

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

The illness experience: Scroll down to [Specialist Publications](#) and 'Improving the spiritual dimension of whole person care: Reaching national and international consensus' (p.12), in *Journal of Palliative Medicine*.

Canada

Palliative sedation: The new debate over end-of-life treatment in Canada

CBC | The Current – 20 May 2014 – Palliative sedation is an end-of-life treatment that renders terminally-ill patients unconscious in the last stages of dying. It is used to alleviate excruciating pain, but some call it a form of "slow euthanasia," and say it may even hasten death. Debate around end-of-life care in Canada is emotional and fraught with tension. However, one thing most of us can probably agree on is that when the time comes, we hope our death would be a quick and painless one. When someone has a terminal illness, doctors have an arsenal of drugs to make patients comfortable. But sometimes, these drugs aren't enough to ease the pain. <http://www.cbc.ca/thecurrent/episode/2014/05/20/palliative-sedation-the-new-debate-over-end-of-life-treatment-in-canada/>

Of related interest:

- CBC NEWS | Online – 21 May 2014 – **'Palliative sedation creating debate over end-of-life treatment.'** Dr. Jose Pereira, the medical chief of palliative care at the Ottawa Hospital and Bruyère Continuing Care in Ottawa, has used palliative sedation and said it is an important and useful option that is only used when symptoms such as pain, breathlessness or delirium are intolerable. Pereira added the symptoms must also be refractory, meaning all other drugs that have been tried have failed to control the symptoms. The treatment is seen by some health experts as blurring the lines between a sound clinical therapy and euthanasia. <http://www.cbc.ca/news/canada/ottawa/palliative-sedation-creating-debate-over-end-of-life-treatment-1.2648436>

Noted in Media Watch, 9 July 2012, #261 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 July 2012 – **'Framework for Continuous Palliative Sedation Therapy (CPST) in Canada.'** Canada does not have a standardized ethical and practice framework for continuous palliative sedation therapy. Canadian practice varies. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0498>

N.B. See additional articles on the issue of palliative (or terminal) sedation noted in past issues of Media Watch: 12 May 2014, #357 (pp.5-6), and 10 February 2014, #344 (pp.10-11).

Selling death

CBC | Under the Influence – 17 May 2014 – While death is usually a forbidden word in advertising, the subject of death is slowly becoming more mainstream. This episode looks at the one industry that truly specializes in it – the funeral business. From QR codes on headstones, to live cams on caskets, to fish reefs made from your ashes, funeral homes are starting to market brand new services to attract customers. 'Under the Influence' also looks at the recent popularity of death as entertainment, with the record-breaking audiences for The Walking Dead and a certain reality show called "Best Funeral Ever." <http://www.cbc.ca/undertheinfluence/season-3/2014/05/17/selling-death-1/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CBC News – 22 May 2014 – **'Dying with dignity bill restored by new Quebec government.'** Quebec's new Liberal government reintroduced the end-of-life care bill as it was before the [provincial] election call in March – when it was only steps away from its adoption. When elected in April with a majority government, Premier Philippe Couillard said the bill was a priority. The end-of-life care law would allow some forms of medical aid in dying. Liberal Health Minister Gaétan Barrette stood side-by-side with members of the National Assembly from the three other parties – showing unanimous support for what was known as Bill 52 "Between the four of us, we think the

bill will pass strongly," Barrette said. Parti Québécois [PQ] MNA Véronique Hivon, who was the PQ minister behind the original legislation, said the rare show of cooperation across party lines is reassuring. <http://www.cbc.ca/news/canada/montreal/dying-with-dignity-bill-restored-by-new-quebec-government-1.2651286>

Specialist Publications

'A right to voluntary euthanasia? Confusion in Canada in Carter' (p.15), in *Notre Dame Journal of Law, Ethics & Public Policy*.

U.S.A.

Bill could give terminally ill patients hope

MISSOURI | KSDK News (St. Louis) – 22 May 2014 – A bill passed by Missouri lawmakers is meant to give terminally ill patients one last shot. Supporters of the 'Right to Try' law say it could bring new hope to those left with none. [The 'Right to Try'] allows patients who have exhausted all Federal Drug Administration-approved options to try experimental treatments, even if they've only cleared the first phase of testing. Doctors at Siteman Cancer Center say this is a good thing, because right now, medical research and technology is moving faster than the approval process. Missouri is one of three states [the others being Colorado and Louisiana] where lawmakers have passed a 'Right to Try' bill this year. In Arizona, the issue will go to a public vote in November. <http://www.ksdk.com/story/news/local/2014/05/22/right-to-try-bill-hope/9463707/>

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.

