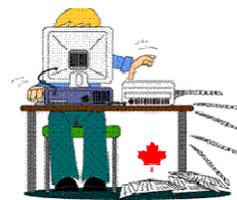


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

U.K. advocacy initiative: Scroll down to [Specialist Publications](#) and 'New guide published to help public hold politicians to account on end of life care' (p.6), posted by the National Council for Palliative Care.

[U.S.A.](#)

"Spotlights difficulties involved in making decisions"

Man at center of family's end-of-life care dispute dies

INDIANA | FOX News – 21 March 2013 – Paul Smith, 88, a former lawyer and magistrate from Carmel, died Monday night. He had been in a hospital since late December. His condition deteriorated, and doctors believed he was near the end of his life. In 2004, Smith drew up a living will naming his daughter, Judy Sly, as guardian. According to that directive, Smith did not want his life prolonged if such care served only to draw out his death. Another daughter, Susan Rissman, said she'd cared for her father for years and didn't agree with the doctors' assessment of her father's condition. She also claimed her father was being denied food and water. During a court hearing in January, doctors said Smith would likely die soon. He was taken off a ventilator, and his end-of-life directives were followed. Smith, however, did not die. He began asking for food and water, prompting Rissman to ask a court to intervene. Twice, she asked Hamilton Superior Judge Steven Nation to appoint an independent guardian to manage Smith's care. Last month, she appealed to Nation for an independent review of her father's care. Nation denied all three requests, citing Smith's existing living will. <http://fox59.com/2013/03/20/man-at-center-of-familys-end-of-life-care-dispute-dies/#axzz2OGgstStX>

Noted in Media Watch, 21 January 2013:

- INDIANA | *The Indianapolis Star* – 12 January 2013 – '**Battle over father's medical care spotlights difficulties involved in making decisions.**' The responses and requests uttered by the gravely ill Paul G. Smith from his bed at St. Vincent Hospital carry little weight. http://www.indystar.com/article/20130112/LIFE/301120336/End-life-case-splits-family?nclick_check=1

Patient wishes should guide end-of-life care, researchers say

USA NEWS & WORLD REPORT | Online – 21 March 2013 – Dying patients are happier, less depressed, have less pain and survive longer when their end-of-life care wishes are known and followed, researchers report.¹ This type of patient-centered care can also help keep health costs down for patients who don't want aggressive treatment, the University of California, Los Angeles research team said. "You can improve care while reducing cost by making sure everything you do is centered on what the patients want, what his or her specific goals are and tailor a treatment plan to ensure we provide the specific care he or she wants," Dr. Jonathan Bergman, a clinical scholar and fellow in the urology department, said. In many cases, dying patients are given aggressive treatments that don't help them and result in higher costs. Patients who want aggressive care should receive it, but many don't want it and haven't been asked about their wishes ... who are testing patient-centered care on cancer patients. To change the situation, doctors need to be educated about patient-centered care, the researchers said. <http://health.usnews.com/health-news/news/articles/2013/03/21/patient-wishes-should-guide-end-of-life-care-researchers-say>

1. 'Improving value by emphasizing patient-centered care at the end of life,' *JAMA Surgery*, 20 March 2013 – Medical care during life's final stages is often poorly coordinated and inattentive to patient preferences, typically owing to a failure to ascertain each individual's goals. <http://archsurg.jamanetwork.com/article.aspx?articleid=1670370>

Serious questions about patient care at San Diego Hospice

CALIFORNIA | KPBS News (San Diego) – 19 March 2013 – Patient eligibility and money weren't the only problems at San Diego Hospice, poor patient care almost cost the business its Medicare contract in 2012. Documents obtained by the KPBS and *inewssource* Investigations Desk provide the first indication that questions about patient care, not just problems with documentation and eligibility, were plaguing one of the country's oldest and most respected hospices. Inspection reports obtained through the Freedom of Information Act revealed various kinds of violations: patients were given the wrong doses of medication, one man had bedsores and was lying in his own blood, and nearly 800 patients were sent home with poorly labeled syringes that could have put them at risk of an overdose. <http://www.kpbs.org/news/2013/mar/19/san-diego-hospice-nearly-lost-medicare-contract-be/>

Noted in Media Watch, 11 February 2013:

- CALIFORNIA | *U-T San Diego* – 4 February 2013 – '**San Diego Hospice files for bankruptcy.**' The Hospice's financial problems began in mid-November, when it revealed it faced the possibility of refunding millions to Medicare because its admissions policies did not follow ... guidelines closely enough. <http://www.utsandiego.com/news/2013/feb/04/hospice-files-for-bankruptcy/>

Noted in Media Watch, 21 January 2013:

- CALIFORNIA | *Kaiser Health News* – 16 January 2013 – '**Slowly dying patients, an audit and a hospice's undoing.**' Across the country, hospices with generous admissions policies may find themselves on life support too. Medicare, which heavily funds hospice programs, is cracking down on the industry's growing habit of embracing those whose deaths aren't imminent. <http://www.kaiserhealthnews.org/Stories/2013/January/16/san-diego-hospice.aspx>

Specialist Publications

'How to talk about hospice' (p.8), in *American Medical News*.

'New palliative care guidelines stress certification, diversity' (p.9), in *Internal Medicine News*.

'Curiosity killed the cat: Generating curiosity in palliative care' (p.9), in *Psychodynamic Practice: Individuals, Groups & Organisations*.

For elderly patients, CPR unlikely to be the right medicine

CALIFORNIA | *Portland Press Herald* (Maine) – 19 March 2013 – The 911 call last month that led to an emergency dispatcher begging workers at a Bakersfield, senior living facility to perform CPR on a woman captured the attention of the public. A staff worker told the dispatcher it was against the facility's policy to intervene. The woman, Lorraine Bayless, died. It is difficult to understand how liability concerns could dissuade anyone from helping a person in distress. However, this stark event should awaken us to another question: Should we be performing CPR on 87-year-olds in a community setting such as a senior home? It is very likely that performing CPR on Bayless would not have served her well. Studies of CPR performed on individuals 85 years and older who suffer cardiac arrest in a community setting show that few – perhaps 4 in 100 – survive to leave the hospital, and the majority of these "survivors" are moderately to severely neurologically compromised. For the small number of elderly patients who survive the ambulance ride to the hospital and then make it through the emergency room to be admitted to the intensive care unit, treatment is nearly always burdensome, including being attached to life-sustaining machines. Only rarely does such treatment yield continued life meaningful to the patient. http://www.pressherald.com/opinion/for-elderly-patients-cpr-unlikely-to-be-the-right-medicine_2013-03-19.html

Noted in Media Watch, 11 March 2013:

- *USA TODAY* | Online – 7 March 2013 – **'CPR death highlights end-of-life decision.'** Independent living facilities and assisted living facilities often advertise their medical/nursing care as a reason to place mom or dad into their facility. Many such facilities routinely promote the presence of 24-hour nursing availability, assistance with medication delivery, and the provision of custodial and rehabilitation services in addition to room and board. With such claims, consumers might understandably, but erroneously, believe these homes are health care facilities. <http://www.usatoday.com/story/opinion/2013/03/07/cpr-health-care/1965889/>

End-of-life care and the news media

Writing about the end of life: May not be fun, but it is important

HEALTH JOURNALISM | Online – 16 March 2013 – Writing about death, and the care people receive at the end of their lives, isn't fun, but it's important, Lisa Krieger, a science and medicine writer for the *San Jose Mercury News*, said at the recent Association of Health Care Journalists' conference 'Health Journalism 2013.' "It matters to us," Krieger said. "It matters to the dying and it really matters to the surviving." Krieger moderated a panel featuring Muriel Gillick, a physician at Harvard Vanguard Medical Associates, and Ellen Goodman, the co-founder of a project that encourages people to talk about their end-of-life care wishes. <http://healthjournalism.org/blog/2013/03/writing-about-the-end-of-life-maybe-not-fun-but-important-ahcj13/>

N.B. Lisa Krieger and Dai Sugano won a prestigious award from the Association of Health Care Journalists for their work detailing how harsh the end-of-life experience can be and gentler ways to die. See **'Cost of Dying' series wins national health care journalism award,** noted in Media Watch, 4 March 2013. 'Cost of Dying' series: www.mercurynews.com/cost-of-dying

