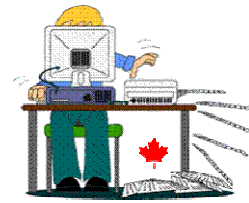


Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010 ©

Compiled & Annotated by Barry R. Ashpole

In their own words: Scroll down to [Specialist Publications](#) and 'Palliative care patients' experiences of healthcare treatment' (p.9), a thematic analysis published in *International Journal of Social Welfare*.

Canada

Parliamentary committee on palliative and compassionate care

Representative sample of recent news media coverage:

- MANITOBA | *Winnipeg Free Press* – 17 June 2010 – **'Don't give MDs power to pull plug: Disabled.'** Giving Manitoba doctors the power to pull the plug on a patient discriminates against disabled people who may fall short of the minimum standards to remain on life-support, local advocates told a Parliamentary committee. <http://www.winnipegfreepress.com/local/dont-give-mds-power-to-pull-plug-disabled-96545859.html>
- ONTARIO | *Sun* (Toronto) – 14 June 2010 – **'The fight for compassion.'** Sharon Ruth ... mother of 13-year-old leukemia survivor Colleen will appear before the parliamentary committee ... to argue for greater benefits for parents with sick children. Ruth's been fighting for Employment Insurance compensation which would allow a parent to stay home from work with pay during the serious illness of a child. <http://www.torontosun.com/news/canada/2010/06/13/14379361.html>

From Media Watch dated 26 April 2010:

- SUN MEDIA | Online report – 22 April 2010 – **'MPs band together to study palliative care.'** Spurred by private member's bill that supported [physician] assisted suicide, MPs from three federal parties said ... they'll band together to work on improving palliative and elder care. [The group hopes to produce its recommendations by the end of the current parliamentary session.] <http://www.torontosun.com/news/canada/2010/04/21/13671026-qmi.html>

N.B. Recent issues of Media Watch highlighted three Canadian reports that focus on income protection and job security for family caregivers: **'Project caregivers from financial ruin,'** a Maytree Policy in Focus, published online @ <http://maytree.com/policyPDF/MaytreePolicyInFocusIssue11.pdf>; **'The uncompassionate elements of the Compassionate Care Benefits Program: A critical analysis,'** a University of Waterloo study, available @ <http://ped.sagepub.com/cgi/content/abstract/17/1/50>; and, **'Evaluating Canada's Compassionate Care Benefit: The Perspective of Family Caregivers,'** a McMaster University (School of Geography & Earth Sciences) study, also available on line @ <http://www.coag.uvic.ca/eolcare/documents/CCB%20evaluation%20final%20report%20-%20English.pdf>

Situation critical: Waits for long-term care daunting

ONTARIO | Metroland Media – 14 June 2010 – Ontario's long-term care system is paralyzed and failing its most vulnerable residents. More than 600 government-funded homes are supposed to provide high-quality, round-the-clock care to the frail elderly. But [a] special report [by Metroland Media] shows seniors stuck on record wait lists, entangled in bureaucracy, and subject to pressure tactics that jeopardize their rights. <http://news.quelphmercury.com/Life/article/646804>

- ONTARIO | *Mississauga News* – 18 June 2010 – **'Seniors struggle to find proper care.'** For hard-to-place seniors with a need for a higher level of care, waits can be two or more times the average. In rural areas and Northern Ontario, families may be separated by hundreds of kilometres, if there are beds at all. On average, less than 40% of applicants get their first-choice home. <http://www.mississauga.com/news/article/835813--seniors-struggle-to-find-proper-care>
- ONTARIO | *Ottawa Citizen* – 18 June 2010 – **'Many seniors needlessly on nursing home lists.'** Eastern Ontario has the longest wait for nursing-home beds in the province, but many of the people in line really just need a little help to stay at home, according to [a] study of the queue for long-term care. <http://www.ottawacitizen.com/health/Many+seniors+needlessly+nursing+home+lists/3168570/story.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | *Western Catholic Reporter* – 21 June 2010 – **'Euthanasia is community's ultimate act of abandonment, says ethicist.'** Euthanasia and assisted suicide represent the ultimate abandonment of a person by a community, says a Winnipeg-based clinical ethicist. <http://www.wcr.ab.ca/news/2010/0621/webster062110.shtml>
- SASKATCHEWAN | *Western Catholic Reporter* – 21 June 2010 – **'Better palliative care can quell euthanasia debate.'** Better provision of palliative care to the dying would go a long way to reduce the calls for legalized euthanasia. <http://www.wcr.ab.ca/news/2010/0621/palliative062110.shtml>

N.B. Available is **'Assisted (or Facilitated) Death: The Debate in Canada,'** which summarizes notable developments (as reported in past issues of Media Watch) – highlighting also those in other countries – that inform discussion of the issue in Canada. Contact information at the foot of p.12.

