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 and research.

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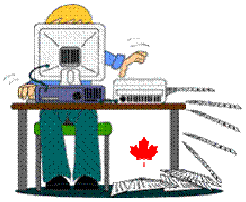


Compiled & Annotated by Barry R. Ashpole

Global perspective: Scroll down to Specialist Publications and 'Why different countries manage death differently: A comparative analysis of modern urban societies' (p.9), published in the *British Journal of Sociology*.

Canada

Drug shortage forces hospice to turn away dying patient

ONTARIO | *Toronto Star* – 17 March 2012 – An Oakville hospice that cares for cancer patients in their final days had to turn away a potential patient last week because it had run out of a key medication used in end of life care. The Ian Anderson House, Ontario's first hospice to care exclusively for terminal cancer patients, was unable to accept a man with cancer whose wife wanted him to die in hospice. The patient required the anti-convulsion medication phenobarbital to prevent distressing and potentially fatal seizures. The hospice and the pharmacy it relies on were unable to procure the injectable version of the drug due to the ongoing nationwide drug shortage. http://www.thestar.com/news/article/1148085--drug-shortage-forces-hospice-to-turn-away-dying-patient

Of related interest:

- ONTARIO | CBC News (Ottawa) – 13 March 2012 – **'Palliative care providers fear drug shortage.'** Dr. Susan Gick ... says she is concerned about a reduced inventory after Sandoz Canada, the country's leading maker of painkillers, halted production of many drugs for operational upgrades. Sandoz supplies the palliative care industry with approximately 90% of its medications. http://www.cbc.ca/news/canada/ottawa/story/2012/03/13/ottawa-palliative-care-drug-shortage.html

- BRITISH COLUMBIA | 1130 News (Vancouver) – 12 March 2012 – **'Dying patients affected by drug shortage in Canada.'** The Canadian Cancer Society is asking the federal government to do something about a shortage of drugs needed for treating cancer patients ... [and] ... those living out the last days of their lives. http://www.news1130.com/news/local/article/340177--dying-patients-most-affected-by-drug-shortage-in-canada

From Media Watch dated 27 February 2012:

- QUEBEC | Sun News – 25 February 2012 – **'Info in short supply on looming nationwide drug shortage.'** http://www.sunnewsnetwork.ca/sunnews/canada/archives/2012/02/20120225-091903.html

From life-saving care to end-of-life care

When ICU beds are scarce, doctors' goals change

ALBERTA | Reuters (Calgary) – 15 March 2012 – When hospitals are short on beds in the intensive care unit, doctors are more likely to switch from life-saving care to end-of-life care, a new Canadian study shows.[1] But it's not clear whether that means patients die any sooner, researchers report. Even if they do, that's not necessarily a bad thing, said Dr. Scott Halpern, a critical care expert at the University of Pennsylvania in Philadelphia, who wrote a commentary on the findings.[2] "A lot of ICU beds in this country are filled with patients that are either too sick to benefit or too well to benefit," Halpern told Reuters Health. "The present study is interesting in that it raises the possibility that scarcity may in fact be the mother of expedited end-of-life decision-making," he added. http://www.reuters.com/article/2012/03/15/us-when-icu-beds-idUSBRE82E1AY20120315

1. 'Intensive care unit bed availability and outcomes for hospitalized patients with sudden clinical deterioration,' *Archives of Internal Medicine*, published online 12 March 2012. http://archinte.ama-assn.org/cgi/content/abstract/archinternmed.2011.2315

2. 'Deferred admission to the intensive care unit: Rationing critical care or expediting care transitions?,' *Archives of Internal Medicine*, published online 12 March 2012. http://archinte.ama-assn.org/cgi/content/full/archinternmed.2012.114

It may be easier to get into a cemetery than a long-term care bed

ONTARIO | *Hamilton Spectator* – 13 March 2012 – There are 200 beds in St. Patrick's Home, a long-term care residence not far from Carleton University in Ottawa. There were 395 people waiting for one of those beds to become available the last time St. Patrick's CEO Linda Chaplin checked her list. That's more than just an arithmetic puzzle. "It is heartbreaking," said Chaplin. The sad truth is that some of the people on the waiting list will get a spot in an Ottawa cemetery before they get a bed in St. Patrick's Home. http://www.thespec.com/news/local/article/686004--it-may-be-easier-to-get-into-a-cemetary-than-a-long-term-care-bed

U.S.A.