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>

Alzheimer's 'epidemic' now a deadlier threat to elderly

NATIONAL PUBLIC RADIO | Online – 19 March 2013 – Alzheimer's disease ... is now the sixth leading cause of death in the U.S., and figures released by the Alzheimer's Association show that deaths from the disease increased by 68% between 2000 and 2010.¹ "It's an epidemic, it's on the rise, and currently [there is] no way to delay it, prevent it or cure it," says Maria Carrillo, a neuroscientist with the Association. More than 5 million people in the U.S. have the disease, she says, and that number could reach nearly 14 million by 2050. One reason Alzheimer's deaths are going up is that deaths from other causes, like heart disease and prostate cancer, are going down, Carrillo says. <http://www.npr.org/blogs/health/2013/03/19/174651566/alzheimers-epidemic-now-a-deadlier-threat-to-elderly>

Noted in Media Watch, 14 January 2013:

- *END OF LIFE JOURNAL*, 2013;3(1). **'Talking about death in dementia.'** Although dementia may strip away memories and coherent verbal communication, it does not take away feelings, such as shame, embarrassment, pride, happiness, empathy, fear, anxiety, or the sense of... <http://endoflifejournal.stchristophers.org.uk/clinical-skills/communication-vignettes-talking-about-death-in-dementia>

N.B. Several articles on end-of-life care for people with dementia are noted in this issue of Media Watch (p.9).

Why Maryland needs hospice behind bars

MARYLAND | *The Washington Post* – 17 March 2013 – Over the past two years, dozens of Maryland prisoners have died at the hospital on the grounds of the former Maryland House of Correction in Jessup. The causes of death ranged from cancer to heart, liver and renal diseases to hepatitis to simple wear and tear on bodies damaged by decades of alcohol and drug abuse. Maladies, in other words, that warranted hospice care. But these men died scared and alone. No friends or family could sit vigil with them; no hospice volunteers offered them comfort. Granted, these men committed crimes against the people of Maryland, so they were where they were as a result of their own actions. But American justice forbids cruel punishment. It is cruel to make a man face death alone. http://www.washingtonpost.com/opinions/why-maryland-needs-hospice-behind-bars/2013/03/15/db5139e8-762e-11e2-95e4-6148e45d7adb_story.html?wprss=rss_localopinions

Extract from *The Washington Post* article

Those of us living behind bars become shadows of humanity. In life, we are greatly diminished. When death beckons, the specter of fear takes hold. I ask that you allow us the simple dignity of hospice care so that we don't have to face that fear alone.

N.B. The writer is serving two life terms at Jessup Correctional Institution.

Of related interest:

- WYOMING | *Star-Herald* (Scottsbluff, Nebraska) – 24 March 2013 – **'Hospice offered behind prison walls.'** The end-of-life journey is being made easier for inmates at the Wyoming Medium Correctional Institution, thanks to a new program that involves staff, other inmates and patient family members. http://www.starherald.com/news/local_news/hospice-offered-behind-prison-walls/article_0017c032-943c-11e2-9e79-001a4bcf887a.html

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.13.

Supporting our caregivers: America's invisible health care workforce

USA TODAY | Online – March 2013 – Most people think of family caregiving as taking care of an elderly person — maybe your mother with Alzheimer's disease or your husband who has had a heart attack. But family caregiving actually occurs in all kinds of life situations: from the parents of children with special needs, to the families and friends of wounded soldiers; from a partner coping with cancer, to a young couple dealing with a diagnosis of MS. Some caregivers are in the "sandwich generation" – caring for their elderly parents while they have children of their own at home. http://seniorcare2share.com/wp-content/uploads/2013/03/usatoday_supplement.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CONNECTICUT | CBS News (Hartford) – 20 March 2013 – '**Connecticut assisted suicide bill gets legislative hearing for first time in State's history.**' The bill is modeled after assisted suicide measures already on the books in Oregon, Washington and Montana. <http://newyork.cbslocal.com/2013/03/20/conn-assisted-suicide-bill-gets-legislative-hearing-for-first-time-in-states-history/>