Specialist Publications

Of particular interest:

'We can do better than euthanasia – we must.' Scroll down to p.12 for a letter to the editor published in *Canadian Family Physician*.

'Time to move on from the euthanasia debate.' Scroll down to p.12 for an editorial published in the *Canadian Medical Association Journal*.

Virtual tombstones catching on

CANWEST NEWS SERVICE
| Online report – 20 June 2010 – Generations of Canadians have died with uncertainty over whether they'd be remembered. Baby boomers, however, won't be taking any chances. Ensuring virtual life after death, new microchip-enabled headstones allow the Me Generation to share their stories from the grave, with passersby simply swiping markers with a cellphone to retrieve biographical details – everything from the deceased's political beliefs to their favourite recipes. <http://www.theprovince.com/Virtual+tombstones+catching/3178050/story.html>

U.S.A.

'Presumed consent' legislative proposal for organ donations sparks debate

NEW YORK | *Press & Sun Bulletin* – 19 June 2010 – A proposal to flip New York's organ-donation system on its head by presuming people are donors unless they indicate otherwise has the state Legislature buzzing. Polls have found that the majority of New Yorkers would like to be donors, yet just 13% of residents 18 and older are on the state Donate Life Registry. More than 9,600 people in the state need organ transplants, according to the New York Organ Donor Network. Last year, there were just 423 deceased organ donors in New York. "This legislation opens up the door to abuse via hastened death of vulnerable people and overriding of family concerns," Jerome Higgins, chairman of The Long Island Coalition for Life, wrote in a memo to lawmakers. <http://www.pressconnects.com/article/20100619/NEWS01/6190348/1112/-Presumed-consent--legislative-proposal-for-organ-donations-sparks-debate>

New initiative to improve palliative care in the ICU

CENTER TO ADVANCE PALLIATIVE CARE | Press release – 16 June 2010 – In a major national effort to integrate and improve palliative care in the ICU, the Center to Advance Palliative Care has launched The IPAL-ICU Project. Supported by the National Institute on Aging of the National Institutes of Health and developed by experts in both critical care and palliative care, The Project will be the central U.S. hub for shared expertise, evidence, tools and resources. The goal is to promote a paradigm shift in the way that critically ill patients, and their families, are cared for in the ICU. <http://www.capc.org/news-and-events/releases/06-16-10>

From Media Watch dated 8 March 2010:

- *CRITICAL CARE MEDICINE*, 2010;38(3):808-818. **'Patients and families define high-quality palliative care in the intensive care unit.'** A shared definition of high-quality intensive care unit palliative care emerged [in this study]: timely, clear and compassionate communication by clinicians; clinical decision-making focused on patients' preferences, goals and values; patient care maintaining comfort, dignity and personhood; and, family care with open access and proximity to patients, interdisciplinary support in ... and, bereavement care for families of patients who died. http://journals.lww.com/ccmjournals/Abstract/2010/03000/In_their_own_words_Patients_and_families_define.11.aspx
- *CRITICAL CARE & RESUSCITATION*, 2010;12(1):28-35. **'Palliative care teams in the intensive care unit: A randomised, controlled, feasibility study.'** This feasibility study was difficult to conduct and did not generate any robust conclusions about the utility of involving palliative care teams in end-of-life care in the ICU. Larger studies are technically possible, but unlikely to be feasible. http://www.ncbi.nlm.nih.gov/pubmed/20196711?itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum&ordinalpos=8

Quotable Quotes: Truth

As individuals we go to extraordinary lengths in our day-to-day lives to avoid being the bearer of "bad news." We consciously work in overdrive to "soften the blow," "sugar-coat the message," to be "politically correct" or "culturally sensitive." As a consequence, we risk living much of our lives dodging truth. Are we losing the ability or capacity to communicate – or hear what we need to hear – with empathy and without hurt or hurting? In our day-to-day vocabulary, as an example, "openness" and "transparency" have replaced "honesty" and "truth." Truth-telling is a fundamental principle of end-of-life care ...but, is the "conspiracy of silence" that often prevails as a death approaches nothing more than a manifestation of a life-long discomfort with acceptance of the inevitable or of truth itself?