Study shows senior health care improves nationally, but Louisiana 49th overall

LOUISIANA | KATC News (Lafayette) – 21 May 2014 – Although a nationwide study shows a general positive national trend in senior health care, Louisiana ranked 49th overall. Nationally, the report indicates declines in physical inactivity, improvements in quality of nursing home care, reductions in avoidable hospitalizations, and increased preparation for end-of-life care. The study rated Minnesota as the healthiest state for seniors for the second year... Hawaii ranked second, followed by New Hampshire, Vermont and Massachusetts. Mississippi is the least healthy state for seniors, followed by Louisiana (49), Kentucky (48), Oklahoma (47), and Arkansas (46). <http://www.katc.com/news/study-shows-senior-health-care-improves-nationally-but-louisiana-49th-overall/>

1. 'United Health Foundation's America's Health Rankings Senior Report 2014.' <http://www.americashealthrankings.org/senior>

Medicare hospice care coverage

All eyes on hospice care

THE NATIONAL LAW REVIEW | Online – 20 May 2014 – In 2013, the Department of Justice [DOJ] and the Office of Inspector General charged the nation's largest for-profit hospice chain, Vitas Innovative Hospice Care, with false Medicare billings, inappropriately admitting patients with "aggressive marketing tactics," and misleading patients and families about Medicare hospice benefits. This suit is just one of many recently filed against hospice providers, indicating that they are being watched keenly by enforcement authorities and government agencies. According to a report released in 2012 by the U.S. Department of Health & Human Services and the DOJ, Medicare spending on hospice care for nursing home residents increased by 70% between 2005 and 2011. In 2011 alone, Medicare spent \$13.7 million on hospice services in 2011. It should be no surprise in light of these high

spending on hospice care that audits will increase in order to reduce health care costs and curtail fraud and abuse. <http://www.natlawreview.com/article/all-eyes-hospice-care>

Specialist Publications

'Time to death and re-enrollment after live discharge from hospice: A retrospective look,' (p.8), in *American Journal of Hospice & Palliative Medicine*.

'Are advance directives associated with better hospice care?' (p.11), in *Journal of the American Geriatrics Society*

'Few hospices providing complementary and alternative medicine services to patients' (p.14), in *Medscape Medical News*.

Noted in Media Watch, 10 March 2014, #348 (p.5):

- *THE NEW YORK TIMES* | Online – 3 March 2014 – '**Differences in care at for-profit hospices.**' People who pay attention to hospice care have noticed ... two trends in recent years: 1) What began as a grass-roots movement to improve end-of-life care is becoming a business; and, 2) We've also seen hospice patients are increasingly likely to be disenrolled before they die. Patients are getting bounced as corporate bottom lines come to matter more. http://newoldage.blogs.nytimes.com/2014/03/03/differences-in-care-at-for-profit-hospices/?_php=true&_type=blogs&_r=0

1. 'National hospice survey results: For-profit status, community engagement, and service,' *JAMA Internal Medicine*, 24 February 2014. [Noted in Media Watch, 3 March 2014, #347 (p.9)] <https://archinte.jamanetwork.com/article.aspx?articleid=1832198>

N.B. Additional articles on for-profit hospices are noted in Media Watch 3 March 2014, #347 (p.4, pp.9-10) and 13 January 2014, #340 (pp.3-4).

Advance care program to be used in European study

Gundersen's 'Respecting Choices' program goes global

WISCONSIN | WKBT News (La Crosse) – 20 May 2014 – Gundersen Health System launched its end of life care program, Respecting Choices, back in 1993. Since then, hospitals across the country have adopted it. The Respecting Choices program makes that conversation about end-of-life care an ongoing one, so that patients and their families have a plan in place long before they end up in a hospital room. A group of people representing six European countries – the U.K., Amsterdam, Belgium, Denmark, Italy and Slovenia – are at Gundersen this week to learn the ins and outs of Respecting Choices. They're hoping to implement it in their own countries as part of an \$8.5 million study on end-of-life patient care – the biggest of its kind in advance care research. <http://www.news8000.com/news/gundersen-program-goes-global/26063430>

Noted in Media Watch, 10 March 2014, #348 (p.2):

- WISCONSIN | National Public Radio – 5 March 2014 – **'The town where everyone talks about death.'** In this community [of La Crosse], talking about death is a comfortable conversation – neighbors gossip about who on the block hasn't filled out their advance directive. <http://www.npr.org/blogs/money/2014/03/05/286126451/living-wills-are-the-talk-of-the-town-in-la-crosse-wis>

Understanding palliative care

Teaching doctors when to stop treatment

THE WASHINGTON POST | Online – 19 May 2014 – Patients and families often assume their doctors are trained and knowledgeable about end of life, and they assume that if the doctor recommends more tests and treatments, he or she thinks they will help in some way. Patients and families also assume that doctors will tell them when time is running out, what to expect and how best to navigate these unknown and frightening waters. But many doctors don't do these things. Most, in fact, have no training in this. Medical school and residency have traditionally provided little or no instruction on how to continue to care for patients when treatments no longer work. Physicians are trained to make diagnoses and to treat disease. Untrained in skills such as pain and symptom management, communication about what to expect in the future and achievable goals for care, physicians do what we have been trained to do: Order more tests, more procedures, more treat-

ments, even when these things no longer help. Even when they no longer make sense. So how do we fix this? http://www.washingtonpost.com/national/health-science/teaching-doctors-when-to-stop-treatment/2014/05/19/e643d190-caf5-11e3-93eb-6c0037d0e2ad_story.html

Extract from *The Washington Post* article

To change behavior, we must change the education and training of young physicians and the professional and clinical culture in which they practice. New doctors should learn about the management of symptoms such as pain, shortness of breath, fatigue and depression, with intensive training on doctor-patient communication: how to relay bad news, how to stand with patients and their families until death and how to help patients and families make the best use of their remaining time together.

