decision-making. One of those elements is the National Institute of Health & Clinical Effectiveness [NICE]. NICE has been one of the few public institutions in the world frankly engaged in aboveboard, cost-based, health care priority-setting. Rightly or wrongly, it was making the tough calls, out in the open. http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5075

From Media Watch dated 21 June 2010:

U.K. | TIMES (OpEd) – 16 June 2010 – 'Cancer not NICE guidelines kills patients.' Last week saw yet another series of screeching headlines and emotive stories about the latest denial of life-extending drugs to patients with terminal cancer. But much of the discussion has failed to acknowledge the fact that it's cancer that will kill these patients not whether they have access to the latest drugs. http://timesonline.typepad.com/science/2010/06/cancer-not-nice-guidelines-kills-patients.html

From Media Watch dated 15 March 2010:

U.K. | The Independent – 15 March 2010 – 'Scandal of cancer drugs kept from dying victims.'
Thousands of cancer patients are being denied access to costly drugs by the National Institute for
Clinical Excellence ... a year after ministers ordered the institute to relax its spending criteria for
patients close to the end of their lives, campaigners claim. http://www.independent.co.uk/life-style/health-and-families/health-news/scandal-of-cancer-drugs-kept-from-dying-victims-1921426.html

On the meanings and experiences of living and dying in an Australian hospice

HEALTH, 2011;15(1):96-111. In this article the authors explore people's experiences of living and dying in a hospice in-patient unit. The results illustrate the tensions and complexities of entering into the hospice environment and how its character ... shapes experiences near death. Results illustrate the hospice in-patient unit as playing a vitally important role in supporting the end of life. Key themes emergent from the interviews were: loss of self and identity nostalgia; liminality and the home/help dialectic; and the performative elements of dying. To explore and unpack these processes, the authors draw together different facets of previous conceptual work in sociology, working towards a more nuanced conceptualization of the in-patient hospice experience. http://hea.sagepub.com/content/15/1/96.short

Of related interest:

- JOURNAL OF PALLIATIVE MEDICINE | Online article –16 January 2011 'Why do health professionals refer individual patients to specialist day hospice care?' This study provides an insight into reasons for referral to SPDC [specialist palliative day care]. Referrers value the multiprofessional team, the holistic approach to care as useful to managing difficult, complex, and persistent problems in patients wishing to be cared for in the community. Additional benefits include a helpful introduction to hospice services and much needed regular respite for caregivers. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0372
- JOURNAL OF PALLIATIVE MEDICINE | Online article 7 January 2011 'Does sharing research data with participating hospices affect practice?' The research question guiding this study was, "Does receiving individualized feedback about the findings of a research study that the hospice participated in affect clinical practice?" Three issues were examined: 1) Did anyone at the hospice recall receiving the research results? 2) Were the findings shared with the hospice staff? 3) Did the findings influence clinical practice in the hospice? The findings [from the survey of 65 hospices] suggest that providing feedback ... may be used to promote improvements in clinical care. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0181

Palliative caregivers who would not take on the caring role again

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 13 January 2011 – This study sought to determine the prevalence and factors associated with an unwillingness to take on the caregiving role again by interviewing former caregivers of palliative care patients. One in 10 people across the community provided hands-on care for someone close to them dying an expected death in the five years before being interviewed. One in 13 former caregivers indicated that they would not provide such care again irrespective of time since the person's death and despite no reported differences identified in unmet needs between those who would and would not care again. A further one in six would only "probably care again." These data suggest that assessment of willingness to care needs to be considered by clinical teams, especially in the elderly. Despite most active caregivers being willing to provide care again, a proportion would not. http://www.jpsmjournal.com/article/S0885-3924(10)00981-4/abstract

Of related interest:

■ PALLIATIVE MEDICINE | Online article – 12 January 2011 – 'Former palliative caregivers who identify that additional spiritual support would have been helpful in a population survey.' People who identify that additional spiritual support would have been helpful have specific demographic characteristics. There is also a strong association with the likelihood of identifying that a number of other additional supports would have been helpful. Clinically, the need for additional spiritual support should open a conversation about other areas where the need for further support may be identified. http://pmj.sagepub.com/content/early/2011/01/08/0269216310389225.abstract

