

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.

13 January 2014 Edition | Issue #340



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

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The illness experience: Scroll down to [Specialist Publications](#) and 'Some general considerations of a human-based medicine's palliative approach to the vulnerability of the multiply disabled child before the end of life' (p.8), in *Culture, Medicine & Psychiatry*.

U.S.A.

Jahi McMath, Ariel Sharon, and the Valley of Death

TIME MAGAZINE | Online – 9 January 2014 – Today, more and more of us face the uncanny valley of the shadow of death. It's the domain of those, like Jahi [McMath] and former Israeli Prime Minister Ariel Sharon, who suffer grievous injury and are kept on this side of life by elaborate and increasingly heroic medical procedures. Unlike the real valley of the shadow of death, which every human society has known, this uncanny valley is one that we modern human beings have created for ourselves. Far from solving the problems we want medicine to solve – our vulnerability and mortality – it can actually heighten them, leaving us more vulnerable and no less mortal. Life in this uncanny valley's shadow is neither death nor life. It calls forth mourning but also forbids it. It offers the slimmest of hopes, but in many, if not most, cases it slowly squeezes hope out of life one mechanically induced breath at a time. A great deal is at stake in this uncanny valley's shadow. Our society spends extraordinary amounts of money on care at the

end of life. If all that money lead to flourishing health, it would be well spent. But many families choose the uncanny valley without understanding just how hard the journey will be. <http://content.time.com/time/magazine/article/0,9171,2162277,00.html>

N.B. Ariel Sharon died 11 January 2014.

International

'The death of Ariel Sharon: Meaningful conversations are never futile' (p.6), in *The Jerusalem Post*.

Specialist Publications

'Hoping for the best, preparing for the worst: Strategies to promote honesty and prevent medical futility at end-of-life' (p.9), in *Dimensions of Critical Care Nursing*.

Cont.

Of related interest:

- WASHINGTON DC | *The Root* – 7 January 2014 – '**Jahi's family reflects deep mistrust of end-of-life decisions.**' In a country where end-of-life medical discussions have been increasingly dominated by the debate about when medical care can and should ethically be withdrawn, the McMath family has become an exemplar of an alternative set of concerns common in black America. A Pew Research Center poll found substantial differences in the amount, timing and type of medical intervention black and white Americans believe to be appropriate.¹
http://www.theroot.com/articles/culture/2014/01/blacks_don_t_trust_end_of_life_decisions.html?wpisrc=newstories

1. 'Growing minority of Americans say doctors should do everything possible to keep patients alive,' The Pew Research Center, Washington DC, 21 November 2013. [Noted in Media Watch, 25 November 2013, #333 (p.2)] <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/>

N.B. Key findings of The Pew Research Center's November poll (re-released 7 January 2014):
<http://www.pewresearch.org/fact-tank/2014/01/07/5-facts-about-americans-views-on-life-and-death-issues/>

- WISCONSIN STATE JOURNAL (Madison) | Online – 6 January 2014 – '**Health sense: System struggles with end-of-life wishes.**' The Wisconsin Medical Society's Honoring Choices initiative is encouraging residents ... to do advance care planning ... so, why bother, if doctors do what they think they should do anyway? Julie Short, a Madison attorney who helps clients complete power-of-attorney-for-health-care documents, said she had problems when her father was dying from cancer at a hospital in Green Bay. Short, her father's health care agent, said she had a hard time getting doctors to stop doing tests and procedures.
http://host.madison.com/wsj/news/local/health_med_fit/health-sense/health-sense-system-struggles-with-end-of-life-wishes/article_750f97dd-9b56-51a0-bedb-d041f98676d5.html

N.B. Honoring Choices Wisconsin: <https://www.wisconsinmedicalsociety.org/professional/hcw/>

- CNN | Online – 29 December 2013 – '**When "life support" is really "death support."**' Two young females, both brain dead without warning, remain on ventilators while their devastated families challenge the judgments of their hospitals. In one situation, the family believes a miracle is possible, and wants to prolong the patient's biological functioning. In the other case, the family wants to disconnect the patient to honor her wishes. But both families are facing obstacles. The way we talk about neurological death has created a misperception, ethicists say: that "brain death" is somehow not as final as cardiac death, even though, by definition, it is.
http://www.cnn.com/2013/12/28/health/life-support-ethics/index.html?hpt=hp_t1

Hospice care may not begin until after death

IDAHO | *The Bonner County Daily Bee* (Sandpoint) – 8 January 2014 – A patient is terminally ill. Palliative care is in order. Bonner Community Hospice is contacted and immediately the resources of more than seventy-five volunteers are available to guide the patient, family and friends through the process of dying. And, a process it may be; one of putting one's life in order and completing unfinished business. But, sometimes the process doesn't happen. The patient is instead a victim. The death is unexpected, accidental, suicide or murder. Suddenly the surviving loved ones are thrown into the chaos of grief without any warning that it's coming. What then?
http://www.bonnercountydailybee.com/columns/article_e686ac36-782f-11e3-b385-0019bb2963f4.html

[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.14.

Forget funeral selfies. What are the ethics of tweeting a terminal illness?

