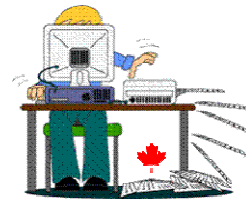


Media Watch...

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.

6 February 2012 Edition | Issue #239



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012 ©

Compiled & Annotated by Barry R. Ashpole

Navigating the emotional terrain of end-of-life care: Scroll down to [Specialist Publications](#) and 'DNR, DNAR, or AND? Is language important?' (p.13), published in *The Ochsner Journal*.

Canada

Life or death – who gets to decide?

CTV NEWS | Online report – 4 February 2012 – Hassan Rasouli, an electrical engineer, brought his family to Toronto from Iran, in the spring of 2010. Five months later, what was supposed to be routine surgery for a benign brain tumor left Hassan unconscious. Bacterial meningitis had infected his brain. His daughter, Mojgan Rasouli, says that within weeks, their surgeon advised the family to remove the mechanical ventilator that was keeping her father alive. Her mother Parichehr Salasel, a family physician licensed to practise in Iran, felt that the doctors were giving up on her husband too soon. "My mother is a doctor and she knows it," Mojgan told W5 (see sidebar right). By January 2011, the family believed that they were starting to see signs of improvement in their father. But his doctor's diagnosis was that Rasouli was in a Persistent Vegetative State (PVS), an irreversible loss of consciousness from which he would not recover. According to court documents, after three months his wife was being pushed

hard to stop treatment. Doctors sought her consent to remove Rasouli from the ventilator and transfer him to palliative care. <http://www.ctv.ca/CTVNews/TopStories/20120203/w5-life-or-death-investigation-120204/>

W5: Pull the Plug

This episode of W5 can be viewed in two parts (click on at menu to right of CTV News report).

Part One: Many of us plan ahead for our last days, making wills to give loved ones directions on our final wishes. But what if those instructions were ignored. W5's Victor Malarek looks at three letters: DNR.

Part Two: Since Iranian immigrant Hassan Rasouli lapsed into unconsciousness in 2010, his family had to go all the way to the Supreme Court to keep the doctors at Toronto's Sunnybrook Hospital from pulling the plug on him.

From Media Watch dated 26 December 2011:

- *GLOBE & MAIL* | Online report – 22 December 2011 – **'Supreme Court to hear Rasouli ... case.'** <http://www.theglobeandmail.com/life/health/end-of-life/supreme-court-to-hear-rasouli-end-of-life-case/article2281641/>

Criteria for referral

Too healthy for palliative care?

ONTARIO | *Ottawa Citizen* – 2 February 2012 – Rose Marie Mondor, of Ottawa, and Donna Cowie-Ducharme, who lives in Sudbury, say their aunt, Rose Loranger, was so close to dying on 20 January that Mondor was told by the elderly woman's doctor to be available to go to hospital in case she passed away. Then, five days later, on 25 January, Mondor was informed by Loranger's case manager at The Ottawa Hospital's General that her aunt was ready to be moved to a long-term care facility. Though palliative care is available in long-term care homes as it is in other facilities ... Mondor says she was told her aunt did not meet the "requirements" to receive it. She says the case worker told her that Loranger's doctor had determined her aunt would live beyond the three-month window

in which palliative care is usually offered. The sisters can't see their aunt lasting that long. Patients receiving palliative care are often in the last weeks or days of their lives. <http://www.ottawacitizen.com/health/healthy+palliative+care/6088041/story.html>

Specialist Publications

Of particular interest:

'It is "too late" or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less' (p.11), published in the *Journal of Pain & Symptom Management*.

Ontario health-care to focus more on clinics, home care

ONTARIO | *The National Post* – 30 January 2012 – Patients accustomed to heading to the hospital for everything from a bad flu to a heart-bypass will begin seeing a potentially historic shift toward more stand-alone clinics, care at home and after-hours doctor visits, Ontario's Health Minister suggested ... as she unveiled a major overhaul of the province's health-care system.¹ Deb Matthews was short on specifics and long on general concepts in her reform plan, touted as an answer to the system's soaring costs and growing demographic pressures. Time and again, though, the message came through that devoting the bulk of the province's health resources to general

hospitals, many of whose patients do not need to be there, makes little sense any more. <http://news.nationalpost.com/2012/01/30/ontario-health-care-to-focus-more-on-clinics-home-care/>

Extract from *The National Post* report

Chronically ill but stable patients stuck in pricey, acute-care hospital beds are a well-documented problem. The minister said the province will try to solve it by funnelling as much money as possible into home-care services – not nursing homes – so the old and infirm can stay in their houses and apartments longer.