Debate over Connecticut hospices moves to legislature

CONNECTICUT | Associated Press – 17 March 2012 – The emotional debate over whether to revamp decades-old regulations in Connecticut and ultimately allow more hospice organizations to offer inpatient services moved to the General Assembly, which is considering a bill that could mandate such a change. The regulation changes have pitted Connecticut Hospice in Branford, a nationally recognized hospital for the terminally ill, against dozens of hospice providers across the state. While advocates for Connecticut Hospice argue that such a modification waters down standards, the other hospice groups maintain that Connecticut families need more local options for end-of-life care. http://www.theday.com/article/20120317/NWS12/303179931/-1/NWS

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/pg/file/owner/MediaWatch

Terminal care

Go gentle into that good night

THE ECONOMIST | Online article – 17 March 2012 – Asked where they would like to spend their last days, Americans almost always say at home, surrounded by people they love. In real life, though, only one in five achieves that. More than 30% die in a nursing home, where almost no one wants to be, and over half end up in a hospital, often in an intensive-care unit, heavily sedated and attached to life-saving equipment until their doctors give up the battle. Death is a difficult subject for anyone, but Americans want to talk about it less than most. They have a cultural expectation that whatever may be wrong with them, it can be fixed with the right treatment, and if the first doctor does not offer it they may seek a second, third or fourth opinion. Litigation is a constant threat, so even if a patient is very ill and likely to die, doctors and hospitals will still persist with aggressive treatment, paid for by the insurer or, for the elderly, by Medicare. That is one reason why America spends 18% of its GDP on health care, the highest proportion in the world. http://www.economist.com/node/21550236

Specialist Publications

Of particular interest:

'Why different countries manage death differently: A comparative analysis of modern urban societies' (p.9), published in the *British Journal of Sociology.*

Of related interest:

- *FORBES* | Online article – 16 March 2012 – **'You are sick! Now what?'** Unfortunately, many people don't think seriously about end of life in the "pre-illness phase," so they are left to prepare for death at the most challenging time – the illness phase and the "too late to do anything about the illness" phase. http://www.forbes.com/sites/carolynmcclanahan/2012/03/16/you-are-sick-now-what/

House passes bills to change advance directives

NEW HAMPSHIRE | Associated Press – 14 March 2012 – The New Hampshire House passed two bills that would change state law that governs governing medical treatment for patients who are unable to speak for themselves. Both bills relate to advance directives that spell out a patient's wishes for limiting life-sustaining treatment or designating medical decision-making power. Under [State] law, patients can use advance directives to indicate whether they should be taken off of life-sustaining treatment or medically administered hydration and nutrition through a living will.http://www.wisconsinrapidstribune.com/usatoday/article/38795637?odyssey=mod%7Cnewswell%7Ctext%7CFRONTPAGE%7Cs

Of related interest:

- IDAHO | Northwest Cable News – 13 March 2012 – **'Senate committee passes end-of-life care bill.'** The Senate State Affairs committee passed a bill ... prohibiting medical personnel from denying life-prolonging treatments and medicines to patients who have requested them. Senator Sheryl Nuxoll ... says patients should maintain the right to extend their lives as long as they desire. http://www.nwcn.com/home/?fId=142546785&fPath=/news/local&fDomain=10222
- CALIFORNIA | *North County Times* – 11 March 2012 – **''No CPR' tattoo a waste of good ink.'** A "No CPR" tattoo is not the same as a written, properly authenticated DNR (Do Not Resuscitate) directive. DNR directives are common and they are legal. Without such a written directive, emergency medical responders have no choice but to take those steps that are necessary to revive the victim. http://www.nctimes.com/news/opinion/commentary/forum-no-cpr-tattoo-a-waste-of-good-ink/article_ddd86ce4-fb09-5319-9bca-c6ac2363fda0.html

Patients appear to find calm, comfort in playing done in sync with vital signs

ILLINOIS | *Chicago Tribune* – 13 March 2012 – Music-thanatology is a component of hospice care, though not one that is not widely practiced, say health care experts specializing in end of life care. Many say it can have positive effects, calming agitated and restless patients. The Midwest Palliative & Hospice Care Center in Glenview is the only known provider of the service in the Midwest, according to local experts. "Typically, patients are being actively managed with other therapies, but I think this is an important component, as well," said Dr. Monica Malec, assistant professor of medicine for geriatrics and palliative care at the University of Chicago. She has also worked with patients at the Midwest Care Center. "Until you experience it, it's hard to imagine it. You can see those changes happening." http://www.chicagotribune.com/news/local/ct-x-music-vigils-20120314,0,6743294.story