International

End-of-life care in Australia

Two beds must soothe shortfall

AUSTRALIA (NEW SOUTH WALES) | *The Daily Advertiser* (Wagga Wagga) – 20 March 2013 – Only two beds will be funded by the state government for public patients under Calvary Hospital's newly approved eight-bed palliative care unit. Concerns have been raised about whether this would be enough to cater for Wagga's growing population and the city's desperate need for accessible hospice-style palliative care. This does not restrict patients to just two beds, but equates to servicing 50 terminally ill patients over 12 months. Currently there are no palliative care beds in Wagga. The \$282 million hospital redevelopment will not change this situation, once completed in 2016. <http://www.dailyadvertiser.com.au/story/1372283/two-beds-must-soothe-shortfall/?cs=147>

Noted in Media Watch, 11 March 2013:

- AUSTRALIAN ASSOCIATED PRESS | Online – 4 March 2013 – '**Dying let down by health system: Report.**' Australians are being let down as they near the end of their life.¹ <http://au.news.yahoo.com/latest/a/-/latest/16292553/dying-let-down-by-health-system-report/>

1. 'Meeting end-of-life care needs for people with chronic disease: Palliative care is not enough,' *Medical Journal of Australia*, 2013;198(4):186-187. Using the term end-of-life care rather than palliative care could help to change health professionals' attitudes to the skills and training they require. <https://www.mja.com.au/journal/2013/198/4/meeting-end-life-care-needs-people-chronic-disease-palliative-care-not-enough>



Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

End of life care in the U.K.

New guide published to help public hold politicians to account on end of life care

U.K. (ENGLAND, WALES & NORTHERN IRELAND) | National Council for Palliative Care (NCPC) – 20 March 2013 – The NCPC and Marie Curie Cancer Care have jointly published a guide to help the public hold politicians to account on end of life care [see sidebar right]. '10 questions to ensure good end of life care in your area' aims to help people in their localities scrutinise and challenge MPs, GP Commissioners, councillors and other decision makers regarding end of life care. Questions include: 'What are people saying about the quality of care their loved ones have received locally?' and 'What support is available locally for carers of people approaching the end of life, including bereavement?' After each question, the booklet explains its relevance and what else could be asked, and provides links to further resources. With almost 600,000 people dying in the U.K. each year, and millions more directly affected by the death of someone close to them, the guide is intended to help ensure end of life care is a priority at a local level. <http://www.ncpc.org.uk/sites/default/files/10%20Questions.pdf>

Time running out for Health & Wellbeing Boards to consider needs of dying people

U.K. (ENGLAND, WALES & NORTHERN IRELAND) | National Council for Palliative Care (NCPC) – 21 March 2013 – With just two weeks to go until England's 152 Health & Wellbeing Boards take on new legal responsibilities as part of the Government's health reforms, almost half have failed to set out what they will do to meet the needs of dying people, according to the NCPC. 'Does dying matter to England's new Health & Wellbeing Boards?' finds of Boards who have made public their strategy only just over half (63 out of 117) had explicitly discussed end of life care ... despite the fact on average almost 3,000 people each year will die in the local authority area covered by a Health Wellbeing Board. <http://www.ncpc.org.uk/sites/default/files/NCPC%20Mapping%20EOLC%20Health%20and%20Wellbeing%20strategy%20briefing%20Feb2013.pdf>

Integration of health and social services in the U.K.

Greater focus on prevention and integration essential to improve Care & Support Bill, warn Peers and MPs

U.K. (ENGLAND) | Joint Parliamentary Committee on the Draft Care & Support Bill – 19 March 2013 – A cross party group of MPs and Peers warns that the Government has not fully thought through the implications of its social care reforms and may leave local authorities open to a deluge of disputes and legal challenges. In a unanimous report, MPs and Peers also warn that without greater integration with health and housing, and a focus on prevention and early intervention, the care and support system will be unsustainable. The Committee also calls for a nationwide campaign to educate people about the need to pay for their own care, saying that adult care and support are poorly understood. <http://www.parliament.uk/business/committees/committees-a-z/joint-select/draft-care-and-support-bill/news/report-publication/>

Noted in Media Watch, 11 July 2011:

- POLITICS U.K. | Online – 4 July 2011 – **'The middle England issue: Report aims to fix elderly care.'** Those who lose their assets to pay for social care may be protected if the government accepts the findings of a major report.¹ Andrew Dilnot's report on elderly care argues that spending on people's care costs should be capped at £35,000, although it accepts any level between £25,000 and £50,000. <http://www.politics.co.uk/news/2011/07/04/the-middle-england-issue-report-aims-to-fix-e>

1. *Fairer Care Funding*, The Report of the Commission on Funding of Care & Support, July 2011. <https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf>

Cont.

