Media Watch...

is intended as an advocacy, research and teaching 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

Humanistic involvement with patients: Scroll down to <u>Specialist Publications</u> and 'What conversations do bereaved parents remember?' (p.16), in *Journal of Palliative Care & Medicine*.

Canada

Why is CPR being used for end-of-life care?

THE GLOBE & MAIL | Online - 4 February 2015 - One of the most difficult and poorly understood issues in end-of-life care is the use of cardiopulmonary resuscitation (CPR). Surveys of the general public's knowledge about the success rate of CPR reveal a wide gap between the perception and the reality. Two major factors are responsible for this misapprehension: public education by TV programs rather than by accurate medical information; and the fact that CPR has come into common hospital practice, even in very inappropriate circumstances. The adverse effects, physical, mental and emotional, of CPR attempts are common and serious. Fractures of the sternum and ribs are a usual occurrence. If "successful" resuscitation does occur, the patient may suffer a variety of mental difficulties ranging from impaired brain function or changed personality, to serious permanent brain damage, regarded by most people as a fate worse than death. For the family, CPR creates a chaotic scene in which they usually must leave the room just at the time they feel most need to be with their loved one. The nurses and doctors are sometimes very uncomfortable, feeling trapped into applying a therapy that they know is not in the patient's best interest. This conflict between good professional judgment and current policy may cause what is called a "slow code." where CPR is performed, but without enthusiasm, when it is known to be futile This is the invidious result of a policy that is as disrespectful to the care team as it is medically useless for the patient. This policy puts physicians in an absurd position, directing them to behave unethically by giving treatment that they know is both harmful and of no benefit. http://www.theglobeandmail.com/globe-debate/why-is-cpr-being-used-for-end-of-lifecare/article22779749/

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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.19.

Noted in Media Watch, 8 December 2014, #387 (p.2):

■ THE NATIONAL POST | Online — 1 December 2014 — 'Do away with the term "do not resuscitate.'" "Should your heart stop beating while under my care, would you like us to attempt CPR (cardiopulmonary resuscitation)?" It is a question most physicians dread asking, as no matter how the issue is raised, patients and family members react at first with shock, aghast that this is even a question at all. Swayed by Hollywood's depiction of cardiac arrests, where 75% of fictional resuscitation attempts are successful and uncomplicated, the initial answer for most patients as to whether to attempt CPR if their heart stops beating in a hospital is an automatic "yes." Unfortunately, statistics are far more grim, and the decision far more difficult. http://fullcomment.nationalpost.com/2014/12/01/brett-belchetz-do-away-with-the-term-do-not-resuscitate/

Noted in Media Watch, 11 August 2014, #370 (p.1):

ALBERTA | CTV News – 7 August 2014 – 'More hospitals welcoming family during patient resuscitation.' When a code blue is announced in hospital and a resuscitation team rushes to a patient's side, tradition has dictated family members get out of the way, both to protect their sensibilities and to give doctors and nurses the room and concentration needed to perform life-saving care. But that notion of separating patient and loved ones is slowly being replaced by a new model of care, in which family members are given the option – and sometimes even encouragement – to remain near the bedside, where their presence is viewed as beneficial. http://www.ctvnews.ca/health/more-hospitals-welcoming-family-during-patient-resuscitation-1.1949413

Refusal to face reality of death leads to increased use of aggressive, futile health-care efforts

CANADA.COM | Online – 2 February 2015 – Seriously ill, hospitalized Canadians are increasingly receiving aggressive, invasive and futile care at end of life because patients and families cannot accept the grim reality that they are dying, according to more than 1,200 doctors and nurses surveyed from across the country. 1 Unrealistic expectations about life-prolonging treatments and disagreements among family members are also preventing crucial discussions around the use - or not - of CPR, artificial ventilators, tube-feeding and other interventions from happening, according to the survey. "If we don't have these conversations, there is a chance of patients receiving care that in the end is going to inflict more suffering than help," said Dr. John You, lead author of the study and an associate professor of medicine and clinical epidemiology and biostatistics with McMaster University's Michael G. DeGroote School of Medicine in Hamilton. "We need to normalize conversations about death and dying so that people can be more comfortable having advance care planning discussions within families before there's a crisis." The study ... involved a survey of 1,256 staff doctors, residents and nurses working in medical teaching units at 13 hospitals in British Columbia, Alberta, Ontario, Quebec, and Newfoundland and Labrador between September 2012 and March 2013. http://o.canada.com/news/refusal-to-face-reality-of-death-leads-to-increased-use-of-aggressive-futile-health-care-efforts

Specialist Publications

'Managing profound suffering at the end-oflife: Should expanding access to continuous deep sedation be the priority?' (p.11), in Bioéthique.

'Goals of care discussion: How hard it can be' (p.12), in *JAMA Internal Medicine*.

'The association between home palliative care services and quality of end-of-life care indicators in the Province of Québec' (p.13), in *Journal of Pain & Symptom Management*.

'Barriers to goals of care discussions with seriously ill hospitalized patients and their families: A
multicenter survey of clinicians,' JAMA Internal Medicine, published online 2 February 2015.
http://archinte.jamanetwork.com/article.aspx?articleid=2107609

Get moving on preparing for "grey tsunami"

THE TORONTO STAR | Online - 2 February 2015 - Canadian health-care planners have known for decades that the "grey tsunami" was approaching. They've had plenty of time to prepare for an aging population. Yet Canada ranks last among 11 countries in a newly released survey of access to medical care by older patients. More than half of Canadians over 55 wait at least two days to see a family doctor or nurse, according to a report ... by the Canadian Institute for Health Information. Older Canadians also wait longer to see a specialist than those in Australia, New Zealand, the U.S., Britain, France, Germany, the Netherlands, Norway, Sweden and Switzerland. The problem is not money. Canada spends more *per capita* on health care than most of the other countries in the survey (\$6,045 per person, exceeded only by the U.S. figure of \$8,895). http://www.thestar.com/opinion/editorials/20 15/02/02/get-moving-on-preparing-for-grey-tsunami-editorial.html

Extract from the Commonwealth Fund survey

Canadians are more likely to plan for their end-oflife needs than people in other countries.