Decreased patient costs from innovative home care program

MICHIGAN | Hospice Michigan – 13 March 2012 – Persons with advanced illness experienced decreased medical care costs while participating in an innovative home care program. By shifting a number of services to the home environment ... patient costs were reduced significantly, for one group by over $3,000 per month. This independent pilot study on advanced illness management strategy was funded by a grant from the Blue Cross Blue Shield of Michigan Foundation and conducted by Hospice of Michigan's Maggie Allesee Center for Quality of Life in collaboration with Wayne State University's School of Social Work. http://www.marketwatch.com/story/hospice-of-michigan-announces-decreased-patient-costs-from-innovative-home-care-program-2012-03-13

Of related interest:

- CONNECTICUT | *Gant Daily* (Clearfield, Pennsylvania) – 14 March 2012 – **'Connecticut weighs its 'nurses only' medication policy for homebound seniors.'** Connecticut ... is looking closely at how it cares for people with chronic conditions ...but ... there's an expensive obstacle in the way – Connecticut law says nurses have to give medications to people in the Medicaid system living at home, and that costs a lot of money. http://gantdaily.com/2012/03/13/connecticut-weighs-its-nurses-only-medication-policy-for-homebound-seniors/

Ethics committees mediate crucial end-of-life decisions

NEW JERSEY SPOTLIGHT | Online article – 13 March 2012 – When a nursing home resident can no longer make decisions, someone else has to make the tough ethical choices. Should the patient's life be prolonged with a ventilator or feeding tube? Has the time come to remove life support? What would this person have wanted? The family and the nursing home staff can wind up at loggerheads, unable to take the next step. The state's ethics committees are helping families and nursing home staff make these tough decisions. The regional panels are made up of trained volunteer professionals with diverse backgrounds, including nursing, social work, long-term care, and clergy. They work under the direction of the Ombudsman for the Institutionalized Elderly... http://www.njspotlight.com/stories/12/0312/2327/

Palliative care and technology

Non-profit planning to replace paper advance directives with patient videos

MEDCITY NEWS | Online report – 12 March 2012 – The next step for Advanced Care Planning Decisions in their work to help patients make end-of-life decisions is to embed patient videos into an electronic medical record to make advanced directives crystal clear. Dr. Angelo Volandes said this iteration of the project will help family members as well as doctors understand exactly how much care a person wants at the end of life. http://www.medcitynews.com/2012/03/non-profit-planning-to-replace-paper-advance-directives-with-patient-videos/

Population trends

75-year study finds dramatic rise in U.S. lifespans

U.S. NEWS & WORLD REPORT | Online report – 13 March 2012 – A look at statistics from 1935 to 2010 found significant improvements in Americans' expected lifespans, mainly due to factors such as better medical care and declines in smoking rates. While death is, of course, inevitable for everyone, the average American's overall risk of dying at a given point in time dropped 60% since 1935, the study found.[1] http://health.usnews.com/health-news/news/articles/2012/03/13/75-year-study-finds-dramatic-rise-in-us-lifespans

1. '75 Years of Mortality in the U.S., 1935–2010,' National Center for Health Statistics, January 2012. http://www.cdc.gov/nchs/data/databriefs/db88.pdf

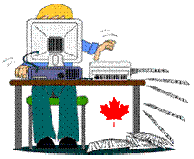
Assisted (or facilitated) death

Representative sample of recent news media coverage:

- VERMONT | *Bennington Banner* – 16 March 2012 – **'Death with dignity bill won't see vote; dies in committee.'** Progress on legislation that would allow terminally ill patients to end their own lives with prescribed medication came to a screeching halt ... and the bill will not advance this year. The death with dignity bill, as proponents call it, or physician-assisted suicide as it is known by opponents, will not clear the Senate Judiciary Committee. The Judiciary Committee heard testimony on the bill, S.103, early this week. http://www.benningtonbanner.com/ci_20193452/death-dignity-bill-wont-see-vote-dies-committee

- NEW MEXICO | *Las Cruces Sun-News* – 16 March 2012 – **'2 doctors file challenge against New Mexico 'right to die' law.'** Two physicians filed a challenge ... against a decades-old New Mexico law that prohibits doctors from helping terminally ill patients die. Cancer doctors Katherine Morris and Aroop Mangalik filed their lawsuit with their attorneys in state district court in Albuquerque. According to the lawsuit, the doctors, both who work at the University of New Mexico Health Science Center, seek to be allowed to prescribe medication to terminally-ill patients who want to end their lives. http://www.lcsun-news.com/las_cruces-news/ci_20186508/2-doctors-file-challenge-against-nm-right-die

