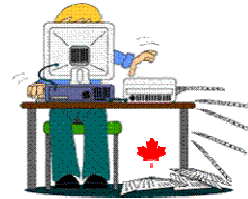


Media Watch...

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

Compiled & Annotated by Barry R. Ashpole

Building on a foundation of knowledge: Scroll down to [Specialist Publications](#) and 'A new model for breaking bad news to people with intellectual disabilities' (p.11), published in *Palliative Medicine*.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | The Court (Osgoode Hall Law School) – 18 January 2012 – '**Canada's assisted suicide debate: Alive and well.**' If you've read a newspaper in the past two months, you'll know that Canada's right-to-die debate has come back to life. Leading the revival is B.C. resident Gloria Taylor, a 63-year-old grandmother ... who was diagnosed with ALS (*aka* Lou Gehrig's disease) in 2009. As is often the case for people suffering from this currently incurable neurodegenerative disease, Gloria's condition deteriorated rapidly. In June of 2011, she decided to add herself as a plaintiff in the British Columbia Civil Liberties Association constitutional challenge of Canada's criminal prohibition on assisted suicide, which had been filed with the B.C. Supreme Court two months earlier. <http://www.thecourt.ca/2012/01/18/canadas-assisted-suicide-debate-alive-and-well/>

U.S.A.

Cinema therapy helps people deal with grief

NORTH CAROLINA | *The Daily Reflecto* (Greenville) – 22 January 2012 – After the death of her father, Maggie Crandall needed more than a good cry. She needed to laugh. Sometimes she needed something uplifting. Other times she needed someone who could just sit quietly in a darkened room with her while she stared at a screen. Someone who could pass her a tissue. Or some popcorn. Or both. She found that at Reel Grief. The local support group, which debuted two years ago, has helped dozens of people use movies to help them face real-life grief. Reel Grief is based on a concept known as cinema therapy, simply defined as viewing movies for therapeutic value. Every other month, participants gather for an informal meeting that features a full-length film, followed by a brief, small-group discussion designed to help people understand the emotions of grief that are playing out inside them. <http://www.reflector.com/look/cinema-therapy-helps-people-deal-grief-884631>

Palliative care's healing powers for caregivers, too

AMERICAN ASSOCIATION FOR RETIRED PERSONS | Online article – 19 January 2012 – Five months ago, my 91-year-old mother suffered a massive stroke and spent six days in the palliative care unit of a Connecticut hospital. The specially trained physician, nurse, social worker, and pastoral counselor kept her pain-free until she died. What they did for me was equally remarkable: they nursed me, the emotionally and physically exhausted caregiver, through what felt like a slow motion death. Their kindness allowed me to heal more quickly than I believe I would have without palliative care. <http://blog.aarp.org/2012/01/19/palliative-care-helps-caregivers/>

Specialist Publications

Of particular interest:

'A beginning understanding of caregivers' spiritual needs when relinquishing a loved one to a palliative care setting' (p.8), published in the *Journal of Religion, Spirituality & Aging*.

What doctors know – and we can learn – about dying

TIME MAGAZINE | Online article – 16 January 2012 – Last month, an essay posted by retired physician Ken Murray¹ ... got a huge amount of attention, some negative but mostly positive. Murray tells the story of an orthopedic surgeon who, after being diagnosed with pancreatic cancer, chose not to undergo treatment. The surgeon died some months later at home, never having set foot inside a hospital again. Critics said that the essay was a biased opinion of how one should die, not an actual analysis of how doctors actually do die. And indeed, much of Murray's essay was anecdotal. Murray writes that his physician friends wear medallions with DNR, or Do Not Resuscitate, orders. They instruct their colleagues to not take any heroic measures and to keep them out of the ICU at the end of life. He's even seen a colleague with a DNR tattoo, something I've been threatening to get for a long time. And yet, there is good evidence that physicians have thought out end-of-life issues more thoroughly than laypeople and are more likely to decline medical intervention. For example, they sign advance directives far more often than the rest of us do. <http://ideas.time.com/2012/01/16/what-doctors-know-and-we-can-learn-about-dying/?xid=gonewsedit>