N.B. This article is based on "I don't want Jenny to think I'm abandoning her": Views on overtreatment,' *Health Affairs*, 2014;33(5):895-898. <http://content.healthaffairs.org/content/33/5/895.full>

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Of related interest:

- *THE NEW YORK TIMES* | Online – 20 May 2014 – **'Do not resuscitate: What young doctors would choose.'** The researcher was presenting her findings to a room full of geriatricians... So a slide revealing one particular statistic didn't cause an audible gasp or murmur. Dr. V.J. Periyakoil, a geriatrics and palliative care specialist at Stanford University, was talking about her survey of nearly 1,100 physicians completing clinical training at two university-affiliated medical centers. Researchers asked what choices they would make for themselves if they were terminally ill. 88.3 percent would choose a do-not-resuscitate or "no code" status. http://newoldage.blogs.nytimes.com/2014/05/20/do-not-resuscitate-what-young-doctors-would-choose/?_php=true&_type=blogs&_r=0

The illness experience

Poll: More stressful to care for spouse than mom

THE WASHINGTON POST | Online – 19 May 2014 – You promise "in sickness and in health," but a new poll shows becoming a caregiver to a frail spouse causes more stress than having to care for mom, dad or even the in-laws.¹ Americans 40 and older say they count on their families to care for them as they age, with good reason: Half of them already have been caregivers to relatives or friends, the poll found. But neither the graying population nor the loved ones who expect to help them are doing much planning for long-term care. In fact, people are far more likely to disclose their funeral plans to friends and family than reveal their preferences for assistance with day-to-day living as they get older. And while 8 in 10 people who've been caregivers called it a positive experience, it's also incredibly difficult. http://www.washingtonpost.com/national/health-science/poll-more-stressful-to-care-for-spouse-than-mom/2014/05/19/74384a7c-df2c-11e3-9442-54189bf1a809_story.html

1. 'Long-Term Care in America: Expectations and reality,' The Associated Press-NORC Center for Public Affairs Research, May 2014. file:///C:/Users/Barry/Downloads/AP-NORC-Long-Term%20Care%20in%20America_FINAL%20WEB.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- VERMONT | *The Rutland Herald* – 22 May 2014 – **'Death with dignity law after one year.'** [Since the law was enacted in May 2013] two physicians have written prescriptions for a terminally ill, mentally competent adult patient ... according to the Vermont Department of Health. Both died from their illness and did not take the medication. One patient obtained a prescription, but did not pick it up at the pharmacy. While few people die by taking the prescribed medication, many people consider the option and are reassured that it exists. Some complete the eligibility process, but never take the medication. Many achieve comfort and peace of mind knowing they have a full range of end-of-life choices. For them, having what they call their "insurance policy" dramatically improves the quality of life's final days. <http://www.rutlandherald.com/article/20140522/OPINION04/705229941/1018/OPINION>



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>

International

Scrapping Liverpool Care Pathway too "extreme"

U.K. (England) | *The Daily Telegraph* – 22 May 2014 – Phasing out the use of the Liverpool Care Pathway because some doctors and nurses do not know how to use it properly is extreme, a leading ethicist has warned.¹ Dr. Anthony Wrigley, of the Centre for Professional Ethics, at Keele University [Staffordshire], said the use of morphine or insulin would not be stopped because some medical staff had used it incorrectly and it should be the same with The Liverpool Care Pathway.² The pathway was aimed at reducing unnecessary tests and treatments in a patient's final days and hours to ensure they die comfortably and peacefully. However cases were highlighted where patients were put on it when they were not dying, or were denied water and food. Often relatives were not informed patients were on the pathway at all. A review last year recommended it be phased out in favour of individual care

plans. Dr. Wrigley said care of the dying in Britain has been rated as the best in the world, partly because of The Liverpool Care Pathway and it should not be phased out. Medical staff should be properly trained in its use to ensure it is correctly applied. <http://www.telegraph.co.uk/health/healthnews/10845915/Scrapping-Liverpool-Care-Pathway-too-extreme.html>

Specialist Publications

'Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting' (p.15), in *Palliative Medicine*.

1. 'Ethics and end-of-life care: The Liverpool Care Pathway and the Neuberger Review,' *Journal of Medical Ethics*, 21 May 2014. <http://jme.bmj.com/content/early/2014/04/21/medethics-2013-101780.abstract>
2. *More care, less pathway: Review of Liverpool Care Pathway for dying patients* [in England], Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

Hospice "champions" could improve experiences of dying in hospital

U.K. (England) | *The Gazette* (Hemel Hempstead) – 21 May 2014 – The Berkhamsted-based Hospice of St Francis is launching a pioneering project which is hoped to improve patients' experiences of dying in hospital. The palliative care centre off Shootersway is working with Watford's Peace Hospice Care on a year-long "hospice champions" scheme, which will see specialist mentorship by a team of hospice workers on eight Watford General Hospital wards. The idea is to encourage hospital staff to deliver compassionate care and communication with end of life patients and their families. The project ... comes as a report from the Royal College of Physicians published last week revealed significant variations in the standards of care for people dying in hospitals across the country.¹ <http://www.hemeltoday.co.uk/news/local/hospice-champions-could-improve-experiences-of-dying-in-hospital-1-6070900>