1. Ontario's Action Plan for Health Care, Ministry of Health & Long Term Care, January 2012. http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_healthychange.pdf

N.B. In December 2011, Hospice Palliative Care Ontario published 'Advancing High Quality, High Value Palliative Care in Ontario.' http://hpc.o.ca/HPCO_Advancing_High_Quality_High_Value_Report.pdf

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>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *Toronto Sun* (OpEd) – 29 January 2012 – **'Dying with dignity: Trust our doctors.'** Legally assisted suicide is an issue that is periodically debated, and a ... [recent] ... poll indicates that two of three Canadians support the idea. When 67% of those polled favour something, it's usually a slam dunk... While doctor-assisted suicide is legal in The Netherlands and Switzerland, it's unlikely to gain traction in North America in the near future. The reason: We aren't convinced those who would make life-death decisions would do so in the applicant's interests and not the bureaucracy's. <http://www.torontosun.com/2012/01/27/dying-with-dignity-trust-our-doctors>

From Media Watch dated 2 January 2012:

- *THE NATIONAL POST* | Online report – 29 December 2011 – **'67% of Canadians support legalizing assisted suicide: Poll.'** More than two-thirds of Canadians support making it legal for doctors to help the terminally ill kill themselves a new poll suggests as the assisted suicide issue once again provokes heated debate across the country. <http://news.nationalpost.com/2011/12/29/67-of-canadians-support-legalizing-assisted-suicide-poll/>

U.S.A.

Should shareholder concerns govern end-of-life care?

CONNECTICUT POST | Online OpEd – 3 February 2012 – Connecticut residents are incredibly fortunate when it comes to access to hospice care. More than 90% of our citizens live within minutes of a hospice facility. But not all hospice care is created equal. In recent years, the proliferation of for-profit hospices owned by publicly traded companies has turned the hospice marketplace into a \$14 billion growth industry with over 18,000 for-profit hospice providers. Having shareholders thrust into the patient-care equation creates conflicts of interest when it comes to how those profits are made. According to the Hospice Patients Alliance, with that growth there is also

rampant Medicare fraud and abuse revolving around reduced medical services for hospice patients. <http://www.ctpost.com/news/article/Should-shareholder-concerns-govern-end-of-life-2999642.php>

Specialist Publications

Of particular interest:

'Marketing by hospices to be focus of federal investigation' (p.11), published in *McKnight's Long-Term Care News & Assisted Living*

Grief in the American workplace

HUFFINGTON POST | Online article – 3 February 2012 – Can you imagine "getting over" the death of someone you love deeply in four days? That's the average paid leave given by American businesses according to 'Grief Index: The Hidden Annual Costs of Grief in America's Workplace.'¹ The truth is there is no "getting over" the death of a loved one in either our business or private life. Rather, it takes time for us to find a new normalcy and to restore our ability to function effectively. Grief can take its toll in all areas of our lives. In terms of the workplace, 'Grief Index' provides an eye-opening perspective on the mental, emotional and financial costs of grief incurred by American businesses. It estimates that one in four employees is grieving at any given time. http://www.huffingtonpost.com/judith-johnson/workplace-grief_b_1248001.html

1. 'Grief Index: The Hidden Annual Costs of Grief in America's Workplace,' Grief Recovery Institute Educational Foundation, 2003. http://www.grief-recovery.us/Articles/The_Grief_Index_2003.pdf

Cont.

From Media Watch dated 30 January 2012:

- *INTERNATIONAL JOURNAL OF WORKPLACE HEALTH MANAGEMENT*, 2012;5(1). **'Family friendly policies: Accommodating end-of-life caregivers in workplaces.'** The findings of this study can directly inform workplace practice, both now and in the years to come, regarding how best to support workers who are also providing informal end-of-life care to family, friends, and others. <http://www.emeraldinsight.com/journals.htm?articleid=17014292&show=abstract>

From Media watch dated 2 January 2012:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2011;17(12):611-617. **'Emotional safety in the workplace: One hospice's response for effective support.'** While physical safety practices and effective human resource support are generally available to staff, one New Zealand hospice has taken this a step further by developing an emotional safety policy that incorporates personal, professional, and organizational measures designed to protect and promote staff members' emotional safety and to minimize stress and fatigue. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=88513;article=IJPN_17_12_611_617

A portrait of family caregivers in black and white

FORBES | Online OpEd – 1 February 2012
– If you are a woman – no matter your race, educational level, or income – caregiving responsibilities are never far from your mind. It may be a reflection of how the country has changed – and how it has not – that black women now worry as much about being victims of discrimination as they do about caring for aging relatives. Yet, while the U.S. has made great strides since the 1960s to end racial discrimination, and since the 1970s to reduce gender discrimination, it has done surprisingly little in recent decades to help alleviate the burden on caregivers. If anything, in some respects the nation seems to be backsliding. Working women pay a financial, emotional, and physical price for caregiving. They suffer high rates of depression and illness. When they take on a greater share of the caregiving burden, they often must cut back on their own working hours and sometimes even quit their jobs. That not only reduces their current household income but also means they'll have less

from Social Security, pensions, and other retirement income when they age. And that, in turn, will place a greater burden on their daughters. That's bad news, no matter what your race. The challenge ... is to find ways to relieve their burdens in an era of fiscal constraints. <http://www.forbes.com/sites/howardgleckman/2012/02/01/a-portrait-of-family-caregivers-in-black-and-white/>