1. 'How doctors die,' Zócalo Public Square, Center for Social Cohesion (posting undated). <http://zocalopublicsquare.org/thepublicsquare/2011/11/30/how-doctors-die/read/nexus/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON POST | Online article – 19 January 2012 – **'Lawrence Egbert, the new face of assisted suicide in America.'** Egbert, 84, estimates he has been present for 100 suicides in the past 15 years, which puts him in the same league with famed assisted-suicide maverick Jack Kevorkian. Egbert sees his own work as a calling and says he provides only guidance and support. But his zeal is tempered by self-doubt. "Once I am a true believer, that's the time I should quit," he says one afternoon. Egbert was acquitted in a case in Arizona, but another case looms in Georgia. http://www.washingtonpost.com/lifestyle/magazine/lawrence-egbert-the-new-face-of-assisted-suicide-in-america/2012/01/18/gIQA80BPAQ_gallery.html#photo=1
- HAWAII | *Star Advertiser* (Honolulu) – 17 January 2012 – **'Assisted suicide not lawful, state says.'** An obscure 1909 law intended to ease suffering of Hansen's disease patients does not make physician-assisted suicide legal in Hawaii, according to an opinion by the state attorney general's office ... in response to an inquiry from Sen. Josh Green, of the Senate Health Committee, who sought clarification amid reports supporters of physician-assisted suicide were seeking a patient willing to test the statute. <http://www.staradvertiser.com/s?action=login&f=y&id=137466873>

International

Palliative care in Australia: Senate inquiry

The good, bad and the ugly

AUSTRALIAN AGEING AGENDA | Online report – 19 January 2012 – Australia's palliative care movement could be in danger of drifting too far away from its grass roots if consumers, advocates, service providers and aged care workers do not redirect it back on course and contribute to the Senate inquiry into palliative care, now underway. Executive director of Palliative Care Council, South Australia, Tracey Watters, believes that the recently announced ... Senate inquiry presents the sector with a 'once in a lifetime' opportunity to tell the government all that is good, bad and ugly about the current state of palliative care services. But, she said, if this opportunity is not seized and the government does not hear the real life stories of older people, their families and friends who have been denied access to vital, quality and timely palliative care services – and the sad tales about the consequences – then the palliative care sector will be at a loss. "From a consumer's

point of view, there seems to be an inordinate number of barriers to accessing specialist palliative care services," Ms. Watters said. "My worry is that in the growth and development of palliative care as a specialty is almost taking it away from its grass-roots (objective), which is to care for people with a terminal illness and help them make use of their time until they die." <http://www.australianageingagenda.com.au/2012/01/19/article/The-good-bad-and-the-ugly/FIPNYKFJUZ.html>

Extract from *Australian Ageing Agenda* article

"Dying is no longer what promotes palliative care... Palliative care is becoming acute care. People are having to get into a crisis situation to get [palliative care] services, which is really juxtaposed to what palliative care should be."

Of related interest:

- AUSTRALIA | *Herald Sun* (Melbourne) – 22 January 2012 – '**Online doctors a new reality.**' A \$20.6 million pilot program starting in July will use the national broadband network to deliver telehealth services to older Australians, cancer patients and those in palliative care. <http://www.heraldsun.com.au/news/breaking-news/online-doctors-a-new-reality/story-e6frf7jx-1226250658940>

Hospices will need 'goodwill of their local communities to keep going'

IRELAND | *The Journal* (Dublin) – 19 January 2012 – The Irish Hospice Foundation (IHF) has said that its services may have to be reduced unless there is an increase in donations following cuts to the palliative care budget. The IHF says that under the Health Service Executive's National Service Plan announced last week, the budget for palliative care is being cut from €81 million in 2011 to €78 million for the coming year – a cut of 3.7%. The organisation says that will mean it will have to rely on increased donations to maintain services. This cut is happening at a time when the numbers seeking hospice support are increasing. "Our primary concern is with patients and their families who are the most vulnerable patients in our health service," IHF CEO <http://www.thejournal.ie/hospices-will-need-goodwill-of-their-local-communities-to-keep-going-ihf-331721-Jan2012/>

Cont.