NEW YORK STATE | *The Guardian* (U.K.) – 8 January 2014 – Lisa Bonchek Adams is dying. She has Stage IV breast cancer and now it's metastasized to her bones, joints, hips, spine, liver and lungs. She's in terrible pain. She knows there is no cure, and she wants you to know all about what she is going through. Adams is dying out loud. On her blog and, especially, on Twitter. She has tweeted over 100,000 times about her health. Lately, she tweets dozens of times an hour. Her Twitter followers are a mixed bag. Some are also battling cancer or work in the medical field, others seem to follow

Adams' life story like a Reality TV show. <http://www.theguardian.com/commentisfree/2014/jan/08/lisa-adams-tweeting-cancer-ethics>

Extract from *The Guardian* article

What is the appeal of watching someone trying to stay alive? Is this the new way of death? You can put a "no visitors sign" on the door of your hospital room, but you welcome the world into your orbit and describe every last Fentanyl patch.

Stay or go? Terminally ill undocumented immigrants face dilemma

CALIFORNIA | New America Media (San Francisco) – 6 January 2014 – Like many undocumented immigrants who have worked a lifetime in this country, [Gil] García faced a dilemma when he was diagnosed with an incurable disease. They often do not know whether to stay in the U.S. to receive the limited emergency medical treatment allowed given their immigration status, or return to their home country to spend the last stage of their life with family members who they often have not seen for decades. In a 2012 ... Ricardo Nuila, of the Baylor College of Medicine in Houston, Texas, wrote "for many undocumented immigrants, terminal illness is a revolving door."¹ <http://newamericamedia.org/2014/01/undocumented-and-dying-latinos-may-find-comfort-in-final-journey-home.php>

1. 'Home: Palliation for dying undocumented immigrants,' *New England Journal of Medicine*, 31 May 2012. [Noted in *Media Watch*, 4 June 2012, #256 (p.12)] <http://www.nejm.org/doi/pdf/10.1056/NEJMp1201768>

OpEd: Protect true hospice care

NEBRASKA | *The Journal Star* (Lincoln) – 4 January 2014 – Some providers of hospice care are giving the movement a bad name. That's a sad development, because the movement originally started by religious and community organizations has helped many spend their final days with a better quality of life. The danger is that the for-profit companies that are gaming the system will damage the image of hospice, and worse, make some people reluctant to enter hospice care. Hospice care is intended for people who are terminally ill, and the goal is to manage a patient's pain, and care for the patient's emotional and spiritual needs. Some patients thoughtfully choose hospice care rather than taking extreme measures that at best might extend life for a few weeks. http://journalstar.com/news/opinion/editorial/editorial-protect-true-hospice-care/article_b207e9cf-1dd5-5baa-aaca-958fdaa61de2.html?comment_form=true

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[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>

Of related interest:

- *THE NEW YORK TIMES* | Online – 7 January 2014 – **'Bounced from hospice.'** Hospices have always had the ability – and under Medicare rules, the obligation – to discharge some patients. The Medicare Payment Advisory Commission, relying on 2009 and 2010 data, has reported that 20% of hospice patients are discharged alive each year; the National Hospice & Palliative Care Organization says its survey shows that a third of discharges are initiated by patients themselves, and two-thirds by hospices. But discharges are climbing. <http://newoldage.blogs.nytimes.com/2014/01/07/bounced-from-hospice/?ref=health&r=0>

Noted in Media Watch, 6 January 2014, #339 (p.2):

- *FORBES* | Online – 1 January 2014 – **'A 2014 hospice ad blitz launches amid Obama-care rollout.'** In an effort to improve public awareness about hospice and palliative care, the industry is launching its first national [multimillion dollar] education and marketing campaign. <http://www.forbes.com/sites/brucejapsen/2014/01/01/amid-obamacare-rollout-hospice-providers-launch-2014-education-campaign/>

Noted in Media Watch, 30 December 2013, #338 (p.2):

- CALIFORNIA | *The Washington Post* – 26 December 2013 – **'Hospice firms draining billions from Medicare.'** The number of "hospice survivors" in the U.S. has risen dramatically, in part because hospice companies earn more by recruiting patients who aren't actually dying... Healthier patients are more profitable; they require fewer visits and stay enrolled longer.¹ http://www.washingtonpost.com/business/economy/medicare-rules-create-a-booming-business-in-hospice-care-for-people-who-arent-dying/2013/12/26/4ff75bbe-68c9-11e3-ae56-22de072140a2_story.html

1. 'Healthy growth in hospice profits,' *The Washington Post*, 26 December 2013. California provides a portrait of how hospice profits have grown. Since 2002, annual net profits have grown by more than tenfold after adjusting for inflation — from \$25 million to \$265 million. <http://apps.washingtonpost.com/g/page/business/healthy-growth-in-hospice-profits/689/>