- *THE ATLANTIC* | Online article – 14 March 2012 – **'The Dutch euthanize their elderly, and other scary GOP lies about Europe.'** The American right sure seems to like stories about foreign countries killing their citizens. Most recently, leading GOP candidate Rick Santorum claimed that 10% of the Netherlands' deaths were from euthanasia, 5% forced, and that "elderly people in the Netherlands don't go to the hospital" or, if they do, wear bracelets saying "do not euthanize me," all of which is false. http://www.theatlantic.com/international/archive/2012/03/the-dutch-euthanize-their-elderly-and-other-scary-gop-lies-about-europe/254462/



Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://www.ipcrc.net/barry-r-ashpole.php

International

Home care for elderly branded 'shocking and disgraceful'

U.K. | BBC News – 16 March 2012 – The standards of care provided for older people in their homes in the UK has been labelled "shocking and disgraceful" by a consumer group. Which? found cases of missed visits, food left out of reach, medication not given and people being left in soiled beds during its investigation. It concluded too many faced a "constant battle" to just get the basic help. Which? said the findings - based on a survey and diaries kept by the elderly – showed the system needed reform. http://www.bbc.co.uk/news/health-17389588

End of life care services letting down lesbian, gay, bisexual and transgender people say leading charities

U.K. | National Council for Palliative Care (NCPC) report – 15 March 2012 – Lesbian, gay, bisexual and transgender (LGB&T) people report feeling let down by end of life care services, according to a new report by the NCPC and the Consortium of Lesbian, Gay, Bisexual & Transgendered Voluntary & Community Organisations. 'Open to all? Meeting the needs of lesbian, gay, bisexual and transgender people nearing the end of life,' draws on a survey of over 700 hospices, care homes and hospitals, as well as clinicians and service users. With more than 3.7 million lesbian, gay and bisexual people and at least 12,500 transgender people in Britain, the report expresses concerns that a significant proportion of the population are not accessing appropriate care when they are dying because of their sexuality or gender identity. Many LGB&T people do not feel that end of life care services are open to them and are concerned that they will face discrimination and a lack of understanding from health and social care providers when they are dying. http://www.ncpc.org.uk/news/87

From Media Watch dated 6 February 2012:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2012;18(1):29-34. **'End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals.'** Negative social attitudes, discrimination, and homophobia affect gay, lesbian, bisexual, and transgender (GLBT) individuals during their lifetimes. These experiences can affect how these individuals access health services and interact with health professionals, resulting in adverse outcomes compared with their heterosexual counterparts. End-of-life experiences can also be shaped by these factors. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=89126;article=IJPN_18_1_29_34

U.K. first on death and dying: North East National Health Service 'Deciding Right' initiative on end of life care

U.K. (ENGLAND) | SKY News (Tyne) – 15 March 2012 – The National Health Service in the North East launched the U.K.'s first region-wide agreement aimed at ensuring people's dying wishes are followed correctly. The 'Deciding Right' initiative has created one single set of documents that can be signed by those with terminal illness who do not want to be resuscitated if their heart stops. The paperwork will be easily recognised by health professionals across the North East and will carry the legal authority to ensure patients' wishes are followed right at the very end of their lives. http://tyneandwear.sky.com/news/article/15021

End of life issues Ireland

IRELAND | Probateireland – 14 March 2012 – End of Life issues are on the agenda in Ireland following the publication of the long awaited Advance Healthcare Decisions Bill 2012. This legislation, if passed, will introduce certainty in this area which is of increasing concern to people. At present under Irish law, Advance Care Decisions (otherwise known as Advance Care Directives or Living Wills) are legally persuasive but not legally binding. The new bill, if enacted, will provide a helpful legal framework to facilitate the making of "living wills" and introduce necessary clarity in regard to their effect. http://probateireland.wordpress.com/2012/03/14/71/

Paediatric palliative care

Dedicated palliative care programme

SOUTH AFRICA (WESTERN CAPE) | The New Age – 14 March 2012 – The province received its first dedicated hospital-based - paediatric palliative care programme, which is funded by The Children's Hospital Trust. The programme offered by The Bigshoes Foundation will assist healthcare professionals at tertiary and district hospitals, specialised children's hospices, homes, and home-based care organisations to provide comprehensive care for children in need of long-term palliative care. Clinical director of the Foundation Michelle Meiring said: "Palliative care is a specialised area of healthcare that focuses on relieving the suffering of patients and their families, when facing life threatening or life-limiting illnesses. Unlike hospice care with its focus on end-of-life care, palliative care is essential for patients as they progress from diagnosis to disease progression and finally to end of life. In South Africa, palliative care has largely developed out of the hospice movement and is predominantly community based." In the Western Cape, more than 80,000 children live with life limiting or life-threatening illnesses that could require palliative care. http://www.thenewage.co.za/46102-1011-53-Dedicated_palliative_care_programme

Specialist Publications

Of particular interest:

'The model of palliative care in the perinatal setting' (p.9), a literature review published in *BMC Pediatrics.*

N.B. Several articles on different aspects of paediatric palliative care were noted in recent issues of Media Watch: 12 March (p.7); 13 February (p.7); and, 9 January (p.10).