Of related interest:

- IRELAND | *Irish Times* – 17 January 2012 – '**Hospice warns of service cuts if Health Service Executive reduces funds.**' One of the State's leading hospices is experiencing severe financial difficulties due to a combination of Government health cutbacks and a drop in fundraising income. The Galway Hospice has warned that it will be unable to sustain its current level of activity if there is any further reduction in HSE [Health Service Service] support. Some 70% of its budget derives from the State; 30% is raised through voluntary fundraising efforts, and through bequests and donations. The Galway Hospice had already agreed in principle with the HSE to provide an additional 14 beds, in line with the report of the National Advisory Committee on Palliative Care.¹
<http://www.irishtimes.com/newspaper/health/2012/0117/1224310354821.html>
- 1. 'Report of National Advisory Committee on Palliative Care,' Department of Health & Children, 2011.
http://www.hse.ie/eng/staff/Resources/FactFile/FactFile_PDFs/Other_FactFile_PDFs/EAGs%20and%20all%20sub%20locations/Report_of_the_National_Advisory_Committee_on_Palliative_Care_2001.pdf
- IRELAND | RTÉ News – 16 January 2012 – '**HSE plans to close 555 nursing home beds.**' The Health Service Executive's national service plan for 2012 says that a minimum of 555 public beds in community nursing homes will be shut this year. It also warns that the Fair Deal nursing home support scheme may run out of funds. <http://www.rte.ie/news/2012/0116/hse.html>

One in five choosing to die in their own homes as figures reach highest level for ten years

U.K. (ENGLAND & WALES) | *Daily Mail* – 19 January 2012 – More than one in five people die in their own homes, the highest figure for ten years. A study suggests the recent trend for Britons to die in hospital against their wishes may have been reversed.¹ A total of 102,416 deaths took place at home in 2010, or just over 20%, compared with 93,907 in 2004 (18.3%). The previous highest figure was 108,086 home deaths in 1999. A King's College London study using Office for National Statistics data found more people in England & Wales are spending their final hours at home despite an overall decline in the number of people dying per year. There was a 3.8% drop in the number of deaths between 2004 and 2010, yet a 9% rise in those dying at home. The rise in home deaths appears to be highest among people with cancer... Almost 54% of people who died in 2010 were in NHS [National Health Service] hospitals and nursing homes, while 10% were in non-NHS hospitals and nursing homes. The proportion of deaths in hospitals and nursing homes fell by 4.5%. Researchers say new policies on 'end-of-life' patient care in the past ten years underpin the shift to dying at home, but that Britain still lags behind other countries such as the U.S. and Canada in allowing people more choice in

their place of death. Number of deaths at home nearly halved from 1974 to 2003 and if the trend had continued, fewer than one in ten people were expected to die at home by 2030. <http://www.dailymail.co.uk/news/article-2088619/One-choosing-die-homes-figures-reach-highest-level-years.html?ito=feeds-newsxml>

People deserve to have their end-of-life care wishes met

U.K. | *The Guardian* – 18 January 2012 – Every minute in the U.K. someone dies. That's over half a million people a year, but many of us are still not receiving good end-of-life care or having our dying wishes met. This can cause unnecessary pain and suffering. Despite recent progress, the gap between what people want when they are dying and what they get remains huge. Although around 70% of us would like to die at home, more than half continue to die in hospital, often after unnecessary and expensive trips to accident and emergency departments and crisis admission. According to the National Audit Office, four in 10 end-of-life patients had no medical need to be in hospital. <http://www.guardian.co.uk/society/2012/jan/18/end-of-life-care-policy>

1. 'Reversal of the British trends in place of death: Time series analysis 2004–2010,' *Palliative Medicine*, published on line 18 January 2012.
<http://pmj.sagepub.com/content/early/2012/01/17/0269216311432329.abstract>

Cont.

Of related interest:

- U.K. | *Yorkshire Evening Post* – 20 January 2012 – **'Health: Dignity in dying.'** A major blueprint for palliative care is also being launched to provide a clear direction for the development of end of life services over the next five years. The fourth Leeds Strategic Framework for Adult Palliative & End of Life Care replaces the Leeds Strategy for Palliative Care, which covered 2006 to 2009. Organisations from across the city have contributed to the strategy which aims to reduce the number of deaths in hospitals and increase the proportion of people who can die in the place that they choose. http://www.yorkshireeveningpost.co.uk/news/news-features/consumer/health_dignity_in_dying_1_4152795