Specialist Publications

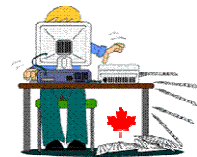
Of particular interest:

'Baby boom caregivers: Care in the age of individualization' (p.9), published in *The Gerontologist*.

'Family perceptions of end-of-life care for long-term care residents with dementia: Differences between the U.S. and The Netherlands' (p.9), published in the *Journal of the American Geriatrics Society*.

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

Towards a life less painful

Morphine manifesto released

INDIA | *The New India Express* – 3 February 2012 – In connection with the World Cancer Day 2012 (4 February), Pallium India, the International Association for Hospice & Palliative Care, the Pain & Policy Studies Group/World Health Organization's Collaborating Centre at the University of Wisconsin, have released a Morphine Manifesto. Signed by leading organisations and foundations from around the world, including those for cancer, pain management, and hospice & palliative care organisations, this manifesto calls for an end to the unethical practice of promoting expensive opioid painkillers without making low cost immediate release oral morphine available. Furthermore, it calls upon governments, health care institutions, and the pharmaceutical industry to assure the accessibility of immediate release morphine to patients in need at a cost that the individual and community can afford. Dr. M. R. Rajagopal, Chairman of Pallium India, and

the driving force behind ... the Morphine Manifesto, said prolonged unrelieved pain destroys the mind, destroys the body and destroys families. "Inexpensive and effective immediate release morphine can relieve most of the pain. We cannot call ourselves a cultured or ethical society if we deprive this relief to those in pain, or worse yet, benefit financially from this suffering by forcing expensive, unaffordable alternatives on them." <http://ibnlive.in.com/news/morphine-manifesto-released/227112-60-123.html>

Specialist Publications

Of particular interest:

'Painful inequities – palliative care in developing countries' (p.12), published in the *New England Journal of Medicine*.

'Stiff upper lip' denying terminally ill a 'good death'

U.K. | *Daily Telegraph* – 3 February 2012 – The British "stiff upper lip" and the stigma surrounding death are denying more than 100,000 people a year the chance of dying in their own homes surrounded by their loved ones, a leading GP has warned. Prof. Mayur Lakhani, chairman of the National Council for Palliative Care, said many terminally ill patients miss out on the consolation of a "good death" because both they and their doctors are too afraid to talk about the end. A practising GP and former chair of the Royal College of General Practitioners, Prof. Lakhani called for a "change of philosophy" in the medical profession to allow for greater acceptance of death, including its "spiritual" dimension. Without a different approach people will continue being condemned to spending their final days in hospitals when they could be in the relative comfort of their own home or a dedicated hospice. <http://www.telegraph.co.uk/health/healthnews/9057372/Stiff-upper-lip-denying-terminally-ill-a-good-death.html>

From Media Watch dated 30 January 2012:

- U.K. | *Daily Mail* – 25 January 2012 – **'GPs told to quiz elderly with serious health problems about 'how they want to die.'** GPs must ask the elderly with serious health problems if they want 'do not resuscitate' orders put in their files, according to senior doctors.¹ They should also find out if patients want to die at home and whether they would rather refuse certain drugs or treatment in their final hours. <http://www.dailymail.co.uk/news/article-2091377/GPs-told-quiz-elderly-want-die.html>

1. 'Anticipatory care planning and integration: A primary care pilot study aimed at reducing unplanned hospitalisation,' *British Journal of General Practice*, published online 25 January 2012. <http://www.ingentaconnect.com/content/rcgp/bjgp/pre-prints/baker0212>

Hospice funding slashed again by Health Services Executive

IRELAND | *Connacht Tribune* (Galway) – 2 February 2012 – Leading cancer care service providers warned this week that new cuts imposed by the Health Services Executive (HSE) will have "dire consequences" for their services. The allocation for the twelve-bed inpatient unit at Galway Hospice this year has been cut by 3% – resulting in a funding shortfall of €105,000. The Hospice has already been forced to 'dig into' its reserves, following funding cuts of 2.3% last year and 5% in 2010. Galway Hospice Chief Executive Sean O'Healy said the announcement will mean a "crushing blow," and warned its coffers could run dry within two years. The inpatient unit costs around €3.5m to operate each year and was funded by the HSE to the tune of €3.8m in 2009. However, continued HSE cuts over the past three years have reduced this to €3.4m. <http://www.galwaynews.ie/24050-hospice-funding-slashed-again-hse>

