Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in ***hospice*** *and* ***palliative care****, and in the quality of* ***end-of-life care*** *in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.*

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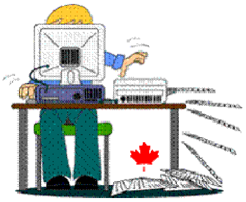


Compiled & Annotated by Barry R. Ashpole

Consumerism in health care: Scroll down to Specialist Publications and 'Terminally ill patients as customers: The patient's perspective' (p.15), in *Journal of Palliative Medicine*.

Canada

Living wills require very precise language

BRITISH COLUMBIA | *The Vancouver Sun* – 17 December 2013 – The Margaret Bentley court case, in which the family of an 82-year-old woman living in a vegetative state wants her request not to be fed honoured, illustrates the importance of being precise when writing a living will [*sic*]. Law professor Isabel Grant, who has seen Bentley's advance directive, said Bentley's document is written in fairly general language. She added making an advance directive too general was a common mistake for any written before 2011. That year the provincial government passed legislation setting out exactly what was required in such directives for them to be legal.[1] Bentley wrote her living will in 1991. "If an advance directive says 'if I don't recognize my children let me die' that wouldn't be enough. It would need to be more specific. It's important to have precise language." http://www.vancouversun.com/business/fp/yourmoney/Living+wills+require+very+precise+language/9298197/story.html

1. 'Health Care (Consent) & Care Facility (Admission) Act,' September 2011. http://www.bclaws.ca/Recon/document/ID/freeside/00_96181_01

Noted in Media Watch, 12 August 2013, #318 (p.1):

- BRITISH COLUMBIA | *The Vancouver Sun* – 6 August 2013 – **'Patient's family sues B.C. as nursing home keeps her alive against her wishes.'** The lawsuit is expected to be precedent-setting as it should clarify end-of-life rights of patients and obligations of health providers. http://www.vancouversun.com/health/Patient+family+sues+Victoria+over+living+will/8756167/story.html

Quotable Quotes

Do more than belong: participate. Do more than care: help. Do more than believe: practice. Do more than be fair: be kind. Do more than forgive: forget. Do more than dream: work. **William Arthur Ward (1921-1994)**

Canadian doctors developing guidelines on right way to withdraw life support

BRITISH COLUMBIA | *The Vancouver Sun* – 16 December 2013 – Canada's critical care doctors are confronting one of the most sensitive issues in end-of-life care: Once the agonizing decision has been made to remove someone from life support, what's the most appropriate way to do so? The first national guidelines are under development on the best way to withdraw life support in patients expected to die. The goal is to set standards for care, support grieving families, and minimize the patient's pain or distress while they're dying, but still alive. But while numerous guidelines exist around deciding when to stop life-sustaining treatments, there's little to guide doctors on the actual withdrawal of life support – including how to avoid doing anything that could be construed as hastening or speeding death. According to [James] Downar [a critical care and palliative care doctor at the Toronto General Hospital who is helping develop the guidelines with the Canadian Critical Care Society[1]] only a handful of Canadian intensive care units use a formal protocol when withdrawing life support. The vast majority of ICU deaths occur through the withdrawal of life support, in most cases, a ventilator or breathing machine. When ventilation is discontinued, the person's oxygen level falls while carbon dioxide rises. Eventually their heart will stop and they will die. Death often takes 30 or 40 minutes, but it could be almost immediate or many days later. http://www.vancouversun.com/health/Canadian+doctors+developing+guidelines+right+withdraw+life+support/9289190/story.html

1. Canadian Critical Care Society's current position paper on withholding or withdrawal of life support (2000): http://www.canadiancriticalcare.org/WLS_statement_jan2013.pdf

N.B. Canadian news media coverage and commentaries and OpEds in specialist publications in the fields of bioethics and medicine on the issue of withdrawal or withholding of life-sustaining treatment (notably regarding the Hassan Rasouli case) have been noted on a regular basis in Media Watch. Most recent: 21 October 2013, #328 (p.1); 22 July 2013, #315 (pp.2-3,7); 27 May 2013, #307 (p.1); and, 17 December 2012, #284 (p.10):

Why Quebec's shift in home care policy is important

QUEBEC | *The Globe & Mail* – 16 December 2013 – Just before the Quebec National Assembly adjourned for the holidays, Health Minister Réjean Hébert tabled Bill 67, the proposed "autonomy insurance" law. On the surface, the legislation would provide an additional $100-million a year for home care and home support services for seniors. Given Quebec already spends $4.3-billion annually on long-term care for seniors, the new monies are modest, not nearly enough to keep pace with burgeoning demand. But the move is important – and will be watched closely by other provinces – because, more than anything, it represents a philosophical shift. Hébert, a respected physician specializing in geriatric care before he made the jump to politics, has been outspoken about the need to slow the stampede of seniors into institutional care and instead provide support for them to continue living in the community. Spending on home care has risen tremendously in recent years. The investment has largely been to get people out of acute-care hospitals more quickly, principally post-surgery. There have not been serious or sustained efforts to offer home care and home support to people with chronic conditions, most of whom are frail seniors. http://www.theglobeandmail.com/life/health-and-fitness/health/why-quebecs-shift-in-home-care-policy-is-important/article15982867/?cmpid=rss1

Extract from *The Globe & Mail* article

Home care is the provision of medical care, by nurses, physicians and other health professionals; home support is the term used to describe ancillary services such as cooking, housecleaning, bathing, transporting and so on. What is rarely acknowledged is that, for people with chronic conditions, the support is just as important as the medical care.

U.S.A.

One final hurdle to a true prison hospice in Maryland

MARYLAND | *The Washington Post* (OpEd) – 20 December 2013 – On 17 [March 2013] I advocated for the creation of a program to allow inmates at Jessup Correctional Institution to provide end-of-life care to their dying peers.[1] Such a program would benefit both the patients, many of whom now face death scared and alone, and the caregivers, who would have a way to serve others at a time of profound need. The initial response to my piece was encouraging, and we have made significant progress to a true hospice program. Two days after my commentary appeared, Jessup Warden John Wolfe told me his superiors at the Maryland correctional department agreed on the need for a hospice. By week's end, Wolfe's administration had created a palliative-care group, made up of medical, mental health, faith and social work personnel at the prison. This panel was instructed to create a hospice program that could serve inmates throughout the state. In July, the prison psychologist asked me to get 10 volunteers from the Inmate Observation Aide (IOA) corps to act as hospice providers. IOA inmates are trained to watch suicidal prisoners to keep them from harming themselves. As the IOA clerk at Jessup, I got the volunteers, and we started our work. http://www.washingtonpost.com/opinions/the-final-hurdle-to-a-true-prison-hospice/2013/12/20/0938da7e-41a8-11e3-a751-f032898f2dbc_story.html

