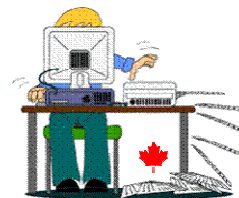


Media Watch...

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

Compiled & Annotated by Barry R. Ashpole

The physical and psychosocial dimensions of care: Scroll down to [Specialist Publications](#) and 'The family conference in palliative medicine: A practical approach' (p.8), in *American Journal of Hospice & Palliative Medicine*.

Canada

Study: Caregivers in Canada, 2012

STATISTICS CANADA | *The Daily* – 10 September 2013 – In 2012, about 8.1 million individuals, or 28% of Canadians aged 15 years and older, provided care to a family member or friend with a long-term health condition, disability or aging needs. New data from the 2012 General Social Survey showed that women represented the slight majority of caregivers at 54%. The survey also found that caregiving responsibilities most often fell to those aged 45 to 64, with 44% of caregivers in this age category. Ailing parents were the most common recipients of care, with 39% of caregivers looking after the needs of their own parents and another 9% doing so for their parents-in-law. The least common were spouses, at 8%, and children, at 5%. For the first time, the survey looked at the types of health condi-

tions requiring care. Age-related needs topped the list, with 28% of caregivers providing care for these needs. Cancer was next at 11%, followed by cardio-vascular disease at 9%, and mental illness at 7%. <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.pdf>

Over one-quarter of caregivers "sandwiched"

Over one-quarter (28%) of caregivers, or 2.2 million individuals, could be considered "sandwiched" between caregiving and raising children. Most were women between the ages 35 and 44, and helping their parents or parents-in-law, while also having at least one child under 18 living at home.

N.B. Statistics Canada has published two articles of related interest: 'Portrait of Caregivers, 2012' presents the number of caregivers and their characteristics, along with the types of help provided, the number of hours of care, the impacts of providing care, and financial support for caregivers. <http://www5.statcan.gc.ca/bsolc/olc-cel/olc-cel?catno=89-652-XIE2013001&lang=eng#formatdisp>; 'Family caregiving: What are the consequences?' discusses the psychological, physical and financial consequences of providing care, with a focus on the relationship between the caregiver and receiver. <http://www5.statcan.gc.ca/bsolc/olc-cel/olc-cel?catno=75-006-X201300111858&lang=eng>

Cont.

Noted in Media Watch, 29 November 2010, #177 (under 'Worth Repeating,' p.9):

- *AFFILIA* (JOURNAL OF WOMEN & SOCIAL WORK), 2008;23(3):223-230. **'Lessons learned in the sandwich.'** In this personal account of caring for an aging father until his death in her home, the author reflects on the personal and professional challenges of being a "sandwich-generation" ... social worker. <http://aff.sagepub.com/content/23/3/223.abstract>

Specialist Publications

'A Canadian experience of integrating complementary therapy in a hospital palliative care unit' (p.13), in *Journal of Palliative Medicine*.

'Perceived barriers and enablers to referrals to community-based hospice palliative care volunteer programs in Canada' (p.14), in *American Journal of Hospice & Palliative Medicine*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUÉBEC MEDICAL ASSOCIATION | Online – 15 September 2013 – **'Dying with dignity: 66% of Québec physicians recognize medical aid in dying as appropriate end-of-life care.'** A survey among Québec physicians indicates the majority of physicians (66%) agree with recognizing medical aid in dying as appropriate end-of-life care. Of the ones who are likely to be asked by a patient, 41% would agree to provide medical aid in dying if their patient met the eligibility criteria. Almost all of the physicians (94%) who responded agree with amending the Act respecting health services and social services to recognize the right to receive palliative care. The great majority (73%) agree with legislative amendments that would make the anticipated medical directives restrictive. <http://www.amq.ca/documents/sondage-mourir-dignite-en.pdf>
- ALBERTA | Global TV News (Edmonton) – 13 September 2013 – **'Series on assisted suicide wins prestigious national award.'** A series, featured on Global Edmonton, has been honoured by the Canadian Medical Association with an Excellence in Health Reporting award. The series ... focused on both the legal and ethical issues surrounding assisted suicide... <http://globalnews.ca/news/839506/global-edmonton-series-on-assisted-suicide-wins-prestigious-national-award/>

N.B. Embedded in this report are links to the two-part series.

U.S.A.

More Filipino Americans will need palliative care

THE PHILIPPINE DAILY INQUIRER (U.S. BUREAU) | Online – 14 September 2013 – In the U.S. today, immigrants like [Ray] Garcia can have access to palliative care should they need it – if they are aware of its effectiveness and availability. Indeed, greater awareness of palliative care by Filipino Americans will be sorely needed in the coming years, judging from the rising number of elderly as well as high incidences of serious illnesses among them. But Filipino older adults over 65, like most Asians, are less likely to enroll in hospice care, an end-of-life component of palliative care. This was the finding of a very large study on the last year of life of Asian and white Medicare beneficiaries registered in the Surveillance, Epidemiology & End Results Program. In a related finding, the Berkeley Forum of the University of California School of Public Health said that 61% of Medicare deaths in California three years ago did not involve hospice care. <http://globalnation.inquirer.net/85601/more-filipino-americans-will-need-palliative-care>