Overhaul of the aged-care system is needed to avoid an imminent crisis claims Australians Deserve to Age Well campaign

AUSTRALIA | *Daily Telegraph* (Sydney) – 30 January 2012 – An overhaul of the aged-care system is needed to avoid an imminent crisis, a coalition of 28 groups has warned the federal government. The group, including health professionals, unions and charitable organisations, has warned the aged-care system designed for Australia in the 1960s is now buckling and in need of urgent reform. Launching the Australians Deserve to Age Well campaign ... the group said that by 2050 the system would need to support 3.5 million older citizens. That represents more than three times the current load. <http://www.dailytelegraph.com.au/news/national/overhaul-of-the-aged-care-system-is-needed-to-avoid-an-imminent-crisis-claims-australians-deserve-to-age-well-campaign/story-e6freuzr-1226256587108>

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: <http://www.hpconnection.ca/newsletter/inthenews.html>

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

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>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | Angus Reid Public Opinion – 31 January 2012 – **'Legal euthanasia supported by majority in Great Britain.'** Most people in Britain continue to endorse the idea of legalising euthanasia in the country, a new Angus Reid Public Opinion poll has found. Most respondents also think that anyone who helps a person to commit suicide should not be prosecuted. In the online survey ... 71% of respondents (+4 since October 2010) are in favour of legalising euthanasia in the U.K., while 16% (-3) oppose this idea. More than four-in-five Britons (86%) believe that legalising euthanasia would give people who are suffering an opportunity to ease their pain, and three-in-four (78%) think it would establish clearer guidelines for doctors to deal with end-of-life decisions. Respondents are evenly divided on whether the legalisation of euthanasia would leave vulnerable people without sufficient legal protection (Agree 42%, Disagree 42%), but three-in-five (61%) reject the notion that it would send the message that the lives of the sick or disabled are less valuable. <http://www.angus-reid.com/polls/44319/legal-euthanasia-supported-by-majority-in-great-britain/>

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

A model program for perinatal palliative services

ADVANCES IN NEONATAL CARE, 2012;12(1):28-36. This article describes a perinatal comfort care 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. Neonatal nurses can become involved either by initiating efforts to form a perinatal comfort care program or by joining an existing team. http://journals.lww.com/advancesinneonatalcare/Abstract/2012/02000/A_Model_Program_for_Perinatal_Palliative_Services.9.aspx

From Media Watch dated 13 December 2011:

- *JOURNAL OF PALLIATIVE MEDICINE*, 2011;14(12):1302-1308. **'Parents' experiences with life-threatening fetal diagnosis.'** This study sought to clarify the experiences and needs of families ... to design responsive perinatal palliative care services, and to establish the feasibility and acceptability of conducting intensive interviews of pregnant women and their partners during their pregnancy with a lethal fetal diagnosis. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0165>

End-of-life care in The Netherlands

Important treatment aims at the end of life: A nationwide study among GPs

BRITISH JOURNAL OF GENERAL PRACTICE, 2012;62(595):e121-e126. Data for 279 patients were studied. Of these, 55% died of cancer and 45% of another disease. Treatment was aimed at palliation for 73% of the patients in months 2 and 3 before death, and for 95% of the patients in the last week of life. Seven per cent received treatment aimed at cure in the last week of life. In a minority of patients, cure/life prolongation and palliation were simultaneously important treatment aims. In the last week of life and in the 2-4 weeks before death, cure was more frequently reported as an important treatment aim in patients with a non-cancer disease than in patients with cancer. In the 2-4 weeks before death, palliation was an important treatment aim for a larger proportion of patients with cancer than patients with other diseases. <http://www.ingentaconnect.com/content/rcgp/bjgp/2012/00000062/00000595/art00032>

N.B. The Netherlands and the U.S. were rated 7th and 9th, respectively, in *The Quality of Death: Ranking End-of-life-Care Across the World*, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Palliative care in the light of legal and regulatory requirements in Germany

BUNDESGESUNDHEITSBLATT - GESUNDHEITSFORSCHUNG - GESUNDHEITSSCHUTZ, 2012;55(2):231-237. In Germany, palliative care has developed rapidly since the establishment of the first palliative care unit in 1983. More improvements in patient-centered care are only possible if legal requirements as well as education of physicians, nurses, and other professionals involved in palliative care are adapted to current needs. Only recently has medical education in palliative medicine been implemented as an integral part of medical studies at German universities. Starting in 2014, physicians applying for a license to practice medicine will have to provide a certificate of basic training in this field. The challenge in upcoming years will be the establishment and enhancement of comprehensive, standardized, and quality-controlled education at the universities. <http://www.springerlink.com/content/3457017t5130nt1p/>

