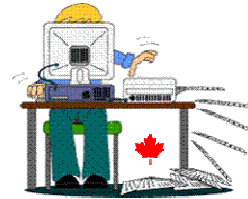


Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry and research.

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Compiled & Annotated by Barry R. Ashpole

Truth-telling: Scroll down to **International** and 'Why did you lie to me, Daddy? Boy, 8, devastated to find his illness is terminal after going on Google' (p.7), published in the U.K.'s *Daily Mail*.

Canada

Issues in pain management

Many with cancer pain aren't on strong painkillers

ONTARIO | Reuters – 9 March 2012 – Despite suffering severe pain, about one in three older cancer patients do not end up taking opioids, the most potent of analgesics, according to a new study from Canada.¹ It's not clear why these patients are not getting their pain treated with opioids, which include morphine, oxycodone and fentanyl. It could be that physicians are not prescribing the medications or that patients are getting prescriptions, but not filling them. They don't have to be in pain. There's effective treatment out there," said Dr. Paul Glare, the chief of Pain & Palliative Care Service at Memorial Sloan Kettering Cancer Center in New York, who was not involved in this study. The researchers gathered information over two years on all cancer patients over age 65 in Ontario who had been screened for pain. Of more than 24,000 people included in the study, 20% reported that they had severe pain. The team looked to see how many of them got a prescription filled for an opioid painkiller... A third of the high-pain group did not fill a prescription within either the month before the pain screening or the week after. I'm not sure I know what the number should have been, but I think I was hoping it would have been a smaller number than that," said Dr. Lisa Barbera, the lead author of the study and a researcher at Sunnybrook Health Sciences Centre in Toronto. <http://www.reuters.com/article/2012/03/09/us-painkillers-idUSBRE8281CE20120309>

1. 'Opioid prescription after pain assessment: A population-based cohort of elderly patients with cancer,' *Journal of Clinical Oncology*, published online 27 February 2012. <http://jco.ascopubs.org/content/early/2012/02/27/JCO.2011.37.3068.abstract?sid=51a417eb-98e4-4acb-95bc-bc2a1850a9bb>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *Lethbridge Herald* – 8 March 2012 – **'South views more liberal: Poll.'** Debate an issue, and southern Albertans will respond. That could explain growing support for doctor-assisted suicide, a Lethbridge political scientist suggests. Two-thirds of Lethbridge and Coaldale residents said they agreed with that end-of-life option [in the] ... year's first Citizen Society Research Lab survey, conducted by Lethbridge College students... College instructor Faron Ellis, who supervised the study, says recent discussion of the assisted-suicide issue seems to have caught the public's attention. <http://www.lethbridgeherald.com/local-news/south-views-more-liberal-poll-3812.html>

U.S.A.

New law solidifies end-of-life wishes for Iowans

IOWA | KCRG-TV9 (Cedar Rapids) – 10 March 2012 – A new law will provide Iowans facing end-of-life care with greater certainty that their treatment choices will be followed. The bill ... allows a patient's health care wishes to be honored through various health care settings with a formal one-page document ... called an Iowa Physician's Order for Scope of Treatment ... a legal doctor's order that notes the patient's preferences for life-sustaining treatments such as CPR, artificial nutrition and more. <http://www.kcrv.com/news/local/New-Law-Solidifies-End-of-life-Wishes-for-Iowans-142178323.html>

N.B. Iowa is the 14th state to pass such a law. More than 30 states provide residents with the planning document 'Physician Orders for Life Sustaining Treatment' (POLST).

Of related interest:

- NEW HAMPSHIRE | *Concord Monitor* (OpEd) – 12 March 2012 – **'Keep the courts out of hospital rooms'** Two [proposed bills] would make the use of advanced-care directives more difficult. In some situations, they could potentially countermand the wishes of a dying individual. They both deserve defeat. <http://www.concordmonitor.com/article/316621/keep-the-courts-out-of-hospital-rooms?CSAuthResp=1331553234%3A76jfednobi4ndr6bfldb0251%3ACsUserId%7CCSGroupId%3AApproved%3A2AE7D6ADB14F9C741460356583AF9653&CSUserId=94&CSGroupId=1>

Transforming the way we die

THE ATLANTIC | Online commentary – 8 March 2012 – For years sociologists, public health professionals, gerontologists, and members of my own field of palliative care have been warning about the looming problems of aging, dying, and caregiving. In 1997 the Institute of Medicine concluded, "Too many people suffer needlessly at the end of life, both from errors of omission and commission." One reason our nation hasn't acted sooner is that there are always more immediate crises to deal with: terrorism, foreign wars, hurricanes, floods, the bursting of financial bubbles, and the near collapse of our economy. All rightly vie for attention of the voting public, politicians, and elected leaders. However, competing social priorities

alone do not explain our country's inaction on these pressing issues.