Barry R. Ashpole, The Second to Last Lecture (Communications & Informed Decision Making), 2007

State Bar's Health Law Section launches new online resource on the Family Health Care Decisions Act

NEW YORK STATE BAR ASSOCIATION | Online posting – 15 June 2010 – The Health Law Section of the New York State Bar Association has launched an informative resource center on the State Bar's website designed to help New Yorkers understand new rules allowing family members to make critical health care and end-of-life decisions for patients who are unable to make their wishes known. The Family Health Care Decisions Act Information Center provides the public, health care professionals, advocates and lawmakers with up-to-date information regarding the new Act that took effect on 1 June. <http://readme.readmedia.com/State-Bars-Health-Law-Section-Launches-New-Online-Resource-on-the-Family-Health-Care-Decisions-Act/1429286>

Of related interest:

- ARKANSAS | *Democrat-Gazette* – 17 June 2010 – '**Church adds defibrillators, DNR policy.**' Pulaski Heights United Methodist Church in Little Rock has set up an Automated External Defibrillator Ministry after purchasing four defibrillator units for the 98-year-old congregation of more than 4,000 members. <http://www.nwaonline.com/news/2010/jun/17/church-adds-defibrillators-dnr-policy-20100617/>

Kentucky prison hospice program lets inmates help others, selves

KENTUCKY | *Courier-Journal* (Louisville) – 13 June 2010 – Steffon Cantrell had been sitting with the dying man for six hours. Occasionally he would rub the man's head, or take his hands, or sing a hymn – anything to remind the man he was not alone. Cantrell, an inmate at the Kentucky State Reformatory, had only known this fellow prisoner since the beginning of his bedside shift. But like a caring family member, he would stay, watching over until the man took his last breath. Cantrell is one of eight inmates at the prison in LaGrange who volunteer as hospice workers for ill and dying prisoners. The volunteers' backgrounds are varied, but they are linked by similarities. Most are serving time for murder. Some are unsure whether they will ever leave prison. And all view their caretaking roles as a way to atone for the lives they once led. <http://www.courier-journal.com/article/20100613/NEWS01/6140301/Kentucky+prison+hospice+program+lets+inmates+help+others++selves>

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. For those interested in prison hospice, a compilation of these articles and reports in a single document is available on request. Media Watch is posted on the *Prison Terminal* website: <http://www.prisonterminal.com/news%20media%20watch.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *TIME MAGAZINE* | Online report – 16 June 2010 – '**Roadside controversy looms with 'right to die' billboards.**' The organization Final Exit Network is putting up billboards to let you know that you have the "right to die." The controversial non-profit announced plans to put up billboards along highways in California, New Jersey and Florida. <http://newsfeed.time.com/2010/06/16/roadside-controversy-looms-with-right-to-die-billboards/>



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.

International

Learning disabled care is 'worse'

U.K. | BBC News – 20 June 2010 – People with learning disabilities receive worse healthcare than the rest of the population some doctors and nurses believe, according to a charity [for people with learning disabilities]. Mencap has found almost half of doctors and a third of nurses from a poll of 1,084 think this is the case. It is urging health trusts to sign a charter which sets out the rights of people with learning disabilities and the responsibilities of hospitals. Mencap's research ... also revealed 45% of doctors and a third of nurses had witnessed a patient with a learning disability being neglected or being denied their dignity. Despite enjoying legal protection, the survey found learning disabled people were being failed because more than a third of health professionals had not had appropriate training. <http://news.bbc.co.uk/2/hi/health/8746802.stm>

N.B. Scroll down to [Specialist Publications](#) and '**An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disability**' (p.11) published in *Palliative Medicine*.

From Media Watch dated 24 May 2010:

- *NURSING TIMES* (U.K.) | Online article – 17 May 2010 – '**A fast track path improves access to palliative care for people with learning disabilities.**' This article describes the development and implementation of a fast track referral pathway for people with learning disabilities at St Francis Hospice in Essex. <http://www.nursingtimes.net/nursing-practice-clinical-research/clinical-subjects/learning-disabilities/a-fast-track-path-improves-access-to-palliative-care-for-people-with-learning-disabilities-/5014791.article>