N.B. National Hospice & Palliative Care Organization response to *The Washington Post* article: <http://www.nhpco.org/press-room/press-releases/nhpco-responds-washington-post>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW MEXICO | *The Albuquerque Journal* – 6 January 2014 – **'New Mexicans advocate for more end-of-life choices.'** New Mexico could be the fifth state in the U.S. to allow its doctors to assist terminally ill patients in hastening their deaths by prescribing them medications ... experts say. These experts advocate for choice and conversation about death and dying ... just as doctors may soon have more control over how they help their patients through it. If 2nd District Judge Nan Nash decides [later] this month in favor of the two oncologists and one terminally ill cancer patient who brought the suit, prescribing fatal drugs to terminally ill patients will no longer be a fourth-degree felony. <http://www.abqjournal.com/331259/news/new-mexicans-advocate-for-more-endoflife-choices.html>
- TEXAS | *The New York Times* – 4 January 2014 – **'Texas Right to Life criticized for playing politics with ratings.'** A rift on how to regulate end-of-life care that broke out during last year's legislative session has carried over into this year's election cycle. And one group's political scorecard has created a minefield in some Republican primary races, leading to heavy criticism from Roman Catholic bishops in Texas. The 2013 scorecard by Texas Right to Life, which grades lawmakers based on their support of legislation related to anti-abortion and end-of-life issues, holds great sway in many [upcoming] Republican primaries. But the Texas Catholic Conference, which lobbies on behalf of the 15 Roman Catholic bishops of Texas and their dioceses, says the group has, in order to exert political power, misrepresented the positions of politicians committed to both anti-abortion causes and the rights of the terminally ill. http://www.nytimes.com/2014/01/05/us/texas-right-to-life-criticized-for-playing-politics-with-ratings.html?_r=0

International

End-of-life care in Australia

OpEd: Death needs a plan similar to childbirth

AUSTRALIA (New South Wales) | *The Newcastle Herald* – 11 January 2014 – "Quality of death" is a controversial topic for many people. While medicine and science have eliminated many diseases and prolonged our life expectancy, death is eventually inevitable for us all. As we seek to manage the quality of the end of our lives, we should all have an interest in building a system that preserves our dignity and ensures that our last days reflect our personal preferences. It makes good sense to plan for impending birth. It increases the chance of good health while reducing fear and stress. Planning helps the family to develop a shared sense of responsibilities and values. There is a growing school of thought that suggests we could start accepting that chronic illness and end-of-life occur and plan for them in the way we currently plan for the start of life. <http://www.theherald.com.au/story/2016237/opinion-death-needs-a-plan-similar-to-childbirth/?cs=308>

Noted in Media Watch, 8 August 2011, #213 (p.2):

- U.S. (Colorado) | *The Daily Camera* – 7 August 2011 – **'Nurse midwives moving into hospice care.'** The transitions of birth and death bring up the same concerns and needs: education, misconceptions, fears, changes in family dynamics, uncertainties, hope, faith, planning, rituals and the loss of control. http://www.dailycamera.com/health-fitness/ci_18623805

Dying in the U.K.

The bedroom tax on bereavement: Grieving families to face spare-room benefit cut within three months

U.K. (England & Wales) | *The Independent* – 9 January 2014 – Families will be hit by the bedroom tax if a room remains unoccupied for just three months after the death of a family member, bereavement charities have warned. There have already been several cases of families in social housing told that rooms left "spare" after the death of a child or other family member will become subject to the controversial spare room subsidy. Currently households are given 52 weeks before they are reassessed, to allow them to decide whether to move or to re-occupy the room before they incur cuts to their housing benefit. But under the Government's flagship Universal Credit scheme, which will see housing benefit rolled in with up to five other benefits in one monthly payment, the stay of grace is to be cut to just three months, the National Bereavement Alliance said. The group said there was an urgent need for a review of the financial impact that recent changes to welfare have on people who have been bereaved, warning that the Government risked adding to the "distress" of grieving families. <http://www.independent.co.uk/life-style/health-and-families/health-news/the-bedroom-tax-on-bereavement-grieving-families-to-face-spareroom-benefit-cut-within-three-months-9047658.html>

Of related interest:

- U.K. (England, Wales & Northern Ireland) | BBC News – 9 January 2014 – **'Bereaved workers "need more support," charity says.'** A National Council for Palliative Care report says the government should look into the "feasibility" of statutory leave from work after a loved one dies.¹ And it calls on all employers to tell workers what help they are entitled to. A survey commissioned by the charity found 32% of people bereaved in the last five years felt their employer did not treat them with compassion. The report ... says 87% of people surveyed felt all employers should have a "compassionate employment policy" including paid bereavement leave, flexible working and other support. <http://www.bbc.co.uk/news/uk-25662920>

1. 'Life After Death,' National Council for Palliative Care in partnership with the Dying Matters Coalition, January 2014. <http://www.ncpc.org.uk/sites/default/files/LifeAfterDeath.pdf>

End-of-life care in India

Plan panel recognition for palliative care scheme

INDIA (Kerala) | *The Hindu* (Chennai) – 7 January 2014 – The Planning Commission has recognised the palliative care programme being implemented in the State under Arogyakeralam as one among the best healthcare schemes in the country, Health Minister V.S. Sivakumar has said. Mr. Sivakumar said that the palliative care scheme, being implemented in 736 local bodies in the State, would be extended to all taluk [i.e., administrative division] hospitals. Thiruvananthapuram [i.e., the state capital] district has already been declared a total palliative care district. Palliative care units have been started in 73 panchayats [i.e., administrations], four municipalities, and the City Corporation in the district. <http://www.thehindu.com/news/national/kerala/plan-panel-recognition-for-palliative-care-scheme/article5546290.ece>

