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 February 2011 Edition | Issue #187



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

Compiled & Annotated by Barry R. Ashpole

Conflicts of interest: Scroll down to <u>Specialist Publications</u> and 'End-of-life treatment of potential organ donors: Paradigm shifts in intensive and emergency care' (p.11), published in *Medical Law Review*

<u>Canada</u>

National Assembly Select Committee on Dying with Dignity

Focus on care, not death, hearing told

QUEBEC | Montreal Gazette - 5 February 2011 - As provincial hearings on "dying with dignity" wrapped up in Montreal, two groups representing some of society's most vulnerable raised concerns about legalizing euthanasia and assisted suicide. The Association guebecoise de gerontology ... called instead for the expansion of palliative care services to provide comfort to the terminally ill. And the Association de spina-bifida et d'hydrocephalie du Quebec argued that a debate on euthanasia is premature, given that health services for the disabled are lacking everywhere. Catherine Geoffroy, president of the association of gerontologists, told the National Assembly committee that assisted suicide and euthanasia are often presented as ways to die with dignity - a dig at the committee, which uses the motto. "In a society where ageism is rampant, where the elderly are often held responsible for the difficulties in access to health care ... how can we believe that consenting to euthanasia would be free of all societal pressures?" Geoffroy asked. Only 10% of Quebecers have access to palliative care at the end of their lives, and many elderly die in nursing homes where there is little palliative care.http://www.montrealgazette.com/news/Focus+care+deat h+hearing+told/4228482/story.html

Surrey police deliver horrible news with incredible humanity

BRITISH COLUMBIA | Surrev Now - 3 February 2011 -Having to tell someone a loved one has died is a horrific job, but somebody has to do it. And if you are a police officer, sooner or later that somebody will be you. Dale Carr ... [of the] ... Royal Canadian Mounted Police's Integrated Homicide Investigation Team, has worn many hats during his more than 20 years as a Mountie. Over that time, he's done roughly 70 next-of-kin notifications, involving everything from heart attacks in the park to brutal homicides.http://www.thenow newspaper.com/SPECIAL+R EPORT+Surrey+police+deliv er+horrible+news+with+incre dible+humanity/4220380/stor y.html

Canadians not ready for elderly parents: Study

ONTARIO | *Toronto Sun* – 4 February 2011 – Most Canadians aren't prepared to take care of their sick relatives or ageing parents, a new survey shows. A Leger survey commissioned by home-care provider We Care Home Health Services found 64% of Canadians say caring for an elder would be overwhelming as they try to balance their own lives. What's more, just 23% of Canadian families have a home-care plan in place, in case a loved one needs it. With the aging population in Canada, and fewer people willing or ready to take on home care, there's worry public health-care providers aren't prepared to deal with what's to come. A survey by the Canadian Medical Association taken in June 2010, found 80% of Canadians worry the country's health-care system will have problems dealing with record numbers of elderly people. According to Statistics Canada, 14.1% of the population is over 65. In another 10 years, that will number will rise to 26.6%. http://www.torontosun.com/news/canada/2011/02/03/17138696.html

From Media Watch dated 30 August 2010:

- CTV NEWS | Online report 26 August 2010 'Many struggle to provide care to aging seniors: Study.' Two new related studies from the Canadian Institute for Health Information [CIHI] found that one in six people – 16% – providing informal care to seniors is experiencing some kind of distress.¹ <u>http://www.ctv.ca/CTVNews/Health/20100826/caregivers-seniors-100826/</u>
 - 1. Supporting Informal Caregivers The Heart of Home Care, CIHI, August 2010 http://secure.cihi.ca/cihiweb/products/Caregiver_Distress_AIB_2010_EN.pdf
- CBC NEWS | Online report 23 August 2010 'Canadians brace for higher health costs: Poll.' Canadians are concerned their quality of health care will decline from the strain posed by aging baby boomers, a new poll suggests. The Canadian Medical Association carried out the poll [conducted 8-21 June 2010 by Ipsos Reid] as part of its annual report card focused on access to health-care services.¹ <u>http://www.cbc.ca/health/story/2010/08/23/cma-health-care-boomers-poll.html</u>