Noted in Media Watch, 4 July 2011:

- U.K. | *The Daily Telegraph* – 1 July 2011 – **'100,000 terminally ill 'do not get proper palliative care.'** Almost 100,000 terminally ill people do not get proper care, according to a review which concluded a new funding system would save millions of pounds and better serve individuals.¹ <http://www.telegraph.co.uk/health/healthnews/8610266/100000-terminally-ill-do-not-get-proper-palliative-care.html>

1. *Palliative Care Funding Review: Funding the Right Care & Support for Everyone*, July 2011. <http://palliativecarefunding.org.uk/wp-content/uploads/2011/06/PCFRFinal%20Report.pdf>

End-of-life care in Ireland

No funding for hospice beds

IRELAND | *Dublin People* – 18 March 2013 – Part of a multi-million euro Northside hospice is to remain closed as funding cannot be provided to open its 24 palliative care beds. The state-of-the-art St. Francis Hospice in Blanchardstown was built to provide specialist end-of-life care. But its desperately needed palliative unit cannot open due to a shortfall of over €4 million. The unit, consisting of 24-ensuite bedrooms, was to be an integral part of the facility but it now lies idle despite an urgent demand for its beds. <http://www.dublinpeople.com/article.php?id=2185&l=100>

Noted in Media Watch, 28 January 2013:

- IRELAND | *Belfast Telegraph* – 21 January 2013 – **'Palliative care a postcode lottery.'** Terminally ill patients are denied adequate palliative care depending on where they live.¹ <http://www.belfasttelegraph.co.uk/news/local-national/republic-of-ireland/palliative-care-a-postcode-lottery-16264166.html>

1. *Evaluation: Programme to Support Palliative and Hospice Care in the Republic of Ireland: Final Report*, Trinity College Dublin, January 2013. [Noted in Media Watch, 21 January 2013] http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation_Programme_Support_Palliative_and_Hospice_Care_%20Republic_of_Ireland.pdf

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

Does end-of-life decision making matter? Perspectives of the older homeless adults

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 21 March 2013 – This qualitative pilot study explored perspectives, needs, and concerns relating to advance care planning among older homeless adults. Key emergent themes included discomfort with the topic, trust in God's decisions, physicians preferred as decision makers, and planning is important but not an immediate concern. Further, people who are homeless want to be approached with sensitivity. Instead of simply eliciting life-sustaining treatment preferences of homeless people, health care professionals should assess their unique concerns and needs regarding death and dying, prepare them to consider their possible end-of-life situation, and assist them to plan in accordance with their needs. <http://ajh.sagepub.com/content/early/2013/03/15/1049909113482176.abstract>

Noted in past issues of Media Watch:

- *BMC Palliative Care* | Online – 15 September 2012 – **'Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals.'** Changes in the rules and regulations that reflect the health needs and circumstances of homeless persons and measures to improve continuity of care have the potential to increase equity in the end-of-life care system for this underserved population. <http://www.biomedcentral.com/content/pdf/1472-684X-11-14.pdf>

Cont.

- *American Journal of Hospice & Palliative Medicine* | Online 5 June 2012 – '**A qualitative study of homelessness and palliative care in a major urban center,**' The findings suggest that in order to increase access and to serve the city's terminally ill homeless better, the following areas must be addressed: 1) increasing positive interaction between the health care system and the homeless; 2) training staff to deal with the unique issues confronting the homeless; 3) providing patient-centered care; and, 4) diversifying the methods of delivery. <http://ajh.sagepub.com/content/early/2012/06/03/1049909112448925.abstract>

How to talk about hospice care

AMERICAN MEDICAL NEWS | Online – 18 March 2013 – About once a year, a patient or family member will "jump up and just walk out of the room when I mention hospice," says David Casarett, MD, chief medical officer of the University of Pennsylvania Health System's hospice program. "They will say: 'We came to Penn for the best possible treatment. You were supposed to save Dad's life, and now you're giving up on him. How dare you do that to my father!'" Even though such harsh reactions may be the exception, Dr. Casarett says, they are enough to make many doctors uneasy about bringing up hospice – a program that offers at-home nursing care, pain and symptom relief, spiritual counseling and other services but typically requires patients to forgo disease-directed treatments that aim to extend survival time. "Physicians don't want to cause that sort of distress," says Dr. Casarett. "We're basically nice people. We don't want to walk in and start a conversation that will make a person start crying." <http://www.amednews.com/article/20130318/profession/130319945/4/>

Cont. next page

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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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.