Defining palliative care

New Hampshire commission to study, promote palliative care

NEW HAMPSHIRE | *The Concord Monitor* – 12 September 2013 – A new legislative commission dedicated to studying palliative care will begin meeting and is seeking public input. "One of the first very basic things we have to do is to have a definition in law of what palliative care means," said Senator John Reagan ... a member of the Commission to Study Palliative Care and a sponsor of the bill that formed it this spring. "It means different things to different people, and that doesn't help you when you're trying to write laws," he said. He plans to bring information he gathered from 20 other states that have defined palliative care in their statutes. The commission then will "have to face the problem that about 16 of them only refer to pallia-

tive care for terminal patients," Reagan said. <http://www.concordmonitor.com/news/84500-52-95/nh-commission-to-study-promote-palliative-care>

Specialist Publications

'Health care decision making in the Veterans Health Administration: The legal significance for informed consent and advance directives' (p.10), in *Marquette Elder's Advisor*.

'Institute of Medicine declares cancer care crisis' (p.13), in *MedPage Today*.

Physician reimbursement

The next step for end-of-life care

THE ATLANTIC | Online – 9 September 2013 – The hourly revenue generated by a physician discussing plans for care is \$87. That same physician, when conducting a procedure such as a colonoscopy or a cataract extraction, will make more than \$300 per hour. Renewed support for a bill that would better compensate U.S. doctors for providing end-of-life counseling highlights the value of these conversations; for patients, physicians, and the healthcare system. The possibility that there may one day be value recognized in end-of-life counseling has been resurrected this summer by Senators Mark R. Warner and Johnny Isakson. Their new bill was introduced in August, and goes beyond the previous, similar bill introduced in March by Representative Earl Blumenauer. Both bills, currently in committees, are intended to reimburse medical professionals for the time invested in these end-of-life conversations, develop a public information campaign, and develop quality metrics to measure the effectiveness in delivering the desired medical care. <http://www.theatlantic.com/health/archive/2013/09/the-next-step-for-end-of-life-care/279358/>

Noted in Media Watch, 15 July 2013, #314 (p.7):

- *THE HASTINGS REPORT*, 2013;43(4):20-28. **'Avoiding a "death panel" redux.'** If engaging in end-of-life conversations and advance care planning not only is desired by many Americans but also might significantly improve patient care at the end of life, then why was a provision that provided reimbursement for physicians to engage in end-of-life planning through Medicare removed from legislation? <http://onlinelibrary.wiley.com/doi/10.1002/hast.190/abstract>

Links updated 16 September 2013

Media Watch Online

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. Complete listing on p.7.

Intensive care treatment is often futile and costly, study finds

CALIFORNIA | *The Los Angeles Times* – 9 September 2013 – Nearly 1 in 5 patients in a hospital's intensive care unit gets care and treatment judged by the physician in charge to be ineffective, needlessly aggressive or pointless given the patient's dire state, a new study says. And the financial costs of that care are steep as well, adding up to \$2.6 million over a three-month period at a single academic medical center. The study, conducted at an unnamed academic medical system in Los Angeles, found of 1,125 patients who spent time in the ICU during a three-month period, 98 received treatment their physicians perceived as "possibly futile," and 123 received treatment that their physicians considered futile. The study followed patients and their physicians and surveyed the latter daily on their view of treatments provided. That ruled out judgments of futility that were colored by a physician's knowledge of a patient's outcome. The study was published in the journal *JAMA Internal Medicine*. <http://www.latimes.com/science/sciencenow/la-sci-intensive-care-futile-20130909,0,7833408.story>

N.B. Scroll down to [Specialist Publications](#) and 'The frequency and cost of treatment perceived to be futile in critical care' (p.0) for an abstract of the *JAMA Internal Medicine* article.

Clear! CPR in the hospital is not always good for the patient

FORBES | Online – 9 September 2013 – Most patients who undergo cardiopulmonary resuscitation (CPR) are old, frail, and very sick. Many will die and many who survive CPR will die anyway before leaving the hospital. And many survivors will have severe neurological problems. Now a physician states ... that hospitals need to change the way they view CPR.¹ When it comes to applying continuous quality improvement processes to CPR, hospitals "tend to focus on the procedural aspects of CPR, such as time to first defibrillation" and the selection of medications, but they "do not regularly scrutinize CPR attempts for appropriate clinical indications." <http://www.forbes.com/sites/larryhusten/2013/09/09/clear-cpr-in-the-hospital-is-not-always-good-for-the-patient/>

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

Noted in Media Watch, 25 June 2012, #259 (p.10):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2012;307(23):2487-2489. '**Challenges of do-not-attempt-resuscitation orders.**' Blinderman and colleagues highlighted the challenges faced when considering do-not-attempt-resuscitation decisions.¹ Their recommendations have a number of similarities with the approach currently used in the U.K. Guidance on this topic comes from a joint statement² ... produced by the British Medical Association, the Resuscitation Council (U.K.), and the Royal College of Nursing, and from the General Medical Council's publication.³ These guidelines identify three situations during which cardiopulmonary resuscitation (CPR) may be withheld: 1) when clinical judgment concludes that CPR will not be successful in restarting the patient's heart and breathing and restoring circulation; 2) when, following careful discussion with the patient (and/or those close to him/her), agreement is reached that benefits of CPR are outweighed by the burdens and risks; and, 3) when a patient has an advanced decision (i.e., living will) or makes an informed decision to refuse CPR. <http://jama.jamanetwork.com/article.aspx?articleid=1187921>