1. 'National Care of the Dying Audit of Hospitals,' Royal College of Physicians, 14 May 2014. [Noted in Media Watch, 19 May 2014, #358 (p.3)]. <http://www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals>

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Representative sample of articles post-publication of the Royal College of Physicians audit:

- U.K. (England) | *Wigan Today* – 21 May 2014 – **'End of life care a priority.'** Wigan hospital chiefs say they are doing all they can to improve end of life care after criticism from doctors who say care levels are "deeply concerning." An audit of care given to more than 6,500 people who had died last year in 149 hospitals carried out by the Royal College of Physicians and Marie Curie found only a fifth of hospitals provided specialist end-of-life care seven days a week – 10 years after this was recommended. <http://www.wigantoday.net/news/local/end-of-life-care-a-priority-1-6628799>
- U.K. (England) | *Lancashire Telegraph* (Blackburn) – 20 May 2014 – **'East Lancs hospitals must do "a lot more work" to improve end-of-life care.'** The Royal College of Physicians found that East Lancashire Hospitals National Health Service Trust, along with most other trusts, has failed to offer "face-to-face" palliative care at weekends, despite a long-standing recommendation that this be provided. It also performed badly for the proportion of patients having necessary medication prescribed for the five key symptoms often experienced near the end of life – pain, agitation, noisy breathing, difficulty breathing, nausea and vomiting. This standard was met in just 34% of cases, compared to the national average of 51%. http://www.lancashiretelegraph.co.uk/news/11225468.East_Lancs_hospitals_must_do_a_lot_more_work_to_improve_end_of_life_care/?ref=var_0

Elder care in the U.K.

Close to home: An inquiry into older people and human rights in home care

U.K. (England) | Equality & Human Rights Commission – 15 April 2014 – The inquiry has found that although many older people receive care at home which respects and enhances their human rights, this is by no means a universal experience. It uncovered areas of real concern in the treatment of some older people and significant shortcomings in the way that care is commissioned by local authorities. <http://www.equalityhumanrights.com/publication/close-home-inquiry-older-people-and-human-rights-home-care>

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

National U.S. study

End-of-life and palliative care curricula in internal medicine clerkships: A report on the presence, value, and design of curricula as rated by clerkship directors

ACADEMIC MEDICINE | Online – 21 May 2014 – The purpose of this national study was to investigate the presence of formal EOL/PC curricula within IM clerkships; the value placed ... on this type of curricula; curricular design and implementation strategies; and, related barriers and resources. The response rate was 77.0% (94/122). Of those responding, 75.8% (69/91) believed such training should occur in the IM clerkship, and 43.6% (41/94) reported formal curricula in EOL/PC. Multiple instructional modalities were used to deliver this content, with the majority of programs dedicating four or more hours to the curriculum. Curricula covered a wide range of topics, and student assessment tools varied. Most felt students valued this education. The qualitative analysis revealed differences in the values ... placed on teaching EOL/PC within the IM clerkship. Although many IM clerkship directors have implemented formal curricula in EOL/PC, a substantial gap remains between those who have implemented and those who believe it belongs in the clerkship. Time, faculty, cost, and competing demands are the main barriers to implementation. http://journals.lww.com/academicmedicine/Abstract/publishahead/End_of_Life_and_Palliative_Care_Curricula_in.99065.aspx

Time to death and reenrollment after live discharge from hospice: A retrospective look

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 20 May 2014 – The author's research supports past findings that over a third of patients dis-enrolled from hospice die within 6 months, indicating ongoing hospice eligibility up to the time of death. Interestingly, if enrollment was revoked by patient or family, as often was done to allow the patient to pursue more aggressive treatments, the mortality risk was higher in the 6 months after discharge. This should prompt careful re-evaluation of dis-enrolled hospice patients in the months after disenrollment, and hospice reenrollment should be continually available and offered during this time. <http://ajh.sagepub.com/content/early/2014/05/19/1049909114535969.abstract>

Patient dignity and privacy

Preference for a single or shared room in a U.K. inpatient hospice: Patient, family and staff perspectives

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 15 May 2014 – Patients [i.e., study participants] most often stated a preference for a shared room, especially if they had experience of being in this room type at the hospice. The main reason ... was the company of others. Patients preferring single rooms cited the benefits of increased privacy, reduced noise and private facilities. Other patients said their room preference would depend on how ill they were. Carers valued the social contact and increased staff presence in shared rooms, but felt that single rooms were easier for visitors and more appropriate when patients reached the end of life. Staff found it easier to observe patients in a shared room, and to maintain privacy and confidentiality in a single room. The study concludes that single and shared rooms should be available in a hospice. Innovative planning can enable the social benefits of shared rooms to be maintained without compromising patients' privacy and dignity. <http://spcare.bmj.com/content/early/2014/05/15/bmjspcare-2013-000514.short>