Pilot scheme for end-of-life support

Helping terminally ill social housing tenants to have a 'good' death

U.K. | *The Guardian* – 18 January 2012 – [Lynda Rand], who has the incurable lung disease bronchiectasis, is keen to remain in her rented one-bedroom home.... To that end, she will soon take delivery of a new bed and receive help finishing off the redecoration of her bathroom. But she has also been promised a Dictaphone, to record some final messages for her daughter, and even tickets to see one of her favourite bands, Boyz II Men, next month in Gateshead. The help and treats are all part of a pilot scheme run by Home Group, the north-east-based social housing and care group founded three-quarters of a century ago in response to the 1936 'Jarrow Crusade' against unemployment and extreme poverty.¹ The aim of the scheme, called 'A Good Death,' is to support clients who are coming to the end of their lives, or who have been diagnosed with a terminal illness, to make practical arrangements and choices to enable them to remain in their own homes for as long as possible. <http://www.guardian.co.uk/society/2012/jan/18/end-of-life-support-homev>

1. 'The Jarrow Crusade,' http://www.bbc.co.uk/history/british/britain_wwone/jarrow_01.shtml

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | *Herald Sun* (Melbourne) – 23 January 2012 – **'Euthanasia campaigner Dr. Philip Nitschke faces death probe.'** Medical authorities are investigating euthanasia campaigner Dr. Philip Nitschke after the death of a terminally ill South Australian woman. An investigator has been appointed to determine whether it was "good medical practice" for Dr. Nitschke to attempt to legally import the death drug Nembutal as a sedative for the 61-year-old woman, who had spoken of ending her life to escape "an awful death." The investigator is working for the Australian Health Practitioner Regulation Agency and the Medical Board of Australia which has the power to revoke medical licences. <http://www.heraldsun.com.au/news/more-news/nitschke-faces-death-probe/story-fn7x8me2-1226250809283>
- SOUTH KOREA | Yon Hap News Agency – 19 January 2012 – **'Seven in 10 South Koreans favor 'passive euthanasia.'** In the survey conducted by the Ministry of Health & Welfare, 72.3% of 1,000 respondents said they are in favor of removing life-support devices when there is little or no hope of recovery for a patient. Nearly 70% of those in favor cited emotional pain to other family members as their main reason for supporting what is known as "passive euthanasia," while 60.2% said economic burdens were a major factor. South Korea currently allows only court-approved euthanasia. <http://english.yonhapnews.co.kr/national/2012/01/19/82/0302000000AEN20120119001400320F.HTML>
- THE NETHERLANDS | Radio Netherlands Worldwide – 16 January 2012 – **'Right to choose.'** At the end of January, the lower house of parliament will debate a controversial bill that expands existing euthanasia legislation. The current euthanasia law will be 10 years old in April; under very strict regulations, Dutch doctors are allowed to help their patients end their lives if they have expressly requested euthanasia. In 2011, there were 2136 reports of euthanasia and assisted suicide. <http://www.rnw.nl/english/article/right-choose>

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

Dementia and palliative care

ANNALS OF LONG-TERM CARE: CLINICAL CARE & AGING, 2012;20(1):21-26. Adopting a palliative care approach to manage end-of-life care issues in patients with a terminal illness can help prevent unnecessary suffering. This is especially important for patients with dementia, whose condition may not be recognized as terminal and are thus subjected to overtreatment with therapies that offer few benefits and a substantial risk of adverse effects. Pain and psychiatric syndromes are common in dementia patients, yet they often go unrecognized or untreated. Appropriately managing these secondary conditions are essential to ensuring that these patients receive humane care.

<http://annalsoflongtermcare.com/article/dementia-and-palliative-care>

Of related interest:

- *ANNALS OF LONG-TERM CARE: CLINICAL CARE & AGING*, 2012; 20(1):17-20. **'Palliative care practice for advanced dementia: Regulatory friend or foe?'** Long term care regulations can be successfully used to uphold comfort-focused practices for residents with life-limiting conditions such as dementia. In this population, burdensome, painful, and defensive interventions can be avoided, especially in the advanced stages of disease. When comfort is documented as the resident's primary goal of care, state and federal regulations underscore the importance of supporting preferences, dignity, and quality of care based upon individualized needs.
<http://annalsoflongtermcare.com/article/palliative-care-practice-advanced-dementia-regulatory-friend-or-foe>

Geriatric patients seeking to avoid 'fates worse than death'