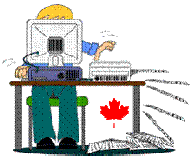
1. 'Why Maryland needs hospice behind bars,' *The Washington Post*, 17 March 2013. [Noted in Media Watch, 25 March 2013, #298 (p.4)]. http://www.washingtonpost.com/opinions/why-maryland-needs-hospice-behind-bars/2013/03/15/db5139e8-762e-11e2-95e4-6148e45d7adb_story.html?wprss=rss_localopinions

Of related interest:

- IOWA | ABC News – 18 December 2013 – **''Prison Terminal': Kidnappers care for murderers at end of life.'** Jack Hall, an 82-year-old former World War II prisoner of war who is serving a life sentence for murder, has spent nearly a decade in the infirmary at Iowa State Penitentiary with a terminal heart ailment. But now, struggling to breathe, he is in his final weeks. His unlikely comforters – kidnappers and murderers – are paid nothing for their hours of caregiving to a growing population of aging inmates. These volunteers do it willingly, knowing one day they, too, will be old and can look forward to a gentle end. "Prison is cold, but death is colder," says one hospice volunteer. Another says he benefits as much from the all-volunteer hospice program as those who are dying. "For me, I'm somebody no one thought I could be." This unique program is the subject of a compelling HBO documentary, 'Prison Terminal: The Last Days of Private Jack Hall,' which was shortlisted this fall in the short-subject category for an Academy Award. It is scheduled to air in March.[1] http://abcnews.go.com/Health/prison-terminal-kidnappers-care-murderers-end-life/story?id=21245481

    1. 'Prison Terminal: The Last Days of Private Jack Hall' trailer: http://vimeo.com/72732605

N.B. Articles and reports focused on the provision and delivery of end-of-life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.18.



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://www.ipcrc.net/barry-r-ashpole.php

Hospice to provide "virtually all" care

THE NATIONAL LAW REVIEW | Online – 19 December 2013 – A hospice patient waives the right to receive other Medicare benefits "related" to the[ir] terminal illness. In turn, the hospice must provide any care necessary for "pain or symptom relief." Focusing upon this waiver/assumption of liability, CMS [Centers for Medicare & Medicare Services] is now redefining the scope of a hospice's duty, requiring hospices to pay for "virtually all" prescription drugs and other care given to hospice patients. In early 2013, CMS revisited hospice reporting requirements on billing. CMS issued a reminder of the requirement that a hospice must code for all co-morbidities and also announced the phase-out of failure to thrive and debility as primary diagnoses. Both instructions ensure that a hospice's responsibility for any admitted patient will be broad, the first by broad listing of any co-morbidities, the second by requiring more concrete primary terminal diagnoses. http://www.natlawreview.com/article/hospice-to-provide-virtually-all-care-first-drugsvaccinations

Specialist Publications

'Palliative care education in U.S. medical schools' (p.15), in *Medical Education.*

'The Lake Wobegon effect: Are all cancer patients above average?' (p.16), in *Milbank Quarterly.*

"But doctor, I want to live": The other side of the "dignified death" debate

FORBES | Online – 18 December 2013 – The emerging narrative about "do not resuscitate" (DNR) orders is that they are not utilized frequently enough. Doctors, it is said, are reluctant to have this discussion with patients, and patients are typically unlikely to initiate such a conversation with their physician. As a result, there are dreadful stories of dying patients who suffer excruciating, highly-medicalized deaths rather than one with the dignity the sufferers might have preferred. Such deaths, policy experts note, would also seem to constitute a regrettable waste of healthcare resources. http://www.forbes.com/sites/davidshaywitz/2013/12/18/but-doctor-i-want-to-live-the-other-side-of-the-dignified-death-debate/

Of related interest:

- GEORGIA | *The Atlanta Journal-Constitution* – 19 December 2013 – **'7 in 10 will need end-of-life care, ready or not.'** The ... Commission on Long-Term Care ... issued 28 recommendations, but it couldn't reach consensus about how to pay for services.[1] It's a tough and expensive problem, but it's something the country can't ignore: most families will eventually face a difficult kitchen table conversation about how to take care of the most important people in their lives. http://www.southcoasttoday.com/apps/pbcs.dll/article?AID=/20131219/LIFE/312190329

1. 'Commission on Long-Term Care,' Report to Congress, September 2013. [Noted in Media Watch, 25 November 2013, #333 (pp.2-3) http://www.ltccommission.senate.gov/Commission%20on%20Long-Term%20Care-%20Final%20Report%209-26-13.pdf

City programs pitch African Americans on the benefits of hospice care

MARYLAND | *The Sun* (Baltimore) – 18 December 2013 – Although hospice care has dramatically increased in popularity over the past few decades, of the 1.6 million Americans who used such services last year, about 82% were Caucasian and fewer than 9% African-American. And in Maryland, predominantly white localities finish near the top in terms of hospice use. Now local health officials are trying to do get more African-Americans interested in hospice care ... http://articles.baltimoresun.com/2013-12-18/health/bs-md-african-americans-and-hospice-20131218_1_hospice-care-end-of-life-care-patient

Cont.

Noted in Media Watch, 7 October 2013, #326 (p.6-7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 October 2013 – **'Barriers to end-of-life care for African Americans from the providers' perspective: Opportunity for intervention development.'** African Americans are less likely to complete advance directives and enroll in hospice. Barriers included: lack of knowledge about prognosis, desires for aggressive treatment, family members resistance to accepting hospice, and lack of insurance. http://ajh.sagepub.com/content/early/2013/10/03/1049909113507127.abstract

  N.B. Noted in this issue of Media Watch are additional articles on African Americans' attitudes towards hospice.

