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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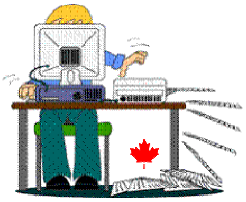


Compiled & Annotated by Barry R. Ashpole

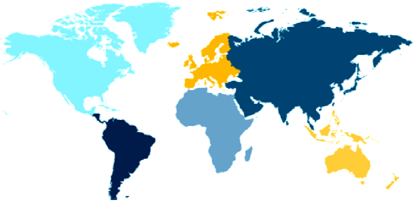
Patient-centred care: Scroll down to Specialist Publications and 'The value of sharing treatment decision making with patients: Expecting too much?' (p.8), in *Journal of the American Medical Association*.

Canada

More and better palliative care is needed

QUÉBEC | *The Montreal Gazette* (OpEd) – 26 September 2013 – An emotional video made public this week in which dying Toronto physician Donald Low expressed his support for medical aid to end the lives of dying patients,[1] and the opening this month of public hearings by the Québec government on Bill 52, its so-called dying-with-dignity legislation, have dramatically thrust the vital issue of how we care for the terminally ill back into the public glare. The West Island Palliative Care Residence in Kirkland has the most in-patient beds (23) of any such centre in Canada, and those of us who run it and care for our patients and their families have an intimate knowledge of the issues being raised by the Dr. Low video and Bill 52. Our conclusion – and that of practically everyone we know in the area of palliative care – is that the best way to help the terminally ill have better deaths is decidedly not to simply kill them with drugs. What is required instead is more and better specialized palliative care, to meet the needs of these patients and their families. http://www.montrealgazette.com/opinion/Opinion+More+better+palliative+care+needed/8963501/story.html

> **N.B.** Dr. Low, 68, who died on 18 September 2013, seven months after he was diagnosed with a malignant brain tumour, was the infectious disease expert who brought an authoritative voice and a calming presence to Toronto during the SARS crisis a decade ago. He wasn't afraid to die, but feared a protracted and painful death. [Source: *The Globe & Mail*, 25 September 2013] http://www.theglobeandmail.com/life/life-video/video-doctors-dying-wish-is-for-canada-to-accept-physician-assisted-suicide/article14494074/



World hospice & palliative care day
Voices for hospices 2013

12 October 2013

http://www.worldday.org/

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | The Canadian Press – 25 September 2013 – **'Assisted suicide Canada: Deb Matthews, Ontario Health Minister, welcomes debate.'** Ontario's health minister says it's time for Canadians and their leaders to talk about assisted suicide, but the federal Conservatives are making it clear that they have no intention of reopening that emotionally charged debate. Canadians need to talk about the taboo subject and end-of-life care, said Ontario Health Minister Deb Matthews. http://www.huffingtonpost.ca/2013/09/25/assisted-suicide-canada-deb-matthews_n_3990015.html?utm_hp_ref=canada-politics

  Of related interest:

  - ONTARIO | CBC News – 26 September 2013 – **'Ontario's Wynne supports national debate on assisted suicide.'** Canadians need to have a debate on whether or not to legalize assisted suicide, whether the federal government wants to deal with the issue or not, Premier Kathleen Wynne said Thursday. http://www.cbc.ca/news/canada/toronto/ontario-s-wynne-supports-national-debate-on-assisted-suicide-1.1869336

- QUÉBEC | *The Montreal Gazette* – 24 September 2013 – **'Ombudsman presents brief on Bill 52, which would allow terminal patients medical assistance to die.'** While the Charter of Québec Values has stolen the spotlight in Québec politics, hearings on Bill 52, an act respecting end-of-life care, are taking place under the radar at the National Assembly. "I've been working on this for nearly four years," Véronique Hivon, the Parti Québécois minister for social services and youth protection, said after [the] Québec ombudsman ... urged rapid adoption of the bill even though some issues, such as how to offer end-of-life care to patients suffering from dementia, remain unresolved. This is the second of four weeks of [public] hearings. http://www.montrealgazette.com/health/Ombudsman+presents+brief+Bill+which+would+allow+terminal+patients+medical+assistance/8954241/story.html

U.S.A.