THE MEDICAL POST (Canada) | Online report – 12 January 2012 – Virtually every presentation at conferences on geriatrics and dementia begins with an acknowledgement that Canada's population is aging. What those presenters don't mention is that those aging Canadians, many of whom have Alzheimer's disease or another form of dementia, also have multiple other diseases or conditions and are increasingly frail. A program, started by two Halifax geriatricians, takes those factors into account when future health care is being planned for such patients. "The byproduct of all the advances in medical technology over the last 50 years is that people are able to survive to accumulate multiple comorbid diseases, so frailty is the dirty little secret of all those medical advances," said Dr. Paige Moorhouse, who designed the Palliative & Therapeutic Harmonization (PATH) process with Dr. Laurie Mallery. http://www.canadianhealthcarenetwork.ca/physicians/clinical/health-index-therapeutics/neurology/seeking-to-avoid-fates-worse-than-death-20343?utm_source=EmailMarketing&utm_medium=email&utm_campaign=ON_Physician_Newsletter

From Media Watch dated 27 December 2010:

- NOVA SCOTIA | *Chronicle-Herald* (Halifax) – 21 December 2010 – **'A place to find comfort.'** Making life – usually the end of life – as pleasant, peaceful and pain-free as possible are among the goals of the PATH (Palliative & Therapeutic Harmonization) Clinic, founded by [Dr. Laurie] Mallery and Dr. Paige Moorhouse at the Queen Elizabeth II Health Sciences Centre. <http://thechronicleherald.ca/ArtsLife/1218300.html>

Augmenting advance care planning in poor prognosis cancer with a video decision aid

CANCER | Online article – 17 January 2012 – Patients with advanced cancer [i.e., study participants] did not change care preferences after viewing the video, but fewer wanted CPR or ventilation. Documented code status was inconsistent with patient preferences. Patients were more knowledgeable after the video, reported that the video was acceptable, and said they would recommend it to others. The current results indicated that this type of video may enable patients to visualize "goals of care," enriching patient understanding of worsening health states and better informing decision making. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.27423/abstract>

A two-session psychological intervention for siblings of pediatric cancer patients: A randomized controlled pilot trial

CHILD & ADOLESCENT PSYCHIATRY & MENTAL HEALTH | Online article – 11 January 2012 – Efforts to provide medical information to siblings, to enhance their coping skills, and to inform parents about their situation seemed to be rewarded by increased medical knowledge, increased sibling-reported psychological wellbeing and more social support resources. No intervention effects could be found with regard to anxiety, posttraumatic stress symptoms, and parent-reported health-related quality of life. <http://www.capmh.com/content/pdf/1753-2000-6-3.pdf>

Ethics briefing

Withdrawing and withholding artificial nutrition and hydration from a patient in a minimally conscious state

JOURNAL OF MEDICAL ETHICS, 2012; 38(1):64-66. In the summer of 2011 the [U.K.] Court of Protection ruled that it would be unlawful to withdraw artificial nutrition and hydration (ANH) from a woman, M, who had been in a minimally conscious state (MCS) for 8 years after contracting viral encephalitis at the age of 43 years. It was reported as the first English legal case concerning the withdrawal of ANH from a patient in a MCS. Although the judge sought to limit the judgement as closely as possible to the facts of the case, it is likely to have a significant impact on treatment decisions in relation to life-sustaining treatment for people in states of low awareness. Under the Mental Capacity Act 2005, decisions made on behalf of adults lacking capacity in England & Wales need to be made on the basis of an assessment of their best interests. The only exception to this is when there is a valid and applicable advance directive refusing the treatment in question. As M had made no advance directive, it fell to the court to make the decision in her best interests. Quoting case law, the court held that, with the exception of patients in a persistent vegetative state, decisions of this kind must be made by adopting a 'balance sheet'

approach, comparing 'the advantages of withdrawing ANH against the advantages of continuing with the treatment.'