1. 'Time to revise the approach to determining cardiopulmonary resuscitation status,' *Journal of the American Medical Association*, 2012;207(9):917-918. [Noted in Media Watch, 12 March 2012, #244 (p.11)] <http://jama.ama-assn.org/content/307/9/917.extract>
2. 'Decisions Relating to Cardiopulmonary Resuscitation,' British Medical Association, Resuscitation Council, Royal College of Nursing, 2007. <http://www.resus.org.uk/pages/dnar.pdf>
3. 'Treatment and Care Towards the End of Life: Good Practice in Decision Making,' General Medical Council, 2010. http://www.gmc-uk.org/static/documents/content/End_of_life.pdf

Prison hospice

Indiana's aging prison population presents health-care challenges

INDIANA | *The Indianapolis Star* – 8 September 2013 – Bryon Bradley, a diminutive, bespectacled, 43-year-old with a mild disposition, was making his daily rounds... "Has everybody's eaten here?" he asked. "It's almost recreation time. Who wants to go to rec[reation]?" Bradley shuffled from bed to bed, checking on his patients before stopping in front of Jerald Jessup, a frail 74-year-old wearing an orange knit cap. The tall, rangy septuagenarian, who suffers from chronic obstructive pulmonary disease and uses a wheelchair, was undecided about rec. So Bradley, a wife killer, made idle chat with Jessup, serving two life sentences and considered one of the most dangerous inmates in Indiana history. The two are joined in an uncommon hospice program at Wabash Valley Correctional Institute in which prisoners take care of other, terminally ill, inmates. <http://www.indystar.com/article/20130907/NEWS02/309070049/Indiana-s-aging-prison-population-presents-health-care-challenges>

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.0.

International

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

Medical experts propose hospital doctors treat patients at home

U.K. | *The Guardian* – 12 September 2013 – Patients could in future be treated at home by hospital doctors under plans for a revolution in the way healthcare is delivered...¹ Hospitals will lose much of their central role in the National Health Service (NHS), with more care and treatment being provided in homes and care homes, under radical proposals drawn up by a landmark inquiry instigated by hospital doctors themselves, which has been broadly welcomed by the government. If implemented, the report ... would lead to a major shift towards caring for the sickest patients at home for longer and out of hospital, unless absolutely necessary, by having health professionals come to them instead of them having to attend regular appointments. The commission, a panel of medical experts, warned that hospitals will not survive unless they dramatically overhaul how they handle the growing number of medical patients, whose more serious ill-

nesses draw heavily on NHS services. <http://www.theguardian.com/society/2013/sep/12/plan-hospital-doctors-treat-patients-home>

Extract from Royal College of Physicians report

Patients who are dying need access to palliative care. For those with life-limiting illnesses, decisions about care escalation must be made before an acute deterioration occurs. The use of advanced care plans, developed in conjunction with the patient or, if incapacitated, with their carers, is essential. Clinical decisions about ceilings of care, based on patients' and carers' wishes alongside projected clinical outcomes, need to be made, as well as decisions about resuscitation. Clinical skills are needed to recognise when a patient is dying, as well as skills in communicating with patients and relatives when that is the case.

1. 'Future Hospital Commission: Care comes to the patient in the future hospital,' Royal College of Physicians, September 2013. http://www.rcplondon.ac.uk/sites/default/files/future-hospital-commission-report_0.pdf

End-of-life care in China

Living will presents difficult choices for family

CHINA.ORG (Beijing) | Online – 9 September 2013 – Choosing to end or sustain a life is a difficult choice no matter where you're from in the world. Li Nan now looks at how people from different parts of China and the world look at living wills. When a loved one can only breathe with the help of a respirator, or have their heart beat using a pacemaker, do you continue fighting to keep them alive, or accept that it's time to let them go? In China, some doctors and volunteers have formed associations to promote ... living wills. It remains to be seen if specific laws will be enacted to put it into wider effect. http://www.china.org.cn/video/2013-09/09/content_29971235.htm

Noted in Media Watch, 3 August 2013, #317 (p.3):

- CHINA | Xinhua News Agency – 1 August 2013 – **'Living will registration stirs dignified death debate.'** A newly-established association advocating living will registration has triggered debate on death with dignity, with many hoping the organization can help preserve patients' rights in terms of receiving life-prolonging treatments. The Beijing Living Will Promotion Association, approved by the Beijing Civil Affairs Bureau, gathered more than 20 medical experts to discuss the necessity of living wills and how to promote the idea of death with dignity in China. http://news.xinhuanet.com/english/china/2013-08/01/c_132594452.htm