Looming demographic shift could spell disaster for area elderly

NEW YORK STATE | American Association for Retired Persons (AARP) – 17 December 2013 – New York State is already at the bottom of the barrel in providing needed supports for 4.1 million unpaid caregivers and AARP warned a looming demographic shift leaving fewer people able to provide that care – valued at $32 billion annually – could spell disaster. The Association joined with fellow advocates at the Salvation Army in Syracuse to call for change, releasing a blueprint for the state to fix New York's caregiver problems and prevent the crisis from becoming a disaster.[1] The Empire State ranks 48th in providing support to the over 4 million unpaid caregivers who deliver an estimated $32 billion per year in care to loved ones, oftentimes older relatives. If that wasn't bad enough, a recent AARP analysis finds the caregiving bubble in New York is about to burst, meaning there will be fewer family members to provide care for older relatives. In 2010 there was a potential pool of 6.6 people aged 45-65 for every person 80 and older who would likely need care at some point. By 2030, the number of potential caregivers in the state will shrink to 4.8 for each person over 80, and in 2050, there will be just 3.5 people to provide the care, according to the analysis. http://states.aarp.org/category/new-york/

1. 'Caregivers in Crisis: New York Must Act,' American Association for Retired Persons, November 2013. http://states.aarp.org/wp-content/uploads/2013/11/Caregivers-in-Crisis-FINAL.pdf

Doctor's view of hospice influences talks with patients, study finds

US TODAY & WORLD REPORT | Online – 16 December 2013 – Doctors who would choose hospice care for themselves if they were dying from cancer are more likely to discuss such care with patients in that situation.[1] While the majority of doctors in the study said they would seek hospice care if they were dying from cancer, less than one-third of those said they would discuss hospice care with terminally ill cancer patients at an early stage of care. Researchers surveyed nearly 4,400 doctors who care for cancer patients... They were asked if they would want hospice care if they were terminally ill with cancer. They were also asked when they would discuss hospice care with a patient with terminal cancer who had four to six months to live, but had no symptoms... In terms of seeking hospice care themselves, 65% of doctors were strongly in favor and 21% were somewhat in favor. Those who were female, who cared for more terminally ill patients or who worked in managed care settings were more likely to favor hospice care for themselves. http://health.usnews.com/health-news/news/articles/2013/12/16/doctors-view-of-hospice-influences-talks-with-patients-study-finds

1. 'Physicians' preferences for hospice if they were terminally ill and the timing of hospice discussions with their patients,' *JAMA Internal Medicine*, 16 December 2013. http://archinte.jamanetwork.com/article.aspx?articleid=1787691

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.17.

International

China austerity campaign extends beyond the grave

CHINA REAL TIME | Online – 20 December 2013 – Not even death can save party cadres from China's latest austerity campaign. China's State Council ... issued a notice asking Communist Party members to dial back on the extravagance at funerals and make them more environmentally sustainable. The official Xinhua news agency warned that party members' lavish funerals are becoming "a platform to show off wealth and connections, with the degree of opulence and number of mourners symbolizing the 'achievements' of the dead, and setting a benchmark for competition among the living." It also warned that in recent years as superstitious customs have seen a resurgence, the cremation rate has fallen, leading to some burials occurring on farmland – wasting natural resources and harming the environment. Some party members are even using funerals to collect large sums of money, it added. http://blogs.wsj.com/chinarealtime/2013/12/20/china-austerity-campaign-extends-beyond-the-grave/

Specialist Publications

'Use of formal advance care planning documents: A national survey of U.K. paediatric intensive care units' (p.9), in *Archives of Disease in Childhood.*

'Lawfully withdrawing life-sustaining treatment' (p.11), in *British Journal of Community Nursing.*

'Towards realistic and flexible advance care planning' (p.13), in *Irish Medical Journal.*

Palliative care in Portugal is "clearly insufficient," says nurse championing change

PORTUGAL | *The Portugal News* (Lagoa) – 19 December 2013 – A Portuguese nurse who has set up an association to promote palliative care in the Algarve [the southernmost region of mainland Portugal] has told *The Portugal News* that government resources currently available to patients are "clearly insufficient" and that society must unite to fill the voids being left by waning health and support services. Maria José Pachaco has worked in primary health care since 1999. In 2006, the opportunity came along for her to help create the Algarve's first state-funded palliative care team which was eventually launched in the Eastern Algarve (Sotovento) in December 2007 and covered Tavira, Vila Real de Santo António, Alcoutim and Castro Marim. Despite one or two privately-run end-of-life and home-care associations having emerged in recent years, to this day – seven years later – the pioneering team in the Sotovento is still the only state-operated one in the Algarve and still only works in that area. Also, due to its limited human resources – it comprises two full-time nurses, three part-time doctors and a part-time social assistant – it cannot provide a 24-hour service. The only other government option available specifically for palliative care patients from all over the Algarve is a ten-bed ward at the Barlavento Hospital in Portimão. http://www.theportugalnews.com/news/palliative-care-in-portugal-is-clearly-insufficient-says-nurse-championing-change/30198

Noted in Media Watch, 24 December 2012, #285 (P.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 December 2012 – **'A cross-sectional survey of the activity of palliative care teams in Portugal.'** Of the 21 teams identified, 10 accepted to participate in the study. A total of 164 patients were included with a median of 15.5 per team: 60 (37%) were identified as inpatients in palliative care units; 59 (36%) by an intra-hospital support team; 26 (16%) as outpatients; and 19 (12%) at home. http://ajh.sagepub.com/content/early/2012/12/20/1049909112469718.abstract

N.B. Portugal was rated 31st (of the 40 countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

"It is ironic that we get free National Health Service care but few get a free home care service"

U.K. (ENGLAND) | *Home Care* – 18 December 2013 – A report from the Health & Social Care Information Centre has revealed that 10% fewer adults are receiving free home care compared to a year ago, showing the impact of budget cuts by local authorities.[1] Age U.K. claims that as local authorities continue to restrict eligibility for the people with highest needs "the situation looks bleaker than ever." http://www.homecare.co.uk/news/article.cfm/id/1561946/it_is_ironic_that_we

1. 'Community Care Statistics, Social Services Activity, England – 2012-2013: Final Release,' Adult Social Statistics Team, Health & Social Care Information Centre, 17 December 2013. https://catalogue.ic.nhs.uk/publications/social-care/activity/comm-care-stats-soc-serv-acti-12-13-fin/comm-care-stat-act-eng-2012-13-fin-rep.pdf

End-of-life care in Africa

Cancer patients suffer from poor access to palliative care

GHANA | *The Financial Times* (U.K.) – 17 December 2013 – Given the limited number of hospital beds, there is a push for children with cancer to return either to local clinics or to their families. But a shortage of drugs and expertise could mean they face a double tragedy: not only do they have no chance of a cure but they will also die in pain. Poor access to palliative care is not unique to Ghana or indeed the developing world. Across the globe, the medical establishment remains nervous about the prescription of powerful drugs to alleviate pain. But Dr. Lorna Renner's patients are disadvantaged by the disease, their young age and their location. World Child Cancer (WCC) ... works with children with cancer in the developing world, where survival rates are much lower than in the west. As part of its work, the WCC tries to help children get the drugs they need and with this aim in mind has worked to encourage training, access and improved education. In Ghana, Dr. Renner and her team – which have run training programmes on drugs for medical staff – are at the forefront of their efforts. http://www.ft.com/intl/cms/s/2/f0fdcbd6-617d-11e3-b7f1-00144feabdc0.html#axzz2nqEl6R2k