<http://jme.bmj.com/content/38/1/64.extract>

The balance between providing support, prolonging suffering, and promoting death: Ethical issues surrounding psychological treatment of a terminally ill client

ETHICS & BEHAVIOR, 2012;22(1):44-59. A psychologist with a client who is terminally ill and wishes to discuss end-of-life options, specifically the option of hastening death, is faced with an ethical dilemma as to how to proceed with treatment. Specifically, he or she is bound by the American Psychological Association's potentially conflicting principles ... which advise a psychologist to "do no harm" as well as "respect ... self-determination." In addition, Standard 4 (Privacy & Confidentiality) mandates that a client's personal information is to remain private, unless that client could be in danger of harming himself or herself or others. This article discusses such a nuanced case and provides considerations as well as guidelines for psychologists to effectively navigate through this sensitive and important dilemma. <http://www.tandfonline.com/doi/abs/10.1080/10508422.2012.638825>

Of related interest:

- *JOURNAL OF INTENSIVE CRITICAL CARE* | Online article – 17 January 2012 – '**The effect of statutory limitations on the authority of substitute decision makers on the care of patients in the intensive care unit: Case examples and review of state laws affecting withdrawing or withholding life-sustaining treatment.**' In many jurisdictions, a clear distinction is made between the authority of a health care power of attorney ... and of next-of-kin, who are limited in this regard. When conflicts arise between critical care physicians and family members regarding projected patient outcome and functional status, these statutory limitations on decision-making authority by next of kin can cause paralysis in the medical care of severely ill patients, leading to practical and ethical impasses. <http://jic.sagepub.com/content/early/2012/01/09/0885066611433551.abstract>

A beginning understanding of caregivers' spiritual needs when relinquishing a loved one to a palliative care setting

JOURNAL OF RELIGION, SPIRITUALITY & AGING, 2012;24(1-2):131-145. There has been little evidence of the importance placed on spiritual care by caregivers of palliative care patients. Qualitative analysis [of interviews with study participants] demonstrated that the importance of spirituality and spiritual care could be classed as positive, negative, or positive and negative. Although the majority of participants indicated spirituality was an important component of their lives, five people did not indicate they had an interest in this area with two participants unclear as to the benefits of spirituality. <http://www.tandfonline.com/doi/abs/10.1080/15528030.2012.633055>

End-of-life decisions in Argentina

THE LANCET, 2012;379(9811):105. The current debate in the U.K. ... transcends borders. In Argentina, an overwhelming majority of the Lower House recently passed a bill authorising changes in the current law of patients' rights. The bill will be further discussed later this year and, if passed, would represent a monumental change in the legal framework of end-of-life care in Argentina. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(12\)60042-7/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60042-7/fulltext)

From Media Watch dated 9 January 2012:

- **LATIN AMERICAN ASSOCIATION FOR PALLIATIVE CARE** | Online posting – **'Palliative Care Atlas in Latin America.'** Accessed 3 January 2012 – The Association has launched 'Palliative Care Atlas in Latin America' ... to identify the degree of development and provide an overview of palliative care across the region. The Atlas will help create a network to allow exchange of experience. <http://www.eapcnet.eu/LinkClick.aspx?fileticket=8YGIFEqJU4o%3d>

A perspective of end-of-life care education in undergraduate medical and nursing students in Buenos Aires, Argentina

JOURNAL OF PALLIATIVE MEDICINE | Online article – 16 January 2012 – The authors [of this study] found that nursing and medical undergraduate students at nursing and medicine schools in the city of Buenos Aires and surrounding areas: a) come in direct contact with terminally ill patients and perceive their suffering; and, b) have a highly positive attitude toward these patients, even though some of them referred to that relationship as arduous and in some cases they tended to avoid emotional involvement because they did not feel well trained ... c) this wish for avoidance was increased in final-year medical and nursing students who had been exposed to a higher number of terminally ill patients; and d) students unanimously manifested the opinion that the teaching about caring of terminally ill patients should be included in the curricula and they would be well disposed to receive it. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0238>



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>

Hospice in America

Hospice care: More patients, less time

MEDPAGE TODAY | Online report – 16 January 2012 – Hospice use may be slowly rising in the U.S., but for shorter periods of time, which could short-change patients, according to a national report. Total patients in hospice rose slightly year over year from 1.3 million in 2006 to 1.6 million in 2010, with 41.9% of all U.S. deaths occurring in hospice by 2010, according to the National Hospice & Palliative Care Organization [NHPCO]. But median time in hospice dropped from 21.1 days in 2009 to 19.7 in 2010, and the average fell as well from 69 to 67.4 days. The trend toward shorter lengths of hospice care was consistent over the several years prior as well, the report noted. "With drops in both the median and average length of service, there is concern that hospice providers are not reaching the patients and family caregivers who need hospice support in a timely manner," J. Donald Schumacher, president and CEO of the organization, said in a press release. Long stays under hospice care remained stable from 2009 to 2010, with 11.8% of all hospice patients cared for more than 180 days in both years. But short durations of care rose. <http://www.medpagetoday.com/Geriatrics/GeneralGeriatrics/30675>