Meaningful conversations are never futile

ISRAEL | *The Jerusalem Post* (OpEd) – 6 January 2014 – For last week's Jerusalem-Tel Aviv commute, I opted for mass transit. As customary, on the hour, the bus driver turned up the radio volume so that we passengers could hear the news. Together, we learned that Ariel Sharon's condition had become critical due to acute renal failure. As we marveled at the breathtaking views along Highway 1, our collective "Tsk, tsk, tsk" implied, "What a shame that Arik's health has deteriorated," but in fact, the former Israeli prime minister has been lying in a vegetative state since his series of strokes in 2006. For the past eight years, healthcare workers and laymen, alike, have understood the 85-year-old's condition to be ... "terminal." Yet how often do we, either as individuals or collectively as a society, choose to dodge the end-of-life questions that Sharon's condition prompts us to consider? Dr. Kenneth Prager points out that advances in biomedical science make it increasingly difficult to die in an intensive care unit. While sophisticated machines allow doctors to make heroic "saves," the same technologies can prolong the dying process for patients with incurable disease. Although Sharon did live to be transferred out of the ICU, some might consider the life-prolonging treatment to be an inap-

propriate and misguided exercise in what many professionals call "medical futility." Prager emphasizes, however, the word "futility" has no meaning out of context. Particularly with human life involved, establishing such context requires clearly defining goals. <http://www.jpost.com/Opinion/Columnists/Perspectives-Meaningful-conversations-are-never-futile-337188>

Noted in Media Watch, 1 July 2013, #312 (p.5)

With Mandela, end-of-life care dilemmas magnified

USA TODAY & WORLD REPORT | Online – 28 June 2013 – The emotional pain and practical demands facing Nelson Mandela's family are universal: confronting the final days of an elderly loved one. There are no rules for how or when the end may arrive. Some choose to let go with little medical interference; others seek aggressive treatment. Nelson Mandela's status as a respected global figure only complicates the situation, doctors and end-of-life experts say. <http://www.usatoday.com/story/news/world/2013/06/28/mandela-end-of-life-dilemmas/2473619/>

1. 'When physicians and surrogates disagree about futility,' *Virtual Mentor* (American Medical Association Journal of Ethics), 2013;15(2):1022-1026. The coming decades will present formidable ethical challenges concerning hopelessly ill patients being kept alive at their families' insistence with ever more sophisticated, powerful, and expensive technologies. The context in which these challenges will play out has evolved as the role and the authority of the physician has changed. <http://virtualmentor.ama-assn.org/2013/12/pdf/ecas2-1312.pdf>

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

Factors associated with futile end-of-life intensive care in a cancer hospital

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 7 January 2014 – Management of critically ill patients involves weighing potential benefit of advanced life support against preserving quality of life, avoidance of futile measures, and rational use of resources. This study aims to identify the predisposing factors involved in the institution and maintenance of futile intensive care support in terminally ill cancer patients in whom no additional treatment for the malignant disease would be offered. The authors conclude that a significant minority of end-of-life care consists of futile treatments. Strategies to increase oncologists' and critical care specialists' alertness to these issues and expand indications of palliative care consultations are recommended. <http://ajh.sagepub.com/content/early/2014/01/03/1049909113518269.abstract>

Of related interest:

- *JOURNAL OF THE COLLEGE OF PHYSICIANS & SURGEONS* (Pakistan), 2014;24(1):2-3. **'Decision-making in end-of-life care.'** Concepts about medical treatment have changed remarkably with the advent of artificial life support systems. Keeping a patient alive by sustaining his cardiac and respiratory activity is no longer the objective. The term used more and more frequently nowadays is to provide patients with a certain quality of life. This has given rise to the concept of palliative care; the ability to accept limitations of medical treatment and to shift efforts from blindly prolonging life to making whatever natural life remains of as high a quality as possible. Treatable or terminal, the doctor's actions should continue to be based on what is best for the patient as a complete human being and not a scientific challenge for his skills. <http://www.icpsp.pk/archive/2014/Jan2014/02.pdf>

The language of dying and death

Euphemistic metaphors in English and Spanish epitaphs: A comparative study

ATLANTIS (Journal of the Spanish Association of Anglo-American Studies), 2013;35(2):99-118. This paper analyses the conceptual organisation underlying death-related metaphorical expressions in English and Spanish. With this in mind, this paper presents a comparative study of death metaphors in a sample of epitaphs from Highgate Cemetery (London, U.K.) and from the Cemetery of Albacete (Albacete, Spain) focusing specifically on those aimed at substituting the notions of "death" and "dying." The results obtained reveal that the conceptual organisations that underlie the euphemistic metaphors for death in English and Spanish derive both from our common bodily experience and from specific cultural constraints. Although the set of conceptual metaphors for the domain of death is similar in both languages, the Spanish epitaphs show a clear preference for source domains in which Jewish-Christian beliefs and political issues play a crucial role, whereas the English epitaphs tend to display a more optimistic, life-like approach to death. http://www.atlantisjournal.org/ARCHIVE/35.2/6_abstract_Eliecer_Crespo_Fernandez.pdf

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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>