Labrador woman fighting for ... benefits to look after gravely ill children

NEWFOUNDLAND & LABRADOR | CBC News – 31 January 2011 – A Happy Valley Goose Bay woman is fighting for benefits for parents who have to leave work to care for a sick child. Right now EI [Employment Insurance] compassionate care benefits are only available for six weeks and only for caregivers of someone who is terminally ill (see sidebar top right). Cathy Peyton left her job when her son John was diagnosed with cancer in 2008. She says there was no compensation program available. http://www.cbc.ca/labradormorning/episodes /2011/01/31/labrador-woman-fighting-for-eibenefits-to-look-after-gravely-ill-children/ Employment Insurance compassionate care benefits website (last updated January 2011): http://www.servicecanada.gc.ca/eng/ei/types/com passionate_care.shtml

Specialist Publications

Of particular interest:

'Nursing schools to teach new ways to cope with death and dying' (p.8), published in *Canadian Medical Association Journal.*

'Navigating the spheres of assisted death' (p.11), published in *Canadian Medical Association Journal.*

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. <u>http://www.pcn-e.com/community/</u>

<u>U.S.A.</u>

Budget cuts may include ending counseling services in hospice care

TENNESSEE | Channel 3 News (Nashville) – 3 February 2011 – Potential TennCare cuts could include eliminating counseling services in hospice care provided by the state's expanded Medicaid program. Hospice patients would still be eligible for medical services like pain control, home health and physician care. But the state would save about \$14 million by doing away with the counseling services. The state cut would also erase a federal match of \$43 million for hospice benefits. http://www.wreg.com/news/sns-ap-tn--haslambudget,0,3811462.story

Of related interest:

 SOUTH CAROLINA | News Channel 15 (Louisiana) – 31 January 2011 – 'Decision to cut hospice care for Medicaid patients reversed.' After a review by Governor Nikki Haley the ... Department of Health & Human Services is taking back a plan to reduce benefits to those in hospice care. <u>http://www.carolinalive.com/news/story.aspx?id=574543</u>

For-profit hospices may choose cheaper-to-treat patients, study finds

CALIFORNIA | Los Angeles Times - 1 February 2011 - [Research findings published in the] ... Journal of the American Medical Association report that for-profit hospice services may be selecting patients who are less expensive to treat - leaving the pricier patients to non-profit agencies.¹ The researchers ... suggested that Medicare's hospice reimbursement system ... may create incentives for profit-seeking providers to avoid taking on the sickest cases. Close to 1 million Americans enrolled in Medicare use hospice services - palliative care intended for the last six months of life – each year. That's about 40% of Medicare patients in all, the authors wrote. Eighty-four percent of patients in hospice are Medicare beneficiaries. Researchers found that forprofit services had a lower proportion of patients with cancer than non-profit providers, and a higher proportion of patients with dementia (which are, generally, less expensive to treat). The team also found that the average length of stay for patients in for-profit hospice was 20 days. while the average length of stay in a non-profit hospice was 16 days. Because costs are highest at the onset of enrollment and near death, longer stays in hospice are more profitable for providers. Between 2000 and 2007 the number of for-profit hospice agencies more than doubled. from 725 to 1,660, while the number of non-profit operators stayed about the same. For-profits have "significantly higher" profit margins than nonprofits, reported the researchers. Indeed, nonprofits, true to their name, operate at a loss. http://www.latimes.com/health/boostershots/laheb-for-profit-hospice-20110201,0,5630476.story

1. JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2011; 305(5):472-479. 'Association of hospice agency profit status with patient diagnosis, location of care, and length of stay.' The objective of this study was compare patient diagnosis and location of care between for-profit and non-profit hospices and examine whether number of visits per day and length of stay vary by diagnosis and profit status. Compared with nonprofit hospice agencies, for-profit hospice agencies had a higher percentage of patients with diagnoses associated with lower-skilled needs and longer lengths of stay. http://jama.amaassn.org/content/305/5/472.abstract