End-of-life care in Scotland

Terminally ill patients missing out on end-of-life treatment

U.K. (SCOTLAND) | *The Herald* (Edinburgh) – 9 September 2013 – Only one in five Scots dying of a disease other than cancer get any kind of palliative care, a new study has revealed.¹ Most people diagnosed as terminally ill with organ failure or dementia either fail to request any specialist end-of-life treatment or are not identified as needing it... But three-quarters of patients suffering from cancer do get specialist care, according to the study from Marie Curie Cancer Care, Edinburgh University and National Health Services Lothian. Anne Finucane, co-author of the report, said: "It is clear from our study that most people with a non-cancer diagnosis are not identified for palliative care before they die. In Scottish society, we need to promote a culture that is less afraid of discussing death and dying. Patients and healthcare professionals should be encouraged to talk more openly about death and dying so that patients have a better understanding of what lies ahead, and are provided the support they need when making important decisions relating to their future

care." Researchers said GPs found such care to be easier to introduce for cancer patients, who often had a clear terminal decline, but harder for those with other life-threatening illnesses, such as liver failure. <http://www.heraldscotland.com/news/health/terminally-ill-patients-missing-out-on-end-of-life-treatment.22090284>

Specialist Publications

'Time of death and presence of family at death in a U.K. hospice' (p.10), in *European Journal of Palliative Care*.

'Palliative care in long-term care settings for older people: Findings from an EAPC Task-force' (p.11), in *European Journal of Palliative Care*.

'Exploring public awareness and perceptions of palliative care: A qualitative study' (p.14), in *Palliative Medicine*.

1. 'How good is primary care at identifying patients who need palliative care? A mixed methods study,' *European Journal of Palliative Care*, 2013;20(5):216-222.

N.B. Access to the *European Journal of Palliative Care* requires a subscription. Contents page: http://www.haywardpublishing.co.uk/_year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=485

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- HUNGARY | Politics.hu – 12 September 2013 – **'Supreme court strikes down euthanasia referendum** .' The Kuria [Hungary's Supreme Court] has struck down the National Election Committee's (OVB) approval for a referendum on euthanasia. The question proposed for the referendum was as follows: "Do you agree that adults suffering from an incurable illness should be allowed to end their lives with medical assistance?" The Kuria said that the private initiative would have ordered parliament to put the issue on its agenda and discuss it, yet the question authorised by the OVB was phrased in a way that people were led to believe they were making a decision on allowing or banning euthanasia themselves. The court thus rejected the question authorised by the OVB and ordered OVB to start a new procedure. <http://www.politics.hu/20130912/supreme-court-strikes-down-euthanasia-referendum/>

Media Watch Online

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://APHN.ORG/CATEGORY/RESOURCES/MEDIA-WATCH/](http://aphn.org/category/resources/media-watch/)

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

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

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.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.palliativecareconsultation.ca/?q=mediawatch>

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events>

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>

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)

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

The family conference in palliative medicine: A practical approach

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 11 September 2013 – The family conferences guided by common sense principles and sound clinical practice (good structure, content, and process) have beneficial outcomes: 1) creation of a therapeutic partnership so the family and medical team collaborate in the difficult task of sophisticated medical and psychosocial care of a complex illness; 2) Enhanced therapeutic management through education and support of the patient and primary caregiver (and other family members) to facilitate self-efficacy and convey realistic hope with careful sequencing of key messages; and, 3) Easier patient transitions from cure- to care-oriented management, with a formal (yet thoughtful and gentle) introduction to the principles and practice of modern palliative medicine. <http://ajh.sagepub.com/content/early/2013/09/10/1049909113499444.abstract>

Noted in Media Watch, 25 March 2013, #298 (p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 March 2013 – **'A prospective study of family conferences: Effects of patient presence on emotional expression and end-of-life discussions.'** 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)

Noted in Media Watch, 17 January 2011, #184 (p.7):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 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)

The family conference

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

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. **BRA**

A multicenter study of physician mindfulness and health care quality

ANNALS OF FAMILY MEDICINE, 2013;11(5):421-428. Mindfulness refers to a person's tendency to remain attentive to their own experience, thoughts and feelings. Over the past decade, it has been recommended that physicians enhance their own capacities for mindfulness when practicing medicine and interacting with patients. This study assesses whether clinician self-rated mindfulness is associated with quality of patient care. Physicians [i.e., study participants] rating themselves as more mindful have more patient-centered communication and more satisfied patients. Measuring the mindfulness of 45 clinicians and later assessing the quality of their interactions with patients infected with the human immunodeficiency virus, researchers found mindful clinicians were more likely to be patient-centered in their communications, more positive in their emotional tone with patients and more likely to be rated highly on communication and overall satisfaction by patients. <http://www.anfammed.org/content/11/5/421/suppl/DC1>

Cont.

Noted in Media Watch, 24 June 2013, #311 (p.13):

- *PALLIATIVE & SUPPORT CARE* | Online – 17 June 2013 – '**Mindfulness in informal caregivers of palliative patients.**' Mindfulness is a significant predictor of improvement in psychological distress, meaning in life, and quality of life three months after the intervention. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8938683&fulltextType=RA&fileId=S1478951513000400>

Noted in Media Watch, 23 April 2012, #250 (p.1):

- CANADA (QUEBEC) | *The Montreal Gazette* – 19 April 2012 – '**McGill's mindfulness meditation teaches doctors coping skills.**' It's not easy to work with critically ill children and stressed-out parents. Doctors in pediatric-palliative care do it every day. Conversations with parents are often tense; frustrations can boil over – on both sides. Pediatrician Stephen Liben [Montreal Children's Hospital] knew he needed to figure out how to cope better with the stress. <http://www.montrealgazette.com/health/Physicians+healing+themselves/6482206/story.html>

Ethical issues in the geriatric patient with advanced cancer "living to the end"