Representative sample of articles on the language of dying and death noted in past issues of Media Watch:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 May 2013 – **'Harnessing complex emergent metaphors for effective communication in palliative care: A multimodal perceptual analysis of hospice patients' reports of transcendence experiences.'** The authors use a multimodal methodology for identifying the prevalence and thematic properties of complex emergent metaphors patients use to report their experiences. Their findings indicate the considerable potential of more complex metaphors for reducing barriers to effective communication in palliative care. [Noted in Media Watch, 3 June 2013, #308 (p.8)] <http://ajh.sagepub.com/content/early/2013/05/23/1049909113490821.abstract>
- *PALLIATIVE MEDICINE* | Online – 24 July 2012 – **'The patient's use of metaphor within a palliative care setting: Theory, function and efficacy. A narrative literature review.'** Engaging with patients at the metaphoric level enables them to create new ways of viewing their situation and opens up new coping strategies. [Noted in Media Watch, 30 July 2012, #264 (p.10)] <http://pmj.sagepub.com/content/early/2012/07/20/0269216312451948.abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 1998;15(5):282-284. **'Communicating with metaphor: A dance of many veils.'** The creative and judicious use of metaphor provides health care practitioners with many veils – veils that shield the dying from the glare of their prognosis, veils particularly valuable and suited in communicating with our palliative patient population. [Noted in Media Watch (under 'Worth Repeating'), 1 February 2010, #134 (p.9)] <http://ajh.sagepub.com/cgi/content/abstract/15/5/282>

Some general considerations of a human-based medicine's palliative approach to the vulnerability of the multiply disabled child before the end of life

CULTURE, MEDICINE & PSYCHIATRY | Online – 3 January 2014 – The aim of medicine is double: to offer a techno-scientific capacity (to cure as much as it is possible and always relieve suffering), and guarantee the meaning and value of the child's human and social capacities. The authors suggest the importance of a medicine always as care-giving whose aim(s) can be either curative or palliative, or even both at the same time with possibilities for moving back and forth between each one, is easily understandable by all professional groups and patients. It is not at the time of the death, at the last moments, that we will be able to introduce what could have given meaning, spirit and comfort in life. It is very early in the life, in the approach of care, to precisely preserve a meaning of life and to take adapted and shared care as a precious tool that we will propose to the patients, to the parents, and to the professionals. Palliative medicine can support a caring and human approach that takes account of the handicapped child's vulnerabilities not only at the end of his/her life, but throughout his/her life. The palliative and reasoning approach requires a specific, adapted training and the development of shared knowledge. Without giving up the indisputable contributions of the evidence-based medicine, it is necessary to develop ... what we could call human-based medicine. <http://link.springer.com/article/10.1007/s11013-013-9355-6>

Of related interest:

- HEALTH CANAL (U.K.) | Online – 8 January 2014 – **'National Institute of Health makes palliative care more attainable for pediatric patients and their families.'** A campaign just launched by the National Institute of Nursing Research [a component of the National Institutes of Health] aims to increase the use of palliative care ... for children with serious illness. <http://www.healthcanal.com/child-health/46443-nih-makes-palliative-care-more-attainable-for-pediatric-patients-and-their-families.html>

Physician Orders for Life-Sustaining Treatment

Hoping for the best, preparing for the worst: Strategies to promote honesty and prevent medical futility at end-of-life

DIMENSIONS OF CRITICAL CARE NURSING, 2014;33(1):22-27. Critical care nurses frequently care for patients nearing end of life. Associated advance care planning is often not introduced as early as it needs to be, and nurses can help to stimulate a culture change by initiating honest discussions about end-of-life treatment options. The Physician Orders for Life-Sustaining Treatment [POLST] form can provide a framework for honesty and information sharing at end of life. http://journals.lww.com/dccjournal/Abstract/2014/01000/Hoping_for_the_Best,_Preparing_for_the_Worst_.7.aspx

Of related interest:

- *RESUSCITATION* | Online – 8 January 2014 – **'Physician Orders for Life-Sustaining Treatment (POLST): Lessons learned from analysis of the Oregon POLST Registry.'** POLST has become a common means of documenting patient treatment preferences. In addition to orders either for Attempt Resuscitation or Do Not Attempt Resuscitation, for patients not in cardiopulmonary arrest, POLST provides three levels of treatment: Full Treatment, Limited Interventions, Comfort Measures Only. Oregon has an electronic registry for POLST forms completed in the state. We used registry data to examine the different combinations of treatment orders. [http://www.resuscitationjournal.com/article/S0300-9572\(13\)00930-1/abstract](http://www.resuscitationjournal.com/article/S0300-9572(13)00930-1/abstract)

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[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.

[Distribution](#)

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

[Something Missed or Overlooked?](#)

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Representative sample of articles on POLST noted in past issues of Media Watch:

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 18 July 2013 – '**Implementing Physician Orders for Life-Sustaining Treatment in California hospitals: Factors associated with adoption.**' Hospitals in poor areas and for-profit (versus non-profit) hospitals were less likely to stock blank POLST forms and to have educated staff, and hospitals with community coalition interaction and in wealthier areas were more likely to handle POLST forms correctly. Although POLST is widely used in California, a significant minority of hospitals remain unprepared three years after implementation. [Noted in Media Watch, 22 July 2013, #315 (p.8)] <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12367/abstract>
- *THE LINACRE QUARTERLY*, 2013;80(2):103-138. The paper offers a critical analysis of POLST, including an analysis of the risks POLST poses to sound clinical and ethical decision-making ... with recommendations to help Catholic healthcare professionals and institutions better address the challenges of end-of-life care. [Noted in Media Watch, 20 May 2013, #306 (p.13)] <http://www.ingentaconnect.com/content/maney/lnq/2013/00000080/00000002/art00002>
- OREGON | *The Oregonian* (Portland) – 20 September 2012 – '**Oregon end-of-life care program spreads, report finds.**' An Oregon effort to ensure people near the end of life receive the care they want continues to spread across the country, according to a new report.¹
 1. 'Report highlights success of Oregon's groundbreaking POLST program,' Oregon Health & Science University, 2012. http://www.ohsu.edu/xd/about/news_events/news/2012/09-19-report-highlights-polst.cfm?WT_featured=news&WT_rank=news