Of related interest:

- *PSYCHODYNAMIC PRACTICE: INDIVIDUALS, GROUPS & ORGANISATIONS* | Online – 15 March 2013 – **'Curiosity killed the cat: Generating curiosity in palliative care.'** A large part of my clinical psychology role involves supervising doctors, nurses and allied health professionals. In supervision, I am trying to create a context where one's looking away can be acknowledged, and the unbearable can be thought about. This is a difficult and delicate task. As well as curiosity opening up new possibilities for thought and action it also means facing anxieties about death and dying ... [which] ... permeate this work and often reduce one's capacity to think and be creative which can lead to a feeling of being helpless, useless and stuck. <http://www.tandfonline.com/doi/abs/10.1080/14753634.2013.771569?journalCode=rpco20>

End-of-life care in India

The high cost of dying

ECONOMIC & POLITICAL WEEKLY, 2013;48(11):44-49. The cost of the inpatient care of decedents is much higher than that of survivors at all stages of life. The differential is significantly higher for those residing in rural areas, staying longer in hospitals, utilising private health facilities and suffering from chronic diseases. The difference is due to physicians in private hospitals prescribing more expensive drugs, subjecting patients to more clinical tests and higher charges on utilisation of amenities and facilities. The economically better-off spend more on healthcare and the end-of-life care. http://www.epw.in/system/files/pdf/2013_48/11/The_High_Cost_of_Dying.pdf

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

New palliative care guidelines stress certification, diversity

INTERNAL MEDICINE NEWS | Online – 22 March 2013 – New palliative care guidelines encourage discipline-specific certification for each of the major disciplines in a palliative care program, even for chaplaincy. The guidelines are critical in raising the bar to guide the training of professionals and the development of programs, said Dr. Diane Meier, coleader of the National Consensus Project for Quality Palliative Care, which released the guidelines during the recent annual meeting of the American Academy of Hospice & Palliative Medicine. Since the guidelines' last revision in 2009, the Accreditation Council for Graduate Medical Education recognized hospice and palliative medicine as a subspecialty of 11 different parent boards. That paved the way for the development of hospice and palliative medicine fellowships, now an eligibility requirement for the board certification exams. This year, the Centers for Medicare & Medicaid Services also began implementing an annual quality reporting program for hospice organizations that includes a financial incentive for hospice provider participation. Data from roughly 600 hospitals are also filed with the Center to Advance Palliative Care, which releases a report card on access to palliative care in U.S. hospitals. <http://www.internalmedicineneeds.com/single-view/new-palliative-care-guidelines-stress-certification-diversity/bbefdbef54ee9446c9a13e25acc62348.html>

Palliative care consultations for heart failure patients: How many, when, and why?

JOURNAL OF CARDIAC FAILURE, 2013;19(3):193-201. In preparation for development of a palliative care intervention for patients with heart failure (HF) and their caregivers, the authors aimed to characterize the HF population receiving palliative care consultations (PCCs). Reviewing charts from January 2006 to April 2011 ... 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. [http://www.onlinejcf.com/article/S1071-9164\(13\)00030-4/abstract](http://www.onlinejcf.com/article/S1071-9164(13)00030-4/abstract)

Cont.