National Hospice & Palliative Care Organization press release 2 February 2011

Hospice profit status is not a reflection of quality

"The Organization wants to stress that this ... article doesn't provide any correlation between the profit status of a hospice program and the quality of care provided. It is concerned that people looking at this study may overlook the critical importance of quality measures when discussing the provision of hospice care." http://www.nhpco.org/i4a/pages/index.cfm?pagei d=6164

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MONTANA | Great Falls Tribune 6 February 2011 'Legislature to take up end-of-life rights battle this week.' Lawmakers on the Senate Judiciary Committee will hear competing bills [this week]. State Senator Anders Blewett [Democrat-Great Falls], has proposed a measure that would put into state law a Montana Supreme Court ruling that supporters say effectively legalizes physician-assisted suicide. <u>http://www.greatfallstribune.com/article/20110206/NEWS01/102060317</u>
- HAWAII | Star Advertiser (Honolulu) 4 February 2011 'Senate panel to debate assisted suicide.' Hawaii would become the fourth state to legalize physician-assisted suicide under a proposal being brought back for debate in the Legislature... Senate Bill 803 would allow a terminally ill, competent adult to receive medication to end life. The bill specifically prohibits mercy killings, lethal injections and active euthanasia, and requires patients to receive informed consent. http://www.staradvertiser.com/news/hawaiinews/20110204 Senate panel to debate assisted sui cide.html
- IDAHO | Associated Press 4 February 2011 'Idaho lawmakers open door for end-of-life debate.' State lawmakers have opened the door to an end-of-life debate ... with legislation to ban assisted suicide in Idaho. Republican Senator Russ Fulcher introduced a bill ... that would make it a felony to assist in the suicide, or attempted suicide, of another person. Fulcher says there is a national effort under way to create a "right" to assisted suicide for people who are dying and his bill aims to keep that movement from encroaching upon Idaho, which is already surrounded by states that allow some form of assisted suicide. http://www.khg.com/Global/story.asp?S=13970632

International

'Hands off our hospice'

New hospice revelation

U.K. (SCOTLAND) | *Dunoon Observer* – 4 February 2011 – A week after over 3,500 signatures were gathered in support of a campaign to stop Cowal Hospice becoming a day centre, the *Dunoon Observer* is launching a campaign to retain a dedicated in-patient hospice facility in Dunoon. By the time you read this nearly every shop window in Dunoon will be sporting a 'Hands off our hospice' poster. The campaign will continue until NHS [National Health Service] Highland recognise Cowal's demand that a dedicated in-patient hospice remains in Dunoon. Together with the existing Facebook campaign ... we hope to focus the minds of the 35 administrative and management staff at Dunoon General Hospital. In a new development, an NHS Highland statement ... stated that plans to replace the residential hospice with a day centre were put forward by Cowal Hospice Partnership which, Cowal and Bute Locality Manager Viv Smith claimed, comprised Argyll and Bute Community Health Partnership, Argyll and Bute Council and the Hospice Trustees' Committee. However, the *Standard* can reveal that neither Argyll and Bute Council or Cowal Hospice Trust are members of Cowal Hospice Partnership. <u>http://www.dunoon-observer.com/index.php?option=com_content&view=article&id=1852:new-hospice-revelation&catid=1:news</u>



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 death whisperer

AUSTRALIA | *The Age* – 2 February 2011 – Bright, upbeat Molly Carlile is not your stereotypical grief and palliative care expert. She says people expect her to look like a funeral director, "somebody very sombre, dressed in black or white and quietly spoken." Then there is the unusual job title – death talker – she uses when giving talks at health conventions and community groups. Once people talk it out, she says, "they can get on with the living, and it's not hanging there, like a sword of Damocles, over their head." Ms. Carlile ... loves her unconventional career, which began when she was 19, eight weeks into nursing training at a city hospital. A 34-year-old patient ... was dying of liver cancer. During long bedside talks, the woman told her she feared how her kids would remember her and how they would cope without her. Ms. Carlile helped her make a scrapbook of wishes for each child, stories about their births and messages to read on future milestones such as 21st birthdays. Somewhat more at peace, the woman died three weeks later. http://www.theage.com.au/national/melbourne-life/the-death-whisperer-20110201-1acgi.html