Noted in Media Watch, 2 December 2013, #334 (p.9)

- *ANNALS OF ONCOLOGY*, 2013;24(suppl11):xi7-xi13. **'The Global Opioid Policy Initiative project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East: Introduction and methodology.'** This project has been undertaken in collaboration with the Union for International Cancer Control, the Pain and Policy Studies Group of the University of Wisconsin, and the WHO, together with a consortium of 17 international oncology and palliative care societies. http://annonc.oxfordjournals.org/content/24/suppl_11/xi7.abstract

Liverpool Care Pathway ban was "scapegoat" warns consultant

U.K. (ENGLAND & WALES) | *The Daily Telegraph* (London) – 17 December 2013 – The demise of The Liverpool Care Pathway [LCP] is a "tragedy" and is equivalent to banning the Highway Code because of bad drivers, a consultant in palliative care has warned.[1] Claud Regnard, a consultant at St Oswald's Hospice in Newcastle, said the guidelines had been made "scapegoat" for sloppy care given by physicians. And he said the failure to implement an alternative would leave bad doctors able to: "continue their poor practice without fear of being discovered for years." The LCP was designed to provide dignity for those dying with terminal illnesses. But ministers announced this summer that the LCP would be phased out after an independent review uncovered evidence of abuse, including patients being unnecessarily sedated and denied food and water.[2] http://www.telegraph.co.uk/health/healthnews/10520567/Liverpool-Care-Pathway-ban-was-scapegoat-warns-consultant.html

Cont.

1. 'The demise of The Liverpool Care Pathway: Should we ban the highway code because of bad drivers?' *AGE & AGEING*, 16 December 2013. The Neuberger report failed to show The Liverpool Care Pathway was the cause of poor end-of-life care and made it the scapegoat for poor communication and faulty decision-making. Two consequences of the report: an excellent review of care pathways and a recommendation to establish a national end-of-life coalition... http://ageing.oxfordjournals.org/content/early/2013/12/08/ageing.aft195.abstract

2. *Independent Report: Review of Liverpool Care Pathway for dying patients* [in England), Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients

Noted in Media Watch, 9 December 2013, #335 (p.4):

- U.K. (ENGLAND & WALES) | *The Daily Telegraph* (London) – 1 December 2013 – **'Liverpool Care Pathway being "rebranded" not axed.'** Doctors who led criticism of the pathway say new draft guidance, seen by *The Daily Telegraph*, outlining a replacement scheme will perpetuate many of its worst practices, allowing patients to suffer days of dehydration, or to be sedated, leaving them unable to even ask for food or drink. Professor Patrick Pullicino, a consultant neurologist ... said the new plan "lacks essential key components of the Neuberger report and perpetuates errors that were central to the dysfunction of the pathway." http://www.telegraph.co.uk/health/healthnews/10487109/Liverpool-Care-Pathway-being-rebranded-not-axed.html

Of related interest:

- U.K. (SCOTLAND) | BBC News – 20 December 2013 – **'Liverpool Care Pathway to be phased out in Scotland.'** A controversial system of caring for dying patients is to be phased out in Scotland. The Scottish government said new guidelines would be given to health boards next year. Interim guidance has been issued in the meantime, which the government said placed a strong emphasis on "good, consistent communications by medical professionals with families and loved ones of patients."[1] http://www.bbc.co.uk/news/uk-scotland-25464265

    1. 'Interim Guidance: Caring for people in the last days and hours of life,' National Health Service Scotland, December 2013. http://www.scotland.gov.uk/Resource/0044/00441053.pdf

    Noted in Media Watch, 15 July 2013, #314 (p.3):

    - U.K. (SCOTLAND) | *The Scotsman* (Edinburgh) – 14 July 2013 – **'Review for end-of-life regime in Scotland.'** Scottish ministers are to consider the future of a controversial end-of-life regime north of the Border. The move came after it emerged yesterday that a review of the regime in England was expected to recommend it should be phased out. http://www.scotsman.com/news/health/review-for-end-of-life-regime-in-scotland-1-3001009

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | *The Irish Times* (Dublin) – 21 December 2013 - **'Marie Fleming dies after long battle with multiple sclerosis.'** Marie Fleming, who lost a landmark Supreme Court challenge for the right to an assisted suicide ... died peacefully at home after her condition deteriorated. http://www.irishtimes.com/news/ireland/irish-news/marie-fleming-dies-after-long-battle-with-multiple-sclerosis-1.1635129

    Noted in Media Watch, 6 May 2013, #304 (p.6):

    - IRELAND | *The Independent* (Dublin) – 29 April 2013 – **'Marie Fleming loses Supreme Court right-to-die case.'** A full, seven-judge Supreme Court gave its ruling in a "right to die" action brought by Ms. Fleming, who wants to be helped to end her life at a time of her choosing. http://www.independent.ie/irish-news/courts/marie-fleming-loses-supreme-court-righttodie-case-29228686.html

Cont.

- FRANCE | Radio France Internationale – 17 December 2013 – **'French citizens' panel backs medically assisted suicide.'** A citizens' panel has recommended that France legalise medically assisted suicide, one of President François Hollande's campaign promises in 2012, but opposed euthanasia. Medically-assisted suicide, when a doctor provides enough lethal substances to a patient who uses them to end his or her life, has caused lively debate in France, as in many other countries. The panel, called the "Conference of Citizens," was made up of 18 citizens picked by a polling company to represent the French population. It concluded that medically assisted suicide it is "a legitimate right" that should be given to people who are close to death or suffering from a terminal illness. http://www.english.rfi.fr/france/20131217-french-citizens-panel-backs-medically-assisted-suicide

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

Use of formal advance care planning documents: A national survey of U.K. paediatric intensive care units

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 12 December 2013 – This survey aimed to identify and compare paediatric ACP [advance care planning] documents that are in use within U.K. hospitals with a PICU [paediatric intensive care unit]. Twentyfour (86%) questionnaires were returned [in a survey of lead clinicians in the U.K.]; 14 (58%) responded that formal ACP documents were currently in use within their hospital trust. Of the remainder, 2 (8%) detailed plans to launch local ACP documents in the near future, 1 (4%) had a 'Children & Young Persons Deterioration Management Document,' and 3 (12%) listed rapid discharge and extubation pathways. Six (25%) provided details of the document in use. They varied widely in terms of their presentation, content and intended use with some having been developed locally and others having been adopted across regions. There is variation around the U.K. in the existence of formal ACP documents for paediatric patients with palliative care needs, as well as variation in the type of document that is used. http://adc.bmj.com/content/early/2013/12/12/archdischild-2013-304463.short

Extract from *Archives of Disease in Childhood* article

Consideration of a national policy [on paediatric advance care planning] should be informed by further review and evaluation of these documents, as well as current practice...