"Curative" treatments and palliative care: The lack of consensus

CURRENT OPINION IN ONCOLOGY | Online – 19 May 2014 – A survey was performed to assess whether authors who report about palliative treatments or palliative care share a common understanding of "curative" treatments. In the care for cancer patients, unambiguous terminology is essential for the participatory and interdisciplinary decision-making process. Clinicians, researchers and policy makers should be aware of the difference between curative and disease-modifying therapies. Otherwise, this may be a major source of misunderstandings as disease-modifying therapy may be indicated in the incurable stages of the disease as well. In these palliative situations, it is essential to identify the realistic aim(s) of the therapy: prolongation of life, alleviation of suffering or both. Of 107 authors from publications about cancer who used both "palliative" and "curative" in the same abstract, 42 (39%) responded. The majority [survey respondents] understood "curative" treatments as "aimed at complete absence of disease for the rest of life," but 43% did not share this view. For example, 19% stated that the term describes cancer-directed therapy for prolongation of life or even regardless of the aspired goal. http://journals.lww.com/oncology/Abstract/publishahead/Curative_treatments_and_palliative_care_the.99523.aspx

Of related interest:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(2):149-169. **'Recommendations for hospice care to terminally ill cancer patients: A phenomenological study of oncologists' experiences.'** Four themes emerged: a) feelings of discomfort and relief; b) being different from others; c) experience with non-hospice patients; and, d) factors influencing the decision to recommend hospice. Future research and a flexible interdisciplinary practice model are suggested ... and ... recommendations for hospice care are presented. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2014.906373#.U334bXJdX8k>

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Noted in Media Watch, 13 February 2013, #240 (p.10)

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 7 February 2012 – **'Palliative care: A life-line to quality of life.'** Promoting quality of life and preventing suffering are essential aspects of practice for clinicians whose ambition it is to deliver high-quality cancer care. American Society of Clinical Oncology's Provisional Clinical Opinion offers the opportunity to bring clinicians a significant step forward in delivering truly patient-centered, family-focused care...¹
<http://jop.ascopubs.org/content/early/2012/02/07/JOP.2011.000530.full.pdf+html>
- 1. 'American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, published online 7 February 2012. [Noted in Media Watch, 13 February 2012, #240 (p.10); see sidebar above]
<http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract>

Quality of cancer care in Spain: Recommendations of a patients' jury

EUROPEAN JOURNAL OF CANCER CARE | Online – 20 May 2014 – A modified citizen's jury was organised with the participation of 30 members and four experts as witnesses. For one day jurors representing 13 of 17 Spanish Autonomous Communities were met to make recommendations for improving the quality of cancer care in Spain. Concerns were identified regarding care fragmentation, test delays, duplications and poor social and emotional support. Some recommendations highlighted the need to improve the access to psycho-oncology care as well as support in social care and counselling, addressing patients to specific care. Some strategies proposed by the jury included a 24-hour call centre, continuity in palliative care, and appropriate follow-up and support after the end of therapy. In conclusion, the experience of cancer should include access to multiple specialists, effective coordination of care, accurate information about the disease and treatment options, and timely attention to symptoms and psychosocial needs.
<http://onlinelibrary.wiley.com/doi/10.1111/ecc.12208/abstract>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 20 May 2014 – **'Does palliative care education matter to medical students? The experience of attending an undergraduate course in palliative care.'** Students [at the University of Navarra, Spain], reported being surprised by the humane and holistic features of the course, and they found that what they learned in the course is applicable to all patients and prepares them to work better as doctors.
<http://spcare.bmj.com/content/early/2014/05/20/bmjspcare-2014-000646.abstract>

Noted in Media Watch, 4 February 2013, #291 (p.5):

- *BMC PALLIATIVE CARE* | Online – 31 January 2013 – **'Impact of a home-based social welfare program on care for palliative patients in the Basque Country.'** This project represents a dramatic advance with respect to other studies conducted to date, and demonstrates how, through the provision of personnel trained to provide social care for patients in the advanced stages of illness, and through strengthening the co-ordination of such social services with existing healthcare system resources, the resulting holistic structure obtains cost savings within the health system and improves the efficiency of the system as a whole.
<http://www.biomedcentral.com/content/pdf/1472-684X-12-3.pdf>

N.B. Spain was rated 26th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

[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>

Sustainable deathstyles? The geography of green burials in Britain

THE GEOGRAPHICAL JOURNAL | Online – 15 May 2014 – The authors map the emergence of a new mode of burial and remembrance in Britain. Since a "green" burial ground was established in Carlisle in 1993, sites for so-called "green," "natural" or "woodland" funerals have proliferated. There are now more than 270 such sites in Britain. Drawing on a postal and email survey sent to all managers/owners and visits to 15 green burial grounds ... the authors chart their growth, establishment and regulation and describe the landscapes associated with them. This requires, and leads to, wider reflections on nature, capital, consumption, culture and the body. <http://onlinelibrary.wiley.com/doi/10.1111/geoj.12087/abstract;jsessionid=B9F94AECA4F2BA2E1207A9416C9CF8D8.f03t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Evaluations of hypothetical bereavement and grief: The influence of loss recency, loss type and gender

INTERNATIONAL JOURNAL OF PSYCHOLOGY | Online – 19 May 2019 – Individuals often hold strict and erroneous expectations for how others should grieve, yet this issue has been sparsely researched. As expected, subjects [i.e., study participations] deemed it inappropriate to show positive emotions and experiences 1 month after a hypothetical death and more inappropriate to show negative reactions 1 year later, and there were generally higher expectations of socially appropriate behaviour for those who lost a child rather than a spouse. Unexpectedly, there were no significant differences regarding the gender of the bereaved. This study is among the first to show experimentally the widespread expectation that grief should be experienced early and be short-lived. <http://onlinelibrary.wiley.com/doi/10.1002/ijop.12080/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.