Care homes struggling to meet needs of elderly people, Royal College of Nursing warns

U.K. (ENGLAND) | *The Guardian* – 14 March 2012 – Care homes for elderly people are struggling to meet the needs of residents with complex medical conditions amid cuts in funding, a new report warns.[1] The Royal College of Nursing (RCN) report says elderly people are being admitted to care homes with increasingly severe and complex care needs, having previously been treated in acute hospitals. The survey of 600 care home nurses found 26% felt they did not have adequate equipment and medical supplies, while 38% said there were not enough full-time registered nurses employed to provide suitable care. Almost half of nurses (48%) said residents were being accepted in a bid to fill vacant places despite concerns about levels of care. The RCN report raised concerns about dwindling morale among care home staff, with carers often paid the minimum wage. The union recommends a re-evaluation of how funding is allocated to care homes; the introduction of national guidance on staffing levels; a government review of workforce planning in care homes; and regulation of all healthcare assistants. http://www.guardian.co.uk/society/2012/mar/14/care-homes-struggling-elderly-people

Extract from Royal College of Nursing report

My only concern is that we are now taking in residents who need palliative and terminal care. This means a lot more input from RNs over the short period and the turnover and workload is much increased without any increase in staffing.

1. 'Persistent challenges to providing quality care: An RCN report on the views and experiences of frontline nursing staff in care homes in England', 14 March 2012. http://www.rcn.org.uk/__data/assets/pdf_file/0007/438667/Persistent_challenges_to_providing_quality_care_v5.pdf

Inquiry into palliative care in Australia

Only 10 days left

AUSTRALIAN AGEING AGENDA | Online report – 13 March 2012 – The Senate's Community Affairs References Committee has received only 16 written submissions to its broadest inquiry into palliative care ever, despite the fact that it first called for public comments late last year and there are only 10 more days before the deadline [23 March 2012] passes. Palliative Care Australia has called upon individuals and organisations operating in this space to fulfil their health care responsibilities, stand up for their profession and patients, and tell the Senate what it is really like to work with the dying in Australia. President of Palliative Care Australia, Dr. Scott Blackwell, has urged everyone with an interest in palliative care and a passion for improving people's quality of life – even at the end of life – to submit their personal stories and suggestions about how the system could work better. http://www.australianageingagenda.com.au/2012/03/13/article/Only-10-days-left/BTZQXLREBQ.html

1. Senate Standing Committees on Community Affairs, Palliative Care in Australia website: http://aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/palliative_care/index.htm

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- FINLAND | YLE News – 16 March 2012 – **'Most Finns support euthanasia.'** Every three out of four Finns are in favour of euthanasia for the incurably ill, according to a survey published by the newspaper *Aamulehti*. The poll indicates that 77% of respondents would support euthanasia if it was something terminally ill patients wanted for themselves. Opponents of euthanasia numbered 12% of respondents, while about a tenth of them were not sure either way. Nearly half – 44% – said they would want to undergo euthanasia if they were to become incurably ill. http://www.yle.fi/uutiset/news/2012/03/aamulehti_most_finns_support_euthanasia_3340541.html

- U.K. | BBC News – 12 March 2012 – **''Locked-in syndrome' man to have right-to-die case heard.'** A paralysed man who wants a doctor to be able to lawfully end his life can proceed with his "right-to-die" case, a High Court judge has ruled. Tony Nicklinson, 58 ... has "locked-in syndrome" following a stroke in 2005 and is unable to carry out his own suicide. He is seeking legal protection for any doctor who helps him end his life. The Ministry of Justice argues making such a ruling would authorise murder and change the law governing it. http://www.bbc.co.uk/news/uk-17336774

  N.B. Scroll down to **Specialist Publications** and 'Assisted suicide: A right to professionally-aided death?' (p.13), a nursing perspective on this case published in the *British Journal of Nursing*, 2012;21(4):250-251.