ANNALS OF ONCOLOGY, 2013;24(Suppl.7):vii55-vii58. In this review of the ethical issues confronting physicians who care for patients with advanced life-limiting illnesses like cancer, a philosophical debate continues in the medical community regarding the rightness or wrongness of certain actions (e.g., physician-assisted death, euthanasia), while at the same time there is a strong desire to find a common ground for moral discourse that could guide medical decision-making in this difficult period in the lives of our patients. The authors discuss how a good palliative care can be an alternative to these ethical dilemmas. Although some issues ... remain controversial, there is much common ground based on the application of the four major principles of medical ethics: no malfeasance, beneficence, autonomy and justice. Thus, the physician's primary commitment must always be the patient's welfare and best interests, whether the physician is treating illness or helping patients to cope with illness, disability and death. A key skill here is the communication of bad news and to negotiate a treatment plan that is acceptable to the patient, the family and the healthcare team. Attention to psychosocial issues demands involvement of the patients and their families as partners. Physicians should be sensitive to the range of psychosocial distress and social disruption common to dying patients and their families. http://annonc.oxfordjournals.org/content/24/suppl_7/vii55.abstract?sid=35492d38-9bce-41a9-9a80-934b4ab2597f

Of related interest:

- *BIOETHICA FORUM*, 2013;6(1):26-30. '**Decision-making incapacity at the end of life: Conceptual and ethical challenges.**' To date, there is neither a consensus on the concept of decision-making capacity (DMC) nor a clinical standard for its assessment (criteria, instruments, procedures). Since patient autonomy is widely regarded as a central value and with respect for patients' rights being seen as essential in modern health care, transparent, well argued and clearly defined standards for the assessment of DMC are needed. However, finding appropriate standards for DMC is a conceptual and ethical challenge. http://www.bioethica-forum.ch/docs/13_1/08_Trachsel.pdf

Cont. next page.



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>

- *MARQUETTE ELDER'S ADVISOR*, 2013;14(2):269-303. **'Health care decision making in the Veterans Health Administration: The legal significance for informed consent and advance directives.'** There are significant differences between VA [Veterans Administration] and state law requirements pertaining to health care decision making. The examples highlighting Wisconsin law discussed represent just a small subsection of these differences, which will depend on the state law at issue. An individual's decision to make health care decisions and engage in advance care planning within the VA or under state law can have significant impact on the choices available to that individual, the processes for decision making, and, thus, the clinical outcomes. Individuals eligible to receive care from the VA and health care providers who advise them should be aware of this impact and consider the differences between VA and state law when making health care decisions and participating in advance care planning. <http://scholarship.law.marquette.edu/cgi/viewcontent.cgi?article=1383&context=elders>

N.B. There are an estimated 23 million veterans in the U.S. (Source: Department of Veterans Affairs.)

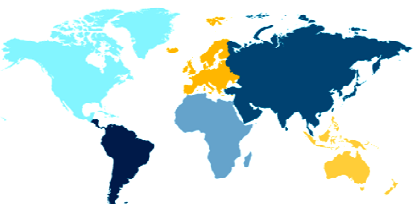
- *ONCOLOGY NURSING FORUM*, 2013;40(5):454-463. **'Shared decision making among individuals with cancer in non-western cultures: A literature review.'** Although most patients wanted to be informed of their diagnosis, patient preferences for information and participation in decision making differed from that of physicians and varied among and within cultures. Shared decision making may be new to patients from non-Western cultures, necessitating assessment, education, and support. Non-Western patients may value having family and friends accompany them when a cancer diagnosis is given, but assumptions based on culture alone should not be made. <http://ons.metapress.com/content/3747t6u0828j33m1/>

Time of death and presence of family at death in a U.K. hospice

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2013;20(5):223-225. In this study, the authors found that deaths were equally distributed across the 24-hour cycle and that a majority of patients had a family member present at the time of death. However, there is a need to ask family members if they wish to be present at the time of death and to facilitate this whenever possible. Overnight accommodation for families is now available at Wisdom Hospice to allow families – particularly those travelling from further away – to stay and be called in quickly if the patient deteriorates at night. The study will be repeated over the coming years to assess whether this has been helpful in allowing family members to be present at the time of death when death occurs at night.

Noted In Media Watch, 12 November 2012, #279 (#10):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2012;14(8):541-550. **""Wrapped in their arms": Next-of-kin's perceptions of how hospital nursing staff support family presence before, during, and after the death of a loved one.'** Family presence is a vital component of quality end-of-life care. The authors interviewed next-of-kin of deceased veterans to explore perceptions of how hospital nursing staff supported and facilitated family presence during the actively dying phase, at the time of death, and immediately following the patient's death. http://journals.lww.com/jhpn/Abstract/2012/12000/ Wrapped_in_Their_Arms_Next_of_Kin_s_Perceptions.9.aspx



World hospice &
palliative care day
Voices for hospices 2015

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

12 October 2013

Maintaining hope in emotionally distressed terminally ill patients

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2013;20(5):232-236. The role of clinicians in instilling or maintaining hope in terminally ill patients is essential but challenging. Cancer patients referred to St Raphael's Hospice (Sutton, U.K.) for psychological distress were asked what gives them or makes them lose hope. Patients and carers were also asked about their preferences regarding disclosure of prognosis. The overwhelming majority of patients wanted to be told the truth about their prognosis. Most patients also hoped for alleviation of pain and other physical symptoms, support from their family and a reasonable

quality of life for as long as possible. This study confirms that it is possible for terminal cancer patients to have hope, and thus better quality of life, and proposes psychological strategies for clinicians to support them.