With aging population comes need for a paradigm shift

NEW YORK STATE | *Westchester County Business Journal* – 26 September 2013 – Chronic conditions and prolonged illnesses are health-care realities that come with longer life expectancies and an aging population. There's a growing need for palliative care... There's already a shortfall of as many as 18,000 specialists in palliative care, with only one physician to every 20,000 older adults with a chronic condition, according to a NPR.org analysis.[1,2,3] Mary Beth Morrissey, a health care attorney and researcher, said part of the solution is a collaborative approach from a wide range of medical professionals and physicians, including specialists with non-palliative focuses. There is urgency behind a paradigm shift nationally and locally because of how large the older population has become and how much older it is likely to get. About 90 million Americans are living with serious illness, according to the Center to Advance Palliative Care,[4] and that number will double in the next quarter century with the aging baby boomer set. Also increasing is the number of "frail elderly" and people older than 85 years old. Chronic illnesses, dementia and long battles with diseases such as cancer and diabetes are increasingly and painfully commonplace. http://westfaironline.com/57908/with-aging-population-comes-need-for-a-paradigm-shift/

Specialist Publications

'Palliative care experience of U.S. adult nephrology fellows: A national survey' (p.14), in *Renal Failure.*

'From the Euthanasia Society to Physician Orders for Life-Sustaining Treatment: End-of-life care in the U.S.' (p.15), in *Cancer Journal.*

Cont.

1. 'As palliative care need grows, specialists are scarce,' National Public Radio, 5 April 2013. http://www.npr.org/blogs/health/2013/04/03/176121044/as-palliative-care-need-grows-specialists-are-scarce

2. 'Progress Report: Physicians Caring for Patients with Serious Illness,' American Academy of Hospice & Palliative Medicine, 2012. [Noted in Media Watch, 27 August 2012, #268 (p.7)] http://www.aahpm.org/uploads/AAHPM_2012_Progress_Report.pdf

3. 'Estimate of current hospice and palliative medicine physician workforce shortage,' *Journal of Pain & Symptom Management*, 2010;40(6):899-911. [Noted in Media Watch, 13 December 2010, #179 (p.9)] http://www.jpsmjournal.com/article/S0885-3924(10)00602-0/abstract

4. 'Palliative Care Facts & Stats,' Centre to Advance Palliative Care, New York (undated). http://www.capc.org/news-and-events/press-kit/press-kit-palliative-care-facts.pdf

Of related interest:

- *FORBES* | Online – 27 September 2013 – **'Reframing the health care debate is a long-term political must.'** While policymakers and pundits re-litigate the most contentious elements [of the Affordable Care Act], there are other politically-dangerous provisions set to go into effect that could pose an even greater headache for candidates running in next year's elections. Nowhere is this more relevant than in Oregon, where a little-known Commission is poised to upend longstanding Medicaid policy and create genuine uncertainty among ... Americans in need of end-of-life care options. It represents the exact opposite direction of where most Americans want to take the debate over the future of the nation's health care system. http://www.forbes.com/sites/dougschoen/2013/09/27/reframing-the-health-care-debate-is-a-long-term-political-must/

Declining hospice enrollment

Hospice of the Valley laying off 100 as business slows

ARIZONA | *Phoenix Business Journal* – 25 September 2013 – Hospice of the Valley is in the process of laying off about 100 of its workers who provide care for the terminally ill. The cuts are a last attempt to get the non-profit's financials in order as the hospice industry nationwide is seeing fewer clients. Levine said she has cut costs, including turning the air conditioner to a higher setting, but is now faced with reducing staff to be more in line with the number of patients the organization is serving. http://www.bizjournals.com/phoenix/news/2013/09/25/hospice-of-the-valley-laying-off-100.html

Gay marriage lawsuit expansion could impact local families

OHIO | 10TV News (Columbus) – 25 September 2013 – The judge handling an emotional case involving end-of-life issues for gay spouses has expanded the suit to apply to any LGBT [lesbian, gay, bisexual and transgender] couples in similar situations. Siobhan Boyd-Nelson says in many ways, her family is the picture of suburban sameness. But something Siobhan admits she hadn't considered was end-of-life issues when spouses are same-sex. Those are the issues raised by two Ohio couples dealing with the death or imminent death of a spouse. Judge Timothy Black of Ohio's Southern District has ruled in favor of both couples, granting them the right to be listed as married on their death certificates, and eventually be buried next to each other. http://www.10tv.com/content/stories/2013/09/25/reynoldsburg-gay-marriage-lawsuit-impact.html