 'How Canada Compares: Results From The Commonwealth Fund 2014 International Health Policy Survey of Older Adults,' Canadian Institute for Health Information, January 2015. http://www.cihi.ca/CIHI-ext-por-

tal/internet/en/Document/health+system+performance/indicators/international/RELEASE 29JAN15

Noted in Media Watch, 5 September 2011, #200 (p.1):

BRITISH COLUMBIA | CBC News – 29 August 2011 – 'Cost of aging population on health care "overblown." Researchers suggest the predicted "grey tsunami" may turn out to be more like a "grey glacier." http://www.cbc.ca/news/health/story/2011/08/29/grey-tsunami-aging-population.html

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online − 6 February 2015 − 'Supreme Court allows doctor-assisted suicide in specific cases.' People with grievous and irremediable medical conditions should have the right to ask a doctor to help them die, Canada's highest court says in a unanimous ruling. The Supreme Court of Canada says a law that makes it illegal for anyone to help a person commit suicide should be amended to allow doctors to help in specific situations. The ruling only applies to competent adults with enduring, intolerable suffering who clearly consent to ending their lives. The court has given federal and provincial governments 12 months to craft legislation to respond to the ruling; the ban on doctor-assisted suicide stands until then. If the government doesn't write a new law, the court's exemption for physicians will stand. All nine justices share the writing credit on the ruling, an unusual action meant to signal particular institutional weight behind the decision. http://www.cbc.ca/news/politics/supreme-court-allows-doctor-assisted-suicide-in-specific-cases-1.2947487
 - Carter vs. Canada (Attorney General): https://scc-csc.lexum.com/scc-csc/scc-csc/scc-csc/en/item/14637/index.do

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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

CBC NEWS | Online - 6 February 2015 - 'Doctor-assisted suicide a therapeutic service, says Canadian Medical Association.' The Canadian Medical Association (CMA) supports patients who seek "medical aid in dying" as well as physicians' choice to participate, the group's president said in response to a Supreme Court decision. As the legal environment changes, the CMA said it will support doctors and patients who find medical aid in dying their best option. "What we want to do is really make sure patients who are eligible under the new rules have access to this therapeutic service, but at the same time we need to be very careful that physicians have the right to contentious objection for moral or ethical ... or religious reasons," CMA president Dr. Chris Simpson said in an interview... Simpson

said the court gave [the federal government] 12 months to answer detailed questions such as: How will consent be determined, such as through discussion and counselling? What is the best way to provide safeguards, such as using two doctors or a board? How could patients apply? http://www.cbc.ca/news/health/doctorassisted-suicide-a-therapeutic-service-says-canadian-medical-association-1.2947779

Specialist Publications

'Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience,' (p.17), in *Journal of Medical Ethics*.

N.B. The Canadian Hospice Palliative Care Association (CHPCA) is still studying the decision. "CHPCA does not have a position on this issue until we review and assess the impact of the decision," the organization wrote in an e-mailed statement. Source: *The Ottawa Sun*, 6 February 2015. http://www.ottawasun.com/2015/02/06/ottawa-groups-split-on-scoc-doctor-assisted-death-decision. The Canadian Society of Palliative Care Physicians revised this month its position statement on "euthanasia and assisted suicide." The Society states "if legalized, [it] should not be provided by palliative care services or palliative care physicians": http://www.cspcp.ca/wpcontent/uploads/2014/10/CSPCP-Position-on-Euthanasia-and-Assisted-Suicide-Feb-6-2015.pdf.

- CTV NEWS | Online 6 February 2015 'Where Canada's political parties stand on assisted suicide.' With the [Supreme Court] decision coming in an election year, the "right to die" debate could transform into a key campaign issue for political parties across the spectrum. Here's where major the federal parties [Conservative, Liberal, New Democratic, Green] stand: http://www.ctvnews.ca/politics/where-canada-s-political-parties-stand-on-assisted-suicide-1.2223916
- CTV NEWS | Online 6 February 2015 'Canada's right-to-die debate.' A chronology of the major events in Canada's right-to-die debate: http://www.ctvnews.ca/canada/canada-s-right-to-die-debate-a-chronology-of-major-events-1.2223937
- THE GLOBE & MAIL | Online 6 February 2015 'Next step in assisted suicide: Ensuring it can be done humanely.' The court has given the federal government and other regulatory bodies 12 months to draft new rules or not. The next big question is: Do we need a new law with restrictions that reflects the court's concern, or is a law needed at all? http://www.theglobeandmail.com/globe-debate/next-step-in-assisted-suicide-humane-rules/article22829985/
- THE GLOBE & MAIL | Online 6 February 2015 'Ottawa must now draft an assisted-suicide law. It should look to Quebec.' The Supreme Court of Canada declared that the law banning assisted suicide violates constitutional rights. While the ball is now in Parliament's court, many difficult questions face elected representatives at the federal and provincial levels. http://www.theglobeandmail.com/globe-debate/ottawa-must-now-draft-a-suicide-law-it-should-look-to-quebec/article22829318/

Noted in Media Watch, 9 June 2014, #361 (p.1):

QUEBEC | CBC News – 6 June 2014 – 'Quebec passes "dying with dignity" bill.' The non-partisan Bill 52, also known as an act respecting end-of-life care, passed ... in a free vote at the National Assembly... The bill passed 94-22. There were no abstentions. http://www.cbc.ca/news/canada/montreal/quebec-passes-dying-with-dignity-bill-1.2665834

U.S.A.

Hearing loss an oft-overlooked problem for hospice patients

REUTERS HEALTH | Online – 4 February 2015 – Among dying hospice patients, hearing problems are often overlooked ... experts say. Families and physicians frequently mistake hearing loss for dementia among the elderly and terminally ill, said Barbara Weinstein, a professor of audiology at the City University of New York. According to the Centers for Disease Control & Prevention, 80% of Americans age 85 and older have hearing impairments. And Medicare and the Medicare Hospice Benefit do not cover hearing aids... Hospices might be able to work "with resources in the community if there was a patient with a need for hearing aids," said Judi Lund Person, Vice-President of Regulatory Affairs for the National Hospice & Palliative Care Organization. http://www.reuters.com/article/2015/02/04/us-hearing-loss-hospice-idUSKBN0L82BT20150204

Selected articles on hearing loss in patients living with a terminal illness noted in past issues of Media Watch:

- HEARING JOURNAL, 2015;68(1):18-22. 'Dying to be heard: Hearing healthcare at the end of life.' Good hearing healthcare is essential for people facing the end of life, and yet it often goes overlooked by care providers and families focused on other medical, financial, social, legal, and additional concerns... [Noted in Media Watch, 29 December 2014, #390 (p.7)] http://journals.lww.com/thehearingjournal/Fulltext/2015/01000/Dying to Be Heard Hearing Healthcare at the End.1.aspx
- JOURNAL OF PALLIATIVE CARE, 2012;28(2):105-112. 'Palliative and end-of-life care in Newfoundland's deaf community.' Key findings [of this Canadian study] indicate the deaf community has limited understanding of their options for palliative and end-of-life care. [Noted in Media Watch, 13 August 2012, #266 (p.6)] http://www.ncbi.nlm.nih.gov/pubmed/22860383
- HEC FORUM, 2002;14(3):197-208. 'American Sign Language and end-of-life care: Research in the deaf community.' The authors describe a community-based participatory research process used to develop a means of discussing end-of-life care needs of deaf seniors. [Noted in Media Watch, 20 August 2012, #267 (p.12, under 'Worth Repeating')] https://dada.cs.washington.edu/research/projects/compression2/jitran/Papers/ASSETS%2020 https://dada.cs.washington.edu/research/projects/compression2/jitran/Papers/ASSETS%2020 https://dada.cs.washington.edu/research/projects/compression2/jitran/Papers/ASSETS%2020 https://dada.cs.washington.edu/research/projects/compression2/jitran/Papers/ASSETS%2020 https://dada.cs.washington.edu/research/projects/compression2/jitran/Papers/ASSETS%2020 <a href="https://dada.cs.washington.edu/research/projects/compression2/jitran/Papers/ASSETS%2020



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

Pain and suffering at life's end are getting worse, not better

NATIONAL PUBLIC RADIO (NPR) | Online - 3 February 2015 - It's been more than 15 vears since the Institute of Medicine released its seminal 1997 [sic] report detailing the suffering that many Americans experience at the end of life and offering sweeping recommendations on how to improve care. But the number of people experiencing pain in the last year of life actually increased by nearly 12% between 1998 and 2010, according to a [new observational] study...2 And the number of people with depression in the last year of life increased by more than 26%. All that happened as guidelines and quality measures for end-of-life care were developed, the number of palliative care programs rose and hospice use doubled between 2000 and 2009. "We've put a lot of work into this and it's not yielding what we thought it should be yielding. So what do we do now?" asked Dr. Joanne Lynn, a study author who directs the Center for Elder Care & Advanced Illness at the Altarum Institute. The study looked at 7,204 patients who died while enrolled in the Health & Retirement study, a survey of Americans over age 50. http://www.npr.org/blogs/health/2015/02/03/ 383522954/pain-and-suffering-at-lifes-endare-getting-worse-not-better

Extract from NPR report:

Most physicians tend to under treat pain and other symptoms at the end of life because they don't recognize them or are hesitant to candidly talk [with their patients] about the process of dying and the pain associated with it...

Specialist Publications

'Patient-physician end-of-life discussions in the routine care of Medicare beneficiaries' (p.13), in *Journal of Aging & Health.*

'An assessment of hospital-based palliative care in Maryland: Infrastructure, barriers, and opportunities' (p.15), in *Journal of Pain & Symptom Management*.

- 'Approaching Death: Improving Care at the End of Life,' Institute of Medicine, National Academy of Sciences, Washington, December 1998. http://www.iom.edu/reports/1998/approaching-death-improving-care-at-the-end-of-life.aspx
- 'Symptom Trends in the Last Year of Life from 1998 to 2010: A Cohort Study,' Annals of Internal Medicine, 3 February 2015. http://annals.org/article.aspx?articleid=2107746

Noted in Media Watch, 22 September 2014, #376 (p.4):

- KAISER HEALTH NEWS | Online 17 September 2014 'Dying in America is harder than it has to be, Institute of Medicine advises.' It is time for conversations about death to become a part of life ... one of the themes of a 500-page report ... by the Institute of Medicine. http://www.kaiserhealthnews.org/Stories/2014/September/17/institute-of-medicine-says-dying-in-america-is-harder-than-it-has-to-be.aspx
 - 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine, National Academy of Sciences, Washington, September 2014. http://www.iom.edu/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf

Panel kills bill allowing cessation of medical care

VIRGINIA | *The Virginian-Pilot* (Norfolk) – 3 February 2015 – The House of Delegates' Health, Welfare & Institutions Committee ... [have] killed a bill ... allowing physicians to cease providing medical care they deem medically or ethically inappropriate. The bill was aimed at relieving health care providers from having to provide treatment they determine is prolonging a patient's suffering without improving their chance of recovery... http://hamptonroads.com/2015/02/va-panel-kills-bill-allowing-cessation-medical-care

Familias en Acción

Culturally sensitive palliative care represents new approach

OREGON | ABC News – 1 February 2015 – Palliative care ... has gained traction across the nation, but the culturally sensitive model embraced by Familias en Acción ... represents a new approach. The method has taken root in Portland and Seattle, and it's being taught to nursing students in California for its potential to improve care and reduce costs. Dr. Woody English, former medical director of palliative care at Providence Health & Services in Portland, said the multifaceted approach "has the ability to transform the usual health care system." Studies show palliative care decreases emotional and medical crises and cuts down on unnecessary emergency room trips and hospitalizations, leading to cost savings sought under the Affordable Care Act. By adding a cultural emphasis, health care professionals aim to address patient needs that would otherwise be overlooked. http://abcnews.go.com/Health/wireStory/culturally-sensitive-palliative-care-represents-approach-28642855

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- STATE OF NEW YORK | *The New York Times* 3 February 2015 'Lawsuit seeks to legalize doctor-assisted suicide for terminally ill patients in New York.' A group of doctors and terminally ill patients are asking New York courts to declare that doctor-assisted suicide is legal and not covered by the state's prohibition on helping people take their own lives. Under long-time interpretations of state law, a doctor who helps a terminally ill patient die by providing a fatal dose of medication can be prosecuted under the manslaughter statute, which covers any-one who "intentionally causes or aids another person to commit suicide." The lawsuit ... contends that the law was intended to prevent someone from, for instance, helping a lovesick teenager commit suicide, but not to stop a doctor from helping a mentally competent, terminally ill patient die. The plaintiffs argue that because doctors are already allowed to help terminally ill patients die in some circumstances, such as when they remove life support, the fact that they cannot hasten death for other terminally ill patients violates the equal protection clause of the State Constitution. <a href="https://www.nytimes.com/2015/02/04/nyregion/lawsuit-seeks-to-legalize-doctor-assisted-suicide-for-terminally-ill-patients-in-new-york.html?ref=health& r=0
- VERMONT | Burlington Free Press (OpEd) 1 February 2015 'Keep patient choice oversight.' Lawmakers should protect the integrity of Vermont's physician-assisted suicide act by extending protections written into the law due to expire this year. There are only three known cases of a person taking his or her own life under the law 'Patient Choice & Control at End of Life' was enacted in 2013. The state's experience to date is far too thin to drop provisions that lend a measure of oversight to a process that amounts to state-sanctioned suicide. Act 39 allows doctors to prescribe medication that can hasten death to patients diagnosed with a condition that, in the words of the law, "within reasonable medical judgment, result in death within six months." Legislators built into the legislation a series of specific documented steps doctor and patient must follow before the physician can prescribe the lethal medication. http://www.burlingtonfreepress.com/story/opinion/editorials/2015/02/01/editorial-keep-patient-choice-oversight/22597773/

International

End-of-life care in the U.K.