Of related interest:

- *PROGRESS IN PALLIATIVE CARE*, 2014;22(3):123-124. **'Bereavement, loss and palliative care – where are we now?'** This issue of *Progress in Palliative Care* focuses on how thinking on bereavement and loss has changed and developed over the last few decades and focuses on the implications for the design and detailed provision of bereavement care in palliative care. Editorial: <http://www.maneyonline.com/doi/full/10.1179/0969926014Z.000000000117>; Contents page: <http://www.maneyonline.com/toc/ppc/22/3>

Are advance directives associated with better hospice care?

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 22 May 2014 – Most [study] participants (35,968, 73%) had advance directives at the time of hospice enrollment. These participants were enrolled in hospice longer ... and had longer survival times before death. They were less likely to die within the first week after hospice enrollment. Participants with advance directives were less likely to leave hospice voluntarily and more likely to die at home or in a nursing home than in an inpatient unit. Participants with advance directives were enrolled in hospice for a longer period of time before death than those without and were more likely to die in the setting of their choice. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12851/abstract>

Continuous sedation until death with or without the intention to hasten Death: A nationwide study in nursing homes in Flanders, Belgium

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 16 May 2014 – In nursing homes in Flanders, continuous sedation until death [CSD] is frequently used to hasten the patient's death. In some cases, CSD can even be considered a substitute for legal euthanasia. The response rate was 57.3%, and 159 of the 378 responding physicians reported a case of CSD (42.1%). According to the reported intentions involved, 62.2% of these cases were considered CSD – cases (no life-shortening pursued), whereas 37.8% were labeled CSD+ (life-shortening pursued). Physician factors such as experience in end-of-life care, palliative care training, training in sedation, or knowledge of sedation guidelines did not affect the outcome distribution (CSD– or CSD+). [http://www.jamda.com/article/S1525-8610\(14\)00210-2/abstract](http://www.jamda.com/article/S1525-8610(14)00210-2/abstract)

Noted in Media Watch, 31 March 2014, #351 (p.12):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 March 2014 – **'Bridging the gap between continuous sedation until death and physician-assisted death: A focus group study in nursing homes in Flanders, Belgium.'** For some [study participants], the difference is clear whereas others consider CSD [continuous sedation until death] a form of euthanasia. Another group situated CSD between pain relief and ending life. <http://ajh.sagepub.com/content/early/2014/03/25/1049909114527152.abstract>

The challenge to health professionals when carers resist truth telling at the end of life: A qualitative secondary analysis

JOURNAL OF CLINICAL NURSING | Online – 22 May 2014 – Staff [i.e., study participants] reported a hiding of the truth by carers and sustained use of activities aimed at prolonging life. Carers frequently ignored the advance of end of life, and divergence between staff and carer approaches to truth-telling challenged professionals. Not being truthful with patients had a deleterious effect on staff, causing anger and feelings of incompetence. Both children's and adult specialist palliative care staff found themselves caught in a dilemma, subject to policies that promoted openness in planning for death and informal carers who often prevented them from being truthful with patients about terminal prognosis. This dilemma had adverse psychological effects upon many staff. <http://onlinelibrary.wiley.com/doi/10.1111/jocn.12634/abstract>

Cont.

Representative sample of articles on hope and truth-telling in the context of end-of-life care noted in recent issues of Media Watch:

- CANADA | *The National Post* – 2 May 2014 – **'Should doctors tell people they're dying? Why soft-pedaling the grim reality could help patients live longer.'** Dr. [Karen] Devon and colleagues have subtly challenged the prevailing wisdom, suggesting there are times when complete openness may not be what patients want, when soft-pedaling the grim nature of an illness might be preferable to full disclosure.¹ <http://news.nationalpost.com/2014/05/02/should-doctors-tell-people-theyre-dying-why-soft-pedaling-the-grim-reality-could-help-patients-live-longer/>
 1. 'Tragic knowledge: Truth telling and the maintenance of hope in surgery,' April 2014, *World Journal of Surgery*. <http://link.springer.com/article/10.1007/s00268-014-2566-3>
- *GLOBAL JOURNAL OF HEALTH SCIENCE*, 2014;6(2):128. **'Disclosing the truth: A dilemma between instilling hope and respecting patient autonomy in everyday clinical practice.'** Transmitting bad news still remains a big problem that health care professionals face in their every day clinical practice. [Noted in Media Watch, 6 January 2014, #339 (p.7)] <http://www.ccsenet.org/journal/index.php/gjhs/article/view/31080>
- *PALLIATIVE MEDICINE* | Online – 15 April 2013 – **'Should palliative care patients' hope be truthful, helpful or valuable? An interpretative synthesis of literature describing health-care professionals' perspectives on hope of palliative care patients.'** Three perspectives on hope ... were found: 1) realistic perspective – hope as an expectation should be truthful, and healthcare professionals focused on adjusting hope to truth; 2) functional perspective – hope as coping mechanism should help patients, and professionals focused on fostering hope; and, 3) narrative perspective – hope as meaning should be valuable for patients, and health-care professionals focused on interpreting it. [Noted in Media Watch, 22 April 2013, #302 (p.12)] <http://pmj.sagepub.com/content/early/2013/04/11/0269216313482172.abstract>
- *CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS*, 2014;23(2):209-219. **'Prognosis terminal: Truth-telling in the context of end-of-life care.'** Persistent problems with the communication of prognosis and the breaking of bad news are analyzed. The author argues that candid, but compassionate, communication between physicians and patients about prognosis is essential to informed decisions about both disease-directed (curative) and palliative therapies. [Noted in Media Watch, 24 April 2014, #346 (p.11)] <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9173735&fulltextType=RA&fileId=S0963180113000741>