Noted in Media Watch, 11 March 2013, #296 (p.8):

- *JOURNAL OF LGBT ISSUES IN COUNSELING*, 2013;7(1):87-116. **'Disenfranchised grief among lesbian and gay bereaved individuals.'** Experiences of grief among lesbian and gay (LG) individuals who have encountered the death of their partner remain invisible within the larger culture and within the counseling literature. This contribution provides a conceptual review of literature regarding the bereavement process of individuals who identify as sexual minorities. http://www.tandfonline.com/doi/abs/10.1080/15538605.2013.758345

Some personality types are more likely to receive nursing home care, researchers find

MCKNIGHT'S LONG TERM CARE NEWS & ASSISTED LIVING | Online – 23 September 2013 – Seniors who fit a particular personality profile are more than twice as likely to receive long-term care in a nursing home, according to newly published research.[1] Based on a self-report questionnaire ... seniors [i.e., study participants] were classified under five personality traits: neuroticism, extraversion, openness to experience, agreeableness and conscientiousness. These are traits commonly used as a conceptual framework by psychologists. Based on participants' healthcare use over a two-year period, the researchers determined that those scoring high for neuroticism were more than twice as likely to spend time in a nursing home. These are seniors who are more likely to feel angry, anxious, depressed or vulnerable, according to the researchers. A higher "openness to experience" score indicated a greater likelihood of home care use, according to researchers. http://www.mcknights.com/some-personality-types-are-more-likely-to-receive-nursing-home-care-researchers-find/article/312779/#

1. 'Is personality associated with health care use by older adults?' *The Milbank Quarterly*, 2013;91(3):491-527. http://onlinelibrary.wiley.com/doi/10.1111/1468-0009.12024/abstract

Care planning

When there's no family

THE NEW YORK TIMES | Online – 23 September 2013 – I rarely write about advance directives and end-of-life discussions without a few readers asking, sometimes plaintively: What if you don't have a family? Not everyone does. Ten years ago, the American Bar Association's Commission on Law & Aging looked into the problem and cited estimates that 4% of older adults are "unbefriended elderly,"[1] a chilling phrase referring to those who can't make decisions for themselves, have no advance directive or surrogate decision makers, and have no family or friends able to assist. Most of them aren't computer literate *Times* subscribers trying to plan ahead... They're primarily lifelong loners in hospitals and nursing homes, the report found. But it's an important question: If you don't have relatives or close friends who can serve as your health proxy or hold your power of attorney ... are you supposed to resign yourself to whatever the emergency room physician or intensive care staff member decides to do, or not do, when you can't direct your own care? http://newoldage.blogs.nytimes.com/2013/09/23/when-theres-no-family/?ref=health&_r=0

1. 'Incapacitated and alone: Healthcare decision making for unbefriended older people,' *Human Rights*, 2004;31(4). Article on the Association's Commission on Law & Aging 2003 report. http://www.americanbar.org/publications/human_rights_magazine_home/human_rights_vol31_2004/spring2004/hr_spring04_incapacitated.html

Of related interest:

- FLORIDA | *The Ledger* (Lakeland) – 28 September 2013 – **'Care facilities can pose threat to last wishes.'** In the last three years, the Agency for Health Care Administration cited 15 Florida nursing homes for failure to honor advance directives in the case of a death, which is a violation of state law. The variety of reasons why things went wrong in these 15 instances suggests that it can happen wherever there is a lack of focused attention on making residents' wishes a priority. http://www.theledger.com/article/20130928/NEWS/130929196?p=2&tc=pg

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.14.