<http://www.theatlantic.com/health/archive/2012/03/transforming-the-way-we-die/253694/>

The surprise question: Would your doctor be shocked if you died?

THE ATLANTIC | Online article – 9 March 2012 – With studies showing an answer to the question is a significant prognostic indicator, it's a simple way of screening for palliative care eligibility. <http://www.theatlantic.com/health/archive/2012/03/the-surprise-question-would-your-doctor-be-shocked-if-you-died/253695/>

How to die like a doctor

FORBES | Online commentary – 7 March 2012 – With the interest lately in how doctors die [see sidebar], now is a great time to help you plan to die like a doctor. In my last post, I discussed how doctors are great at completing their end of life planning, and they make certain the right people are in place to carry out their wishes. They also tend to take charge of making certain their loved ones have the most pleasant end of life possible. When doctors choose how to treat their terminal illness, they take prognosis into account. If prognosis is not good, most opt for comfort care and conservative treatment. Ideally, a death well prepared for is a more comfortable death, and this is what doctors choose. So what can you do to die like a doctor? It takes some preparation, and for most, a change in how life and death are viewed. I'll break this down into phases – pre-illness, illness, and too-late-to-cure illness. <http://www.forbes.com/sites/carolynmccclanahan/2012/03/07/how-to-die-like-a-doctor/>

Hospice in the continuum of care

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Online posting – 6 March 2012 – NHPCO has released a compendium of articles originally published in its member publication *NewsLine* that demonstrate ways in which hospice programs are working to create a more seamless continuum of care for patients and families. <http://www.nhpc.org/i4a/pages/index.cfm?pageID=6594>

Burial blunders common in poorly regulated cemetery industry, advocates say

MARYLAND | Fox News (Baltimore) – 5 March 2012 – After Carolyn Jacobi visited her father's grave in 1995, she walked away angry and disgusted – and determined to dedicate the rest of her life to bringing dignity to the dead. The conditions at Mount Auburn Cemetery in Baltimore, where her father, James Williams, lay buried alongside other distinguished African-Americans and prominent Marylanders, were so deplorable that Jacobi couldn't even locate his headstone. But nothing prepared her for what she discovered that November day: A human skull believed to be her father's was sticking up out of the ground, loosened by Jacobi's stomps of frustration. "I went berserk, as it could be expected," she told FoxNews. "I lost it. That was the catalyst for my movement." Jacobi, 74, founded Eternal Justice, a watchdog of the death care industry, in the hope that she could bring accountability to a poorly regulated industry and peace of mind to those who bury loved ones. <http://www.foxnews.com/us/2012/03/05/burial-blunders-common-in-poorly-regulated-cemetery-industry-advocates-say/>

Physician perspectives on end-of-life care

'Doctors do die differently – how we make certain,' *Forbes* (U.S.), 2 March 2012 (noted in Media Watch dated 5 March 2012, p.2). <http://www.forbes.com/sites/carolynmccclanahan/2012/03/02/doctors-do-die-differently-how-we-make-certain/>

'Why doctors die differently,' *Wall Street Journal* (U.S.), 25 February 2012 (noted in Media Watch dated 5 March 2012, p.2). <http://online.wsj.com/article/SB10001424052970203918304577243321242833962.html>

'How doctors choose to die,' *The Guardian* (U.K.), 19 February 2012 (noted in Media Watch dated 27 February 2012, p.8). <http://www.guardian.co.uk/theguardian/shortcuts/2012/feb/19/death-and-dying-doctors>

'Terminal illness: What doctors don't tell you,' *The Star* (South Africa), 15 February 2012 (noted in Media Watch dated 20 February 2012, p.5). <http://www.iol.co.za/the-star/terminal-illness-what-doctors-don-t-tell-you-1.1234701>

'Why MOST doctors like me would rather DIE than endure the pain of treatment we inflict on others for terminal diseases: Insider smashes medicine's big taboo,' *Daily Mail* (U.K.), 14 February 2012 (noted in Media Watch dated 27 February 2012, p.8). <http://www.dailymail.co.uk/health/article-2100684/Why-doctors-like-die-endure-pain-treatment-advanced-cancer.html>

'What doctors know – and we can learn – about dying,' *Time Magazine* (U.S.), 16 January 2012 (noted in Media Watch dated 23 January 2012, p.2). <http://ideas.time.com/2012/01/16/what-doctors-know-and-we-can-learn-about-dying/?xid=gonewsedit>