European Journal of Palliative Care

Access requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=485

Noted in Media Watch, 26 November 2012, #281 (p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 November 2012 – **'Both maintaining hope and preparing for death: Effects of physicians' and nurses' behaviors from bereaved family members' perspectives.'** About 20% of family members [i.e., study participants] reported that they could neither "maintain hope nor prepare for death." A recommended care strategy for medical professionals could include: 1) discussing achievable goals and preparing for the future and pacing explanation with the family's preparation; 2) willingness to discuss alternative medicine; 3) maximizing efforts to maintain the patient's physical strength; and, 4) avoid saying they could do nothing further for the patient. [http://www.jpmsjournal.com/article/S0885-3924\(12\)00460-5/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00460-5/abstract)

European Association for Palliative Care (EAPC)

Palliative care in long-term care settings for older people: Findings from an EAPC Taskforce

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2013;20(5):251-253. A changing demography across European and other developed countries is leading to an older and, in many cases, more dependent population. Consequently, the demand for long-term care is changing. This has, in turn, led to the consideration of new models of service delivery, funding and quality management in the long-term care sector. A significant proportion of older people (defined as those aged 65 and over) die in long-term care settings – approximately 20% in the U.K. and 15% in Austria. Older people living in long-term care facilities (LTCFs) in Western societies often have non-cancer co-morbidities, and there is a high prevalence of dementia in this population. Palliative care is acknowledged as an appropriate approach to support these people as they are nearing death and is being promoted in LTCFs in a number of ways. However, there are challenges in the implementation of new approaches, partly due to the complexity of care provision.

Noted in Media Watch, 29 April 2013, #303 (p.16):

- *PALLIATIVE MEDICINE* | Online – 23 April 2013 – **'Improving end-of-life care in nursing homes: Implementation and evaluation of an intervention to sustain quality of care.'** While good support from palliative care nurse specialists and GPs can help ensure that key processes remain in place, stable management and key champions are vital to ensure that a palliative care approach becomes embedded within the culture of the care home. <http://pmj.sagepub.com/content/early/2013/04/19/0269216313480549.abstract>

Cont.

Noted in Media Watch, 25 February 2013, #294 (p.8):

- EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (EAPC) | Online – Accessed 18 February 2013 – '**Palliative care in long-term care settings for older people.**' With an ageing population across Europe, older people's needs for care and support are increasing in amount and complexity. Increasing numbers of older people are living with dementia. For some older people changes in physical, psychological and/or social circumstances will require a move into a long-term care facility as they can no longer be supported to live in their own homes. http://www.lancs.ac.uk/shm/research/ioelc/projects/eapc-taskforce-ltc/FinalReportLong-TermCareSettings_Jan22_2013.pdf

N.B. Footnoted are additional articles on end-of-life care in the long-term care setting.

End-of-life care in Australia

Negotiating palliative care in the context of culturally and linguistically diverse patients

INTERNAL MEDICINE JOURNAL, 2013;43(9):1043-1046. There is an increasing emphasis on meeting the healthcare needs of culturally and linguistically diverse (CALD) communities in Australia. Negotiating the point of futility and the transition to specialist palliative care requires not only effective communication but also sensitivity to cultural and linguistic specificities. This can be a challenging process for clinicians, patients and families. Here, the authors outline some of the key challenges currently facing many clinicians in the context of CALD patients, with particular reference to the transitioning of patients to specialist palliative care. They suggest a focus on further research that can systematically document and model existing CALD-specific clinical processes and pathways, which can support the development of targeted educational interventions. <http://onlinelibrary.wiley.com/doi/10.1111/imj.12244/abstract;jsessionid=133EF914D5D39B87A6EC803734471697.d04t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

The frequency and cost of treatment perceived to be futile in critical care

JAMA INTERNAL MEDICINE | Online – 9 September 2013 – In the health system, treatment in critical care that is perceived to be futile is common and the cost is substantial. Advances in medicine enable critical care specialists to save lives as well as prolong dying. An admission to the intensive care unit (ICU) should be considered a therapeutic trial – aggressive critical care should transition to palliative care once it is clear that the treatment will not achieve an acceptable health state for the patient. However, intensive care interventions often sustain life under circumstances that will not achieve an outcome that patients can meaningfully appreciate. Such treatments are often perceived to be "futile" by health care providers. A survey of ICU physicians in Canada found that as many as 87% believed that futile treatment had been provided in their ICU in the past year. In a single-day cross-sectional study performed in Europe, 27% of ICU clinicians believed that they provided "inappropriate" care to at least one patient, and most of the inappropriate care was deemed such because it was excessive. In the U.S., critical care accounts for 20% of all health costs and 1% of the gross national domestic product. Because approximately 20% of deaths in the U.S. occur during or shortly after a stay in the ICU, critical care is scrutinized for the provision of potentially futile resource-intensive treatment. However, information is lacking on the prospective identification of patients who are perceived as receiving futile treatment, factors associated with these perceptions, and the outcomes and costs of the care. Treatment that cannot achieve a patient's goals or that simply maintains a state such as ICU dependence or permanent coma is contrary to professional values, inappropriately uses health care resources, and creates moral distress. Nonetheless, the determination of futility is often value laden. The authors convened a focus group of critical care physicians to establish reasons why treatment might be considered futile. Using these reasons, they surveyed critical care physicians daily during a 3-month period to identify patients whom they perceived to be receiving futile treatment. <http://archinte.jamanetwork.com/article.aspx?articleid=1735897&resultClick=3>