1. 'Facts & Figures: Hospice Care in America,' NHPCO, January 2012 (noted in Media Watch dated 16 January 2012). http://www.nhpco.org/files/public/Statistics_Research/2011_Facts_Figures.pdf

Of related interest:

- *THE ONCOLOGIST* | Online article – 17 January 2012 – '**Palliative care in advanced cancer patients: How and when?**' Early palliative care access can improve symptom control and quality of life and reduce the cost of care. Preliminary results show that early palliative care access can also extend survival. Only a minority of cancer centers in the U.S. have the two most important resources for palliative care delivery: outpatient palliative care centers and inpatient palliative care units. <http://theoncologist.alphamedpress.org/content/early/2012/01/12/theoncologist.2011-0219.abstract>

Controversies in oncologist-patient communication: A nuanced approach to autonomy, culture, and paternalism

ONCOLOGY, 2012;26(1):37-64. Difficult dialogues with patients facing life-changing decisions are an intrinsic part of oncologic practice and a major source of stress. Having a sophisticated approach to the concepts of autonomy, paternalism, and culture can help in addressing difficult dilemmas that arise around the issues of disclosure and decision making. This article addresses some of the most common major challenges in oncologist-patient communication with a nuanced approach to the concepts of autonomy, paternalism, and culture. It introduces the new concept of "voluntary diminished autonomy" and describes the implications this concept has for the consent process. It also attempts to bring clarity to common problems and misconceptions relating to culture, paternalism, and therapeutic privilege as these pertain to the communication practices of oncologists. <http://www.cancernetwork.com/practice/content/article/10165/2016361>

Dealing with ethical dilemmas in oncological communication involving issues of culture and autonomy

ONCOLOGY | Online commentary – 17 January 2012 – Beginning with its provocative opening case vignette, Nathan Cherny's article [see article left] provides an opportunity for us to reflect on and possibly redirect our own attitudes and habits regarding difficult ethical issues in communication with our patients and their families, especially in the setting of cultural and religious diversity. Ultimately, however, Dr. Cherny's paper is a discussion of truthful communication in the setting of cultural diversity – and specifically of the question of whether we can justifiably withhold key information from a patient. <http://www.cancernetwork.com/practice/content/article/10165/2016376>

Cont.

Of related interest:

- *SUPPORTIVE CARE IN CANCER* | Online article – 14 January 2012 – '**Changing preferences for information and participation in the last phase of life: A longitudinal study among newly diagnosed advanced lung cancer patients.**' Over a period of 4 months from diagnosis, half of patients [i.e., study participants] changed their information preferences for palliative care and end-of-life decisions with a possible or certain life-shortening effect (ELDs, e.g., non-treatment decisions) in both directions, from not wanting to wanting the information, but also – and as much – from wanting to no longer wanting it. <http://www.springerlink.com/content/0157513554725g86/>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2012;43(2):182-194. '**The nature and timing of family-provider communication in late-stage cancer: A qualitative study of caregivers' experiences.**' Timely communication with information and meaningful discussion about disease progression can help families prepare for the advanced stages of an illness and approaching death. [http://www.jpsmjournal.com/article/S0885-3924\(11\)00429-5/abstract](http://www.jpsmjournal.com/article/S0885-3924(11)00429-5/abstract)

Resource utilization and cost analyses of home-based palliative care service provision: The Niagara West End-of-Life Shared-Care Project

PALLIATIVE MEDICINE | Online article – 16 January 2012 – This paper analyzes resource utilization and costs of a shared-care demonstration project in rural Ontario (Canada) from the public health care system's perspective. While higher than expenditures previously reported for a cancer-only population in an urban Ontario setting, the costs were still within the parameters of the U.S. Medicare Hospice Benefits, on a par with the *per diem* funding assigned for long-term care homes and lower than both average alternate level of care and hospital costs within the Province of Ontario. The study results may assist service planners in the appropriate allocation of resources and service packaging to meet the complex needs of palliative care populations. <http://pmj.sagepub.com/content/early/2012/01/16/0269216311433475.abstract>

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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.hpcconnection.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>