Of related interest:

 U.K. | BBC Radio 4 – 1 February 2011 – 'Case Notes: End of Life.' As a nation, we don't tend to dwell on the nitty gritty detail of care we might want when we're dying. It's a topic many tend to approach only when required and then might not know what questions to ask, or what support may be on offer. <u>http://www.bbc.co.uk/programmes/b00y2f1c</u>

N.B. The hospice and palliative care movement in the U.K. was debated in the House of Commons 2 February 2011. <u>http://www.theyworkforyou.com/debates/?id=2011-02-02a.1004.0</u>

Extreme world: Dying

CHINA | BBC World Service - 2 February 2011 - Imagine a country in which the population is rapidly ageing and yet people do not want to talk about how to care for the elderly because they think it could bring bad luck. And where most of the people do not even write a will, believing that it could actually bring death one step closer. That country is China. And on the issue of ageing and dying, much of the country has a collective response: "We don't want to talk about it." This is nothing new here. One social commentator told me that these attitudes date back to the time of Confucius who lived 2,500 years ago. The great Chinese philosopher was asked by one his followers about the issue. Confucius replied, "We haven't finished studying life, so why delve into the question of death?" And so the debate largely ended. China's economy has seen remarkable growth in the past 30 years. The country is witnessing the largest migration in history as the young move to factory towns and cities in search of jobs and fortunes. It is seen by many here as a march of progress, but less well documented is the painful process of social upheaval being felt across the country. To be old is to be venerated in China. Tradition dictates that the young should care for the elderly; to die with dignity is to die at home surrounded by the family. Now, largely because of the country's population controls, Chinese society is rapidly ageing. By 2050 it is estimated that more than 400 million Chinese will be of retirement age - a quarter of the population. http://www.bbc.co.uk/news/world-asia-pacific-12334284

Extract from BBC report

To grow old – to possibly die - somewhere other than your home is seen as being abandoned by your family, and in China there is no bigger social stigma. One hospice in Beijing was forced to move locations seven times, because locals felt that a building in which so many people were dying brought bad luck. Opponents blocked the entrances, preventing staff and families from getting into visit their dying relatives. The head nurse at the Songtang hospice, Yuan Jie, says that attitudes need to change. "The Chinese need to realise that hospices offer the best way to care for old people," she says. She compared sending old people to hospices to young children attending kindergartens. "It is," she says, "simply the cycle of life."

From Media Watch dated 17 January 2011:

- CHINA | *The Straits Times* (Singapore) 8 January 2011 'There are few hospices and most hospitals turn away terminally ill patients.' 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. http://admpreview.straitstimes.com:90/vgnexttemplating/v/index.jsp?vgnextoid=42f0a2570f06d210
 VgnVM100000430a0a0aRCRD&vgnextchannel=4e60758920e39010VgnVCM100000a35010aRC
 - 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. <u>http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf</u>

N.B. In Vancouver, Canada, a recent controversy over a proposed hospice to be built on the campus of the University of British Columbia, and next door to a high-rise condominium, focused on an apparent conflict *within* the local Chinese community on attitudes towards dying and death (noted in the issues of Media Watch dated 17 & 24 January 2011).