- U.K. | *This is Lancashire* – 12 March 2012 – **'Assisted suicide debate in Commons.'** Assisted suicide will be debated in Parliament for the first time in 15 years. MPs will vote on guidelines for assisted suicide on 27 March [2012]. The full-day debate will be held in the House of Commons and MPs will decide whether they agree with the Director of Public Prosecutions' policy on assisted suicide ...in place since February 2010. Last month, Patricia Morris, Baroness Morris of Bolton, told the House of Lords the current law combines "deterrence with compassion" and should not be changed. http://www.thisislancashire.co.uk/news/9583757.Assisted_suicide_debate_in_Commons/

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

Literature review

The model of palliative care in the perinatal setting

BMC PEDIATRICS | Online article – 12 March 2012 – Among the 1,558 articles retrieved, the authors did not find any quantitative empirical study. To study the evolution of the model of care, they ultimately included 101 studies...The analysis revealed a gradual conceptual evolution of the model, which includes the notions of family-centered care, comprehensive care (including bereavement) and early and integrative care (also including the antenatal period). A subset of 27 articles that made special mention of antenatal aspects showed a similar distribution. In this subset, the results of the four descriptive clinical studies showed that, in the context of specific programmes, a significant number of couples (between 37 and 87%) opted for PC [palliative care] and to continue with the pregnancy when the foetus has been diagnosed with a lethal illness. Despite the interest that PC has aroused in perinatal medicine, there are no evidence-based empirical studies to indicate the best model of care for this clinical setting. The very notion of PC has evolved to encompass perinatal PC, which includes, among other things, the idea of comprehensive care, and early and integrative care initiated antenatally. http://www.biomedcentral.com/content/pdf/1471-2431-12-25.pdf

Symptom management of spiritual suffering in pediatric palliative care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2012;14(2):109-115. This pediatric palliative care case study illustrates symptom management challenges related to spiritual suffering of a dying adolescent. The nurse plays a critical role in identifying the pediatric patient's verbal and nonverbal cues that may denote spiritual problems, as well as patient, family, and environmental factors. http://journals.lww.com/jhpn/Abstract/2012/03000/Symptom_Management_of_Spiritual_Suffering_in.5.aspx

From Media Watch dated 6 February 2012:

- *ADVANCES IN NEONATAL CARE*, 2012;12(1):28-36. **'A model program for perinatal palliative services.'** This article describes a perinatal ... program in which a) care is provided at the time of diagnoses/antenatally and includes home visits by members of an interdisciplinary hospice team; b) care is collaborative, community-based, and family-centered, and takes place in labor and delivery and on the mother baby unit; and, c) follow-up to the family continues for 1 year after the death. http://journals.lww.com/advancesinneonatalcare/Abstract/2012/02000/A_Model_Program_for_Perinatal_Palliative_Services.9.aspx

Why different countries manage death differently: A comparative analysis of modern urban societies

BRITISH JOURNAL OF SOCIOLOGY, 2012;63(1):123-145. This article seeks to identify the factors that can explain both similarities and differences in the management of death between different modern western nations. Structural factors which affect all modern nations include urbanization and the division of labour leading to the dominance of professionals, migration, rationality and bureaucracy, information technology and the risk society. How these sociologically familiar structural features are responded to, however, depends on national histories, institutions and cultures. Historically, key transitional periods to modernity, different in different nations, necessitated particular institutional responses in the management of dying and dead bodies. Culturally, key factors include individualism versus collectivism, religion, secularization, boundary regulation, and expressivism. Global flows of death practices depend significantly on subjugated nations' perceptions of colonialism, neo-colonialism and modernity, which can lead to a dominant power's death practices being either imitated or rejected. http://onlinelibrary.wiley.com/doi/10.1111/j.1468-4446.2011.01396.x/abstract

Uncertainty in end-of-life care and shared decision making

CRITICAL CARE & RESUSCITATION 2012;14;81-87. Assessing the appropriateness of continuing life support is a difficult task for intensive care unit staff. Part of this difficulty relates to prognostic uncertainty and the varying reliability of clinical decisions. Uncertainty about prognosis is quickly recognised by patients and families, and can be a source of mistrust and potential conflict. The authors discuss the reasons for uncertainty and outline key measures to reduce and manage such uncertainty. Practical certainty, where the clinicians are as certain as they can be, with both prognostication and knowledge of patient wishes, may be an appropriate concept for physicians engaged in end-of-life decisions. It involves accurate prognostication, informed surrogates, advance care planning, time to assess response, and the collective wisdom of experienced clinicians. The family conference should develop an agreed plan through shared decision making. http://www.cicm.org.au/journal_load.php?year=2012&month=march&page=81.php&title=81 Uncertainty%20in%20end-of-life%20care%20and%20shared%20decision%20making%0A%20%20%20%20