Noted in Media Watch, 7 January 2013, #287 (p.12):

- *PEDIATRIC CRITICAL CARE MEDICINE*, 2013;14(1):e34-e44. **'End-of-life care decisions in the PICU: Roles professionals play.'** The authors describe a framework for healthcare professionals' roles in parental end-of-life care decision making in the pediatric ICU that includes directive, value-neutral, and organizational roles. Actively ensuring attention to these roles during the decision-making process could improve parents' experiences at the end of a child's life. http://journals.lww.com/pccmjournal/Abstract/2013/01000/End_of_Life_Care_Decisions_in_the_PICU___Roles.35.aspx

Of related interest:

- *ASIAN NURSING RESEARCH* | Online – 12 December 2013 – **'Taiwanese parents' experience of making a "do not resuscitate" decision for their child in pediatric intensive care unit.'** Three major themes were identified [in this study]: a) "convincing points to sign"; b) "feelings immediately after signing"; and, c) "post signing relief or regret." Feelings following signing the DNR form were mixed and included "frustration," "guilt," and "conflicting hope." Parents adjusted their attitudes to thoughts such as "I have done my best," and "the child's life is beyond my control." Some parents whose child had died before the time of the interview expressed among other things "regret not having enough time to be with and talk to my child." http://www.sciencedirect.com/science/article/pii/S1976131713000674

A follow-up bereavement service: "Completing the patient pathway"

BEREAVEMENT CARE, 2013;32(3):104-110. The article describes an initiative, The Bereavement Care Follow up Service in Cambridge University Hospitals National Health Service Trust which offers brief intervention and support for relatives following the death of a loved one in hospital. The service includes sending a letter of condolence, and offering an opportunity to talk to a member of the team involved in the care of their relative. It presents its historical context, its pertinence to grief theory and practice and gives a description and evaluation of the service. The service provides an alternative, less problem-centred pathway to the standard route for those with problems relating to the hospital and gives relatives the opportunity to voice concerns, and to seek information and answers from those best equipped to meet them (experts in clinical and bereavement care). http://www.tandfonline.com/doi/abs/10.1080/02682621.2013.854541

Of related interest:

- *BEREAVEMENT CARE*, 2013;32(3):124-130. **'A missing link? The role of mortuary staff in hospital-based bereavement care services.'** The authors argue that anatomical pathology technologists have been overlooked as a key group of healthcare practitioners who play a role in bereavement care. http://www.tandfonline.com/doi/abs/10.1080/02682621.2013.854545
- *PSYCHO-ONCOLOGY* | Online – 18 December 2013 – **'They still grieve: A nationwide follow-up of young adults 2-9 years after losing a sibling to cancer.'** A majority (54%) of siblings [i.e., study participants] stated that they had worked through their grief either "not at all" or "to some extent" at the time of investigation. In multiple regression analyses with unresolved grief as the dependent variable, 21% of the variance was explained by lack of social support and shorter time since loss. http://onlinelibrary.wiley.com/doi/10.1002/pon.3463/abstract

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 and research tool.

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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.

Adult cardiopulmonary resuscitation: "Who" rather than "how"

BRITISH JOURNAL OF ANAESTHESIA | Online – 13 December 2013 – Cardiopulmonary resuscitation (CPR) can be a wonderful medical intervention. It can prevent premature death and save "hearts too good to die." However well intentioned, CPR can also prolong inevitable death, increase family duress, extend patient suffering, and squander scarce resources. Like other aspects of contemporary anaethesia and intensive care unit, CPR has a power to be both the best and worst of what we do. http://bja.oxfordjournals.org/content/early/2013/12/13/bja.aet438.extract

Noted in Media Watch, 16 September 2013, #323 (p.4):

- U.S. | *Forbes* – 9 September 2013 – **'Clear! CPR in the hospital is not always good for the patient.'** Most patients who undergo CPR are old, frail, and very sick. Many will die and many who survive CPR will die anyway before leaving the hospital. And many survivors will have severe neurological problems. Now a physician states ... that hospitals need to change the way they view CPR.[1] http://www.forbes.com/sites/larryhusten/2013/09/09/clear-cpr-in-the-hospital-is-not-always-good-for-the-patient/

1. 'Improving quality improvement for cardiopulmonary resuscitation,' *JAMA Internal Medicine*, 9 September 2013. http://archinte.jamanetwork.com/article.aspx?articleid=1735898

Lawfully withdrawing life-sustaining treatment

BRITISH JOURNAL OF COMMUNITY NURSING, 2013;18(12):616-619. The U.K. Supreme Court recently delivered its first judgement based on the application of the 2005 Mental Capacity Act. The plurality judgement given by Lady Hale clarified the law on medical futility and the circumstances under which a district nurse is lawfully able to withdraw life-sustaining treatment. It is essential that district nurses know when care and treatment becomes futile to ensure they are acting lawfully if a decision is taken to withdraw that care and treatment. This article considers the impact of the Supreme Court ruling on district nurse practice. http://www.internurse.com/cgi-bin/go.pl/library/article.cgi?uid=102289;article=BJCN_18_12_616_619;format=pdf

Noted in Media Watch, 4 November 2013, #330 (p.4):

- U.K. | BBC News – 31 October 2013 – **'David James death: Doctors "right" to withhold treatment.'** Judges were right to allow doctors to withhold treatment from a "gravely ill" guitarist, the Supreme Court has ruled. David James, 68, of Liverpool, died in 2012, days after doctors successfully argued in court that stopping treatment was in his best interests. In upholding the ruling, Supreme Court judge Lady Hale said the Court of Appeal had "reached the right result but for the wrong reasons." http://www.bbc.co.uk/news/uk-england-merseyside-24741844

Feasibility and economic impact of dedicated hospice inpatient units for terminally ill ICU patients