Home care in the home stretch

THE NEW YORK TIMES | OpEd – 23 September 2013 – For nearly 40 years, home-care workers, wrongly labeled "companions," have been denied basic federal labor protection, including the right to be paid at least the minimum wage and time and a half for overtime. The Labour Department has moved to address that longstanding injustice, which affects millions of home-health aides, personal-care aides and other caregivers. The department issued a strong new rule that entitles these workers to minimum wage and overtime pay. The rule requires home-care agencies, which employ a vast majority of all home-care workers, to adhere to federal wage-and-hour laws. It also sets out clear rules for families that hire care workers directly, mandating the minimum wage and overtime pay during work hours, but allowing for unpaid hours that caregivers spend sleeping or on breaks. For all its merits, however, the rule has a big drawback. It does not take effect until January 2015. http://www.nytimes.com/2013/09/24/opinion/home-care-in-the-home-stretch.html?_r=0

Specialist Publications

'The future of the Medicare home health program' (p.12), in *Journal of the American Medical Association*.

International

End-of-life care in New Zealand

Specialist Publications

'Palliative care in low- and medium-resource countries' (p.9), in *Cancer Journal.*

Hospice hit hard by "double-whammy"

NEW ZEALAND | *The Waikato Times* – 27 September2013 – It's an organisation which provides vital support for people with terminal illnesses – but now the health of Hospice Waikato itself is ailing. In its 2012-2013 report the charitable trust revealed that while referrals to its services had gone up by 28%, income from grants had gone down by $177,000 over the same period. In total, nearly 900 people received care, either at home, in the community or at the Hospice Waikato in-patient unit in Hamilton. Chief executive Craig Tamblyn said the drop in grant income was "a double-whammy." Hospice needs to raise around $2 million each year to provide the same level of service, but the fiscal environment for charities is very tight. What makes it perhaps tougher for us is that we cover a huge region – the second largest covered by any hospice in New Zealand. http://www.stuff.co.nz/waikato-times/news/9215575/Hospice-hit-hard-by-double-whammy

Indigenous peoples and end-of-life care

Differences in attitudes to dying held by various ethnic communities are prompting new areas of research into palliative care

AUSTRALIA (NEW SOUTH WALES) | SBS News (Sydney) – 24 September 2013 – "I am a Ngangkari and my work is as a traditional healer. In a camp where someone is passing away, a family member will come and speak to me and ask me to go and help. So I go and see this person who is very sick, dying and I will put my hands on them and give them a gentle healing treatment." That's traditional healer Ilawanti Ken speaking ... [in] ... one of the languages from the Central Western Desert region of Australia. Also known as ngangkari, traditional Aboriginal healers play a pivotal role in the end of life care of many Aboriginal people in Central Australia. They believe in the power of combining both Western and traditional approaches in palliative care. The work done by ngangkari highlights one of the ways palliative care is provided in Indigenous communities in Australia. http://www.sbs.com.au/news/article/2013/09/24/developing-new-ways-ease-dying-process

Cont.

Selected articles on the needs of indigenous peoples as end of life approaches noted in past issues of Media Watch:

- *BMC PALLIATIVE CARE* | Online – 23 July 2013 – **'Improving palliative care outcomes for Aboriginal Australians: Service providers' perspectives.'** Study participants reported lack of understanding of Aboriginal culture and being uncertain of the needs and priorities of Aboriginal people during end-of-life care. According to several participants, few Aboriginal people had an understanding of palliative care. [Noted in Media Watch, 29 July 2013, #316 (pp.8-9)] http://www.biomedcentral.com/content/pdf/1472-684X-12-26.pdf

- *RURAL & REMOTE HEALTH* | Online – 8 May 2013 – **'Considering Aboriginal palliative care models: The challenges for mainstream services.'** The Australian government's National Indigenous Palliative Care Needs Study indicated that Australian empirical research on Aboriginal palliative care service provision is in its infancy, and comprehensive data on the rates of Aboriginal access to palliative care services did not exist.[1] [Noted in Media Watch, 13 May 2013, #305 (p.16)] http://www.rrh.org.au/articles/subviewaust.asp?ArticleID=2339

    1. National Indigenous Palliative Care Needs Study, Department of Health & Ageing, 2003. http://www.health.gov.au/internet/main/publishing.nsf/Content/5619BFE763995E17CA256F410011C5C3/$File/needall.pdf