N.B. This article is published in German. Germany was rated 8th in *The Quality of Death: Ranking End of-life-Care Across the World*, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Managing an expected home death

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 1 February 2012 – ...according to experts in end-of-life care, people should have a plan in place for an expected death in the home. Otherwise, the family member present when the death occurs may be left wondering what to do and whom to call. For a planned death, there is no need to call anyone except the physician involved in the deceased's care and the funeral home director. Some people don't realize this, however, and inadvertently turn an expected event into a false emergency. "If a family member panics at the time of death and calls 911, paramedics will respond. A paramedic has to initiate full resuscitation, even if it is obviously not the right thing to do. Police have to be called and the coroner has to be called. If you call 911, it is recognized as an unexpected event and an emergency," says Dr. Doris Barwich, program medical director of end-of-life care for Fraser Health in British Columbia. "People panic and think that calling 911 means they are just calling for help, but what they are doing is triggering a cascade of events." To assist families caring for terminally ill relatives, some provinces have published guidelines on how to manage an expected home death.¹⁻³ http://www.cmaj.ca/site/earlyreleases/1feb12_managing-an-expected-home-death.xhtml

1. Nova Scotia: 'Preparing for an Unexpected Death at Home,' Department of Health & Home Care Nova Scotia. www.gov.ns.ca/health/reports/pubs/PFEDH_brochure.pdf
2. Prince Edward Island: 'Caring for Your Loved One at Home: Guidelines for Managing the Expected Death at Home,' Palliative Care Program & Home Care Nursing. www.gov.pe.ca/photos/original/hss_homedeadth.pdf
3. Manitoba: 'Arrangements for the Expected Death at Home,' the College of Physicians & Surgeons of Manitoba, Guideline #1600. www.cpsm.mb.ca/guidelines/gdl1600.pdf

Culture and care: Bridging the patient-physician divide

EMERGENCY MEDICINE NEWS, 2012;34(2):4-5. Patients don't come to health care providers solely as clinical manifestations of disease; they bring with them their socio-cultural background, including religion and culture that profoundly influence health-related attitudes, beliefs, and practices. When those religious and cultural needs are not understood, acknowledged, or accommodated, that ultimately translates into suboptimal care and an increased burden on the health care system. Understanding these needs and how they affect patients' health attitudes, beliefs, and practices becomes an important priority in reducing health disparities. http://journals.lww.com/em-news/Fulltext/2012/02000/Viewpoint_Culture_and_Care_Bridging_the.13.aspx

Baby boom caregivers: Care in the age of individualization

THE GERONTOLOGIST | Online article – 31 January 2012 – The majority of interviewees [i.e., study participants] refused to be confined to the sole identity of caregiver, as they work to juggle caregiving, work, family, and social commitments. To succeed in this juggling act, they have high expectations of support from services. Based on this approach to caregiving, the authors advance the idea of a "denaturalization" of care, no longer seen as a "natural" destiny or "normal" family responsibility. <http://gerontologist.oxfordjournals.org/content/early/2012/01/31/geront.gnr140.abstr act>

Of related interest:

- *THE GERONTOLOGIST* | Online article – 31 January 2012 – '**Cohort differences in the availability of informal caregivers: Are the boomers at risk?**' Findings of this study ... have implications for institutions and public policy concerned with the informal caregiving needs of Boomers as they age. <http://gerontologist.oxfordjournals.org/content/early/2012/01/31/geront.gnr142.abstr act>

End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2012;18(1):29-34. 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. There are implications for health professionals in terms of equity of access to targeted health care, preventive screening, and visibility in policy, as well as in principles of inclusiveness, dignity and respect, and competence in care. This article takes a brief look at some of the issues specific to the end-of-life care of GLBT individuals, using a case study as an illustrative example. Holistic care at the end of life is a familiar concept to palliative care nurses, but it is important to place greater emphasis on considering competence in aspects of care relating to sexuality. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=89126;article=IJPN_18_1_29_34

From Media Watch dated 30 August 2010:

- U.S. (NEW MEXICO) | *New Mexican* – 28 August 2010 – "**An invisible loss': Gays and lesbians find comfort hard to come by after partner's death.**" Although he is in a new, long-term relationship with Michael Lewallen ... [Tom] Rotella still grieves his former partner 'significantly.' It's that kind of grief that a new support group, sponsored by Odyssey Hospice and RainbowVision, aims to help. <http://www.santafenewmexican.com/Local%20News/-An-invisible-loss->

From Media Watch dated 17 May 2010:

- U.S. (MINNESOTA) | *Pioneer Press* – 12 May 2010 – '**House passes bill that gives gay couples the right to make end-of-life decisions.**' http://www.twincities.com/politics/ci_15065396

Family perceptions of end-of-life care for long-term care residents with dementia: Differences between the U.S. and The Netherlands

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online article – 30 January 2012 – Because previous research favored care in The Netherlands to that in the U.S., findings [of this study] suggest improvement in end-of-life care and outcomes in the U.S. and stability in The Netherlands. Greater hospice use does not explain improvements in the U.S. directly and may relate, at least in part, to care provided by long-term care staff themselves. Better understanding of the nature and process of these improvements may suggest areas for additional improvement. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03816.x/abstract>

Cont.