CRITICAL CARE MEDICINE | Online – 17 December 2013 – End-of-life care is frequently provided in the ICU because patients receiving life-sustaining treatments are often unsuitable for transfer to home or community hospices. This study was designed to: 1) demonstrate the feasibility of ICU to dedicated hospice inpatient unit transfer in critically ill terminal patients; 2) describe the clinical characteristics of those transferred and compare them to similar patients who were not transferred; and, 3) assess [their] operational and economic impact. They are potentially significant sources of bed days and cost savings for hospitals and the healthcare system overall. Barriers include lack of knowledge of the units and provider or family comfort with leaving the ICU. http://journals.lww.com/ccmjournal/Abstract/publishahead/Feasibility_and_Economic_Impact_of_Dedicated.97634.aspx

Ethics and end-of-life care for critically ill patients in China

CRITICAL CARE, 2013;17(6):244. Critical care medicine in China has made great advances in recent decades. This has led to an unavoidable issue: end-of-life ethics. With advances in medical technology and therapeutics allowing the seemingly limitless maintenance of life, the exact time of death of an individual patient is often determined by the decision to limit life support. How to care for patients at the end of life is not only a medical problem but also a social, ethical, and legal issue. A lot of factors, besides culture, come into play in determining a person's ethical attitudes or behaviors, such as experience, education, religion, individual attributes, and economic considerations. Chinese doctors face ethical problems similar to those of their Western counterparts; however, since Chinese society is different from that of Western countries in cultural traditions, customs, religious beliefs, and ethnic backgrounds, there is a great difference between China and the Western world in regard to ethics at the end of life, and there is also a huge controversy within China. http://ccforum.com/content/17/6/244/abstract

Noted in Media Watch, 4 June 2012, #256 (p.14):

- *PSYCHO-ONCOLOGY* | Online – 27 May 2012 – **'Breaking bad news in China – the dilemma of patients' autonomy and traditional norms. A first communication skills training for Chinese oncologists and caretakers.'** Current practice of breaking bad news in China involves disclosure of information first to family members who then decide whether the patient should receive this information. Recently, however, patients' right to be informed has been regulated by law ... a dilemma for oncologists who now have to balance traditional practice with new legal requirements. http://onlinelibrary.wiley.com/doi/10.1002/pon.3112/abstract

Seeking a better way to die with and from dementia

GENERATIONS (American Society on Aging), 2013;37(3):70-73 . A large and growing number of people die with and from dementia, but their care at the end of life is often sub-optimal. This article recommends a palliative approach to the care of people with dementia and their families to counter the negative outcomes associated with aggressive medicine and to improve the experience of dying for all concerned. http://generations.metapress.com/content/b10w739pl205318v/

N.B. This issue of *Generations* focuses on patient-centred care for people living with dementia. Journal contents page: http://generations.metapress.com/content/u6t5t7q882w7/

Noted in Media Watch, 9 December 2013, #335 (p.9):

- *END OF LIFE JOURNAL*, 2013;3(4). **'Palliative care and advanced dementia: The Croydon Project.'** The traditional model of specialist palliative care, with its high level of symptom support input in the last weeks/months of life, is not appropriate for people with dementia as the condition is associated with a longer, dwindling trajectory towards death, associated with progressive decline in physical and cognitive functioning. There is also a fear in some quarters that if people with dementia have access to specialist palliative care, services such as hospices will become inundated with referrals. http://endoflifejournal.stchristophers.org.uk/clinical-practice-development/palliative-care-and-advanced-dementia-the-croydon-project

Noted in Media Watch, 8 July 2013, #313 (p.10):

- *PALLIATIVE MEDICINE* | Online – 4 July 2013 – **'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care.'** The authors provide the first definition of palliative care in dementia ... [and] ... a framework to provide guidance for clinical practice, policy and research. Sixtyfour experts from 23 countries evaluated a set of 11 domains and 57 recommendations. http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract

Cont.

Of related interest:

- *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 6 December 2013 – **'Exploring resource use and associated costs in end-of-life care for older people with dementia in residential care homes.'** The goals of this study are to describe end-of-life care costs of older people with dementia (OPWD) residents in care homes (CHs) with no on-site nursing and evaluate the economic case for an intervention designed to improve end-of-life care for OPWD in CHs. Results represent early work in an under-researched area of care. http://onlinelibrary.wiley.com/doi/10.1002/gps.4061/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false

Towards realistic and flexible advance care planning

IRISH MEDICAL JOURNAL, 2013;106(10). The suffering of the many Irish people who bought houses at the height of the economic boom with variable mortgages is a topical and telling demonstration of the difficulties of planning for the future. What seemed like a good idea in 2006 has become a millstone around many necks, putting huge strains on marriages and family life, and is deservedly a topic of national debate. Signing into a binding written commitment for their financial future has been a bitter experience for this large group of people: how much more painful might it be if they had signed into unhappy binding agreements about their future healthcare? The illusion that the future healthcare can be tightly defined is typified by the case for advance directives, an idea for which enthusiasm has unhappily out-stripped an increasingly critical biomedical literature. This ranges from their description by the majority of ICU staff in one U.S. study as "useless" to clear problems which arise when advance directives are patently in conflict with the patient's best interests. http://www.imj.ie//ViewArticleDetails.aspx?ArticleID=13066

Extract from *Irish Medical Journal* article

The illusion that the future healthcare can be tightly defined is typified by the case for advance directives, an idea for which enthusiasm has unhappily out-stripped an increasingly critical biomedical literature.

Of related interest:

- *ASIAN BIOETHICS REVIEW*, 2013;5(4):363-369. **'Advance care planning in Pakistan: Unexplored frontiers.'** Although the idea of advance care planning [ACP] has developed in the western culture, it is equally significant and relevant to cultures such as ours, which emphasises family involvement in medical decision-making. The premise of advance directives may have been patient autonomy, but the process of ACP does not evolve in isolation. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/asian_bioethics_review/v005/5.4.khan.html

Next of kin's experiences of shame in end-of-life care

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 9 December 2013 – The aim of this study was to gain a greater understanding of the experiences of shame of next of kin in end-of-life care. Seventeen next of kin who had lost a family member were interviewed. The results showed that next of kin's experiences of shame are linked to their perception of the remaining time and are guided by views on morality and what is right and wrong. Shame can occur when the next of kin are involved and actually cause harm to the family member as well as in situations that are beyond their control. Shame can also involve actions that have nothing to do with what they have actually done but is instead a shame that is placed on them by others, for example, health professionals or relatives. Shame is interpreted as experiences of ignominy, humiliation, and disgrace. Second-order shame is also found. It is important that health professionals are aware of these experiences of unhealthy shame when they meet and support next of kin in end-of-life care. http://www.diva-portal.org/smash/record.jsf?pid=diva2:676741

Cont.