Hospice fears increase in demand after cancer crisis warning

U.K. | *The Shields Gazette* (South Shields) – 5 February 2015 – Charity bosses in South Tyneside are facing an increase in demand for their services. The warning follows new statistics which show one-in-two people will develop cancer at some point in their lives. The latest forecast from Cancer Research UK says that the U.K. faces a "crisis" if the Nation Health Service does not plan ahead. Bosses at St Clare's Hospice, in Jarrow, says that the changes will lead to an increased demand on its services. The new figure ... is the most accurate forecast to date from Cancer Research UK... http://www.shieldsgazette.com/news/health/hospice-fears-increase-indemand-after-cancer-crisis-warning-1-7089650

 'Trends in the lifetime risk of developing cancer in Great Britain: Comparison of risk for those born from 1930 to 1960,' British Journal of Cancer, published online 3 February 2015. http://www.nature.com/bjc/journal/vaop/ncurrent/full/bjc2014606a.html

End-of-life care in Ireland

Choosing to die at home can often be a perfect decision for everyone

IRELAND | *The Irish Examiner* (Blackpool, Cork) – 3 February 2015 – Two-thirds of Irish people spend their last days in a clinical environment, be it a hospital, hospice or nursing home, even though three-quarters of us want to die in our own beds... Although 74% of people want to die at home, only about a quarter of people do so... Most people will die in a clinical setting: in the last two years, 38% died in a hospital, 26% at home, 12% in nursing/residential home and 11% in a hospice. This is partly down to the lack of services, says Sharon Foley, CEO of the Irish Hospice Foundation. Every county should have a palliative care structure, incorporating a hospice homecare team, supported by a public health nurse or hospice, plus a palliative care service in each acute hospital. http://www.irishexaminer.com/lifestyle/features/choosing-to-die-at-home-can-often-be-a-perfect-decision-for-everyone-310339.html

 'Enabling More People to Die at Home: Making the Case for Quality Indicators as Drivers for Change on Place of Care and Place of Death in Ireland,' The Irish Hospice Foundation, December 2014. [Noted in Media Watch, 8 December 2014, #387 (p.5)] http://hospicefoundation.ie/wp-content/uploads/2014/12/Enabling-More-People-to-Die-at-Home1.pdf

Noted in Media Watch, 28 October 2013, #329 (p.5):

- IRELAND | The Irish Times (Dublin) 22 October 2013 'Lack of hospice beds leaves terminal patients out in the cold.' More than a decade ago a report from the National Advisory Committee on Palliative Care recommended there should be one hospice bed per 10,000 of the population. However, according to the latest report from the Irish Hospice Foundation, just just two regions the mid-west and northwest come close to fulfilling government policy. http://www.irishtimes.com/life-and-style/health-family/lack-of-hospice-beds-leaves-terminal-patients-out-in-the-cold-1.1568194
 - 'Access to Specialist Palliative Care Services and Place of Death in Ireland,' The Irish Hospice Foundation, May 2013. http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf

End-of-life care in Scotland

Dementia patients suffer due to lack of end-of-life care, says charity

U.K. (Scotland) | The Herald (Edinburgh) - 3 February 2015 - Dementia patients and their families are suffering unnecessarily because of a lack of suitable end-of-life care, according to a leading charity. Marie Curie said that although dementia is regarded as a terminal illness, less than a fifth of patients with the condition receive palliative care before they die. Some receive inadequate pain relief, or are unable to contribute to decisions about their care, and many care homes are effectively acting as hospices, without being designed to do so, and without suitable specialist staff... The research comes after leading dementia expert Professor June Andrews, of the University of Stirling, warned that hospital wards "chew up" dementia patients, often leaving them hungry, thirsty, or in pain.² Marie Curie said that unlike with other conditions, it is often unclear when care of a dementia patent moves from active 'treatment' to more palliative. Confusion and memory loss can be

dismissed as normal signs of ageing, the report says, while there is a shortage of dementia care specialists working in palliative care. For these and other reasons, too few people with dementia get appropriate end of life care and those who do not get it soon enough. http://www.heraldscotland.com/news/health/dementia-patients-suffer-due-to-lack-of-end-of-life-care-says-charity.117552880

Action plan for end-of-life care "due in spring"

U.K. (Scotland) | *The Courier* (Dundee) – 6 February 2015 – An action plan to improve the lives of those suffering from terminal illnesses such as dementia will be published in the spring, the First Minister has revealed. Nicola Sturgeon ... confirmed work was at an advanced stage on the proposals. http://www.thecourier.co.uk/news/politics/action-plan-for-end-of-life-care-due-in-spring-1.824278

- 'Living and dying with dementia in Scotland: Barriers to care,' Marie Curie, February 2015. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-scotland-report-2015.pdf
- 'Expert: Hospitals are meat grinders that chew up dementia sufferers,' The Herald (Edinburgh),
 February 2015. http://www.heraldscotland.com/news/health/hospitals-are-dangerous-for-dementia-warns-expert.117270443

Noted in Media Watch, 15 December 2014, #388 (p.9):

ANNALS OF LONG-TERM CARE, 2014;22(12). 'Caring for the patient with end-stage dementia.' This article reviews four key components to ensuring patients with end-stage dementia receive proper care. First, the challenge of prognostication, a leading barrier to hospice care, is reviewed. Second, care planning strategies ... are examined. Third, strategies for managing complications of dementia, such as behavioral problems, sleep disturbances, and pain, are reviewed. Finally, strategies for helping patients and families through the bereavement process are examined, as skillful end-of-life care will leave a legacy of dignity and peace for the family. http://www.annalsoflongtermcare.com/article/caring-patient-end-stage-dementia

Noted in Media Watch, 18 August 2014, #371 (p.10):

■ JOURNAL OF ALZHEIMER'S DISEASE | Online – 4 August 2014 – 'Needs of people with severe dementia at the end-of-life: A systematic review.' Ten studies published from 1993-2013 were identified, encompassing qualitative, quantitative, and a mixed-methods study. Data synthesis yielded seven themes, with physical, social, and psychological needs the categories most frequently mentioned. http://iospress.metapress.com/content/8wk34806v5630580/