End of life care improves for Norfolk children

U.K. | *EDP24* – 20 June 2010 – Children who are nearing the end of their lives will now be offered a specialist round-the-clock nursing service in their own homes. NHS [National Health Service] Norfolk has commissioned the East Anglian Children's Hospice (EACH) at Quidenham to provide on-call specialist nursing at home for youngsters who are terminally ill. The 24/7 on-call service ... forms an extra component of the extensive service already provided by the care team at EACH. <http://www.edp24.co.uk/content/edp24/news/story.aspx?brand=EDPOnline&category=News&tBrand=EDPOnline&tCategory=xDefault&itemid=NOED18%20Jun%202010%2015%3A38%3A26%3A430>

From Media Watch dated 7 June 2010:

- *BMC PALLIATIVE CARE* | Online article – 4 June 2010 – '**Paediatric palliative home care by general paediatricians: A multi-method [German] study on perceived barriers and incentives.**' A local network of specialist support on site and a 24/7 on-call service are necessary in order to facilitate the implementation of basic palliative care by paediatricians in their own practice. <http://www.biomedcentral.com/content/pdf/1472-684x-9-11.pdf>

N.B. Scroll down to [Specialist Publications](#) and '**Fears, misconceptions keeping children from best end-of-life care**' (p.10) published in *Oncology Times*.

Uncertainty still surrounding palliative care

NEW ZEALAND | *Otago Daily Times* – 19 June 2010 – Health policy-makers may have underestimated demand for palliative care and are still coming to terms with how increased demand for before-death care will affect stretched resources, Hospice New Zealand chief executive Mary Schumacher says. Ms Schumacher is a member of the pan-sector Palliative Care Council, which has launched the country's first attempt to understand demand for palliative care and how that demand will change on the back of the growing and ageing population. <http://www.odt.co.nz/news/dunedin/111407/uncertainty-still-surrounding-palliative-care>

Court grants woman right to die

AUSTRALIA | ABC News – 18 June 2010 – A South Australian woman ... has been given the right to die by refusing to take food and medication without her carers facing prosecution. The judgment is believed to be a first in South Australia and reflects a similar ruling in Western Australia last year. The woman in her 70s told her nursing home to stop giving her food and drink and the drug insulin, knowing she would die. South Australian Supreme Court Justice Chris Kourakis does not consider her refusal to be suicide. The nursing home was concerned it might be breaking the law by carrying out her wishes, but the woman argued it would be illegal for the home not to do so.

<http://www.abc.net.au/news/stories/2010/06/17/2930149.htm?section=justin>

From Media Watch dated 17 August 2009:

- AUSTRALIA | *The Australian* – 14 August 2009 – **'Patient wins right to end life.'** In a landmark ruling, Perth spastic quadriplegic Christian Rossiter has won the right to starve to death after the Supreme Court of Western Australia declared his carers had a legal obligation to comply with his request to stop feeding him.
<http://www.theaustralian.news.com.au/story/0,25197,25931567-23289,00.html>

Of related interest:

- NEW ZEALAND | *Timaru Herald* – 18 June 2010 – **'Do not resuscitate' tattoo means exactly what it says.** Paula Westoby is very black and white about what she wants, with "do not resuscitate" tattooed across her chest.
<http://www.stuff.co.nz/timaru-herald/news/3825942/Do-not-resuscitate-tattoo-means-exactly-what-it-says>

- FOCUS TAIWAN | Online report – 17 June 2010 – **'Insurance cards to carry emergency treatment waivers.'** Health insurance cards marked with [a] notice that the holder does not want to receive emergency treatment in the terminal stage of life will be legally binding, a health official said.
http://focustaiwan.tw/ShowNews/WebNews_Detail.aspx?Type=aALL&ID=201006170041

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>

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/>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-provides-global-roundup-of-end-of-life-issues-n-96.htm>

Mothers share their stories of life as unpaid carers

U.K. (NORTHERN IRELAND) | *Belfast Telegraph* – 17 June 2010 – Two east Belfast women tell their stories in a new booklet highlighting the crucial role played by carers here. The booklet, issued by Carers Northern Ireland in association with the Equality Commission, urges people to support carers' rights to have the same chance as anyone else of a full life. There are currently 185,000 carers in Northern Ireland, carrying out unpaid work to the value of £3.12 billion. It is estimated that the average carer is saving the country £15,260 per year. However, carers themselves are paying a significant personal cost. <http://www.belfasttelegraph.co.uk/community-telegraph/east-belfast/news/mothers-share-their-stories-of-life-as-unpaid-carers-14846879.html>