'How doctors die,' Zócalo Public Square, Center for Social Cohesion (U.S.) – posting undated (noted in Media Watch dated 23 January 2012, p.2). <http://zocalopublicsquare.org/thepublicsquare/2011/11/30/how-doctors-die/read/nexus/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GEORGIA | 11 Alive News (Atlanta) – 8 March 2012 – **'Assisted suicide would be banned under new law.'** Assisting in another person's suicide would become a felony crime in Georgia punishable by up to a decade in prison under legislation passed by House lawmakers. The legislation... responds to a state Supreme Court ruling in February that struck down a 1994 law banning people from publicly advertising suicide. <http://www.11alive.com/news/article/231853/3/Assisted-suicide-would-be-banned-under-Ga-law>
- MASSACHUSETTS | *Sentinel & Enterprise* (Boston) – 7 March 2012 – **'Assisted-suicide testimony gets emotional.'** A proposed bill allowing physician-assisted suicide brought emotional testimony from supporters and opponents at a hearing of the Joint Committee on the Judiciary. The Death with Dignity Act [Bill H.3884, An Act Relative to Death with Dignity], which mirrors legislation passed in Oregon [1998] and Washington [2009], would allow terminally ill individuals given less than six months to live to self-administer a lethal dose of medication if they have clearance from two doctors. http://www.sentinelandenterprise.com/local/ci_20119662/assisted-suicide-testimony-gets-emotional
- OREGON HEALTH AUTHORITY | Online posting – 6 March 2012 – **'Death with Dignity Act: 2011 Report.'** Oregon's [1998] Death with Dignity Act (DWDA) allows terminally-ill adult Oregonians to obtain and use prescriptions from their physicians for self-administered, lethal doses of medications. As of 29 February 2012, prescriptions were written for 114 people during 2011 under the provisions of the DWDA, compared to 97 during 2010. Twenty-five of the 114 patients who received DWDA prescriptions during 2011 did not take the medications and died of their underlying illness. <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>

Media Watch Online

The weekly report can be accessed at several websites, among them:

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

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

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

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

U.S.A.

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

Europe

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

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

International

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

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

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

International

Palliative care in Finland

Doctors want terminal care written into law

FINLAND | YLE News – 11 March 2012 – Specialist doctors are calling for legislation that would mandate the provision of end-of-life care throughout Finland. They want to see a strong push in this direction as recommendations from the Ministry of Social Affairs & Health have failed to bring tangible results in public health services. The recently initiated debate on euthanasia has shed light on some facts regarding the terminally ill. About 300,000 of such patients in Finland are in need of palliative care... 15,000 require end-of-life care. Finland has about 60 doctors specialising in the field. The number of terminal care facilities can be counted on the fingers of one hand, which is nowhere near enough. Meanwhile the Health Ministry's recommendations have not been incorporated in public health services. Half of the country's hospital districts and large cities have been neglecting the matter, with many lacking even preliminary plans for terminal care provision. http://www.yle.fi/uutiset/news/2012/03/doctors_want_terminal_care_written_into_law_3324094.html

End-of-life care and the economy

Kate Middleton's cancer charity funding is slashed in half

U.K. | *Daily Mirror* – 10 March 2012 – Under-fire Health Secretary Andrew Lansley has cut funds for one of the Duchess of Cambridge's most cherished charities ...in HALF. The gaffe-prone Tory, already in deep trouble over his hated NHS [National Health Service] reforms, has lopped £700,000 off the £1.4million government money normally given to East Anglia Children's Hospices. Kate became its patron after hearing moving stories from parents of terminally-ill children cared for by the charity. Now Lansley's blunder will cast a shadow over her first royal public address as she opens a new hospice in Ipswich ... in a ceremony expected to be watched by millions worldwide. <http://www.mirror.co.uk/news/uk-news/kate-middletons-cancer-charity-funding-758050>

Palliative care patients moved to Queen Elizabeth II [Hospital]

AUSTRALIA (QUEENSLAND) | Quest Newspapers (Brisbane) – 7 March 2012 – Queensland Health has removed the publicly-funded palliative care beds from Oxley's Canossa Private Hospital. Canossa Services director Sheree Richards said the contract to fund up to 10 palliative care beds expired ... and public patients were transferred to Queen Elizabeth II [QEII] Hospital. Metro South Health District CEO David Theile said QEII's Palliative Care Unit opened this week and beds at Canossa were still open to Queensland Health public patients under an ongoing agreement. <http://www.couriermail.com.au/questnews/south/public-beds-close-at-hospital-contrary-to-official-chatter/story-fn8m0tyy-1226291931326>

Istanbul funeral home fosters Muslim-Christian understanding

TURKEY | *EurasiaNet Weekly Digest* (Istanbul) – 9 March 2012 – More than 40 years ago, Kirkor Çapan, an ethnic Armenian, and his father set up what today is one of the last Christian funeral homes still operating in Istanbul. But the funeral parlor is not a religious island unto itself. With so few Christians left in Turkey, the stonemasons and carpenters working with Çapan are Muslim Turks. "There are no more non-Muslim master craftsmen in my profession," commented stonemason Senol Ekinçi, one of Çapan's craftsmen, who has been carving Christian and Jewish tombstones for 35 years. Standing in the Greek-Orthodox cemetery in the Istanbul neighborhood of Sisli, where he is responsible for the graves' maintenance and renovation, Ekinçi explained what drew him to work on non-Muslim tombstones. <http://www.eurasianet.org/node/65110>