Improving the spiritual dimension of whole person care: Reaching national and international consensus

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 May 2014 – Two conferences, 'Creating More Compassionate Systems of Care' (November 2012) and 'On Improving the Spiritual Dimension of Whole Person Care: The Transformational Role of Compassion, Love and Forgiveness in Health Care' (January 2013), were convened with the goals of reaching consensus on approaches to the integration of spirituality into health care structures at all levels and development of strategies to create more compassionate systems of care. The conferences built on the work of a 2009 consensus conference, 'Improving the Quality of Spiritual Care as a Dimension of Palliative Care.' Conference organizers in 2012 and 2013 aimed to identify consensus-derived care standards and recommendations for implementing them by building and expanding on the 2009 conference model of interprofessional spiritual care and its recommendations for palliative care. The 2013 conference built on the 2012 conference to produce a set of standards and recommended strategies for integrating spiritual care across the entire health care continuum, not just palliative care. Deliberations were based on evidence that spiritual care is a fundamental component of high-quality compassionate health care and it is most effective when it is recognized and reflected in the attitudes and actions of both patients and health care providers. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.9427>

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Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 20 May 2014 – **'The spiritual environment in New Zealand hospice care: Identifying organisational commitment to spiritual care.'** Spiritual matters naturally arise in many people who have either a serious illness or are nearing end-of-life. The literature shows many examples of spiritual assessments, interventions and care; however, there is a lack of focus on organisational support for spiritual care. We aimed to ascertain the structural and operational capacity of New Zealand's hospices to attend to the spiritual needs and concerns of patients, families and staff. <http://spcare.bmj.com/content/early/2014/05/20/bmjspcare-2013-000632.abstract>

Guidelines for implementing culturally competent nursing care

JOURNAL OF TRANSCULTURAL NURSING, 2014;25(2):109-121. The global migration of populations presents nurses with the challenge of delivering care to unprecedented numbers of patients with health care beliefs and practices that may differ from their own. The global migration of nurses to meet worldwide shortages places migrating nurses in the similar situation of caring for patients with different cultural backgrounds. There is growing evidence of increasing inequalities in access to health care and health outcomes among populations in local, national, and global contexts. There is a need to advocate for vulnerable populations to lessen the impact of social inequalities on their health. These challenges heighten the need to identify guidelines for the delivery of culturally competent care for an increasingly diverse population and minimize health inequities regardless of geographic location. The purpose of this document is to present universally applicable guidelines for implementing culturally competent care. These guidelines can serve as a resource for nurses in various roles – clinicians, administrators, researchers, and educators – by emphasizing cultural competence as a priority of care for the populations they serve. The guidelines are designed to be adapted to the socio-cultural context and unique health care delivery system of the user. They are not meant, however, to supersede ethical codes, human rights conventions, or legal requirements. <http://tcn.sagepub.com/content/25/2/109.extract>

Palliative home care of children: An opinion survey of orphaned parents

KLINISCHE PÄDIATRIE, 2014;226(03):182-187. In Germany, 500 children die of malignancies per year. Many families wish to be cared for in a home setting at the end-of-life. 84 relatives of 49 children participated... Duration of care varied between 3-246 days. All 49 patients died at home. 98.8% of the respondents were satisfied with their decision for home care. The symptoms pain (86.9%) and fatigue (85.7%) were reported most frequently. Satisfaction with symptom control was high... The respondents were satisfied with communication ... and end-of-life care... Satisfaction with psychosocial care ... was significantly lower... Parents who stayed in contact with the paediatric palliative care team by phone and in person were more satisfied with aftercare. From parental view satisfying home-care of children with cancer is feasible. Symptom control succeeds in a home setting. <https://www.thieme-connect.de/products/ejournals/abstract/10.1055/s-0034-1371841>

N.B. German language article.



11 October 2014

Who Cares? We Do!