Cancer not NICE guidelines kills patients

U.K. | *TIMES* (OpEd) – 16 June 2010 – 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. The cruel reality is that it's neither NICE [National Institute for Clinical Excellence] nor the NHS [National Health Service] that has given them a "death sentence," but Mother Nature. Following a three-year review by an independent committee, health watchdog NICE concluded that lapatinib was no more cost effective or clinically beneficial than existing treatments for HER2-positive advanced breast cancer. It's obviously a little more complicated than that, but it doesn't take an expert to realise that a finite pot of money and growing number of expensive treatments to fund makes for tricky decisions. <http://timesonline.typepad.com/science/2010/06/cancer-not-nice-guidelines-kills-patients.html>

From Media Watch dated 14 June 2010:

- U.K. | *Daily Mail* – 9 June 2010 – **'NHS denies dying mother chance to live long enough to see her son, 4, start school...'** Mikki Blunden, 37, who has breast cancer, has been given just weeks to live. Her only hope of surviving to see her son Thomas, four, start school in September is a "wonder drug" called lapatinib. <http://www.dailymail.co.uk/news/article-1285185/Mother-given-just-weeks-live-denied-wonder-drug-NHS.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>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *Independent* – 20 June 2010 – **'GP's admission may lead to fresh charges.'** The police are considering whether there is scope for fresh charges against Dr Howard Martin, who was struck off the medical register last week after he was found guilty of giving unjustifiably high doses of powerful painkillers to 18 patients. <http://www.independent.co.uk/news/uk/crime/gps-admission-may-lead-to-fresh-charges-2005429.html>
- U.K. (SCOTLAND) | *Scotsman* – 19 June 2010 – **'Opponents deal a blow to MacDonald's assisted suicide bill.'** Margo MacDonald's bid to introduce assisted suicide in Scotland has been dealt a blow, with the vast majority of people giving evidence to Holyrood [the Scottish parliament] on the issue declaring that they oppose her bill. <http://news.scotsman.com/health/Opponents-deal-a-blow-to.6372261.jp>
- THE NETHERLANDS | *Dutch News* – 16 June 2010 – **'Sharp growth in euthanasia deaths.'** The number of reported deaths by euthanasia rose 13% last year to 2,636, following an increase of 10% in 2008, the NRC [Handelsblad newspaper] reports, quoting figures due to be published at the beginning of July. The 2008 increase led the health ministry to set up an investigation into the increase. http://www.dutchnews.nl/news/archives/2010/06/sharp_growth_in_euthanasia_dea.php
- SWITZERLAND | *Swiss Info* – 16 June 2010 – **'Federal Court overturns assisted suicide deal.'** The Swiss Federal Court has declared an accord between the Zurich prosecutor's office and an assisted suicide organisation [Exit] null and void. Swiss law does not permit such deals. http://www.swissinfo.ch/eng/politics/Federal_Court_overturns_assisted_suicide_deal.html?cid=9113304

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

Living wills' lack of specifics limits their usefulness

AMERICAN MEDICAL NEWS | Online article – 18 June 2010 – Living wills fail to capture patients' end-of-life care wishes because they do not ask about the real-life scenarios patients are likely to face as they get close to death, according to a new study.¹ Patients [i.e., participants in the study] first were asked a question used in many Pennsylvania living wills, probing whether to "withdraw life-sustaining treatment that serves only to prolong the process of dying." Patients then were queried about their desires about more specific scenarios, such as whether to use antibiotics to treat their pneumonia if they also have Alzheimer's disease. There was a 23% average correlation between the responses. "This study points out that if you talk to people in more detail, there's more nuance to their decisions than just results from a simple question about what they want in a living will document," said Charles F. von Gunten, MD, PhD, editor-in-chief of the *Journal of Palliative Medicine* and provost of the Institute for Palliative Medicine at San Diego Hospice. <http://www.ama-assn.org/amednews/2010/06/14/prsd0618.htm>

1. *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 9 April 2010 – **'Ask a different question, get a different answer: Why living wills are poor guides to care preferences at the end of life.'** Living wills have a poor record of directing care at the end of life, as a copious literature attests. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2009.0311>

N.B. The journal article was noted in Media Watch dated 12 April 2010.

Is the WHO analgesic ladder still valid?