N.B. Several articles on end-of-life care for people living with dementia are noted in Media Watch, 23 June 2014, #363 (p.11).

pq. 9

End-of-life care in Wales

New patient resuscitation guidance for Wales

U.K. (Wales) | BBC News – 2 February 2015 – New guidance on whether to resuscitate patients who are approaching the end of their lives is being issued to medics. For the first time, all hospitals in Wales will follow the same procedure to decide if patients should receive cardiopulmonary resuscitation. The Welsh government said it would ensure the best interest of patients. Baroness Ilora Finlay, a professor in palliative medicine, said the policy will "avoid futile attempts to start a person's heart when it stops." http://www.bbc.com/news/uk-wales-31085511

National Health Service Wales' Do Not Attempt Cardiopulmonary Resuscitation Policy, February 2015): http://www.wales.nhs.uk/news/35793

Hindu healer Babaji Davender Ghai reignites funeral pyre plans

U.K. (England) | *The Chronicle* (Newcastle) – 1 February 2015 – A Hindu healer who fought to legalise open-air cremations is ready to make them commonplace – five years after winning a landmark court battle. Babaji Davender Ghai spent years battling the system and almost went bankrupt fighting to make funeral pyres legal. Funeral pyres are said to be essential to the Hindu and Sikh belief in reincarnation. http://www.chroniclelive.co.uk/news/north-east-news/newcastle-hindu-healer-babaji-davender-8557432

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SLOVAKIA | Slovenian Press Agency 4 February 2015 'Debate in parliament shows opposing views on euthanasia.' A debate on end-of-life treatment ... saw medical professionals and philosophers on opposite banks regarding the topic. While Slovenian doctors oppose euthanasia, philosophers think that individuals should be given the option to end their lives with medical assistance. http://www.sta.si/en/vest.php?s=a&id=2100333
- U.K. (Isle of Man) | BBC News 3 February 2015 'Assisted dying bill rejected by Isle of Man politicians.' Isle of Man politicians have rejected a call to introduce a [private member's] bill to allow assisted dying. Members of the House of Keys [the Isle of Man's parliament] voted 17 to five against the motion. http://www.bbc.com/news/world-europe-isle-of-man-31110603
- U.K. (Scotland) | *The Scotsman* (Edinburgh) 3 February 2015 'Four-fifths of Scots back state assisted suicide.' Almost four-fifths of Scots think it is important for controversial proposals on assisted suicide to become law, a poll has suggested. 78% of those questioned said it was either of "high importance" or "middling importance" that the proposed legislation was passed by the Scottish Parliament. http://www.scotsman.com/news/health/four-fifths-of-scots-back-state-assisted-suicide-1-3677854

N.B. Assisted Suicide (Scotland) Bill (published January 2015). This briefing outlines the current law in relation to assisted dying as well as the policy background to the Bill. It explores public opinion and the frequency of different types of assisted dying in the U.K. It goes on to detail the Bill's provisions as well as some of the issues raised in the Health & Sport Committee's call for written evidence. http://www.scottish.parliament.uk/ResearchBriefingsAndFactsheets/S4/SB 15-02 Assisted Suicide Scotland Bill.pdf

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

Emergency department-triggered palliative care in advanced cancer: Proof of concept

ACADEMIC EMERGENCY MEDICINE | Online – 29 January 2015 – The American College of Emergency Physicians and the American Society of Clinical Oncology recommend early palliative care consultation for patients with advanced, life-limiting illnesses, such as metastatic cancer. This study documented a low baseline rate of palliative care involvement as part of usual care in patients with advanced cancer being admitted from the emergency department. Early referral to palliative care in the context of a research study significantly increased the likelihood that patients received a consult, thus meriting further investigation of how to generalize this approach. http://onlinelibrary.wiley.com/doi/10.1111/acem.12573/abstract;jsessionid=0448F94C72488BDF29BCF5A1D855D0C6.f04t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false

Of related interest:

- ACADEMIC EMERGENCY MEDICINE | Online 29 January 2015 'If not us, then who?'
 Palliative care referral from the emergency department.' Goals of care discussion.
 http://onlinelibrary.wiley.com/doi/10.1111/acem.12593/abstract
- PALLIATIVE MEDICINE | Online 29 January 2015 'What's in a name? A qualitative exploration of what is understood by "palliative care" in the emergency department.' There are entrenched contradictions and tensions surrounding the term "palliative care"; confronting these is likely to require more than re-branding, and will promote better care for this vulnerable patient group... http://pmj.sagepub.com/content/early/2015/01/23/0269216314560801.abstract

Managing profound suffering at the end-of-life: Should expanding access to continuous deep sedation be the priority?

BIOÉTHIQUE, 2015;4(2). This paper argues that in addressing and managing profound suffering at the end-of-life, the priority should not be the legalization of physician-assisted suicide or voluntary active euthanasia in jurisdictions where these practices are not currently available. Rather, concerted efforts should be made by society and the health-care provider community to expand patient access to proportionate distress-relieving sedation and continuous deep sedation. https://papyrus.bib.umontreal.ca/xmlui/bitstream/handle/1866/11367/2.pdf?sequence=1

Worth Repeating

'Refractory pain, existential suffering, and palliative care: Releasing an unbearable lightness of being' (p.18), in Cornell Journal of Law & Public Policy.

Of related interest:

PEDIATRICS | Online – 2 February 2015 – 'Are we allowed to discontinue medical treatment in this child?' One of the most difficult ethical dilemmas in pediatrics today arises when a child has complex chronic conditions that are not curable and cause discomfort with no prospect of any improvement on quality of life. In the context of medical futility, it is harmful to prolong medical treatment. The question is: How can medical treatment be discontinued when the child is not dependent on mechanical ventilation or ICU treatment? What is the appropriate palliative care and does it justify the use of sedatives or analgesics if this also might shorten life? http://pediatrics.aappublications.org/content/early/2015/01/28/peds.2014-0548.abstract

Integration of palliative care in the context of rapid response: A report from the Improving Palliative Care in the ICU Advisory Board

CHEST, 2015;147(2):560-569. In this article, The Improving Palliative Care in the ICU (IPAL-ICU) Project brings together interdisciplinary expertise and existing data to address the following: special challenges for providing palliative care in the rapid response setting, knowledge and skills needed by rapid response teams (RRTs) for delivery of high-quality palliative care, and strategies for improving the integration of palliative care with rapid response critical care. The authors discuss key components of communication with patients, families, and primary clinicians to develop a goal-directed treatment approach during a rapid response event. They also highlight the need for RRT expertise to initiate symptom relief. Strategies including specific clinician training and system initiatives are then recommended for RRT care improvement. The authors conclude by suggesting that as evaluation of their impact on other outcomes continues, performance by RRTs in meeting palliative care needs of patients and families should also be measured and improved. http://journal.publications.chestnet.org/article.aspx?articleID=2107414