Noted in Media Watch, 7 January 2013:

- *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 PC and many participants felt that PC services are needed to fill the gaps in their care. [http://www.heartandlung.org/article/S0147-9563\(12\)00398-6/abstract](http://www.heartandlung.org/article/S0147-9563(12)00398-6/abstract)
- *HOME HEALTHCARE NURSE*, 2013;31(1):29-36. **'Uncertainties of the heart: Palliative care and adult heart failure.'** 11 of 16 articles reviewed indicated palliative care is underused. http://journals.lww.com/homehealthcarenurseonline/Abstract/2013/01000/Uncertainties_of_the_Heart_Palliative_Care_and.6.aspx

Noted in Media Watch, 1 October 2012:

- *EUROPEAN JOURNAL OF AGEING* | Online – 22 September 2012 – **"Who is going to explain it to me so that I understand?" Health care needs and experiences of older patients with advanced heart failure.** Heart failure was not recognized as a potentially life-limiting disease, and the patients had no experience with palliative care services. The study emphasizes the need for improving communication with patients with advanced heart failure. <http://www.springerlink.com/content/4001j18092105526/>

Keeping cancer patients out of the hospital at the end of life

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2013; 11(3):229-230. Caring for patients at the end of life is perhaps the most noble of the medical arts and for oncologists it is a daily reality. All too often, cancer takes a deadly toll, and oncologists are actively engaged in the management of the dying patient. Such care includes treatment with appropriate therapies and referral to specialists for appropriate palliative interventions. But these treatment decisions are the "easy" part of medical care for the clinical team. The more challenging tasks lie in communicating to patients and their families what can – and cannot – be achieved and what the future is likely to hold. Those conversations depend on familiarity with the disease but also on familiarity with the person who has the disease: understanding their preferences, social supports, financial circumstances, cogni-

tive function, and personality. Patients know a lot about one aspect, which is their own preference for the place of death. <http://www.jnccn.org/content/11/3/229.extract>

Patient dying in hospital: An honoured guest in an honoured place?

QJM | Online – 13 March 2013 – [In *Modern Hospice Design: The Architecture of Palliative Care* (London: Routledge, 2009)] Ken Worpole reviewed the architecture and design of hospital spaces in which the dying find themselves. The idea of hospital being an honoured place with dying patients as honoured guests opens a new window into our daily reality of working in hospitals. <http://qjmed.oxfordjournals.org/content/early/2013/03/13/qjmed.hct064.extract>



A prospective study of family conferences: Effects of patient presence on emotional expression and end-of-life discussions

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 18 March 2013 – Limited research has taken place examining family conferences (FCs) with patients with advanced cancer and their caregivers in the palliative care setting. Patients [in this study] verbalized distress frequently (73%). Primary caregiver's verbal expression of emotional distress was high (82%), but not significantly affected by the patient presence. Verbal expressions of emotional distress by other family members were more common when patients were absent (87%) than when present (73%). Questions concerning advance directives (21%), symptoms anticipated at death (31%), and caregiver well-being (29%) were infrequent. Patient presence was significantly associated with increased discussions regarding goals of care and decreased communication concerning prognosis and what symptoms dying patients may experience. There was a high frequency of expression of emotional distress by patients and family members in FCs. Patient participation was significantly associated with decreased verbal emotional expression by family members but not the primary caregiver and was associated with

fewer discussions regarding the prognosis and what dying patients may experience. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00103-6/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00103-6/abstract)

The family conference

'The Family Conference,' one of three videotaped lectures I gave during my visit in 2012 to Singapore, can be viewed at the Centre for Biomedical Ethics website: <http://centres.sg/node/116>

On CENTRES' website is a posting of related interest. Under 'What's New' is a link to 'Preparing to Die at Home: Information for the Caregiver,' the first in a series of booklets published some years ago, an initiative of the palliative care team at Cambridge Memorial Hospital, Ontario, Canada: http://www.centres.sg/sites/default/files/Journeys_Booklet1.pdf

My visit to Singapore was at the invitation of the Centre for Biomedical Ethics, at the National University of Singapore, and the Lien Centre for Palliative Care, Duke-NUS.