CANADIAN FAMILY PHYSICIAN, 2010;6(6):514-517. The author's proposed modification of the WHO analgesic ladder is not intended to negate or advise against use of the original ladder. On the contrary, after 24 years of use the analgesic ladder has demonstrated its effectiveness and widespread usefulness; however, modifications are necessary to ensure its continued use for knowledge transfer in pain management. <http://www.cfp.ca/cgi/reprint/56/6/514>

Of related interest:

- *CANADIAN FAMILY PHYSICIAN*, 2010;6(6):544-546. **'Killing the symptom without killing the patient.'** Two questions in particular are clinical stumbling blocks for the appropriate and effective use of opioids in serious illness: Do opioids cause respiratory depression, especially in patients with cardiopulmonary disease? Do opioids shorten life when required to treat severe symptoms? In other words, can you kill the symptom without killing the patient? <http://www.cfp.ca/cgi/reprint/56/6/544>
- *MEDSCAPE* | Online interview – 17 June 2010 – **'Psychological aspects of pain management.'** Pain specialists have been trying for years to educate clinicians on how best to manage pain, yet many patients still seem to suffer needlessly. <http://www.medscape.com/viewarticle/723724>

Challenges to improving end of life care of people with advanced dementia in the U.K.

DEMENTIA, 2010;9(2):259-284. The end of life care received by patients with advanced dementia and their carers is of increasing importance as the incidence of dementia is set to rise in the next 30 years. Currently, inappropriate admissions to hospital are common in the U.K. and patients are less likely to be referred to palliative care services, receive less pain control but undergo more invasive interventions compared to their cognitively intact counterparts. Patients and families are seldom informed of the terminal nature of dementia and advance care planning discussions are rare. The aim of this study was to improve the understanding of end of life care needs for this patient group and their carers, and to use this information to devise an intervention to improve care. <http://dem.sagepub.com/cgi/content/abstract/9/2/259>

Cont.

From Media Watch dated 14 June 2010:

- *DRUGS & AGING*, 2010;27(6):435-449. **'Withholding, discontinuing and withdrawing medications in dementia patients at the end of life: A neglected problem in the disadvantaged dying?'** Recent years have seen a growing recognition that dementia is a terminal illness and that patients with advanced dementia nearing the end of life do not currently receive adequate palliative care. However, research into palliative care for these patients has thus far been limited. <http://www.ingentaconnect.com/content/adis/dag/2010/00000027/00000006/art00001>

From Media Watch dated 22 February 2010:

- *JOURNAL OF NUTRITION, HEALTH & AGING* | Online article – 30 January 2010 – **'Recommendations on end-of-life care for people with dementia.'** Collaborating with national Alzheimer societies in Europe, the authors offer practical recommendations for the end-of-life care. <http://springerlink.com/content/c4897762718x3603/?p=dd5a021ec18946ffa2e7f4149c9dd0fa&pi=6>

From Media Watch dated 8 June 2009:

- *LA REVUE DE MÉDECINE INTERNE*, 2009;30(6):475-562. **'Soins palliatifs et maladie d'Alzheimer.'** This article presents a review of palliative care interventions for patients with Alzheimer's disease and other dementias. <http://www.sciencedirect.com/science/journal/02488663>

Palliative care patients' experiences of healthcare treatment

INTERNATIONAL JOURNAL OF SOCIAL WELFARE, 2010;19(3):262-271. Palliative care patients often have long healthcare careers, which enables them to compare different professionals and services, thus offering a more powerful and complex analysis of patient experience than that obtainable from analysis of complaints or satisfaction surveys, and permits some understanding to be obtained of the attitudes that condition evaluations of services. The patients balanced negative views with positive experiences. They appreciated open, listening, equal and friendly relationships with professionals in which careful explanation fostered their confidence in the overall service. They criticised inflexible services that did not consider their broad needs, and in which relationships with professionals were characterised by busy-ness and professional distance. <http://www3.interscience.wiley.com/journal/122394414/abstract>

Of related interest:

- *NURSING CLINICS OF NORTH AMERICA* | Online article – 21 May 2010 – **'Is a good death possible after withdrawal of life-sustaining therapy?'** The objective of this [hermeneutic phenomenological] study was to understand if families perceived that their family members had a good or a bad death when a family member had LST withdrawn after an unexpected, life-threatening illness or injury. [http://www.nursing.theclinics.com/article/S0029-6465\(10\)00036-8/abstract](http://www.nursing.theclinics.com/article/S0029-6465(10)00036-8/abstract)

Death of a parent and the children's experience: Don't ignore the elephant in the room

JOURNAL OF INTERPROFESSIONAL CARE, 2010;24(4):450-459. This paper explores two interlinked components of practitioner's support to children when a parent or carer is at the end of life or has died. The primary issue relates to communication and the competence and confidence of practitioners when working with this community of children. The paper suggests that related to this is the lack of training practitioners receive, both as students and through continual professional development, within the fields of social care and health. The metaphor of the elephant in the room is used to delineate how practitioners avoid such discussions and thereby miss opportunities to support children experiencing potentially the most traumatic life event they have faced. Drawing on current research and the author's experience and reflections as a researcher and practitioner the paper suggests that children experiencing the death of a parent or carer are not being recognized as children in need but rather requiring interventions from specialist services. <http://informahealthcare.com/doi/abs/10.3109/13561820903274871>

Life-prolonging treatment in nursing homes: How do physicians and nurses describe and justify their own practice?