Of related interest:

■ PALLIATIVE MEDICINE | Online – 29 January 2015 – 'Hospital rapid response team and patients with life-limiting illness: A multicentre retrospective cohort study.' Patients with a life-limiting illness had worse outcomes post–rapid response team consultation. The authors' findings suggest a routine clarification of goals of care for this cohort, within 3 days of hospital admission, may be advantageous. These discussions may provide clarity of purpose to treating teams, reduce the burden of unnecessary interventions and promote patient-centred care... http://pmj.sagepub.com/content/early/2015/01/23/0269216314560802.abstract

Goals of care discussion: How hard it can be

JAMA INTERNAL MEDICINE | Online – 2 February 2015 – Mechanical ventilation. Internal cardioverter defibrillators. Hemodialysis. Extracorporeal membrane oxygenation. Cardiopulmonary resuscitation. Percutaneous gastrostomy feeding tubes. Multidrug chemotherapy. Dying used to be less complicated when unaccompanied by decisions about high-tech interventions. We forestall mortality but at the cost of increasing end-of-life complexity. Clinicians help patients manage this complexity with open communication about prognosis, patients' values and goals, and the impact of life-sustaining therapies. Since the 'Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment' of the mid-1990s, however, we have known that seriously ill patients rarely communicate end-of-life preferences to physicians. Recent studies show that more patients fill out advance directives and consider end-of-life care options, but few report having discussions with their clinicians. Yet evidence is mounting that goals of care discussions lead to better outcomes, particularly improved quality of life near the end of life and reduced costs. http://archinte.jamanetwork.com/article.aspx?articleid=2107606

1. 'The <u>Study</u> to <u>Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT),' *Journal of the American Medical Association*, 1995;274(20):1591-1598. http://jama.jamanetwork.com/article.aspx?articleid=391724</u>

Of related interest:

AMA JOURNAL OF ETHICS, 2015;17(2):111-115. 'Professionalism and appropriate expression of empathy when breaking bad news.' Breaking bad news empathically to patients requires recognizing signs and patterns from patient cues, and the set of potential responses is as broad as a good differential diagnosis. As a physician, you need to note the patient's affect as you walk in the room. Does her face indicate a sense of dread? Does he seem determined? Does her greeting indicate all is well and that the information you hold will be unexpected? These cues should guide your response. It may be best to present information bluntly to relieve the tension an anxious patient displays. Other times, taking a gentler approach is better. http://journalofethics.ama-assn.org/2015/02/ecas1-1502.html

- JOURNAL OF AGING & HEALTH | Online 2 February 2015 'Patient-physician end-of-life discussions in the routine care of Medicare beneficiaries.' Medicare reimbursement for physicians who discussed end-of-life care and planning with a patient during an office visit was cut from the 2010 Affordable Care Act. Less than 1% reported an end-of-life conversation with a physician during the course of routine care. However, conversations were associated with greater trust in one's physician and higher rates of completion of family advance care plans. http://jah.sagepub.com/content/early/2015/02/0898264315569458.abstract
- JOURNAL OF PALLIATIVE MEDICINE | Online 6 February 2015 'Conversations about end of life: Perspectives of nursing home residents, family, and staff.' Residents, families, and staff [i.e., study participants] rarely talked about end-of-life (EOL) care preferences, nor did they pass along information about preferences or initiate conversations about EOL care with each other. Three categories explained missed conversations: inquiry ("no one asked"); assumptions (presence of an advance directive: "They know me"); and, conveying (lack of conveying information or wishes). http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0316
- PALLIATIVE CARE | Online 2 February 2015 'Age as a factor in do not attempt cardio-pulmonary resuscitation decisions: A multicentre blinded simulation-based study.' The authors highlight a potential gap between current practice and supporting evidence base. http://pmj.sagepub.com/content/early/2015/02/02/0269216314566838.abstract
- PALLIATIVE MEDICINE | Online 2 February 2015 'Admission of the very elderly to the intensive care unit: Family members' perspectives on clinical decision-making from a multicenter cohort study.' There is incongruity between family values and preferences for end-of-life care and actual care received for very elderly patients who are admitted to the intensive care unit. Deficiencies in communication and decision-making may be associated with prolonged use of life-sustaining treatments in very elderly critically ill patients, many of whom ultimately die. http://pmj.sagepub.com/content/early/2015/02/02/0269216314566060.abstract

The association between home palliative care services and quality of end-of-life care indicators in the Province of Québec

JOURNAL OF PAIN & SYMPTOM MAN-AGEMENT | Online - 2 February 2015 - In Canada, governments have increased spending on home care to promote better end-of-life care. In the province of Québec, home palliative care services (HPCS) are provided by Public Local Community-Based Health Care Service providers (Centres Locaux de Services Communautaires [CLSC]) with universal coverage. Accordingly, there should be no regional variations of these services and their effect on quality of end-oflife palliative care (QEoLPC) indicators. Overall, 27,255 (52.1%) decedents had at least one HPCS. Significant variations in the adjusted performance of CLSC in delivering HPCS were found. Higher performance led to a lower proportion of men having more than one emergency room visit during the last month of life ... and for women, a higher proportion dying at home ... and spending less time in hospital... Provision of HPCS remained limited ... when present were associated with improved QEoLPC indicators. http://www.jpsmjournal.com/article/S0885-3924(15)00063-9/abstract

Disaster planning for home health patients and providers: A literature review of best practices

HOME HEALTH CARE MANAGEMENT PRAC-TICE | Online - 27 January 2015 - Individuals receiving care in the home are vulnerable during disasters due to high rates of chronic disease, cognitive impairment, functional limitations, and physical disabilities as well as dependence on life-saving treatments and equipment. Increasing disaster preparedness among home health care recipients decreases the likelihood of adverse health outcomes and lessens the burden on community hospitals and emergency responders. This review addressed preparedness on three levels: organization, provider, and patient. The results indicate gaps between established and recommended tools and policies and adopted policies, and demonstrate marked differences in approaches to evaluation, classification, educaand triage between organizations. tion, http://hhc.sagepub.com/content/early/2015/01/27/ 1084822314567536.abstract

Of related interest:

- PALLIATIVE MEDICINE | Online 5 February 2015 'A national [U.K.] survey exploring views and experience of health professionals about transferring patients from critical care home to die.' Transferring critically ill patients home to die is poorly explored in the literature. While ... supported in critical care, its frequency in practice remains low. Patient stability and level of intervention are important factors in decision-making in this area. Views held about this practice are influenced by previous experience and the professional role held. http://pmj.sagepub.com/content/early/2015/02/05/0269216315570407.abstract
- PRIMARY HEALTH CARE | Online 30 January 2015 'Caring for dying family member raises concerns about medication.' This study explored family members' experiences of managing medications for someone dying at home. The authors interviewed fifty-nine bereaved family carers who had cared for someone dying at home for at least two week. http://rcnpublishing.com/doi/abs/10.7748/phc.25.1.15.s22?journalCode=phc
 - **N.B.** See 'Managing end-of-life medications at home accounts of bereaved family carers,' *BMJ Supportive & Palliative care*, published online, 25 September 2014. [Noted in Media Watch, 29 September 2014, #377 (p.9)] http://spcare.bmj.com/content/early/2014/09/25/bmjspcare-2014-000658.short?rss=1
- PALLIATIVE MEDICINE | Online 2 February 2015 'Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial.' The Carer Support Needs Assessment Tool provided a formal structure to facilitate discussions with family caregivers to enable needs to be addressed. Such discussions can also inform an evidence base for the ongoing development of services for family caregivers, ensuring that new or improved services are designed to meet the explicit needs of family caregivers. http://pmj.sagepub.com/content/early/2015/02/02/0269216314566061.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.

An assessment of hospital-based palliative care in Maryland: Infrastructure, barriers, and opportunities

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 30 January 2015 – Maryland recently passed legislation mandating that hospitals with greater than 50 beds have palliative care (PC) programs. Although the state's health agency can play a key role in ensuring successful implementation of this measure, there is little actionable information from which it can guide resource allocation for enhancing PC delivery statewide. Twenty-eight hospitals (60.9%) provided information on their PC services. Eighty-nine percent of these hospitals reported the presence of a structured PC program. The profile of services provided by PC programs was largely conserved across hospital geography and size. The most common barriers reported to PC delivery were lack of knowledge among patients/families and "lack of physician buy-in;" the majority of hospitals reported that networks and/or conferences to promote best practice sharing in PC would be useful supports. http://www.jpsmjournal.com/article/S0885-3924(15)00039-1/abstract

Opioid availability and palliative care in Nepal: Influence of an International Pain Policy Fellowship

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2015;49(1):110-116. Globally, cancer incidence and mortality are increasing, and most of the burden is shifting to low- and middle-income countries (LMICs), where patients often present with late-stage disease and severe pain. Unfortunately, LMICs also face a disproportionate lack of access to pain-relieving medicines such as morphine, despite the medical and scientific literature that shows morphine to be effective to treat moderate and severe cancer pain. In 2008, an oncologist from Nepal, one of the poorest countries in the world, was selected to participate in the International Pain Policy Fellowship, a program to assist LMICs, to improve patient access to pain medicines. Following the World Health Organization public health model for development of pain relief and palliative care, the Fellow, working with colleagues and mentors, has achieved initial successes: three forms of oral morphine (syrup, immediate-release tablets, and sustained-release tablets) are now manufactured in the country; health-care practitioners are receiving training in the use of opioids for pain relief; and, a new national palliative care association has developed a palliative care training curriculum. http://www.jpsmjournal.com/article/S0885-3924(14)00217-6/abstract

The effectiveness of interdisciplinary teams in end-of-life palliative care: A systematic review

JOURNAL OF PALLIATIVE CARE, 2014;30(1):44-45. The fact that the authors found only a limited number of existing high-quality studies in their review precludes definitive conclusions about the effectiveness of interdisciplinary teams in end-of-life palliative care for adult patients. Indeed, the weakness of the literature base limits the range of advantage, the quality of the evidence, and the number of conclusions that can be drawn. Nevertheless, their systematic review provides preliminary evidence that interdisciplinary palliative care teams can improve patients' satisfaction and a few organizational aspects of care. The authors' analyses lend support to the argument that funding and developing interdisciplinary palliative care teams is a way to improve patient care. file:///C:/Users/Barry/Downloads/Article%20Revue%20syst%C3%A9matique%20interdisciplinarit%C3%A9 soins palliatifs%20(2014).pdf

Of related interest:

HEALTH SERVICES RESEARCH, 2015;50(1):217-236. 'Cost savings from palliative care teams and guidance for a financially viable palliative care program.' The authors of this article attempt to quantify the cost savings of palliative care and to also identify differences in savings according to interdisciplinary team structure, patient diagnosis, and the timing of consult. http://www.ingentaconnect.com/content/bpl/hesr/2015/00000050/0000001/art00013

■ JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 4 February 2015 – 'The geriatric imperative facing palliative care.' The majority of palliative care providers are seeing an aging patient population as a result of the confluence of two main factors: 1) the general population is living longer; and, 2) as palliative care providers, most of the diseases for which we are consulted, such as congestive heart failure or cancer, are diseases that are more common in the elderly. http://www.jpsmjournal.com/article/S0885-3924(15)00036-6/abstract

What conversations do bereaved parents remember?

JOURNAL OF PALLIATIVE CARE & MEDICINE, 2015;5:202. Bereaved parents [i.e., study participants] had memories of specific conversations with healthcare professionals years following their child's death. They did not recall family meetings or technically-oriented moments, but moments marked by relational aspects. Insensitivity or lack of empathy were negative themes. Empathic protectiveness, personal disclosure, and authenticity at moments in care created enduring positive memories. The findings [of this study] support the importance of humanistic involvement with patients, demonstrating the enduring impact of healthcare professionals in critical life events. http://omicsgroup.org/journals/what-conversations-do-bereaved-parents-remember-2165-7386.1000|202.pdf

Palliative care in Latin America from the professional perspective: A SWOT analysis

JOURNAL OF PALLIATIVE MEDICINE | Online - 6 February 2015 - The development of palliative care (PC) in Latin America (LA) has been slow compared to other regions. A Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis may contribute to the identification of barriers and successful strategies. A total of 577 [expert] statements were provided. Among the strengths were integration into health systems and increasing number of professionals with PC training. Among weaknesses were lack of national PC programs, limited connection between policymakers and professionals, and barriers in the availability of Opportunities were increased opioids. awareness of policymakers and higher interest of students and professionals. Threats were competing funding for other services and medications, limited interest of the pharmaceutical industry in producing affordable opioid medications, and emphasis by the media on opioid diversion and abuse. http://online.liebertpub.com/doi/abs/10.1089/ jpm.2014.0120