Human rights watchdog intervenes in 'do not resuscitate' case

U.K. | *The Guardian* – 9 March 2012 – The U.K.'s human rights watchdog is intervening in a landmark case over the use of "do not resuscitate" orders for NHS [National Health Service] patients. The Equality & Human Rights Commission is an independent party to the case being brought by the husband of a woman who died in Addenbrooke's hospital, Cambridge, last year. David Tracey alleges medical staff at the hospital unlawfully issued two such orders without the consent of his 63-year-old wife, Janet, or discussion with her and that by doing so deprived her of her right to life and subjected her to degrading treatment. He also says that he was thereby denied respect for his personal and family life. The Cambridge University Hospitals NHS trust, to which Addenbrooke's belongs, and the Department of Health deny acting unlawfully under the 1998 Human Rights Act and dispute the Tracey family's account of what happened at the hospital. <http://www.guardian.co.uk/society/2012/mar/09/watchdog-intervenes-do-not-resuscitate-case>

From Media Watch dated 29 August 2011:

- U.K. | *The Guardian* – 26 August 2011 – '**Do not resuscitate: Final word is with medical staff, whatever patient feels.**' <http://www.guardian.co.uk/society/2011/aug/26/do-not-resuscitate-medical-patient>

Helping more people die at home would save National Health Service cash: Charity

U.K. (ENGLAND) | *Daily Telegraph* – 9 March 2012 – Around two thirds of all people want to die at home but only one in five actually do. As well as helping people have a 'good death' at home in accordance with their wishes the National Health Service [NHS] would save money on expensive hospital care, a charity has said. Taking into account the cost of nurses visiting to administer pain relief and keep patients comfortable, the NHS would still save money because hospital care is so expensive. Specialist palliative care in hospital costs £425 per day, according to Marie Curie Cancer Care. Nursing care costs vary around the country and according to the level of care needed but are cheaper. Even the modest step of reducing the hospital stay of 30,000 patients in the last stages of life by just four days could save the NHS £34 million, it was calculated. Marie Curie Cancer Care estimates that cutting the hospital stays of just 12% of all people who currently die in hospital in England each year could save the NHS millions. At present, just over half of all deaths happen in hospital – in 2010 this meant 245,570 people died there. Imelda Redmond, director of policy and public affairs at the charity, said: "The NHS has to save £20 billion by 2015. Savings on the scale required can only be achieved through service redesign that can be rapidly implemented across the NHS." <http://www.telegraph.co.uk/health/healthnews/9131489/Helping-more-people-die-at-home-would-save-NHS-cash-charity.html>

Reviving autopsy

U.K. | *Economist* – 3 March 2012 – The study of death is never a cheerful topic, but it has gone through a particularly gloomy patch in the past few decades. A recent tally by America's Centres for Disease Control and Prevention showed that in 2007 only 8.5% of deaths in America were investigated by autopsy. In 1972 the figure was 19.3%. Britain's coroners are more active, but perhaps not more accurate. In Britain, 22% of deaths lead to an autopsy. According to a government review, however, one in four is of miserable quality. The upshot in both cases is not just that the causes of individual deaths may be misascribed. More seriously, data about the processes of disease are lost, and those diseases are thus not as well understood as they might have been. Relatives of the deceased, meanwhile, often do not like the idea of bodies being cut up at the behest of coroners. <http://www.economist.com/node/21548481>

Why did you lie to me, Daddy? Boy, 8, devastated to find his illness is terminal after going on Google

U.K. | *Daily Mail* – 2 March 2012 – When their eight-year-old was diagnosed with terminal illness, Dominic and Caroline Stacey thought it best to keep the tragic news from him. They had, however, not reckoned on Dominic Junior's inquisitive nature. He looked up the disease he called 'tired legs' on Google and discovered the truth. Lil Dom – as he is nicknamed – then confronted his parents and asked why they had not told him, and had been so upbeat about his condition, Duchenne muscular dystrophy. The rare disease causes muscle degeneration and difficulties with walking and breathing that eventually lead to death. Average life expectancy is 25. Mr. Stacey, a 33-year-old youth worker, said the aftermath of Lil Dom's discovery was traumatic for the family. "He came up to me and asked me why I had lied to him," he said. "We sat him down and ex-

plained everything. It was one of the hardest conversations I've ever had. We were all in bits." <http://www.dailymail.co.uk/health/article-2108738/Duchenne-muscular-dystrophy-Boy-8-finds-illness-terminal-going-Google.html>

Specialist Publications

Of particular interest:

'Decisions about life-sustaining measures in children: In whose best interests?' (p.8), published in *Acta Paediatrica*.