JOURNAL OF MEDICAL ETHICS | Online article – 16 June 2010 – This study reveals a need to improve decision-making routines according to ethical ideals and legislation. Conflicts between relatives and healthcare professionals in the decision-making process deflect the focus from searching for the best possible treatment for the terminal patient. Further discussion is required as to whether the concept of autonomy is applicable in situations in which the patient is impaired and dying. <http://jme.bmj.com/content/early/2010/06/16/jme.2010.036244.abstract>

Content and spiritual items of quality-of-life instruments appropriate for use in palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 14 June 2010 – Despite the importance of palliative care and quality of life (QoL) as an outcome measure, little research [has] evaluated the QoL instruments that are used in end-of-life situations. Most of the instruments [evaluated by the authors] covered only one or two QoL domains, and none of the instruments covered all QoL domains included in the [authors'] framework. Most spirituality items concerned the meaning or purpose of life. This study provides information about the domains-included QoL instruments that are suitable for use in palliative care. [http://www.jpmsjournal.com/article/S0885-3924\(10\)00308-8/abstract](http://www.jpmsjournal.com/article/S0885-3924(10)00308-8/abstract)

Soliciting an herbal medicine and supplement use history at hospice admission

JOURNAL OF PALLIATIVE MEDICINE | Online article – 17 June 2010 – Reconciling medication use and performing drug utilization review on admission of a patient into hospice care are essential in order to safely prescribe medications and to prevent possible adverse drug events and drug-drug interactions. As part of this process, fully assessing herbal medicine and supplement use in hospice patients is crucial, as patients in hospice may be likely to use these medications and may be more vulnerable to their potential adverse effects. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2009.0378>

Fears, misconceptions keeping children from best end-of-life care

ONCOLOGY TIMES, 2010;32(12):50-53. Watching their child endure the late stages of cancer, one in eight parents considers hastening the child's death, according to a study in *Archives of Pediatrics & Adolescent Medicine*.¹ Only 9%, though, voice their sentiments, and only half that many actually ask a doctor to carry out the request. "Parents who considered hastening death were associated with the child experiencing significant suffering at the end of life," said the study's senior author, Joanne Wolfe, Director of Pediatric Palliative Care at Dana-Farber Cancer Institute and Children's Hospital, Boston. The study ... was a survey of 141 parents of children who had died of cancer. In a previous study, Dr. Wolfe and colleagues found that 89% of pediatric cancer patients who died at those institutions suffered significantly from at least one symptom in their last month of life. "Despite the best intentions of oncology teams, they don't have the time to deliver comprehensive care to children facing the end of life." http://journals.lww.com/oncology-times/Fulltext/2010/06250/Fears_Misconceptions_Keeping_Children_from_Best.8.aspx

1. *ARCHIVES OF PEDIATRICS & ADOLESCENT MEDICINE*, 2010;164(3):231-237. 'Considerations about hastening death among parents of children who die of cancer.' A total of 19 of 141 parents [i.e., participants in a cross-sectional survey conducted at two tertiary care U.S. pediatric institutions] considered requesting hastened death for their child and 9% discussed hastening death; consideration of hastening death tended to increase with an increase in the child's suffering from pain. <http://archpedi.ama-assn.org/cgi/reprint/164/3/231>

N.B. The journal article was noted in Media Watch dated 8 March 2010.