Palliative care in Japan

The current status and issues regarding hospital-based specialized palliative care service in Japanese regional cancer centers: A nationwide questionnaire survey

JAPANESE JOURNAL OF CLINICAL ONCOLOGY | Online article – 6 March 2012 – A total of 242 of 288 institutions (84%) returned the questionnaires. Responses indicated that 99% had palliative care consultation teams. For the process of palliative care consultation service, 90% defined the palliative care consultation request methods, 92% implemented seminars about palliative care for health-care workers in the hospital and 31% had joint meetings with the clinics and home nursing station in the community. Palliative care services have rapidly been developed and implemented in Japan. However, to improve the quality of palliative care services and provide more specialized palliative care within the limits of resources, it will be necessary to review the system in the future. http://jjco.oxfordjournals.org/content/early/2012/03/06/jjco.hys022.abstract

Behavioral and psychological symptoms in moderate to severe Alzheimer's disease: A palliative care approach emphasizing recognition of personhood and preservation of dignity

JOURNAL OF ALZHEIMER'S DISEASE, 2012;29(1):1-13. Clinicians often perceive a disconnect between evidence-based guidelines and the challenges of treating BPSD [behavioral and psychological symptoms of dementia] in moderate to severe AD [Alzheimer's disease]. Reconciliation of salient ethical issues can help bridge this disconnect. The authors propose a palliative care approach that prioritizes the recognition of personhood and the preservation of dignity. They present case illustrations, discuss the concepts of dignity and personhood during palliative care in AD, and encourage the use of the bioethical grid in navigating complex clinical challenges. http://iospress.metapress.com/content/1797172u35601461/?p=43c23662e3f24abdaa75b1008706d720&pi=0

Of related interest:

- *JOURNAL OF CLINICAL ONCOLOGY* | Overview of series – 12 March 2012 – **'Caring for the whole patient: The science of psychosocial care.'** The series is designed to provide oncology professionals with the most recent information on the psychological, psychiatric, and social aspects of cancer care. http://jco.ascopubs.org/content/early/2012/03/06/JCO.2011.41.4078.full.pdf+html

  N.B. To access the articles in the series: http://jco.ascopubs.org/content/early/recent (scroll down to 'Palliative and Supportive Care').

Palliative sedation in end-of-life care and survival: Systematic review

JOURNAL OF CLINICAL ONCOLOGY | Online article – 12 March 2012 – Eleven published articles were identified describing 1,807 consecutive patients in 10 retrospective or prospective non-randomized studies, 621 (34.4%) of whom were sedated. The most frequent reason for sedation was delirium in the terminal stages of illness. Comparing survival of sedated and non-sedated patients, the sedation approach was not shown to be associated with worse survival. Even if there is no direct evidence from randomized clinical trials, palliative sedation, when appropriately indicated and correctly used to relieve unbearable suffering, does not seem to have any detrimental effect on survival of patients with terminal cancer. In this setting, palliative sedation is a medical intervention that must be considered as part of a continuum of palliative care. http://jco.ascopubs.org/content/early/2012/03/06/JCO.2011.37.3795.abstract

From Media Watch dated 20 February 2012:

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2012;2(1):9-11. **'Intention, procedure, outcome and personhood in palliative sedation and euthanasia.'** This article attempts to demonstrate that palliative sedation is fundamentally different from euthanasia when it comes to intention, procedure, outcome and the status of the person. http://spcare.bmj.com/content/2/1/9.abstract

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online article – 13 February 2012 – **'Considerations of physicians about the depth of palliative sedation at the end of life.'** The authors found two approaches toward the depth of continuous sedation: starting with mild sedation and only increasing the depth if necessary, and deep sedation right from the start. http://www.cmaj.ca/content/early/2012/02/13/cmaj.110847.1

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/CurrentNewsandEvents/tabid/88/Default.aspx (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/inthenews.html

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

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.palliativecareconsultation.ca/?q=mediawatch

U.S.A.

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

Europe

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/news.htm (Scroll down to 'International End of Life Roundup')

International

Australasian Palliative International Link: http://www1.petermac.org/apli/links.htm (Scroll down to 'Media Watch')

Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

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

Withdrawal of life-sustaining treatment

How valuable is expert evidence when assessing a patient in a vegetative state?