'Barriers to conducting advance care discussions for children with life-threatening conditions' (p.8), published in *Pediatrics*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *New Internationalist*, 2012;450(3):34-36. **'Should assisted suicide be legalized?'** Right-to-die campaigner Debbie Purdy and palliative medicine professor Ilora Finlay go head-to-head. Purdy is living with multiple sclerosis and is notable for her challenge to the law in England & Wales as relates to assisted suicide.¹ Finlay is a member of the British House of Lords and of the All-Party Parliamentary Group on Dying Well.² <http://www.newint.org/sections/argument/2012/03/01/assisted-suicide-dying-legalized-debate/>

- U.K. | *Guardian* – 31 July 2009 – **'Right-to-die law to be clarified.'** The Director of Public Prosecutions for England & Wales is to issue urgent guidance to clarify the law on assisted suicide after Debbie Purdy ... won a historic judgement from the House of Lords (noted in Media Watch dated 3 August 2009). <http://www.guardian.co.uk/uk/2009/jul/31/assisted-suicide-law-debbie-purdy>
- BRITISH MEDICAL JOURNAL* | Online report – 28 October 2010 – **'Group is launched to present "hard evidence" against physician assisted suicide.'** A public policy think tank ... has been launched by two members of the House of Lords. Lord Alex Carlile and Baroness Ilora Finlay, co-chairs of Living & Dying Well, have both fervently opposed any change in the law on this issue (noted in Media Watch dated 1 November 2012). <http://www.bmj.com/content/341/bmj.c6120.extract>

From Media Watch dated 12 September 2011:

- U.K. | Press Association – 6 September 2011 – **'Crown Prosecution Service defends assisted suicide policy.'** The Crown Prosecution Service [CPS] has not implemented a "blanket policy" banning the prosecution of cases of assisted suicide. The Director of Public Prosecutions admitted that no prosecutions had been brought for the offence since new CPS guidelines were issued 18 months ago. http://www.google.com/hostednews/ukpress/article/ALeqM5iN_fqEpb6eE-ILmiALw9EgoT-Pg?docId=N0213081315284850926A

N.B. Director of Public Prosecutions interim policy on prosecuting assisted suicide, September 2009. http://www.cps.gov.uk/news/press_releases/144_9/

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

Decisions about life-sustaining measures in children: In whose best interests?

ACTA PAEDIATRICA, 2012;101(4):333-336. The report seeks to examine the notion that in the arena of paediatric critical care medicine, the decision-making process regarding life-sustaining measures may place insufficient priority upon the child's best interests. The author's examine actual, de-identified clinical situations, encountered in the critical care arena in two categories: 1) cases that challenge the imperative to act in the child's best interests; and, 2) cases that compromise the ability of parents and caregivers to use child-centred, best-interests approaches to decision-making. Clarity surrounding the implications of a clinical decision for the patient is essential. Decisions that are not focused squarely on the child's best interests may compromise the delivery of optimally ethical end-of-life care. <http://onlinelibrary.wiley.com/doi/10.1111/j.1651-2227.2011.02531.x/abstract>

Of related interest:

- *PEDIATRICS* | Online article – 12 March 2012 – '**Rising national prevalence of life-limiting conditions in children in England.**' In 2010, the prevalence of life-limiting conditions in children in England was double the previously reported estimates and had increased annually in all areas over the past decade. This clearly identifies an escalating need for specialist pediatric palliative care services. <http://pediatrics.aappublications.org/content/early/2012/03/07/peds.2011-2846.abstract>
- *PEDIATRICS* | Online article – 5 March 2012 – '**Barriers to conducting advance care discussions for children with life-threatening conditions.**' The top three barriers to advance care discussions were: unrealistic parent expectations, differences between clinician and patient/ parent understanding of prognosis, and lack of parent readiness to have the discussion. Nurses identified lack of importance to clinicians and ethical considerations as impediments more often than physicians. Conversely, physicians believed that not knowing the right thing to say was more often a barrier. <http://pediatrics.aappublications.org/content/early/2012/02/29/peds.2011-2695.abstract>

Palliative care nursing for children in the U.K. and Ireland

BRITISH JOURNAL OF NURSING, 2012; 21(5):276-281. This article discusses palliative care for children ... [and] ... highlights national and international developments in this area, describes current services, and makes recommendations for future developments. <http://www.internurse.com/cgi-bin/go.pl/library/abstract.html?uid=90165>

Of related interest:

PAEDIATRICS & CHILD HEALTH, 2012; 22(3):115-120. '**Developments in paediatric palliative care.**' This article tracks the development of paediatric palliative care from the appreciation of children's entitlement to high quality palliative care in the 1970s through to the formal recognition of paediatric palliative medicine as a subspecialty by the Royal College of Paediatrics and Child Health in 2009. <http://www.sciencedirect.com/science/article/pii/S175172221100268X>

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>



Who are the chronically costly? Health care's 1%

AMERICAN MEDICAL NEWS | Online report – 5 March 2012 – The costliest 1% of patients consume one-fifth of all health care spending in the U.S., according to federal data. Health systems are trying to reduce the imbalance. They are older patients with cancer, diabetes, heart disease and other serious chronic conditions. Many have multiple health problems, and their relatives might not be helping with their care. Most have private insurance, are white and female. They are the costliest 1% of patients in the U.S. Caring for them accounts for more than 20% of what the nation spends on all of its health care. In contrast, the least costly half of all patients are associated with only 3% of total health spending, according to an Agency for Healthcare Research & Quality analysis.¹ <http://www.ama-assn.org/amednews/2012/03/05/gvsa0305.htm>

1. 'The Concentration and Persistence in the Level of Health Expenditures over Time: Estimates for the U.S. Population, 2008-2009,' [U.S.] Agency for HealthCare Research & Quality, January 2012. http://meps.ahrq.gov/mepsweb/data_files/publications/st354/stat354.shtml

Surrogate decision makers' interpretation of prognostic information

ANNALS OF INTERNAL MEDICINE, 2012;12(156):360-366. [Study] participants' interpretations of prognostic statements expressing a low risk for death were relatively accurate, but interpretations of statements conveying a high risk for death were more optimistic than the actual meaning. Interpretations of the statement "90% chance of surviving" did not differ from the actual meaning, but interpretations of "5% chance of surviving" were more optimistic and showed substantial variability. Two main themes from the interviews explained this trend: surrogates' need to register optimism in the face of a poor prognosis and surrogates' belief that patient attributes unknown to the physician would lead to better-than-predicted outcomes. Inaccurate interpretations of physicians' prognostications by surrogates arise partly from optimistic biases rather than simply from misunderstandings. <http://www.annals.org/content/156/5/360.abstract>

Development and measurement of palliative care cultural standards using clinical indicators

ASIA-PACIFIC JOURNAL OF CLINICAL ONCOLOGY, 2012;8(1):3-9. Australia is a culturally and linguistically unique country with one of the most diverse migrant populations in the world. For example, more than 25% of the population have been born overseas and comprise people from more than 200 countries, including Asian countries. To highlight this point, in 2008 Australia's overseas-born population accounted for 30% of all deaths. Although there have been many efforts by the Australian Government to establish culturally sensitive health services over the last 30 years or so, more work is required to ensure that culturally sensitive end of life care is provided, especially because of differences in culture and traditions at the end stage of life. It is vital to consider the needs of culturally and linguistically diverse groups in the palliative care setting, as highlighted in the literature, the including inequitable health outcomes in the healthcare requirements of people from the non-dominant culture. This article focuses on migrants who are considered to represent Asian culture. This group is broadly defined to include people from the many countries bordering Australia, including Malaysia, Hong Kong, Singapore, Taiwan and China. <http://onlinelibrary.wiley.com/doi/10.1111/j.1743-7563.2011.01510.x/full>

Of related interest:

- *THE GERONTOLOGIST* | Online article – 8 March 2012 – '**Turning the lens inward: Cultural competence and providers' values in health care decision making.**' The provider's challenge is to understand her own unacknowledged anxieties, prejudices, and fears around such charged issues as truth telling, individual agency, capacity, death and dying, and the value of life itself and address their impact on the delivery of care. A social constructivist perspective and the clinical concept of cultural countertransference are proposed as aides in achieving this awareness and improving care. <http://gerontologist.oxfordjournals.org/content/early/2012/03/08/geront.gns008.abstract>

**Living wills under close scrutiny:
Medical consultation is indispensable**

DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT, 2012;137(10):487-90. Since September 2009 the handling of living wills has been regulated by law. Even though a medical consultation is not imperative for the drawing up of a living will, first surveys have shown that medical information about clinical pictures and treatment options lead to an important specification of living wills. For the first time in Germany, a questionnaire has been developed to investigate the impact of medical consultations on the content of living wills. It revealed that nearly all the people surveyed who had already drawn up a living will wished to change the content of their completed will after attending the seminar because the previous version was no longer in accordance with their wishes. In the light of the frequent difficulties in hospitals concerning how to apply a living will to an actual clinical situation, the authors believe that structured medical consultations to be indispensable. <https://www.thieme-connect.com/DOI/DOI?10.1055/s-0031-1298998>

N.B. Text in German

Of related interest:

- *THE GERONTOLOGIST* | Online article – 2 March 2012 – '**Hospice decision making: Diagnosis makes a difference.**' Differences in decision making by diagnosis suggest the need for research about effective means for tailored communication in end-of-life decision making by type of illness. <http://gerontologist.oxfordjournals.org/content/early/2012/03/02/geront.gnr160.abstract>

The retreat from advanced care planning

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2012;307(9):915-916. The specter of death panels lives. As a reminder of their origin, the House of Representatives version of what eventually became the Affordable Care Act (i.e., the health care reform bill passed in 2010) included a provision authorizing Medicare to reimburse physicians for the time they spend discussing with patients their goals and preferences surrounding end-of-life care. "Advanced care planning" is the term used for the process of patients' thinking about and communicating their values and preferences, whereas the term "advanced directive" refers to the related legal document. The advanced care planning process helps ensure that individuals receive the health care they desire at the end of their lives. The provision had widespread bipartisan support until the summer of 2009, when Sarah Palin morphed talk of providing support for patients who wanted to have a discussion with their physicians concerning their priorities into rhetoric alluding to "death panels." <http://jama.ama-assn.org/content/307/9/915.extract>

Quotable Quotes

Suffering is like a fire: Those who sit closest feel the most heat; a picture of a fire gives off no warmth. That's why it's typically the son or daughter who has been physically closest to an elderly parent's pain who is the most willing to let go. Sometimes an estranged family member is "flying in next week to get all this straightened out." This is usually the person who knows the least about her struggling parent's health; she'll have problems bringing her white horse as carry-on luggage. This person may think she is being driven by compassion, but a good deal of what got her on the plane was the guilt and regret of living far away and having not done any of the heavy lifting in caring for her parent.

Craig Bowron MD, 'Our unrealistic attitudes about death, through a doctor's eyes,' *Washington Post*, 17 February 2012. http://www.washingtonpost.com/opinions/our-unrealistic-views-of-death-through-a-doctors-eyes/2012/01/31/gIQAeaHpJR_story.html

Palliative care in Ireland

Right time, right place, right care

IRISH MEDICAL TIMES | Online report – 9 March 2012 – A collaboration between the Irish Hospice Foundation, the Irish College of General Practitioners and the Health Service Executive is making inroads in the field and significant plans are in place to aid GPs in providing such care in an organised and balanced fashion. The trio of organisations established the Primary Palliative Care programme in 2010 to help and support GPs in managing patients with life-limiting conditions who were expected to die within 12 months. At the end of November of last year, the partnership released a report detailing the needs associated with primary palliative care and some of the measures required to meet them. The findings – based on a survey of 182 primary care professionals – were emphatic and unambiguous: two-thirds requested training in symptom control; almost 50% wanted training to care for imminently-dying patients in their own homes; and most respondents expressed a significant desire for more palliative care training generally. Gaps in service provision – such as flexible out-of-hours nursing, improved communication between primary, secondary and tertiary care, access to specialised equipment and the need for psychological support – were also placed in stark relief by the report. Other research has also borne out what palliative care professionals were already aware of – that 80% of people with end-stage disease want to die at home. <http://www.imt.ie/features-opinion/2012/03/right-time-right-place-right-care.html>

1. 'Primary Palliative Care in Ireland – Identifying Improvements in Primary Care to Support the Care of Those in Their Last Year of Life,' Irish College of General Practitioners, Irish Hospice Foundation, and Health Service Executive, November 2011 (noted in Media Watch dated 5 December 2012). <http://www.lenus.ie/hse/bitstream/10147/192381/1/Primary%20Palliative%20Care%20in%20Ireland.pdf>

Time to revise the approach to determining cardiopulmonary resuscitation status

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2012;207(9):917-918. In U.S. hospitals, cardiopulmonary resuscitation (CPR) is the *de facto* default option – patients must "opt out" by requesting or consenting to a do-not-attempt-resuscitation order. Despite its worthy intent, requiring all patients or their surrogates to consent to a do-not-attempt-resuscitation order to avoid CPR has resulted in an ethically unjustifiable practice that exposes many patients to substantial harms. Whenever there is a plausible risk of cardiac arrest, the standard approach is to ask patients or their surrogates about their preferences regarding CPR. However, the very act of asking can suggest to the patient and family that CPR may be beneficial, even when the clinician believes otherwise. Additionally, research in cognitive psychology has revealed that default options are often interpreted as recommendations or guidelines, or as the path of least resistance, and that such default options significantly affect decision making. <http://jama.ama-assn.org/content/307/9/917.extract>

A multifaceted approach to spreading palliative care consultation services in California public hospital systems