Palliative care in Latin America

Atlas de Cuidados Paliativos de Latinoamérica, Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch, 7 January 2013, #287, (p.8)]

Spanish language edition:

http://cuidadospaliativos.org/uploads/2012/10/atlas/Atlas%20de%20Cuidados%20Paliativos%20en%20Latinoamerica.pdf;

Portuguese language edition:

http://cuidadospaliativos.org/uploads/2014/1/Atlas%20P ortugues.pdf;

English language edition:

http://cuidadospaliativos.org/uploads/2013/12/Atlas%20 of%20Palliative%20Care%20in%20Latin%20America.p df

Atlas de Cuidados Paliativos de Latinoamérica: Edición Cartográfica 2013, Asociación Latinoamericana de Cuidados Paliativos, 2013. [Noted in Media Watch, 2 December 2013, #334 (p.5)]

Spanish language edition:

http://cuidadospaliativos.org/uploads/2014/3/Atlas%20Latinoamerica%20-%20edicion%20cartografica.pdf

Noted in Media Watch, 16 June 2014, #362 (p.12):

PALLIATIVE MEDICINE | Online - 12 June 2014 - 'Palliative care development in Latin America: An analysis using macro indicato.' Recently, the Latin American Association for Palliative Care developed 10 indicators to monitor the development of palliative care and enhance the development of regional and national strategies. Most of the indicators are useful for assessing national levels of palliative care development. These may be applicable to other world regions. http://pmj.sagepub.com/content/early/2014/06/12/0269216314538893.abstract

An exploratory study of end-of-life prognostic communication needs as reported by widowed fathers due to cancer

PSYCHO-ONCOLOGY | Online – 6 February 2015 – Effective physician communication about prognosis is a critical aspect of quality care for families affected by terminal illness. This is particularly important for spousal caregivers of terminally ill parents of dependent children, who may have unique needs for communication about anticipated death. Major themes addressed by [survey] respondents were the importance of clear and honest communication and physician bedside manner. They also identified unmet information needs, including wanting to know prognosis sooner. Relevant sub-themes included death coming as a surprise, avoidance, and caregiver regret. http://onlinelibrary.wiley.com/doi/10.1002/pon.3757/abstract

Jewish perspective on end-of-life

Rituals in death and dying: Modern medical technologies enter the fray

RAMBAM MAIMONIDES MEDICAL JOUR-NAL, 2015;6(1):1-7. Throughout human history, rites and rituals at the end of life have been important components of all societies, cultures, and religions. Until the advent of modern medicine with all its complex technologies, these activities were primarily focused on what family members and designated religious or cultural leaders brought into the process to assist and guide the dying person and his family and community through the dying process and through many defined activities to celebrate the person's life after death had occurred. Modern medicine has in many ways replaced the personal rites and rituals, the songs, chants, music, and appeal to the guiding spirits with complex medical interventions. These are often the happenings that are remembered and referred to during the after-death "celebration" of the person's life and last days, hours, and moments of death. Physicians and other health care professionals must become more aware - through participating in advance care planning and discussion of

their patients' important values, and listening carefully to family comments during the dying period — because what may seem to them to be just part of clinical medicine can, for the family of the dying person, have a very profound and lasting effect on how they recall and recount that last and very important period of life and prologue to death. http://www.rmmj.org.il/userimages/408/1/PublishFiles/418Article.pdf

Praying to die

JOURNAL OF RELIGIOUS ETHICS, 2015; 43(1):1-27. While the vast majority of relevant prayers seek renewed health and prolonged life, what might prayers for someone to die look like? What ethical dimensions are involved in such liturgical expressions? By examining both prayers for oneself to die ... [or] ... for someone else to die, this essay discerns reasons why it may be good ... to pray for a patient's demise. http://onlinelibrary.wiley.com/doi/10.1111/jore.1 2084/full

Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ JOURNAL OF MEDICAL ETHICS | Online - 3 February 2015 - 'Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience.' The hypothesis that legal regulation of physician-assisted dying slows development of palliative care (PC) is not supported... On the contrary, regulation appears to have promoted the expansion of PC. Continued monitoring of both permissive and non-permissive countries, preferably also including indicators of quantity and quality of delivered care, is needed to evaluate longer-term effects. http://jme.bmj.com/content/early/2015/02/03/medethics-2014-102116.abstract

■ THE LINACRE QUARTERLY, 2015;82(1):49-54. 'A template for non-religious-based discussions against euthanasia.' The discussion over physician assisted death and euthanasia remains ongoing in secular academic medical institutions across the U.S. and much of the western world. These debates have incentivized efforts to develop a framework for arguments against euthanasia that will find traction in an environment generally hostile to religion and religious thought. The authors present arguments given by the "con" side in a student-led debate over physician assisted death and euthanasia at Vanderbilt University with the hope that they will provide a foundation for future discussions promoting truth and life without alienating our secular colleagues. http://www.maneyonline.com/doi/abs/10.1179/2050854914Y.0000000036

Worth Repeating

Refractory pain, existential suffering, and palliative care: Releasing an unbearable lightness of being

CORNELL JOURNAL OF LAW & PUBLIC POLICY, 2011;20(3):469-532. Since the beginning of the hospice movement in 1967, "total pain management" has been the declared goal of hospice care. Palliating the whole person's physical, psycho-social, and spiritual states or conditions is central to managing the pain which induces suffering. At the end-stage of life, an inextricable component of the ethics of adjusted care requires recognition of a fundamental right to avoid cruel and unusual suffering from terminal illness. This article urges wider consideration and use of terminal sedation, or sedation until death, as an efficacious palliative treatment and as a reasonable medical procedure in order to safeguard the "right" to a dignified death. Once the state establishes a human right to avoid refractory pain of whatever nature in end-stage illness, a coordinate responsibility must be assumed by health care providers to make medical judgments consistent with preserving the best interests of a patient's quality of life by alleviating suffering. The principle of medical futility is the preferred construct for implementing this professional responsibility. Rather than continue to be mired in the vexations quagmire of the doctrine of double effect - all in an effort to "test" whether end-stage decisions by health care providers are licit or illicit – a relatively simple test of proportionality, or cost-benefit analysis, is proffered. Imbedded, necessarily, in this equation is the humane virtue of compassion, charity, mercy or agape. http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1804326

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Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2015/02/media-watch/#CHINESE

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 | HPC Consultation Services (Waterloo Region/Wellington County): http://hpcconnection.ca/general-resources/in-the-news/

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/ [Scroll down to 'Additional Resources']

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://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes

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