Trends in specialized palliative care for non-cancer patients in Germany: Data from the National Hospice & Palliative Care Evaluation (HOPE)

EUROPEAN JOURNAL OF INTERNAL MEDICINE | Online – 6 January 2014 – Despite the continuously growing number of patients with non-malignant diseases, their number in PC [palliative care] services is still low. As small steps in the right direction have been taken, integrating PC ideas earlier into treatment of chronic diseases to improve quality of life of NCs [non-cancer patients] during the final stages of their diseases will continue to challenge the health care system in terms of workload, need of more staff and further training of medical professionals dealing with NCs in the future. [http://www.ejinme.com/article/S0953-6205\(13\)01014-5/abstract](http://www.ejinme.com/article/S0953-6205(13)01014-5/abstract)

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 10 January 2014 – '**Holistic assessment of supportive and palliative care needs: The evidence for routine systematic questioning.**' There is evidence to suggest that patients with cancer and other non-malignant chronic progressive illnesses can experience distressing symptoms, or concerns, which can often remain unrecognised. The purpose of this article is to provide an overview of holistic needs assessment in the fields of supportive and palliative care and to present evidence of the value of routine systematic questioning. There is at present no standardised systematic, evidence-based holistic approach to screening patients for supportive and palliative care needs. <http://spcare.bmj.com/content/early/2014/01/10/bmjspcare-2012-000324.abstract>
- *PALLIATIVE MEDICINE* | Online – 8 January 2014 – '**Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: A cross-sectional study.**' Of deaths in high-income countries, 75% are caused by progressive advanced chronic conditions. Palliative care needs to be extended from terminal cancer to these patients. However, direct measurement of the prevalence of people in need of palliative care in the population has not been attempted. Direct measurement of prevalence of palliative care needs on a population basis is feasible. Early identification and prevalence determination of these patients is likely to be the cornerstone of palliative care public health policies. <http://pmj.sagepub.com/content/early/2014/01/08/0269216313518266.abstract>

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- *PROGRESS IN PALLIATIVE CARE* | Online – Accessed 7 January 2014 – **'Non-cancer palliative care: Experience and challenges faced in a palliative program from Singapore.'** The authors report their experience and insights in managing non-cancer cases in an integrative model of care over the past 4 years. They find that most families and patients suffering from end stage non-cancer conditions are able to accept palliative care after honest communication and are able to talk about end-of-life plans. The majority of patients can achieve satisfactory symptom control, be cared for, and die in a place of their choice with the support of a palliative home care program without the need for frequent hospitalizations. <http://www.maneyonline.com/doi/abs/10.1179/1743291X13Y.0000000054>

Noted in Media Watch, 18 November 2013, #293 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2013;3(1). **'End-of-life care for non-cancer patients.'** The origins and early development of palliative care focussed on patients with cancer, apart from sporadic developments in a few non-malignant diseases such as motor neuron disease and acquired immunodeficiency syndrome (AIDS). In the U.K., this has been compounded by the setting of palliative care outside the National Health Service, principally funded by cancer-related charities who, at the time, were instituted to relieve the suffering associated with cancer. In the U.K. and many areas of the world where it was first adopted ... this led to the traditional model of palliative care services, involved only in people with a prognosis of a few weeks or months. As a result, services have focused primarily on cancer leading to service and symptom management inequalities for equally needy patients with non-malignant diseases. <http://spcare.bmj.com/content/3/1/2.extract>

""Not the 'grim reaper service"": An assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure

JOURNAL OF THE AMERICAN HEART ASSOCIATION | Online – 2 January 2014 – Providers [i.e., study participants] had limited knowledge regarding what palliative care is, and how it can complement traditional HF [heart failure] therapy to decrease HF-related suffering. Interviews [with cardiology, primary care, and palliative care providers] identified ... potential barriers: 1) the unpredictable course of HF; 2) lack of clear referral triggers across the HF trajectory; and, 3) ambiguity regarding what differentiates standard HF therapy from palliative care. Nevertheless, providers expressed interest for integrating palliative care into traditional HF care, but were unsure of how to initiate collaboration. Palliative care referral for HF patients may be suboptimal due to limited provider knowledge and misperceptions of palliative care as a service reserved for those near death. These factors represent potentially modifiable targets for provider education, which may help to improve palliative care referral ... with unresolved disease-related burden. <http://jaha.ahajournals.org/content/3/1/e000544.abstract?sid=0cecc158-d515-4d9f-bcbb-a124374c1c70>

Of related interest:

- *EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING* | Online – 6 January 2014 – **'Palliative care for those with heart failure: Nurses' knowledge, attitude, and preparedness to practice.'** Palliative care training is urgently needed to improve knowledge, attitude, coping, and preparedness to practice. Guidance to assist healthcare professionals involved in palliative care for those with cardiac disease needs to be developed and provided. <http://cnu.sagepub.com/content/early/2014/01/06/1474515113519521.abstract>

Representative sample of articles on palliative care for patients with heart failure noted in past issues of Media Watch:

- *HEART*, 2013;99(2):A11. **'Training in cardiology: Is end-of-life care being addressed?'** This [online] survey shows that despite being part of the national curriculum for training in cardiology since 2010, trainees' level of confidence in delivering end-of-life care in advanced heart failure and discussing prognosis ... is poor. [Noted in Media Watch, 3 June 2013, #308 (p.11)] http://heart.bmj.com/content/99/suppl_2/A11.2.abstract

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- *JOURNAL OF CARDIAC FAILURE*, 2013;19(3):193-201. **'Palliative care consultations for heart failure patients: How many, when, and why?'** Palliative care consultations (PCCs) are not being initiated until the last month of life. Earlier referral for PCC may allow for integration of a broader array of palliative care services. [Noted in Media Watch, 25 March 2013, #298 (p.9)] [http://www.onlinejcf.com/article/S1071-9164\(13\)00030-4/abstract](http://www.onlinejcf.com/article/S1071-9164(13)00030-4/abstract)
- *HEART & LUNG: THE JOURNAL OF ACUTE & CRITICAL CARE* | Online – 18 December 2012 – **'Patient and family members' perceptions of palliative care in heart failure.** Lack of awareness [among study participants] of palliative care (PC) and the conflation of PC and hospice were barriers to this specialist care and many participants felt that PC services are needed to fill the gaps in their care. [Noted in Media Watch, 7 January 2013, #287 (p.8)] [http://www.heartandlung.org/article/S0147-9563\(12\)00398-6/abstract](http://www.heartandlung.org/article/S0147-9563(12)00398-6/abstract)

Care partners and online patient portals

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 6 January 2014 – Each year, more than 65 million people in the U.S. (29% to 39% of the population) provide care for a chronically ill, disabled, or elderly family member or friend. Such caregivers, who help with both basic life functions and managing medical care, are critical to helping people maintain their health and remain in their communities. Many chronically ill and older people also have loved ones who, distinct from caregivers, serve as "care partners." These care partners do not provide day-to-day care or serve as surrogate decision makers but do help navigate health care – facilitating communication with physicians, discussing complex issues requiring shared decision making, and assisting with challenging self-management tasks. The care partner or partners may include a spouse, parent, friend, or relative who assists with health, perhaps across geographic distance. Health care systems today do not optimally identify or engage these individuals and frequently even push them away by creating barriers to obtaining patient information that may help in the care of their family member, often in the name of privacy and security, sometimes invoking the [U.S.] Health Insurance Portability & Accountability Act. There is potential for improving care if care partners and families can be more effectively engaged through the electronic health record; this can be accomplished without undermining patient privacy or the security of protected health information. <http://jama.jamanetwork.com/article.aspx?articleid=1810285>

The Nurse Practitioner and policy in end-of-life care

NURSE SCIENCE QUARTERLY, 2014;27(1):170176. The focus of this column is the interface between policy and end-of-life care, particularly as provided by advanced nurse practitioners. The complexities of end-of-life along with barriers in practice can diminish quality of life for patients and their families. Changes in policy are needed to enable nurse practitioners their full scope of practice in a way that benefits patients and families at end-of-life. Three areas particularly relevant to policy for nursing practitioners and end-of-life care are addressed: scope of practice, reimbursement, and prescribing practices. Other recommendations for policy and end-of-life care are discussed. <http://nsq.sagepub.com/content/27/1/70.abstract>

Complicated grief – a challenge in bereavement support in palliative care: An update of the field

PROGRESS IN PALLIATIVE CARE | Online – Accessed 8 January 2014 – Until a distinctive and clearly defined concept of complicated grief exists and validated assessment tools are applicable, attention to new effective interventions is of vital importance in the provision of bereavement care. Bereavement counsellors in palliative care need to work to provide a clearer platform for evidence-based treatments for complicated grief within the remit of palliative care, or the lack of focus on complicated grief in palliative care is a complicating factor for the bereaved caregivers. <http://www.maneyonline.com/doi/abs/10.1179/1743291X13Y.0000000078>

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Of related interest:

- *SOCIAL WORK* | Online – 1 January 2014 – **'Witness to suffering: Mindfulness and compassion fatigue among traumatic bereavement volunteers and professionals.'** Compassion fatigue comprises ... secondary traumatic stress and burnout. Because prior research suggests that compassion satisfaction may protect against compassion fatigue, the authors hypothesized that a) mindfulness would be positively correlated with compassion satisfaction; b) mindfulness would be inversely correlated with compassion fatigue; and, c) there would be differences between respondents with a personal history of traumatic bereavement and those with no such history. <http://sw.oxfordjournals.org/content/early/2014/01/01/sw.swt044.abstract>

Improving the organization of palliative care by implementing quality indicators and national and setting-specific interventions: Study protocol of the IMPACT project