Of related interest:

- *AMERICAN JOURNAL OF ALZHEIMER'S DISEASE & OTHER DEMENTIAS* | Online article – 31 January 2012 – '**Palliative care for advanced dementia: A pilot project in 2 nursing homes.**' This article describes a pilot project involving training, case consultations and administrative coaching over a period of 1 year aimed at introducing palliative care in two nursing homes... Implications for implementing a program of palliative care in nursing homes are discussed. <http://aja.sagepub.com/content/early/2012/01/04/1533317511432732.abstract>
- *ANNALS OF INTERNAL MEDICINE*, 2012;156(1):45-51. '**Advanced dementia: State of the art and priorities for the next decade.**' Research over the past 25 years ... has delineated abundant opportunities for improvement, including greater recognition of advanced dementia as a terminal illness, better treatment of distressing symptoms, increased access to hospice and palliative care services, and less use of costly and aggressive treatments that may be of limited clinical benefit. http://www.annals.org/content/156/1_Part_1/45.abstract?sid=2e111ab3-a1df-4f14-bf66-315a8d86cbba

A survey of the perspectives of patients who are seriously ill regarding end-of-life decisions in some medical institutions of Korea, China and Japan

JOURNAL OF MEDICAL ETHICS | Online article – 17 January 2012 – Patients in Far-Eastern countries gave various responses regarding end-of-life care decisions. Although familial input is still influential, most patients think of themselves as the major decision maker and accept the necessity of advance directives with Westernization of the society. Artificial ventilation withdrawal and even active euthanasia may be acceptable to them. <http://jme.bmj.com/content/early/2012/01/17/medethics-2011-100153.abstract>

New Zealanders' knowledge of palliative care and hospice services

JOURNAL OF THE NEW ZEALAND MEDICAL ASSOCIATION, 2012;125(1348):51-60. This project investigated ... views about palliative care and local hospice services. There was a reasonably good understanding of the concept of palliative care. However, participants could not always identify local hospices, with younger people and males more unaware of accessible hospice services. Low levels of understanding point to the need for continued public education so that the holistic nature of palliative care is understood and accessible hospice services are sought when required. <http://journal.nzma.org.nz/journal/abstract.php?id=5021>

From Media Watch dated 21 June 2010:

- NEW ZEALAND | *Otago Daily Times* – 19 June 2010 – '**Uncertainty still surrounding palliative care.**' 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. <http://www.odt.co.nz/news/dunedin/111407/uncertainty-still-surrounding-palliative-care>

From Media Watch dated 4 January 2010:

- NEW ZEALAND | Ministry of Health online report – December 2009 – '**Gap analysis of specialist palliative care in New Zealand.**' This gap analysis confirmed the anecdotal evidence that there are wide variations in the provision of hospice and other specialist palliative care at both local and regional levels. [http://www.moh.govt.nz/moh.nsf/pagesmh/9843/\\$File/palliative-care-gap-analysis-09.pdf](http://www.moh.govt.nz/moh.nsf/pagesmh/9843/$File/palliative-care-gap-analysis-09.pdf)

N.B. New Zealand was rated 3rd in *The Quality of Death: Ranking End of-life-Care Across the World*, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

It is "too late" or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 30 January 2012 – When families [i.e., study participants] stated that referral was "at the right time," their perceptions were based on the patient having refused earlier referral, a rapid decline in the patient's condition resulting in the late referral, or a belief in all things coming together as they were meant to. In contrast, when families stated that referral was "too late," their reasons were centered on concerns with the health care providers' role in decision making, with the leading concerns being inadequate physician communication, not recognizing the patient as dying, or problematic hospice delays in referral from the nursing home or home health agency. Despite the patient refusing an earlier hospice referral, five family members believed the referral was "too late." Whereas family members identified expected concerns with communication, more than one in three stated an earlier hospice referral was not possible. [http://www.jpmsjournal.com/article/S0885-3924\(11\)00766-4/abstract](http://www.jpmsjournal.com/article/S0885-3924(11)00766-4/abstract)

From Media Watch dated 2 January 2012:

- *BMC MEDICAL INFORMATICS & DECISION MAKING* | Online article – 23 December 2011 – **'Extensions to regret-based decision curve analysis: An application to hospice referral for terminal patients.'** Despite the well documented advantages of hospice care, most terminally ill patients do not reap the maximum benefit from hospice services, with the majority of them receiving hospice care either prematurely or delayed. Decision systems to improve the hospice referral process are sorely needed. <http://www.biomedcentral.com/content/pdf/1472-6947-11-77.pdf>

Integrating spiritual care within palliative care: An overview of nine demonstration projects

JOURNAL OF PALLIATIVE MEDICINE | Online article – 3 February 2012 – Spiritual care is an essential domain of quality palliative care as determined by the [U.S.] National Consensus Project for Quality Palliative Care and the National Quality Forum. Studies have consistently indicated the desire of patients with serious illness and end-of-life concerns to have spirituality included in their care. While there is an emerging scholarly body of literature to support the inclusion of spirituality as part of a biopsychosocial-spiritual approach to health care, palliative care programs lack empirical guidance needed to effectively integrate best spiritual care practices. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0211>

Marketing by hospices to be focus of federal investigation

MCKNIGHT'S LONG-TERM CARE NEWS & ASSISTED LIVING (U.S.) | Online article – 2 February 2012 – Federal officials plan to spend more time this year examining how hospices market themselves to nursing homes, according to a 2012 work plan released by the Department of Health & Human Services' Office of Inspector General. It's not difficult to see why the government is taking notice. Once a little-known component of the healthcare sector, hospice care has blossomed into a \$14 billion industry. But some critics are taking issue with the way such growth has been achieved. <http://www.mcknights.com/marketing-by-hospices-to-be-focus-of-federal-investigation/article/225053/>

From Media Watch dated 30 January 2012:

- U.S. (FLORIDA) | *Palm Beach Post* (OpEd) – 22 January 2012 – **'Take the profit out of dying.'** In 2006, when the Legislature and then-Governor Jeb Bush allowed for-profit hospices to operate in Florida, this paper predicted that the move would undermine the successful hospice model. Six years later, it has done exactly that. <http://www.palmbeachpost.com/opinion/editorials/take-the-profit-out-of-dying-2118554.html>

Painful inequities – palliative care in developing countries

NEW ENGLAND JOURNAL OF MEDICINE, 2012;366(3):199-201. Morphine, the World Health Organization-sanctioned first-line treatment for severe pain, costs pennies per dose to manufacture. Yet 80% of the world's population, including more than 5 million patients with terminal cancer, lacks adequate access to pain treatment. In more than 150 countries, morphine is simply not available. "There isn't a single government that couldn't procure morphine if they wanted it," says Meg O'Brien, who directs the Global Access to Pain Relief Initiative (GAPRI, a program of the Union for International Cancer Control and the American Cancer Society). "But no one is demanding it." Physicians' perceptions about palliation are at the root of the problem. Many physicians seem to believe that to discuss pain control is to admit defeat. This barrier is not unique to resource-poor countries. Even in the U.S., whose palliative care movement has been under way for decades, many physicians were surprised when researchers showed that treating pain does not hasten death but, rather, prolongs survival. In many countries, physicians learn only about opiates' side effects, not their potential benefits, said Dr. M.R. Rajagopal, a palliative care physician in India. "Modern principles of pain relief and palliative care still aren't taught to medical students in 80% of the world," he said, noting that many

physicians in India finish training without ever seeing a morphine tablet.

<http://www.nejm.org/doi/full/10.1056/NEJM1113622>

Extracts from *Human Rights Watch World Report 2012*

GUATEMALA (p.250-251): The government has not made oral morphine available in most of the country and has failed to ensure health care workers are adequately trained in modern pain treatment methods. Guatemala has some of the most restrictive regulatory policies in the region, discouraging doctors from prescribing pain medication and preventing patients in severe pain from accessing treatment.

INDIA (p.332): Hundreds of thousands of persons with incurable diseases suffer unnecessarily from severe pain because the Indian government has failed to ensure access to safe, effective, and inexpensive pain drugs. In an important step forward, the Medical Council of India recognized palliative care as a medical specialty. But more than half of government-supported regional cancer centers still do not offer palliative care or pain management, even though more than 70% of their patients need it, resulting in severe but unnecessary suffering for tens of thousands.

N.B. Download Human Rights Watch World Report 2012 at: <http://www.hrw.org/world-report-2012>. Enter keywords 'palliative care.'