Noted in Media Watch, 7 May 2012, #252 (p.12):

- *SCANDINAVIAN JOURNAL OF CARING SCIENCES*, 2012;26(4):787-795. **'Guilt and shame – a semantic concept analysis of two concepts related to palliative care.'** The theoretical viewpoint of the study was based on the fundamental motive in caring science, the suffering person and his/her health and life situation, which according to the philosophy of palliative care also includes the next of kin. The latter often wish to participate in the care of their loved ones and it is thus important for them to be able to make decisions that can generate a meaningful participation. http://onlinelibrary.wiley.com/doi/10.1111/j.1471-6712.2012.00992.x/pdf

Of related interest:

- *HEALTH COMMUNICATION* | Online – 17 December 2013 – **'Understanding social support burden among family caregivers.'** Caregivers [i.e., study participants] providing hospice care experience social support burden resulting from perceived relational barriers between friends and family, the inclination to remain in control, recognition of the loss of the patient as a source of social support and guidance in decision making, family dynamics, and decreased availability of emotional support. http://www.tandfonline.com/doi/abs/10.1080/10410236.2013.815111

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 December 2013 – **'Exploring the collective hospice caregiving experience.'** Caregiver pairs [i.e., study participants] had higher anxiety and depression scores than solo caregivers. Emotional, financial, and physical quality of life were associated with decreased depression, whereas only emotional and financial quality of life were correlated with lower levels of anxiety. Social support was associated with lower levels of depression and anxiety. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0289

"Yes it's sad, but what should I do?": Moving from empathy to action in discussing goals of care

JOURNAL OF PALLIATIVE MEDICINE | Online – 17 December 2013 – The communication skills of noticing emotional cues and responding empathically are necessary but insufficient for some conversations about redefining goals of care. For some patients, an empathic response by a clinician is insufficient to move the conversation forward. We describe an expert approach that links empathy to action. In this approach, the authors outline: 1) how affect provides a spotlight that illuminates what is important; 2) how empathy affords a way to connect with patients and families that engages deep values; 3) how clinicians can infer deep values through an associative process with patients; and, 4) how clinicians can then design actions with patients and families and nurture their commitment to the actions. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0197

Noted in Media Watch, 30 September 2013, #325 (p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 September 2013 – **'"Isn't there anything more you can do?" When empathic statements work, and when they don't.'** The query, "Isn't there anything more you can do?" represents a classic informational question with an emotional subtext. In the authors previous work they have emphasized the value of noticing the emotional cue implicit in this question, and responding with an empathic statement. Yet responding explicitly to patients' emotions is not the best initial communication strategy for all patients. In this paper they discuss four different opening communication strategies – verbalize empathy, exchange information, contain chaos, respect searching – for patients who ask, "Isn't there anything more you can do?" http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0193

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-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, exchange of ideas, information and materials. http://www.pcn-e.com/community/pg/file/owner/MediaWatch

Terminally ill patients as customers: The patient's perspective

JOURNAL OF PALLIATIVE MEDICINE | Online – 17 December 2013 – Consumerism in health care defines patients as self-determined, rational customers. Yet, it is questionable whether vulnerable patients, such as the terminally ill, also fulfill these criteria. Vulnerable contexts and the patient's perspective on being a customer remain relatively unexplored. This study addresses this research gap by analyzing terminally ill patients' views on being customers. In many ways, palliative patients [i.e., study participants] contradict the image of a self-determined customer. The palliative patient role is characterized by the concept of relational self-determination rather than an unrestricted self-determination. Self-attribution as a customer still occurs when positively associated with a person-centered, individualized treatment. Thus, the customer and patient role overlap within the palliative care setting because of the focus on the individual. The idealized customer role cannot be arbitrarily applied to all medical fields. Palliative patients are dependent on the physician, regardless of whether the customer or patient role is preferred. Hence, self-determination must be understood in relational terms, and physicians must recognize their crucial role in promoting patients' self-determination in the context of shared decision-making. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0141

From the archives:

- *BRITISH JOURNAL OF SOCIAL WORK*, 2009;39(6):1101-1117. **"Consumer," "expert by experience," "service user" – what's next?'** This article challenges the terms we use to describe the relationship between those who assess and commission services and those who are the recipient of those services http://bjsw.oxfordjournals.org/content/39/6/1101.short
- *HEALTH EXPECTATIONS*, 2005;8(4):345-351. **'Patient, consumer, client, or customer: What do people want to be called?'** Many alternatives to "patient" incorporate assumptions, which care recipients may find objectionable. http://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2005.00352.x/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false

Palliative care education in U.S. medical schools

MEDICAL EDUCATION, 2014;48(1):59-66. Medical educators in the U.S. perceive the teaching of palliative care competencies as important, medical students experience it as valuable and effective, and demographic and societal forces fuel its necessity. Although it is encouraged by the Association of American Medical Colleges, the only palliative care-related mandate in U.S. medical schools is the Liaison Committee on Medical Education directive that end-of-life (EoL) care be included in medical school curricula, reinforcing the problematic conflation of EoL and palliative care. A review of U.S. medical school surveys ... reveals varied and uneven approaches – from 2 hours in the classroom on EoL to weeks of palliative care training or hospice-based clinical rotations. Palliative care competencies are too complex and universally important to be relegated to a minimum of classroom time, random clinical exposures, and the hidden curriculum. Given the reality of overstrained medical school curricula, developmentally appropriate, basic palliative care competencies should be defined and integrated into each year of the medical school curriculum, taking care to circumvent the twin threats of curricular overload and educational abandonment. http://onlinelibrary.wiley.com/doi/10.1111/medu.12292/abstract;jsessionid=2FBCD9A6EFEAB3DC99DF08C1D05F1770.f04t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false

The role of palliative care in medical education

ANNALS OF INTERNAL MEDICINE, 2013; 159(12):848-849-849. This commentary discusses palliative care and argues that it teaches good medical practice and the art of medicine and should be an essential and longitudinal component of medical education and training. http://annals.org/article.aspx?articleid=1789252

Cont.