Home page: <http://www.worldday.org/>

Materials: <http://www.worldday.org/materials/>

Few hospices providing complementary and alternative medicine services to patients

MEDSCAPE MEDICAL NEWS | Online – 23 May 2014 – Only 29% of hospices in the U.S. employ massage, art, or music therapists, according to the first national survey to examine such services. "We were surprised, given the focus of interdisciplinary care and symptom management in hospice, that these services are not being used more," said study investigator Sarah Dain, a medical student at the Icahn School of Medicine at Mount Sinai, New York. "Interest in complementary and alternative medicine is growing, and patients are requesting these services. They are beneficial to patients and would be wonderful to include in hospice care." She presented the survey results here at the [recent] American Geriatrics Society 2014 Annual Scientific Meeting. <http://www.medscape.com/viewarticle/825676>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/5/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 | 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']

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>

End-of-life in the U.K.

Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting

PALLIATIVE MEDICINE | Online – 22 May 2014 – The sensitivity, specificity and predictive values of the Gold Standards Framework Prognostic Indicator Guidance [GSFPIG] in this study are comparable to, or better than, results of studies identifying patients with a limited life expectancy in particular disease states (e.g., heart failure and renal failure). Screening utilising GSFPIG in the acute setting could be the first step towards implementing a more systematic way of addressing patient need – both current unrecognised and future anticipated – thereby improving outcomes for this population. <http://pmj.sagepub.com/content/early/2014/05/21/0269216314536089.abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *HEALTHMED*, 2014;8(4):493-500. **'Evaluation of views of the university hospital nurses on euthanasia.'** 54.2% of the nurses [i.e., study participants] reported they would want the right to euthanasia for themselves, while 76.3% stated they might ask for euthanasia for a relative or family member. 69.5% of the participants reported they did not want euthanasia to be legalized, and 78.5% believed it would be mainly ... abused by relatives for their inheritance if euthanasia were ever legalized, whereas 16.3% stated euthanasia should be applied to the patients requesting euthanasia. It was found religious beliefs played a significant role on the views of 85.5% of the nurses. The authors concluded nurses generally have adequate information about euthanasia, while more than half of them did not want euthanasia to be implemented and legalized as they thought legalization would lead to a significant amount of abuse. <http://web.a.ebscohost.com/abstract?direct=true&profile=ehost&scope=site&authtype=crawler&jrnl=18402291&AN=95846328&h=PSULHu9%2fqPRoZAOI4kqK4CBWQc7IY8ibq8guZOHW1ycoAfrbkSXlKpzkBjb3tNXFLnTPrfGZBBn%2fJceG8TVw%3d%3d&cr=c>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2014;311(19):1963-1964. **'Pediatric euthanasia in Belgium: Disturbing developments.'** On 13 February 2014, Belgium's Parliament approved an amendment of the 2002 Belgium Act on Euthanasia to allow euthanasia for chronically ill children. The amendment, supported by a majority of Belgians and recently signed into law by King Philippe, permits euthanasia for children who are experiencing "constant and unbearable suffering." In addition to requiring the child's own voluntary and explicit request for euthanasia, the law requires parental consent, excludes children with an intellectual disability or mental illness, and mandates a multidisciplinary team carefully examine the child's capacity for discernment. <http://jama.jamanetwork.com/article.aspx?articleid=1863566>
- *NOTRE DAME JOURNAL OF LAW, ETHICS & PUBLIC POLICY*, 2014;28(1). **'A right to voluntary euthanasia? Confusion in Canada in Carter.'** In *Carter v. Canada* (Attorney General), Justice Lynn Smith held that the Canadian Criminal Code's prohibitions on murder and assisting suicide infringe Sections 7 and 15 of the Canadian Charter of Rights & Freedoms to the extent that those prohibitions outlaw voluntary, active euthanasia and physician-assisted suicide.¹ This article suggests the judgment is defective in at least four key respects: 1) misunderstanding the principle of the inviolability of human life; 2) concluding that laws against assisting suicide discriminate against those physically incapable of committing suicide; 3) evading the logical "slippery slope" argument; and, 3) (as the Irish High Court has since concluded in *Fleming v. Ireland*²) misinterpreting the evidence from jurisdictions with relaxed laws. Although the judgment of Justice Smith has been reversed by the British Columbia Court of Appeal, the reversal turned on questions of constitutional law, not on these four criticisms. http://scholarship.law.nd.edu/cgi/viewcontent.cgi?article=1718&context=ndjepp&sei-dir=1&referer=http%3A%2F%2Fscholar.google.ca%2Fscholar%3Fq%3Dassisted%2Bsuicide%26btnG%3D%26hl%3Den%26scisbd%3D1%26as_sdt%3D0%252C5#search=%22assisted%20suicide%22

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1. 'Doctor-assisted suicide ban upheld in B.C,' CBC News (Canada), 10 October 2013. The B.C. Court of Appeal, in a split decision, has affirmed the law against assisted suicide, in a controversial and historic right-to-die case. [Noted in Media Watch, 14 October 2013, #327 (p.2)] <http://www.cbc.ca/news/canada/british-columbia/doctor-assisted-suicide-ban-upheld-in-b-c-1.1958888>
2. 'Marie Fleming loses Supreme Court right-to-die case,' *The Independent* (Dublin), 29 April 2013. [Noted in Media Watch, 6 May 2013, #304 (p.6)] <http://www.independent.ie/irish-news/courts/marie-fleming-loses-supreme-court-righttodie-case-29228686.html>

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