JOURNAL FOR HEALTHCARE QUALITY, 2012;34(2):77-85. Historically, California's 17 public hospital systems – those that are county owned and operated, and those University of California medical centers with the mandate to serve low income, vulnerable populations – have struggled to implement Palliative Care Consultation Services (PCCS) – this, despite demonstrated need for these services among the uninsured and Medicaid populations served by these facilities. This article describes the SPCPH's distinctive design, features of the public hospital PCCS, patient and team characteristics, and PCCS provider perceptions of environmental factors, and SPCPH features that promoted or impeded their success. <http://onlinelibrary.wiley.com/doi/10.1111/j.1945-1474.2011.00197.x/abstract;jsessionid=5B1D61D2941D8EA926E5105AAD1D153B.d04t04?userIsAuthenticated=false&deniedAccessCustomisedMessage=>

Assisted (or facilitated) death

Attitudes towards end of life issues among people with multiple sclerosis

JOURNAL OF NEUROLOGY, NEURO-SURGERY & PSYCHIATRY, 2012;83(3):e1. The authors sought to explore the attitudes towards end of life issues among people with MS [multiple sclerosis] ... and MND [motor neurone disease] ... via online surveys posted ... on the MS Society website and MND chat-sites. **Advance decisions:** 12% of people with MS [PwMS] and 75% of people with MND [PwMD] had written an advance decision; 51% PwMS wanted more information. **Mood:** 34% of PwMS and 51% of PwMND had considered suicide since their diagnosis; 64% of PwMS and 65% of PwMND would like the healthcare team to ask about their mood. **Assisted suicide and dying:** 77% of PwMS and 85% of PwMND believed in the right to choose how and when we die; 77% of PwMS and 71% of PwMND believed that assisted suicide should be legalised in their country; 31% of PwMS and 22% of PwMND had considered going abroad for assisted suicide. **Communication and the doctor-patient relationship:** 7% of PwMS and 43% of PwMND had discussed such issues with a doctor or nurse; 21% of PwMS and 53% of PwMND wished to do so; 51% of people with both PwMS and PwMND considered it not a problem if their clinician was involved in assisted suicide; a further 28% of PwMS and 21% of PwMND felt it would not affect the treatment of their condition. Results highlight a need for better patient education and openness about end of life options ... and a greater exploration of these issues on a wider scale. <http://jnnp.bmj.com/content/83/3/e1.78.abstr.act?sid=2d78f642-d629-4e9d-a43d-5561f4889829>

Prevalence of formal accusations of murder and euthanasia against physicians

JOURNAL OF PALLIATIVE MEDICINE | Online article – 8 March 2012 – Over half of the respondents [to an Internet-based survey] had had at least one experience in the last 5 years in which a patient's family, another physician, or another health care professional had characterized palliative treatments as being euthanasia, murder, or killing. One in four stated that at least one friend or family member, or a patient had similarly characterized their treatments. Respondents rated palliative sedation and stopping artificial hydration/nutrition as treatments most likely to be misconstrued as euthanasia. Overall, 25 physicians (4%) had been formally investigated for hastening a patient's death when that had not been their intention – 13 while using opiates for symptom relief and six for using medications while discontinuing mechanical ventilation. In eight (32%) cases, another member of the health care team had initiated the charges. At the time of the survey, none had been found guilty, but they reported experiencing substantial anger and worry. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0234>

Media Watch dated 20 May 2010:

- AVISO (Canadian Hospice Palliative Care Association) | Letter to the Editor – Spring 2010 – '**Informing discussion on end of life issues.**' Much emphasis is rightly placed by the palliative care community on the quality of life for those living with a terminal illness. Implicit is the concept of informed decision making. Many ethical issues, however, have muddied public discussion on euthanasia and assisted suicide. http://www.chpca.net/aviso/AVISO_62_EN.pdf

N.B. Scroll down to p.6 of AVISO and "Letter to the Editor."

[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>

Worth Repeating

Deathbed scenes as imagined by the young and experienced by the old

DEATH STUDIES | Online article – 14 August 2007 – This study compares the deathbed scenes anticipated by students enrolled in university death education courses with the actual deathbed scenes experienced by elderly people with terminal cancer. Most students expected to live into old age and then die a) at home, b) with the companionship of loved ones, c) quickly (usually in a day or less), and d) without pain or other symptoms, while e) remaining alert and lucid. Thoughts about an afterlife were seldom introduced. The students' concept of a deathbed scene worse than the expected usually involved the addition of pain or "lingering on." Respondents found it difficult to improve on their expected deathbed scene because, in effect, they had already substituted "desired" for "most likely to happen." Location of the deathbed scene in old age is consistent with the probable life expectancy of the respondents, but the easeful death (quick and asymptomatic) is at variance with observations made of terminally ill people. A major purpose of this study is to introduce the deathbed scene as a situation deserving clinical and conceptual attention, and to make available a set of primary coding categories useful in developing a basic data base.

<http://www.tandfonline.com/doi/abs/10.1080/07481189008252362?prevSearch=deathbed&searchHistoryKey=>

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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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