Mapping the cultural landscape in palliative care and music therapy

MUSIC & MEDICINE, 2011;3(1):9-14. In recent decades, the fields of palliative care and music therapy have undergone rapid formal and global development, to be practiced in many countries and cultures. Simultaneous with the global development of palliative care and music therapy has been the world-wide movement of migrants and refugees which has "resulted in many ... societies ... becoming increasingly ethnically and culturally diverse." This has led to a growing awareness of the richly diverse cultural experiences and traditions that both clinicians and clients bring to end-of-life care and music therapy. This paper maps the discussion of cultural issues in palliative care and music therapy. http://mmd.sagepub.com/content/3/1/9.abstract

N.B. This issue of *Music & Medicine* focuses on music therapy and supportive cancer care. Contents page: http://mmd.sagepub.com/content/3/1.toc

Care or custody? An evaluation of palliative care in prisons in North West England

PALLIATIVE MEDICINE | Online article – 14 January 2011 – The findings [of this study] highlight tensions between the philosophies of care and custody and the challenges in providing palliative care in a custodial setting. This paper suggests ways in which some challenges can be overcome in practice. http://pmj.sagepub.com/content/early/2011/01/14/0269216310393058.abstract

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of (p.12).

Achieving the preferred place of care for hospitalized patients at the end of life

PALLIATIVE MEDICINE | Online article – 12 January 2011 – The audit [on discussion of preferred place of care (PPC)] was first done in 2007 and was repeated in 2009. There was an increase in recording PPC. Overall PPC wishes were ascertained for 87% of the patients seen by the team. The PPC was achieved in 76% of cases. The number of patients wishing to die in hospital significantly increased over the audit cycle (from 10% to 30%). Approximately one-third of patients changed their minds regarding PPC. The data highlights the need to distinguish between preferred place of care and preferred place of death. Patients' wishes regarding PPC change as death approaches. A greater number of patients wished to die in hospital than was expected. http://pmj.sagepub.com/content/early/2010/12/01/0269216310387459.abstract

Assisted (or facilitated) death

Representative sample of recent articles, etc:

• ARCHIVES OF IRANIAN MEDICINE, 2011;14(1):54-55. **'Euthanasia, terminal illness and quality of life.'** In this essay the author has attempted to present the plight of those people suffering from pain or paralysis, where no hope or dignity remains, as well as that of those who love and care for them. The laws of the land are arbitrary judgments laid down by law givers to preserve harmony within a society, when faced with a social dilemma. Euthanasia is such a dilemma and only a few states in the world have embraced this human problem. http://www.ams.ac.ir/aim/011141/0011.pdf

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 (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

Worth Repeating

Death in America circa 2000

Ambivalence and ambiguity in hospitalized, critically ill patients and its relevance for palliative care

JOURNAL OF PALLIATIVE MEDICINE. 2000;3(1):17-22. The problem of death in America is not one of a clear-cut dichotomy between what health professionals are trained to do and what patients and families desire. It is not simply about the need for better communication between practitioners and patients, though that is vitally important. And it is not merely about an obvious choice between "heroics" and "humanity." The actual situation is both much more muddled and far less rational than the cultural conversation suggests. The problem of death in America is about the extension of medicine's "gaze" as a cultural phenomenon to advanced age and the very end of life. It is about the complex ways in which work is conducted and rules are enacted in American hospitals at the end of the 20th century. It is about the diffuse power of litigation that hangs over every hospital activity to problematize decision making, action, and acquiescence to patient surrogates. It is about the vast gulf between lay and professional understandings of human physiology and the role of technology. It is about a pervasive cultural confusion about the nature and end of the

human life span. And it is about not knowing what to want, or how to decide. Although social debate on the problem is necessary and urgent as many observers of healthcare have noted, it is not the sort of dilemma that can be solved through the courts, legislation, and discrete hospital policies about resuscitation. Resolving the problem of death in America will depend on a broad reconsideration of medicine's dominant role in social life to reshape institutional practices and values and to re-acknowledge a transition process from life to death, one that is highly variable from person to person (Kaufmann¹).http://www.liebertonline.com/do i/pdfplus/10.1089/jpm.2000.3.17

Kaufman argues that the cultural conversation about the problem of death in America focuses on the "seemingly insoluble tensions between, on the one hand, 'death with dignity/a 'good death' and personal control in dying and, on the other hand, the pain, suffering, loneliness, and the lack of autonomy brought about by the use of advanced technology in the hospital setting."

 Gerontologist, 1998;38:715-725. 'Intensive care, old age, and the problem of death in America,' http://gerontologist.oxfordjournals.org/content/38/6/715.abstract

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