From Media Watch dated 21 March 2011:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 14 March 2011 – **'A shared care model pilot for palliative home care in a rural area: Impact on symptoms, distress, and place of death.'** Shared care models build on family physician capacity and as such are promising in the development of palliative home care programs to improve access to quality palliative home care and foster health system integration. [http://www.jpmsjournal.com/article/S0885-3924\(11\)00031-5/abstract](http://www.jpmsjournal.com/article/S0885-3924(11)00031-5/abstract)

A new model for breaking bad news to people with intellectual disabilities

PALLIATIVE MEDICINE | Online article – 16 January 2012 – Breaking bad news is best seen as a process, not an event or a linear series of events. Bad news situations usually constitute a wide range of discrete items or chunks of information. 'Building a foundation of knowledge' is central to the model. Information needs to be broken down into singular chunks of knowledge that can be added over time to people's existing framework of knowledge. Three other aspects should be considered at all times: capacity, people and support. Patients who have IDs [intellectual disabilities] do not easily process verbal information in a clinical setting. The new model for breaking bad news to people with IDs needs to be tested in practice using robust outcome measures. The model's relevance to wider patient groups should also be evaluated. <http://pmj.sagepub.com/content/early/2012/01/16/0269216311433476.abstract>

From the archives (noted in Media Watch dated 27 December 2010):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2008;14(4):189-194. **'Communication difficulties and intellectual disability in end-of-life care.'** This paper maps the communication difficulties experienced by people with intellectual disabilities within a palliative care setting, drawing on several research studies carried out by the authors. These include the time-consuming nature of effective communication, and difficulties around breaking bad news. The paper explores the ways in which people with intellectual disabilities may (mis)understand verbal information. Strategies for managing communication difficulties are outlined, including ways to use clear, unambiguous language. <http://www.ddhospicepalliativecare.org/comdif.pdf>

A 'beautiful death': Mortality, death, and holidays in a Mexican municipality

SOCIAL SCIENCE & MEDICINE | Online article – 16 January 2012 – This study explored holiday-related trends using mortality data from Yautepec (Morelos, Mexico) collected between 1986 and 2008. Analysis found that mortality increased on Christmas Day and All Saints' Day. Mortality increased on Candlemas Day among women, and increased on New Year's Day among men. More deaths caused by cardiovascular disease among women and traumatic injuries among men occurred during holidays than in non-holiday periods. [In this study] the "beautiful death" emerged as the main concept in the interpretation of death; this concept was related to the expectation of a good death and the particularly special nature of death during a holiday because of the involvement of religious entities, such as God, the Virgin Mary, and/or a saint, at the moment of death. The results suggest that, in the studied region, death can be interpreted as a "beautiful process". <http://www.sciencedirect.com/science/article/pii/S0277953612000147?v=s5>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *AUSTRALIAN & NEW ZEALAND JOURNAL OF PSYCHIATRY* | Online article – 16 January 2012 – **'Assisted dying in liberalised jurisdictions and the role of psychiatry: A clinician's view.'** There remain significant concerns about the accuracy of psychiatric assessment in the terminally ill. Mental processes are more relevant influences on a hastened wish to die than are the physical symptoms of terminal malignant disease. Psychiatric review of persons requesting euthanasia is relevant. It is not obligatory or emphasised in those legislations allowing assisted dying. Psychiatry needs to play a greater role in the assessment processes of euthanasia and physician-assisted suicide. <http://anp.sagepub.com/content/early/2012/01/12/0004867411434714.abstract>

Worth Repeating

From diagnosis to death: A case study of coping with breast cancer as seen through online discussion group messages

JOURNAL OF COMPUTER-MEDIATED COMMUNICATION, 2011;16(2):331-361. This qualitative online case study highlights the power that writing and sharing one's journey can have, not only for the individual writing messages, but also for those reading the messages. More research is needed to understand if sharing one's story with others via an electronic format changes the way one copes with an illness and/or changes how other support group members perceive their own illness. An obvious next step in this line of research is to replicate the longitudinal study of online posting qualitative analysis with more case studies. Longitudinal studies are needed to determine if involvement in an online support group influences one's social network, length of survival, quality of life, etc. Little is known about the difference in process and outcomes between research-based online support groups and those peer-led, self-forming groups on the internet. <http://onlinelibrary.wiley.com/doi/10.1111/j.1083-6101.2011.01542.x/full>

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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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.

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