PROGRESS IN PALLIATIVE CARE | Online – Accessed 8 January 2014 – There is a wide gap between knowledge about palliative care and its application in everyday clinical practice, affecting many patients in our ageing population. However, changing health care practice is a complex and challenging process. Therefore, the European Union funded IMplementation of quality indicators in PAlliative Care sTudy (IMPACT) project aims to develop optimal implementation strategies to improve the organization of palliative care for people with cancer or with dementia in Europe. <http://www.maneyonline.com/doi/abs/10.1179/1743291X13Y.0000000080>

Noted in Media Watch, 22 July 2013, #315 (p.13):

- *PALLIATIVE MEDICINE* | Online – 16 July 2013 – **'Validation of quality indicators for the organization of palliative care: A modified RAND Delphi study in seven European countries (the Europall project).'** No international set of quality indicators to measure the organizational aspects of palliative care settings exists. In total, five were rated as useful [by the authors]. These ... concerned: definition of a palliative care service, accessibility to palliative care, specific infrastructure to deliver palliative care, symptom assessment tools, specific personnel in palliative care services, documentation methodology of clinical data, evaluation of quality and safety procedures, reporting of clinical activities, and education in palliative care. <http://pmj.sagepub.com/content/early/2013/07/15/0269216313493952.abstract>

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

Towards compassionate care through aesthetic rationality

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online – 6 January 2014 – The Francis Report¹ ... revealed that while the [Staffordshire National Health] Trust [in the U.K.] appeared to be compliant with the standards set by official regulating bodies, the quality of care provided to patients was often appalling. While the Report constituted a "critical moment" in health care, its findings resonated with widespread concern in the U.K. and elsewhere that health care is sometimes characterised by a lack of compassion. The Francis Report partially attributed this lack of compassion to a task-based culture which tended to prioritise the meeting of targets over the quality of care provided to patients. Older patients, in particular, were identified as being vulnerable to neglect. This qualitative study of hospice volunteers responds to concerns regarding the quality of organisational forms of care by considering how motivations to care may be sustained and enhanced within organisational contexts. Charitable and third sector organisations, such as the hospice in this study, have been identified as potentially relevant to other health and social care contexts precisely because they emphasise values such as altruism and goodwill. The authors' sociological approach suggests that altruism or compassion can be encouraged within contexts that emphasise a sociability of care. They argue that a sociability of care may be encouraged in organisational contexts if dominant understandings of rationality are extended through the incorporation of aesthetic rationality. <http://onlinelibrary.wiley.com/doi/10.1111/scs.12109/abstract>

1. 'Report of the Mid Staffordshire National Health Service Foundation Trust Public Inquiry,' February 2013. [Noted in Media Watch, 11 February 2013, #292 (p.5)] <http://www.midstaffspublicinquiry.com/report>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/1/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 Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

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>

Interventions concerning competence building in community palliative care services: A literature review

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online – 4 January 2014 – The review of the literature identified 15 publications which dealt with interventions regarding education and competence building. The publications represent individual studies, only two of which were controlled. All conclude that competence building has a positive effect according to the professionals. It is unknown whether or how patients and relatives feel a positive effect from the interventions just as it is unknown how the development of competencies has actually led to a more developed practice. The effect of local competence building in palliative care in the primary sector is lacking. Methods are needed to further examinations of how a competency has actually led to a more developed practice. <http://onlinelibrary.wiley.com/doi/10.1111/scs.12020/abstract>

Of related interest:

- *SCANDINAVIAN JOURNAL OF CARING SCIENCES* | Online – 4 January 2014 – **'The needs of informal caregivers of elderly people living at home: An integrative review.'** The inclusive nature of integrative review method enabled the authors to provide a good understanding of underlying issues on the needs of informal caregivers. Challenges ... are to broaden and enhance the scope of research ... to provide effective support to intervention projects, services, and care to informal caregivers. <http://onlinelibrary.wiley.com/doi/10.1111/scs.12019/abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BMC PALLIATIVE CARE* | Online – 8 January 2014 – **'Voluntary stopping of eating and drinking at the end of life: A systematic search and review giving insight into an option of hastening death in capacitated adults at the end of life.'** The terminally ill person's autonomy and control are important in preserving the quality of life in situations of unbearable suffering. Voluntary stopping of eating and drinking at the end of life has been discussed over the past 20 years as one possibility of hastening death. This article presents a systematic search and review' of published literature. <http://www.biomedcentral.com/content/pdf/1472-684X-13-1.pdf>
- *JOURNAL OF MEDICAL ETHICS* | Online – 3 January 2014 – **'Labelling of end-of-life decisions by physicians.'** Potentially life-shortening medical end-of-life practices ... remain subject to conceptual vagueness. This study evaluates how physicians label these practices by examining which of their own practices ... they label as euthanasia or sedation. In the vast majority of practices labelled as euthanasia, the self-reported actions of the physicians corresponded with the definition in the Belgian euthanasia legislation; practices labelled as palliative or terminal sedation lack clear correspondence with definitions of sedation as presented in existing guidelines. In these cases, an explicit life-shortening intention by means of drug administration was present in 21.6%, life shortening was estimated at more than 24 h in 51% and an explicit patient request was absent in 79.7%. Results suggest, unlike euthanasia, the concept of palliative or terminal sedation covers a broad range of practices in the minds of physicians. <http://jme.bmj.com/content/early/2014/01/03/medethics-2013-101854.abstract>

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