Grieving process complicated

'They buried our baby for £5 and nothing more was said'

IRISH TIMES | Online article – 2 February 2011 - There are countless mass infant graves scattered around Ireland, left unmarked, unconsecrated and containing hundreds of bodies. They are a legacy of Roman Catholic tradition, which stipulated that babies who died before being baptised did not go to heaven, but to an in-between state known as limbo. Baptism, it decreed, corrected humanity's original sin in falling away from God. As a consequence, children who died at birth were forbidden to be buried on consecrated ground and denied a funeral service. Instead they were buried in anonymous plots known as "cillín." Veiled in secrecy, mired in shame, the burials usually took place in the middle of the night along cemetery boundaries to get the babies as close to sacred ground as possible. Limbo complicated the grieving process for Eithne Hyland's stillbirths in 1974, 1977 and 1982,

posing insurmountable challenges to her faith. Hyland believes the Catholic Church's attitude towards stillborns was so widely accepted that it made maternity wards unsympathetic places. Parents were not allowed to see or hold a child who died at birth, the logic being that any opportunity for attachment would prolong the grieving. http://www.irishtimes.com/newspaper/featur es/2011/0202/1224288760646.html

In 2007, the [Catholic Church's] International Theological Commission announced that there was "hope for the salvation of children who have died without baptism." Though this upheld the concept of limbo, priests were finally allowed to bless limbo graves and bury the unbaptised in church grounds.

Of related interest:

U.K. | Daily Mail – 5 February 2011 – 'Modern face of mourning: The colourful 'poundland' shrines across Britain that councils are trying to wipe out.' All my life I've loved to walk in graveyards, reading tombstones commemorating long-dead grandfathers, mothers, sons ... grief expressed in the timeless symbolism of carved angels, broken urns, cherub heads, flowers and hourglasses. I believe it useful to meditate on the quiet dignity of the inscriptions - the love expressed in a simple, well-tended grave is a fitting memorial to life and loss. What a contrast to look at a new face of grief in modern Britain. http://www.dailymail.co.uk/news/article-1353815/Colourful-poundland-graveyard-shrines-British-councils-trying-wipe-out.html

Liverpool Care Pathway

Death row drug fed to dying Scottish pensioners

U.K. (Scotland) | *Daily Record* – 1 February 2011 – A drug given to U.S. Death Row prisoners is being used on dying old folk in Scotland's hospitals. Medics use the sedative midazolam as part of a highly controversial "pathway to death" care plan for people judged by doctors to be in the last hours of their lives. But patients' leaders warned ... that the widespread use of the Liverpool Care Pathway (LCP) in Scotland's NHS [National Health Service] is robbing pensioners of the chance of life. They claim that, for some old folk, being put on the LCP is effectively a death sentence. Supporters of the LCP, including the Scottish Government, argue that it is a humane and well thought-out way to make the dying comfortable at the end of life. Crisis Ministers told all Scotland's health boards in 2008 that use of LCP was "good practice." But some senior doctors fear that patients who could recover are wrongly being put on LCP. And they say that once people are on the "pathway to death," the drugs they are given will mask any signs that they are getting better. http://www.dailyrecord.co.uk/news/scottish-news/2011/02/01/death-row-drug-fed-to-dying-scottish-pensioners-86908-22890605/

From Media Watch dated 25 October 2010:

- BRITISH MEDICAL JOURNAL | Online letter 19 October 2010 'Good death for all remains distant goal.' Ellershaw and colleagues again defend their Liverpool Care Pathway.^{1,2} The pathway has obvious appeal, but it has proved controversial, and reports of misuse remain disturbingly frequent. Despite decades of research in the care of patients with cancer, the accurate prediction of dying ... remains difficult. http://www.bmj.com/content/341/bmj.c5815.extract
 - 1. BRITISH MEDICAL JOURNAL | Online article 16 September 2010 'Achieving a good death for all.' http://www.bmj.com/content/341/bmj.c4861.extract
 - 2. Liverpool Care Pathway website: http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/

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.