Barry R. Ashpole

Noted in Media Watch, 17 January 2011:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 14 January 2011 – 'Is the patient's voice under-heard in family conferences in palliative care? A question from Sydney, Australia.' The patient's voice [in this study] was not always clearly heard and not always documented. This raises practical questions about the documentation of that voice in the various types of family interactions that occur in palliative care settings. Importantly, it also raises ethical questions about the place of the principle of "respect for patient autonomy" in the family conference setting. [http://www.jpsmjournal.com/article/S0885-3924\(10\)00983-8/fulltext](http://www.jpsmjournal.com/article/S0885-3924(10)00983-8/fulltext)

If you had less than a year to live, would you want to know? A seven-country European population survey of public preferences for disclosure of poor prognosis

PSYCHO-ONCOLOGY | Online – 18 March 2013 – Among 9344 respondents [to this population based survey], data revealed an international preference (73.9%) to always be informed in the scenario of having a serious illness such as cancer with less than a year to live. This varied from 67.6% in Italy to 80.7% in Flanders. A minority (21.1%) did not want such information unless they ask, or at all. People younger than 70 years, men, those with experience of illness and with more education were more likely to want to know of limited time left. The models confirmed the influence of four factors in more than one country (age, gender, education and most concerning problem) and added 11 country-specific factors to which national policies and clinical practice should respond. These findings confirm a majority public preference to be informed in a scenario of poor prognosis. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3283/abstract>

Cont.

Of related interest:

- *PSYCHO-ONCOLOGY* | Online – 15 March 2013 – **'Does awareness of terminal status influence survival and quality of life in terminally ill cancer patients?'** Awareness of prognosis may negatively impact survival and quality of life in terminally ill cancer patients. The patient's preference for and individual susceptibility to receiving such information should be assessed carefully before disclosure. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3275/abstract>

Changes in end of life care 5 years after the introduction of a Rapid Response Team: A multicentre retrospective study

RESUSCITATION | Online – 18 March 2013 – Rapid Response Teams (RRTs) are intended to stabilize deteriorating patients on the ward, but recent studies suggest that RRTs may also improve end-of-life care (EOLC). The authors sought to study the effect of introducing an RRT on EOLC at their respective institutions, and compare the EOLC care received by patients who were consulted by the RRT with that of patients who were not consulted by the RRT. The introduction of an RRT was not associated with significant improvements in EOLC at our institutions. [http://www.resuscitationjournal.com/article/S0300-9572\(13\)00154-8/abstract](http://www.resuscitationjournal.com/article/S0300-9572(13)00154-8/abstract)

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[Media Watch Online](#)

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: <http://www.palliativecarewa.asn.au/news.php> (Scroll down to 'International palliative care news and journal articles')

Canada

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

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

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

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

Europe

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

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

International

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>

Noted in Media Watch, 28 January 2013:

- *JOURNAL OF CRITICAL CARE* | Online – 22 January 2013 – '**Rapid response teams, do not resuscitate orders, and potential opportunities to improve end-of-life care.**' In a retrospective review, the typical consultation was for an elderly patient with chronic illness. More than 90% had a "full resuscitation" order at the time of consultation. Among those who changed their resuscitation order, fewer than 20% were referred to the palliative care or spiritual care service, or prescribed comfort medications as needed, within 48 hours of the RRT consultation. [http://www.jccjournal.org/article/S0883-9441\(12\)00329-2/abstract](http://www.jccjournal.org/article/S0883-9441(12)00329-2/abstract)

Worth Repeating

Existential loneliness and end-of-life care: A systematic review

THEORETICAL MEDICINE & BIOETHICS, 2010;31(2):141-169. Patients with a life-threatening illness can be confronted with various types of loneliness, one of which is existential loneliness (EL). Since the experience of EL is extremely disruptive, the issue of EL is relevant for the practice of end-of-life care. Still, the literature on EL has generated little discussion and empirical substantiation and has never been systematically reviewed. In order to systematically review the literature, the authors 1) identified the existential loneliness literature; 2) established an organising framework for the review; 3) conducted a conceptual analysis of existential loneliness; and, 4) discussed its relevance for end-of-life care. They found that the EL concept is profoundly unclear. Distinguishing between three dimensions of EL – as a condition, as an experience, and as a process of inner growth – leads to some conceptual clarification. Analysis of these dimensions on the basis of their respective key notions – ever present, feeling, defence; death, awareness, difficult communication; and inner growth, giving meaning, authenticity – further clarifies the concept. http://download.springer.com/static/pdf/368/art%253A10.1007%252Fs11017-010-9141-1.pdf?auth66=1364404881_76135805b20d3e814fd2c412b2834208&ext=.pdf

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