SOLICITORS JOURNAL (U.K.) | Online article – 12 March 2012 – The legal system is sometimes called upon to assess the level of mental functioning of individuals in a persistent vegetative state (PVS). Such questions can arise both in cases involving the possible withdrawal of life-sustaining treatment, and in compensation claims. In addressing these questions the courts rely on expert evidence, but experience shows that medical experts may disagree as much as laymen about the level of an individual's mental functioning. A foundation stone of the legal debate around PVS is the decision in *Airedale National Health Service Trust Respondents v Bland* [1993] AC 789. Anthony Bland was a victim in the Hillsborough disaster and suffered anoxic brain damage following severe injuries which resulted in his brain being starved of oxygen. The case was the first decision by the Court of Appeal that life-sustaining treatment could be removed [and] involved several expert witnesses. An appeal to the House of Lords failed as the "court had been assisted by expert medical evidence from witnesses of the highest calibre and of the very greatest experience." http://www.solicitorsjournal.com/story.asp?sectioncode=3&storycode=19759&c=3&eclipse_action=getsession

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *AUSTRALIAN & NEW ZEALAND JOURNAL OF PSYCHIATRY*, 2012;46(3):185-187. **'Neither euthanasia nor suicide, but rather assisted death.'** Euthanasia is an ever-present topic in the community, but every decade or so it becomes more prominent, usually in association with impending legislation. Now is such a time. Euthanasia is a deceptively simple term. It can have different meanings... http://anp.sagepub.com/content/46/3/185.full.pdf+html

Cont. on next page

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.

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1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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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.

- *BRITISH JOURNAL OF NURSING*, 2012;21(4):250-251. **'Assisted suicide: A right to professionally-aided death?'** The article examines the recent decision in the case ... in which a man in a locked-in state seeks assistance in dying ... [and] ... explores the issue of professional assistance in the suicide process... http://www.internurse.com/cgi-bin/go.pl/library/abstract.html?uid=89838

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2012;14(2):141-148. **'Washington State Death With Dignity Act: A survey of nurses' knowledge and implications for practice Part 2.'**[1] Main themes that emerged were lack of knowledge about the Death With Dignity Act itself and facility policy on the Act. Nurses have strong feelings in favor of and in opposition to the law often with a clear expression of conflict related to personal beliefs, the Nursing Code of Ethics, and facility policy. Most nurses would refer a patient to another source if asked about the ... Act. Gaps in knowledge about the Act contribute to fear of job loss and other ethical conflicts associated with responding to patients who may inquire about the law. A potential barrier exists with regard to nurses providing patients with accurate information about the law. http://journals.lww.com/jhpn/Abstract/2012/03000/Washington_State_Death_With_Dignity_Act__A_Survey.10.aspx

    1. 'The Washington State Death With Dignity Act: A survey of nurses knowledge and implications for practice Part 1,' *Journal of Hospice & Palliative Nursing*, 2012;14(1):45-52.http://journals.lww.com/jhpn/Abstract/2012/01000/The_Washington_State_Death_With_Dignity_Act__A.8.aspx

Death inspectors or the 'professionals' of death during the late nineteenth and early twentieth century Transylvania

MORTALITY | Online article – 12 March 2012 – The paper highlights ... aspects of death and its registration in the second half of the nineteenth and beginning of the twentieth century in Transylvania. The main question is: who were the funerary professionals at this time? While it is possible to identify various categories that could be considered 'professional', this paper focuses mainly upon death inspectors. With statutory status under the Sanitary Law of 1876, the death inspectors outnumbered doctors, and the main feature of their job was to certify death. According to the law, burial was not possible without their consent. The death inspectors provided a connection between the fact of death and its registration. They periodically conveyed information to the local authorities about the death rate and evolution of different epidemics. Their professional techniques were based on the everyday practice of identifying the signs of death rather than on scientific knowledge. Their existence was a response to the lack of medical personnel in Transylvania at the time, and they tried to meet the needs of a rural society from multiple perspectives. http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.651835

Worth Repeating

"What bothers you the most?" Initial responses from patients receiving palliative care consultation

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2008;25(2):88-92. The purpose of this investigation is to describe how hospitalized palliative care patients respond to the question "What bothers you the most?" at the time of initial consultation. A retrospective descriptive content analysis of first person responses routinely recorded during initial interview was carried out. Responses were grouped in 7 major categories: physical distress (44%); emotional, spiritual, existential, or non-specific distress (16%); relationships (15%); concerns about the dying process and death (15%); loss of function and normalcy (12%); distress about location (11%); and, distress with medical providers or treatment (9%). Fifteen percent of responses were unable to be reliably categorized. http://ajh.sagepub.com/content/25/2/88.short

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