N.B. Commentary of this article: <http://archinte.jamanetwork.com/article.aspx?articleid=1735891>

A qualitative study of recently bereaved people's beliefs about death: Implications for bereavement care

JOURNAL OF CLINICAL NURSING | Online – 5 September 2013 – Three themes emerged that reflect the beliefs and experiences of bereaved people. The first describes people's understanding of death in terms of five positions: religious, dualist, eco-spiritualist, materialist, and death-as-transition. The second addresses a range of views about the possibility of life after death: resurrection, reuniting, and reincarnation. The third describes ways in which people felt their relationship with the deceased person continues after death: continuity as sense of presence, and continuity as memory, legacy and love. Some were reluctant to express a firm view about death. <http://onlinelibrary.wiley.com/doi/10.1111/jocn.12326/abstract;jsessionid=13502D17D406FC7086954E3A97166CC3.d02t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

A Canadian experience of integrating complementary therapy in a hospital palliative care unit

JOURNAL OF PALLIATIVE MEDICINE | Online – 10 September 2013 – The provision of complementary therapy in palliative care is rare in Canadian hospitals. An Ontario hospital's palliative care unit developed a complementary therapy pilot project within the interdisciplinary team to explore potential benefits. Massage, aromatherapy, Reiki, and Therapeutic Touch™ were provided in an integrated approach. This paper reports on the pilot project, the results of which may encourage its replication in other palliative care programs. An integrated complementary therapy program enhances regular symptom management, increases comfort, and is a valuable addition to interdisciplinary care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0295>

Noted in Media Watch, 24 January 2011, #185 (p.4):

- *U.S. NEWS* | Online – 19 January 2011 – **'Many U.S. hospices provide alternative therapies: Report.'** Prior research suggests although complementary and alternative therapies are not commonly covered by medical insurance, these services can help improve a critically ill patient's quality of life by alleviating symptoms of pain and anxiety, helping to provide comfort. <http://health.usnews.com/health-news/family-health/pain/articles/2011/01/19/many-us-hospices-provide-alternative-therapies-report>

Cancer care in the U.S.

Institute of Medicine declares cancer care crisis

MEDPAGE TODAY | Online – 10 September 2013 – The rise in demand for cancer care, a shrinking provider workforce, growing healthcare costs, and an increasingly complex disease are creating a "crisis in cancer care delivery," the Institute of Medicine says. A new course for cancer care needs to be charted that better coordinates care and improves data collection on outcomes and quality, the body said in a report.¹ Roughly 14 million Americans – 4% of the U.S. population – have had cancer. That number is expected to grow to 18 million by 2030 with 2.3 million new cases each year. Meanwhile, the ranks of several healthcare professions key to cancer care are expected to fall short of demand in coming years – including physicians. Furthermore, the cost of cancer care is rising at a faster rate than other fields of medicine, nearly doubling from \$72billion in 2004 to \$125billion in 2010, and is expected to increase another 39% – to \$173billion – by 2020. <http://www.medpagetoday.com/HematologyOncology/Chemotherapy/41495>

1. 'Delivering High-Quality Cancer Care: Chartering a new Course for a System in Crises,' Institute of Medicine, 2013. http://www.nap.edu/catalog.php?record_id=18359

Cont.

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 9 September 2013 – '**How are palliative care cancer populations characterized in randomized controlled trials? A literature review.**' A substantial variation exists in how palliative care cancer populations are described... Few variables are consistently registered and reported. There is a clear need to standardize the reporting. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00390-4/abstract](http://www.jpmsjournal.com/article/S0885-3924(13)00390-4/abstract)

End-of-life care in Ireland

Exploring public awareness and perceptions of palliative care: A qualitative study

PALLIATIVE MEDICINE | Online – 11 September 2013 – Most participants [in this study] had a general knowledge of palliative care, largely influenced by their own personal experience. They identified that palliative care was about caring for people who were dying and maintaining comfort in the last days of life. Participant's expectations of services included the following: holistic support, symptom management, good communication and practical support to enable choice and carer support. Key aspects identified for promoting palliative care were the development of understanding and use of the term itself and targeted educational strategies. Experience of palliative care generates understanding in the general public who also have ideas for increasing knowledge and awareness. The findings can inform policymakers about strategies to raise public awareness of palliative care. <http://pmj.sagepub.com/content/early/2013/09/10/0269216313502372.abstract>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 September 2013 – '**Perceived barriers and enablers to referrals to community-based hospice palliative care volunteer programs in Canada.**' Two studies were conducted ... in two Atlantic Canadian provinces. In study 1, a physician, home support nurse manager, social worker, and volunteer coordinator (VC) were interviewed. More barriers than enablers were identified. Based on these results and a review of the literature, a 'Perceived Barriers and Enablers to Hospice Palliative Care Volunteer Referrals Questionnaire' (PBEQ) was developed. In study 2, 10 VCs completed the PBEQ and rated the extent to which they perceived 18 items to be barriers to referrals, the extent to which they perceived 12 items to be enablers to referrals, and, described additional barriers and enablers. A Tips for Referrals sheet was created. <http://ajh.sagepub.com/content/early/2013/09/11/1049909113504482.abstract>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 September 2013 – '**The effect of palliative care on patient functioning.**' Palliative care is increasingly viewed as a care option that should not only be offered to patients very near the end of life. An important question is whether increased use of palliative care soon after a patient's referral will improve patient functioning, an aspect of quality of life. Increased use of palliative care was associated with improved patient functioning. This held true at very low as well as very high levels of initial functioning. The strongest predictor of subsequent patient functioning is their initial status. Accounting for patient-specific differences to precisely determine the impact of palliative care on patient functioning is difficult. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0040>