Noted in Media Watch, 9 December 2013, #335 (p.11):

- *JOURNAL OF PALLIATIVE CARE & MEDICINE* | Online – Accessed 5 December 2013 – **'Learning and teaching palliative care: Can we do better?'** Twenty years ago, James and MacLeod identified a number of aspects of palliative care education that were problematic.[1] http://www.omicsgroup.org/journals/Learning-and-Teaching-Palliative-Care-Can-We-Do-Better-2165-7386.1000e124.pdf

    1. 'The problematic nature of education in palliative care,' *Journal of Palliative Care*, 1993;9(4):5-10. There are many aspects of palliative care that are problematic: a) lack of a long tradition and adequate conceptualization of palliative care; b) significance of psychological, emotional, and spiritual aspects; c) importance of but inadequate understanding of symptom control; d) fact that palliative care is not curative in the accepted sense; e) its multi-professional nature; f) range of different settings of palliative care; and, g) palliative caregivers have to perform their duties in situations where the emotional and psychological demands on them may be immense. General issues relevant to palliative care education are reviewed. http://www.ncbi.nlm.nih.gov/pubmed/7510805

Noted in Media Watch, 16 July 2012, #262 (p.10):

- *HEALTH LEADERS* | Online – 13 July 2012 – **'Palliative care challenged by physician shortage.'** Medical schools have increased their emphasis on palliative care education, but there is a shortage of palliative care physicians. While there is about one cardiologist for every 71 people experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative care physician for every 1,200 people living with a serious or life-threatening illness, according to the Center to Advance Palliative Care.[1] http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage

    1. 'Estimate of current hospice and palliative medicine physician workforce shortage,' *Journal of Pain & Symptom Management*, 2012;40(6):899-911 [Noted in Media Watch, 13 December 2010, #179 (p.9)] http://www.jpsmjournal.com/article/S0885-3924(10)00602-0/abstract

The Lake Wobegon effect: Are all cancer patients above average?

MILBANK QUARTERLY, 2013;91(4):690-728. When elderly patients face a terminal illness such as lung cancer, most are unaware that what we term in this article "the Lake Wobegon effect" taints the treatment advice imparted to them by their oncologists.[1] In framing treatment plans, cancer specialists tend to intimate that elderly patients are like the children living in Garrison Keillor's mythical Lake Wobegon: Above average and thus likely to exceed expectations. In this article, the authors use the story of their mother's death from lung cancer to investigate the consequences of elderly people's inability to reconcile the grave reality of their illness with the overly optimistic predictions of their physicians. They recognize that a desire to instill hope in patients shapes physicians' messages. The authors argue, however, that the automatic optimism conveyed to elderly, dying patients by cancer specialists prompts those patients to choose treatment that is ineffective and debilitating. Rather than primarily prolong life, treatments most notably diminish patients' quality of life, weaken the ability of patients and their families to prepare for their deaths, and contribute significantly to the unsustainable costs of the U.S. health care system. http://onlinelibrary.wiley.com/doi/10.1111/1468-0009.12030/full

Extract from *Milbank Quarterly* article

The case described in this article suggests how physicians can better help elderly, terminally ill patients make medical decisions that are less damaging to them and less costly to the health care system.

N.B. Lake Wobegon is the mythical town in Minnesota popularized by Garrison Keillor in his American Public Radio program 'A Prairie Home Companion.'

Cont.

Of related interest:

- *JAMA INTERNAL MEDICINE* | Online – 16 December 2013 – **'The elephant in the room – your patient is dying: A teachable moment.'** Effective discussions with patients facing terminal illness that address the true underlying prognosis, or the so-called elephant in the room, must be initiated early and should involve members of the palliative care team. http://archinte.jamanetwork.com/article.aspx?articleid=1787694

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2013/12/media-watch/

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://www.ipcrc.net/archive-global-palliative-care-news.php

PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

PALLIMED (Hospice & Palliative Medicine Blog): http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/updates/international-palliative-care-resource-center-media-watch/

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: http://palliativecarewa.asn.au/site/helpful-resources/ [Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Canada

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

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.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/ [Scroll down to 'Additional Resources']

ONTARIO | Toronto Central Hospice Palliative Care Network: http://www.tcpcn.ca/news-events [Scroll down to 'Media Watch']

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://www.eapcnet.eu/Themes/Organization/Links.aspx [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *HEALTH POLICY* | Online – 15 December 2013 – **'Obligatory consultation of an independent physician on euthanasia requests in The Netherlands: What influences the SCEN physicians judgment of the legal requirements of due care?'** SCEN (Support & Consultation on Euthanasia in The Netherlands) physicians have been trained to provide such consultations. The authors analyzed 1,631 euthanasia requests, involving 415 SCEN physicians. Patient characteristics that were associated with a lower likelihood to meet due care requirements were: being tired with life, depression and not wanting to be a burden. Physical suffering and higher patient age were related to greater chances of meeting the requirements. There was no clear association between SCEN physicians' characteristics and their judgment. Psychological suffering involves a greater chance that SCEN physicians judge that requirements for due care are not met. http://www.sciencedirect.com/science/article/pii/S0168851013003138
- *JOURNAL OF MEDICAL ETHICS* | Online – 13 December 2013 – **'Assistance in dying for older people without a serious medical condition who have a wish to die: A national cross-sectional survey.'** Although it is lower than the level of support for assistance in dying for patients whose suffering is rooted in a serious medical condition, the authors' finding that a substantial minority of the general public supports physician assistance in dying for older people who are tired of living implies that this topic may need to be taken seriously in the debate... http://jme.bmj.com/content/early/2013/11/29/medethics-2012-101304.abstract

Worth Repeating

Professional tears: Developing emotional intelligence around death and dying in emergency work

JOURNAL OF CLINICAL NURSING, 2011; 20(23-24):3364-3372. Care of the dying, the deceased and the bereaved is largely conducted by nurses and nowhere is this more demanding than at the front door of the hospital, the Emergency Department. Whilst some nurses find end-of-life care a rewarding aspect of their role, others avoid opportunities to develop a relationship with the dying and bereaved because of the intense and exhausting nature of the associated emotional labour. Emergency nurses [i.e., study participants] develop expertise in end-of-life care giving by progressing through three stages of development: 1) investment of the self in the nurse-patient relationship; 2) management of emotional labour; and, 3) development of emotional intelligence. Barriers that prevent the transition to expertise contribute to occupational stress and can lead to burnout and withdrawal from practice. Despite the emotional impact of emergency deaths, nurses who invest their therapeutic self into the nurse-patient relationship are able to manage the emotional labour of caring for the dying and their relatives through the development of emotional intelligence. They find reward in end-of-life care that ultimately creates a more positive experience for patients and their relatives. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2011.03860.x/abstract

Extract from *Journal of Clinical Nursing* nurse article

The emergency nurse caring for the dying patient is placed in a unique and privileged position to make a considerable impact on the care of the patient and the experience for their family. This model can build awareness in managing the emotive aspects involved in care delivery and develop fundamental skills of nursing patients near the end of life.

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