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

Thirty-five years of end-of-life issues in U.S. medical schools

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 30 January 2011 – Between 1975 and 2010, the overall offerings in death and dying increased so that 100% of U.S. medical schools, beginning in 2000, offered something on death and dying. A multidisciplinary-team approach continued over the 35-year period. Palliative care is offered to some extent in 99% of U.S. medical schools today. Numerous end-of-life topics are currently covered in the curriculum. http://ajh.sagepub.com/content/early/2011/01/26/1049909110397608.abstract

Of related interest:

 CANADIAN MEDICAL ASSOCIATION JOURNAL | Online report – 2 February 2011 – 'Nursing schools to teach new ways to cope with death and dying.' The Canadian Association of Schools of Nursing will test new ways to include more palliative care training in undergraduate nursing programs, after a survey of 91 nursing schools revealed many inadequately prepare graduates to deal with death and dying. <u>http://www.cmaj.ca/earlyreleases/2feb11_nursing-schoolsto-teach-new-ways-to-cope-with-death-and-dying.dtl</u>

Complicated grief and related bereavement issues for DSM-5¹

DEPRESSION & ANXIETY, 2011;28(2):103-117. Bereavement is a severe stressor that typically incites painful and debilitating symptoms of acute grief that commonly progresses to restoration of a satisfactory, if changed, life. Normally, grief does not need clinical intervention. However, sometimes acute grief can gain a foothold and become a chronic debilitating condition called complicated grief. Moreover, the stress caused by bereavement, like other stressors, can increase the likelihood of onset or worsening of other physical or mental disorders. Hence, some bereaved people need to be diagnosed and treated. A clinician evaluating a bereaved person is at risk for both over-and under-diagnosis, either pathologizing a normal condition or neglecting to treat an impairing disorder. The authors of DSM IV focused primarily on the problem of over-diagnosis, and omitted complicated grief because of insufficient evidence. The authors revisit bereavement considerations in light of new research findings. 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. <u>http://www.nytimes.com/2010/08/15/opinion/15frances.html? r=1</u>

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. <u>http://www.npr.org/templates/story/story.php?storyld=128874986</u>

The inhospitable hospital

ILLNESS, CRISIS & LOSS, 2011;19(1):27-39. Personal illness narratives are used to highlight deficiencies in hospital care and to challenge hospitals to become more hospitable and less like factories for treating illnesses. An alienating hospital environment where staff focus on technical tasks and functions can drive patients and family members into a state of deep isolation and disconnectedness just when they need compassion and understanding. It is also suggested that hospital staff may actually benefit from learning to relate to patients at an emotional level and that compassion fatigue and burn out are more likely to

Hospice care could easily be enhanced

develop when staff maintain their distance. http://baywood.metapress.com/app/home/co ntribution.asp?referrer=parent&backto=issue ,3,11;journal,1,49;linkingpublicationresults,1: 103734,1

Extract from Illness, Crisis & Loss

Acute health care still has much to learn from models of hospice and palliative care that recognize the personhood of both patients and staff.

IRISH HEALTH | Online report – 7 February 2011 – Hospice and palliative care could be enhanced and extended throughout Ireland without the need for any additional resources, the Irish Hospice Foundation (IHF) has insisted. According to IHF chief executive, Eugene Murray, there is a strong case for re-allocating some of the money currently spent on hospital beds to hospice and community-based palliative care services. He said that with a reconfiguration of the balance between different types of bed provision and care staff, palliative care could be available to everyone, regardless of their disease or location. For example, most regions have 100 beds per 10,000 of population comprising acute, community hospital, private nursing home and hospice beds. <u>http://www.irishhealth.com/article.html?id=18630</u>

 Ireland 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. <u>http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf</u>

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: <u>http://www.mhpcn.ca/Physicians/resources.htm</u> (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

What does cancer treatment look like in consumer cancer magazines? An exploratory analysis of photographic content in consumer cancer magazines

JOURNAL OF HEALTH COMMUNICATIONS | Online article – 1 February 2011 – In an exploratory analysis of several highly circulated consumer cancer magazines, the authors evaluated congruency between visual images of cancer patients and target audience risk profile. The authors assessed 413 images of cancer patients/potential patients for demographic variables such as age, gender, and ethnicity/race. They compared this profile with actual risk statistics. The images in the magazines are considerably younger, more female, and more White than what is indicated by U.S. cancer risk statistics. The authors also assessed images for visual signs of cancer testing/diagnosis and treatment. Few individuals show obvious signs of cancer treatment. Most images feature healthier looking people, some actively engaged in construction work, bicycling, and yoga. In contrast, a scan of the editorial content showed that nearly two thirds of the articles focus on treatment issues. On the basis of these models/theories, the authors provide recommendations for consumer cancer magazines, suggesting that the imagery be adjusted to reflect cancer diagnosis realities for enhanced message attention and comprehension. http://www.informaworld.com/smpp/content~db=all~content=a933009506~frm=abslink