Dignity: A unifying concept for palliative care and human rights

PROGRESS IN PALLIATIVE CARE | Online – 13 September 2013 – The concept of human dignity is complex. Its meaning and emphasis have shifted over time. It is a concept that occupies a central place in two disciplines – palliative care and human rights law. This article examines the evolution of the meaning of dignity, the nature of intrinsic and extrinsic dignity and its place in palliative care and human rights law (especially as it pertains to the international right to health care). http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney_ppc_167

Cont.

Noted in Media Watch, 11 February 2013, #292 (p.10-11):

- *PALLIATIVE MEDICINE*, 2013;27(2):101-102. **'The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care.'** The European Association for Palliative Care, the International Association for Hospice & Palliative Care, the World Palliative Care Alliance, and Human Rights Watch have formulated 'The Prague Charter for Palliative Care as a Human Right.' <http://pmj.sagepub.com/content/27/2/101.full>; The Prague Charter: <http://www.eapcnet.eu/Themes/Policy/PragueCharter.aspx>

N.B. Footnoted are several articles on palliative care as a human right.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 12 September 2013 – **'Physician-assisted suicide – polling results.'** Recently ... readers [were given] the opportunity to share their opinions on physician-assisted suicide in Clinical Decisions, an interactive feature in which experts discuss a controversial topic and readers vote and post comments ... [and which] ... presented the case of a 72-year-old man in Oregon who was receiving palliative care for metastatic pancreatic cancer and was contemplating physician-assisted suicide. State laws in Oregon and Washington permit physicians to assist patients with such requests through the use of life-terminating drugs. Experts provided opposing viewpoints on physician-assisted suicide. Readers from 74 countries cast 2356 unique votes; U.S. readers from 49 states cast 1712 votes. Overall, 65% of the readers thought that physician-assisted suicide should not be permitted; the rate among U.S. voters was similar, with 67% voting against physician-assisted suicide. Among the 74 countries, 11 had a majority of votes in favor of permitting physician-assisted suicide. Readers in those countries cast a total of 97 votes; the largest number of these votes (37) was cast by readers from Mexico. Eighteen U.S. states had a majority of votes supporting physician-assisted suicide. Interestingly, Oregon and Washington were not in that group. More than 200 comments were posted. Readers opposed to physician-assisted suicide questioned whether suicide was a civil right or a human right, expressed the belief that assisting suicide violated a physician's oath to do no harm, and worried about a slippery slope in which physician-assisted suicide could eventually lead to euthanasia. Comments in favor of physician-assisted suicide highlighted the importance of honoring patients' autonomy and noted that if physicians assist at birth, they should also have a role in assisting at death. <http://www.nejm.org/doi/full/10.1056/NEJMclde1310667>
- *JOURNAL OF HUNTINGTON'S DISEASE*, 2013;2(3):323-330. **'Euthanasia and advance directives in Huntington's disease: Qualitative analysis of interviews with patients.'** The most important frame of reference regarding end-of-life wishes in Huntington's disease patients or known gene carriers is the experience with an affected parent. Family is important when thinking about the end of life and advance directives, even more so than the patient's physician. Knowledge about the ... law is limited. The majority of interviewees expressed some kind of wish regarding end of life, probably more than they had revealed to their physician, but were sometimes hesitant to discuss it. Knowledge on how to deal with wishes, advance directives and response shift is limited. In general, patients underestimate the requirement for sound professional support when considering euthanasia or physician assisted suicide and the value of an advance directive. In an attempt to improve knowledge and communication about end-of-life issues, physicians should ask the patient directly about their wishes. <http://iospress.metapress.com/content/4135510247lt8l87/>
- *PLoS ONE* | Online – 4 September 2013 – **"Righteous minds" in health care: Measurement and explanatory value of social intuitionism in accounting for the moral judgments in a sample of U.S. physicians.'** The broad diversity in physicians' judgments on controversial health care topics may reflect differences in religious characteristics, political ideologies, and moral intuitions. We tested an existing measure of moral intuitions in a new population (U.S. physicians) to assess its validity and to determine whether physicians' moral intuitions correlate with their views on controversial health care topics as well as other known predictors of these intuitions such as political affiliation and religiosity. The survey included ... questions on physicians' judgments about controversial health care topics including abortion and euthanasia. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0073379>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

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Something Missed or Overlooked?

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

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