An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disability

PALLIATIVE MEDICINE | Online article – 17 June 2010 – Research suggests that shortcomings exist in the provision of palliative care to people with intellectual disabilities. Fifty-nine per cent of palliative care staff and 67% of intellectual disability services staff [i.e., participants in this mixed-methods study] had cared for someone with intellectual disability who had died, but level of experience was low. Both palliative care and intellectual disability services staff lacked confidence in their ability to provide palliative care. Staff were challenged by perceived 'differences' and 'difficulties' in the provision of care. They endorsed a partnership approach to care but focus group discussions revealed that a shared desire to cooperate was insufficient to guarantee effective collaboration.
<http://pmj.sagepub.com/cgi/content/abstract/0269216310371413v1>

From Media Watch dated 15 March 2010:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2010;16(2):93-98. **'Exploring the needs of hospice staff supporting people with an intellectual disability.'** This article defines the population involved, explores the literature which provides a contextual backdrop against which the research sits, introduces the methods and procedures used, and describes and discusses these findings in relation to the palliative care provision for people with an ID from a hospice perspective. It concludes by recognizing that appropriate education and training remain essential preparation for hospice workers when caring for someone with an ID. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=46755;article=IJPN_16_2_93_98

The significance of fatigue in relatives of palliative patients

PALLIATIVE & SUPPORTIVE CARE, 2010;8(2):137-142. The relatives [i.e., participants in this pilot study] were very tired and identified worries, uncertainty, the patient's suffering, and many demands as

the causes for the fatigue. The most obvious consequences of the tiredness were a lack of motivation, feelings of insufficiency and apathy, and putting their own interests aside. The health care system could make the situation easier for relatives of patients in palliative care by providing good care for the patient, and psychosocial support and respite care for the relatives.
<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=7808865&fulltextType=RA&fileId=S1478951509990885>

Media Watch: Editorial Practice

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

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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.

Patterns of nurse–physician communication and agreement on the plan of care

QUALITY & SAFETY IN HEALTH CARE, 2010;19(3):195-199. Interdisciplinary communication is critically important to provide safe and effective care, yet it has been inadequately studied for hospitalised medical patients. Our objective was to characterise nurse-physician communication and their agreement on patients' plan of care. Nurses and physicians (i.e., participants in this study did not reliably communicate with one another and were often not in agreement on the plan of care for hospitalised medical patients. <http://qshc.bmj.com/content/19/3/195.abstract>

From Media Watch dated 22 March 2010:

- *NURSING CLINICS OF NORTH AMERICA*, 2010;45(1):71-79. **'Different worlds: A cultural perspective on nurse-physician communication.'** Although numerous studies have documented the value of effective nurse-physician communication on patient outcomes and on nurse and physician satisfaction, communication between many physicians and nurses continues to be poor. [http://www.nursing.theclinics.com/article/S0029-6465\(09\)00088-7/abstract](http://www.nursing.theclinics.com/article/S0029-6465(09)00088-7/abstract)

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *CANADIAN FAMILY PHYSICIAN*, 2010;6(6):526-527. **'We can do better than euthanasia – we must.'** Euthanasia takes us in the wrong direction. It distorts patient-doctor relationships, leaves physicians off the hook too easily in challenging situations, violates health professionals' moral autonomy, and dehumanizes physicians as they become executioners. We can do better than euthanasia – we must. <http://www.cfp.ca/cgi/content/full/56/6/526-a>
- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2010;182(9):877. **'Time to move on from the euthanasia debate.'** As physicians, we should promote honest dialogue; help define actions and terms; avoid further polarization of this important debate with our own values and ideologies; and help educate the public to enable engagement in this very important societal issue. Then "euthanasia" can experience its own gentle death. <http://www.cmaj.ca/cgi/reprint/182/9/877>

Worth Repeating

Dying abroad

U.K. | *Guardian Weekly* – 28 November 2007 – The grim reaper pays heed neither to time nor place of death. For a world awash with increasing numbers of expatriates dotted around the globe, inevitably more will die abroad. The British Foreign & Commonwealth Office puts the number of British passport holders who live abroad at 13 million. Of these, thousands die each year. It will be your relatives and friends left behind who ensure that you are not relegated to a pauper's grave in a foreign clime. And lest we forget, the task of repatriating mortal remains to the homeland is costly and fraught with complexity. The cultural and legal aspects of death and dying are as varied across the globe as the practices of marriage and divorce. No two countries are alike. Take embalming. In France a body cannot be transported without a police tag and the local mayor's approval. After 24 hours, the body must be embalmed and placed in a wooden coffin. In Islamic countries, it is common for the deceased to be buried before sundown or within 24 hours, without embalming. In the U.S., embalming is common practice. In many countries – when embalming does take place – it is a qualified embalmer's job, whereas in some countries, for example Portugal and Spain, it is against the law for anyone but a qualified doctor to undertake this procedure. <http://www.guardian.co.uk/money/2007/nov/28/expat-finance-health>

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