Death, time and the theory of relativity

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 31 January 3011 – Many people believe that spending large amounts of money on end-of-life care is unjustified and even irrational. This fails to recognize that the value of time, particularly quality time, appears to increase as death draws near. Paying for treatment that merely allows patients and families to avoid confronting the inevitability of death is wrong. However palliative care, which can bolster the quality of a patient's remaining days, provides benefits that extend to the family and beyond. How can the notion of time gaining value toward the end of life be incorporated into conventional costbenefit analyses? http://www.jpsmjournal.com/article/S0885-3924(10)01061-4/abstract

Comparing three life-limiting diseases: Does diagnosis matter or is sick, sick?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 31 January 3011 – At advanced stages, cancer, congestive heart failure, and chronic obstructive pulmonary disease produce high rates of hospitalization, disability, and annual mortality. Despite similar prognoses, patients with cancer often are treated differently than those with other illnesses, the former being seen as a terminal vs. chronic. The purpose of this study was to compare the functional capacity, emotional well-being, and quality of life of patients in three disease groups to assess whether diagnosis distinguishes differences in patient experience, and compare patients with cancer and non-cancer diagnoses. http://www.jpsmjournal.com/article/S0885-3924(10)01053-5/abstract

Applying motivational interviewing techniques to palliative care communication

JOURNAL OF PALLIATIVE MEDICINE | Online article – 3 February 2011 – Palliative care relies heavily on communication. Although some guidelines do address difficult communication, less is known about how to handle conversations with patients who express ambivalence or resistance to such care. Clinicians also struggle with how to support patient autonomy when they disagree with patient choices. Motivational Interviewing (MI) techniques may help address these responses. Specifically, MI techniques such as reflective statements and summarizing can help reduce a patient's resistance, resolve patient ambivalence, and support patient autonomy. Not all the MI techniques are applicable, however, in part because palliative care clinicians do not guide patients to make particular choices but, instead, help patients make choices that are consistent with patient values. Some elements from MI can be used to improve the quality and efficacy of palliative care conversations. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0495

Can we make reports of end-of-life care quality more consumer-focused?

JOURNAL OF PALLIATIVE MEDICINE | Online article – 2 February 2011 – The goal of this [nationwide telephone] study was to define families' priorities for various aspects of end-of-life care, and to determine whether scores that reflect these priorities alter facilities' quality rankings. There appears to be wide variation in the importance that families place on several aspects of end-of-life care. <u>http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0321</u>

End-of-life treatment of potential organ donors: Paradigm shifts in intensive and emergency care

MEDICAL LAW REVIEW | Online article – 31 January 2011 – This article details and comments upon the current critical and historic debate affecting the medical treatment of potential deceased organ donors in the last phase of their lives. The significance stems from the challenge to the legal and ethical paradigm that the end-of-life care of patients should not be dictated or even influenced by the needs of others or of society as a whole. This gives expression to both the notion that the value of the lives of individuals should not be weighed in utilitarian fashion and that ... one should not be used instrumentally purely as a means to the ends of others. Many allege that to manipulate a patient's medical treatment in the interests of organ recipients is to fail to show respect for persons and amounts to a transgression of the duty of non-maleficence or *primum non nocere*.<u>http://medlaw.oxfordjournals.org/content/early/2011/01/30/medlaw.fwq032.full</u>

Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England

PALLIATIVE MEDICINE | Online article – 31 January 2011 – Nursing homes are a common site of death, but older residents receive variable quality of end-of-life care. Problems in accessing support for end-of-life care ... included variable support by general practitioners (GPs), reluctance among GPs to prescribe appropriate medication, lack of support from other agencies, lack of out of hours support, cost of syringe drivers and lack of access to training. Most care homes were implementing a care pathway. Those that were not rated their end-of-life care as in need of improvement or as average. Case studies suggest that critical factors in improving end-of-life care in nursing homes include developing clinical leadership, developing relationships with GPs, the support of 'key' external advocates and leverage of additional resources by adoption of care pathway tools. http://pmj.sagepub.com/content/early/2011/01/26/0269216310387964.abstract

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- BRITISH JOURNAL OF PSYCHIATRY, 2011;198(2):83-84. 'Assisted suicide: Why psychiatrists should engage in the debate.' This editorial suggests that psychiatrists should engage in the debate because the issues at stake will affect us, and we are likely to have a significant part to play were the law to be changed. The authors suggest that there are three main areas where psychiatrists' expertise may be informative: a) the extent to which safeguards to limit the availability of assisted dying to target groups can be applied safely and fairly, including to individuals with psychiatric disorders; b) the complexities inherent in assessing mental capacity; and, c) the degree to which individuals adapt or change their desires, particularly in relation to suicidal behaviours. http://bjp.rcpsych.org/cgi/content/abstract/198/2/83
- CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article 31 January 2011 'Navigating the spheres of assisted death.' The issues of assisted death and palliative care in Canada should be discussed in the context of human rights. While the topic of assisted death has been a recent discussion in Canada, we cannot address [the former] until the issue of equal access to palliative care has been resolved. In Canada, at least 70% of residents lack access to palliative care and for those who do have access, it is inequitable. and distress," writes Mary Shariff, Assistant Professor, Faculty of Law, University of Manitoba. <u>http://www.cmaj.ca/embargo/cmaj091845.pdf</u>.

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Worth Repeating

When the tumor is not the target

Preschool as palliative care

Some may say, "What's the big deal? The kid went to school." Certainly, much emphasis has been placed on assisting and encouraging school-age children who are being treated for cancer to return to school as soon as possible. What's unusual in this case is that this child was only 4 years old. By law, he was not required to attend school until he was 6 years old. We tapped into limited public preschool resources designed to give healthy children a better chance to succeed in their education, but for this child, preschool was the sum total of his education.

JOURNAL OF CLINICAL ONCOLOGY, 2008;26(22):3797-3799. The American Academy of Pediatrics' goal of palliative care is "to add life to the child's years, not simply years to the child's life." Clearly, by enabling Keshaun (a pseudonym to protect the privacy of the patient's family) to attend preschool, we achieved this goal for him. Can it get any better than for the teachers to so clearly see him as a unique individual that they lost sight of the undeniable fact that he would die relatively soon? His teachers simply missed him when he didn't feel well enough to attend school. The medical team saw him losing muscle mass and endurance, and knew that his death was approaching. The school was heavily represented at Keshaun's funeral. Several

teachers came to support his family and grieve the end of Keshaun's presence in their own lives. So many were deeply affected, and we were concerned about whether we had done them more harm than good by encouraging the school to accept this child. It was an elective decision after all. Keshaun was younger than the law required children to attend school, and even if he had been older, we could have advocated for a home school program. Because of our concerns, we made one more visit to the school, a grief follow-up visit. The teachers genuinely appreciated our presence. They indicated how significant their grief had been. Yet, even during that 1hour visit, positive progress in the grieving process was apparent. One teacher discussed how we had clearly told them that Keshaun would die, vet somehow it just hadn't occurred to her that he really would die. At the end of the meeting, we had to know: had we made the right decision to support this family's pursuit of preschool enrollment, or had we subjected more people to grief unnecessarily? So, we asked the teachers, "Knowing what you know now, that Keshaun would be a part of your class for such a long time, die, and leave such a big hole in your lives, would you do it all again?" Their answer, a resounding "Yes." http://jco.ascopubs.org/content/26/22/3797.f ull

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