From Media Watch dated 10 October 2011:

- U.K. | Press Association – 8 October 2011 – **"Slow progress' on palliative care.'** Almost half of the world's countries have no provision for palliative care, according to new research.¹ The Worldwide Palliative Care Alliance study found 98 of the world's 234 countries (42%) do not have a hospice or palliative care services available to seriously-ill people and their families and carers. <http://www.google.com/hostednews/ukpress/article/ALeqM5hCRxllJXZTgP5NPCTqkJ6C0Tk38w?docId=N0823071318000768608A>

1. 'Mapping level of palliative care development: A global update,' Worldwide Palliative care Alliance, 2011. <http://www.thewpca.org/latest-news/mapping-report-2011/>

From Media Watch dated 6 June 2012:

- HUMAN RIGHTS WATCH | Press release – 2 June 2011 – **'Global: Tens of millions face death in agony.'** Tens of millions of people worldwide are denied access to inexpensive medications for severe pain, Human Rights Watch said in a [new] report.¹ The report details the failure of many governments to take even basic steps to ensure that people with severe pain due to cancer, HIV, and other serious illnesses have access to palliative care, a health service that seeks to improve quality of life. <http://www.hrw.org/en/news/2011/06/02/global-tens-millions-face-death-agony>

1. 'Global State of Pain Treatment: Access to Medicines & Palliative Care,' Human Rights Watch, June 2011. <http://www.hrw.org/node/98936>

DNR, DNAR, or AND? Is language important?

THE OCHSNER JOURNAL, 2011;11(4): 302-306. The American Heart Association in 2005 moved from the traditional do not resuscitate (DNR) terminology to do not attempt resuscitation (DNAR). DNAR reduces the implication that resuscitation is likely and creates a better emotional environment to explain what the order means. Allow natural death (AND) is the name recommended in some settings to make the meaning even clearer. Most hospitals still use the ... DNR term. Medical

staffs should consider moving to DNAR and in some settings to AND. Language is important. <http://www.ochsnerjournal.org/doi/abs/10.1043/1524-5012-11.4.302>

This issue of *The Ochsner Journal* includes several articles on different aspects of end-of-life care. Journal contents page: <http://www.ochsnerjournal.org/toc/ochs/11/4>

From Media Watch dated 3 December 2010:

- U.S. | *New York Times* – 6 December 2010 – '**D.N.R. by another name.**' The key question: Should your parent have a D.N.R. order, meaning "do not resuscitate"? Before you answer, another key question: Would that decision be any clearer, easier or less painful if the order was instead called A.N.D., for "allow natural death"? <http://newoldage.blogs.nytimes.com/2010/12/06/d-n-r-by-another-name/?partner=rss&emc=rss>

From Media Watch dated 9 March 2009:

- *USA TODAY* | Online commentary – 2 March 2009 – "**Do not resuscitate' vs. 'allow natural death.**" Could three words change the way severely ill patients and their loved ones think about death? http://www.usatoday.com/news/health/2009-03-02-DNR-natural-death_N.htm

U.S. Population Reference Bureau

Planning for retirement and end-of-life care

TODAY'S RESEARCH ON AGING, 2012;24:1-7. The plans individuals make for retirement strongly influence their well-being and financial security in old age. And end-of-life planning (writing living wills, selecting a durable power of attorney for health care, and holding informal discussions with family members) can protect older adults from unwanted medical treatments should they become incapacitated and unable to express their preferences. This newsletter highlights work by National Institute on Aging supported researchers and others that examines the impact of planning for retirement and end-of-life care on the well-being of older people and their families. <http://www.prb.org/pdf12/TodaysResearchAging24.pdf>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BRITISH MEDICAL JOURNAL* | Online report – 30 January 2012 – '**Doctors can help "right to die" man prepare his legal case without fear of prosecution.**' Doctors and lawyers may investigate possible means for a man with locked-in syndrome to end his life and may prepare his case without fear of prosecution or action against them by their regulators, the High Court in London has declared. The unprecedented declaration paves the way for a challenge to guidelines from the director of public prosecutions for England and Wales, which state that doctors and other healthcare professionals who assist a suicide are more likely to be prosecuted than relatives or friends. <http://www.bmj.com/content/344/bmj.e762>

Worth Repeating

Can we overcome the effect of conflicts in rendering palliative care? An introduction to the Middle Eastern Cancer Consortium

CURRENT ONCOLOGY REPORTS | Online article – 3 May 2011 – The Middle East has been experiencing an ongoing political conflict for the past several decades. This situation has been characterized by hostility often leading to violence of all sources. At times, such a conflict led to the outbreak of a military war, which was followed by an enmity between religious, ethnic, cultural, and national populations. In such environmental situations, palliative care professionals often confront major challenges including bias, mistrust, and mutual suspicion between patients and their treating clinicians. In order to overcome such obstacles, while rendering palliative care services, all professionals involved need careful planning and execution of their treatment plans. The latter is however possible, and sometimes successful even across lines of conflict, thereby promoting understanding, mutual respect, and tolerance between the involved communities and individuals. <http://www.springerlink.com/content/a222x2w44r7l8r58/>

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.

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