End-of-life care in Australia

Philip Kennedy Centre hospice to close after $1m state funding cuts

AUSTRALIA (SOUTH AUSTRALIA) | *The Herald Sun* (Melbourne) – 24 September 2013 – The hospice at the Philip Kennedy Centre ... will close by the end of the year after its $1m state government funding was dropped. The unit, the only hospice located within an Australian nursing home, currently accommodates a dozen seriously ill patients who have just months to live. A spokesperson for Southern Cross Care, which manages the hospice, insisted no decision had been made on the future on 28 "highly skilled" nurses amid fears some will be made redundant. http://www.heraldsun.com.au/news/national/philip-kennedy-centre-hospice-to-close-after-1m-state-funding-cuts/story-fnii5yv7-1226726431809

Of related interest:

- AUSTRALIA (NEW SOUTH WALES) | ABC News – 20 September 2013 – **'Should palliative care happen at home?'** While most terminally ill Australians die in hospital, many would prefer to die at home. But funding pressures and medical models mean it's a choice not often available. http://www.abc.net.au/news/2013-09-20/should-palliative-care-happen-at-home/4972578

End-of-life care in Singapore

Today's hospices are built for yesterday

SINGAPORE | *The Straits Times* – 24 September 2013 – Dying patients and their family members lack adequate private spaces as hospices are not designed to support palliative care services. Some hospices are also isolated from the community as there no communal spaces or facilities which the public can opt to use. These are some of the key findings from a nine-month review commissioned by Lien Foundation and ACM [Ang Chin Moh] Foundation.[1] This first of its kind, the review gave some suggestions on how they can develop better hospices for the future. http://www.straitstimes.com/breaking-news/singapore/story/review-hospice-care-todays-hospices-are-built-yesterday-20130924

1. 'Hospitable Hospice: Redesigning Care for Tomorrow,' Lien Foundation, ACM Foundation. https://www.dropbox.com/s/iwundjli0q6i854/HOSPITABLE%20HOSPICE%20I%20Ap.Issues%20&%20insights%20overview.pdf

Cont.

Of related interest:

- SINGAPORE | *The Straits Times* – 27 September 2013 – **'Singapore's caregiver crunch.'** Singapore's rapidly ageing population has sparked a race to meet the surge in demand for care services for the elderly and infirm. Tied closely to this but less visible are the needs of a growing army of caregivers whose lives are disrupted when a family member needs round-the-clock care as a result of old age or illness. http://www.straitstimes.com/the-big-story/caregiver-crunch/story/singapores-caregiver-crunch-20130927

Elder care in Australia

83% of older patients return home after hospital stay

AUSTRALIAN INSTITUTE OF HEALTH & WELFARE | Online – 20 September 2013 – The majority of older Australians admitted to hospital are able to return to their home in the community after they are discharged. 'Movement between hospital and residential aged care 2008-2009,' focuses on people aged 65 and over and includes the first analysis of the use of hospitals by people already in residential care. About 90% of the 1.1 million hospitalisations a year for older Australians were for people who lived at home in the community. Nearly all the rest were for those living in residential aged care. http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129544618

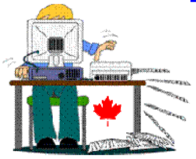
Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | News Talk ZB (Auckland) – 27 September 2013 – **'Labour withdraws voluntary euthanasia bill.'** Labour's decided to withdraw a voluntary euthanasia bill, saying it doesn't want it to become an election-year political football. The move's been welcomed by the moral conservative Bill English who says it's a very socially difficult and divisive issue... http://www.newstalkzb.co.nz/auckland/news/nbpol/801830008-labour-withdraws-voluntary-euthanasia-bill

- AUSTRALIA (TASMANIA) | ABC News – 26 September 2013 – **'Tasmanian MPS given conscience vote on euthanasia bill.'** MPs will be allowed a conscience vote on a private member's bill to introduce assisted dying laws being tabled in Parliament. The legislation would allow terminally ill patients to end their lives as soon as 10 days after making the initial request to their doctor. The private member's bill is sponsored by both the Premier, Lara Giddings, and Greens Leader Nick McKim, who says there is overwhelming popular support for the change. http://www.abc.net.au/news/2013-09-26/tasmanian-mps-consider-euthanasia-bill/4981808

- THE NETHERLANDS | *Dutch News* (Amsterdam) – 24 September 2013 – **'Euthanasia requests rose in 2012.'** The number of people opting to die by euthanasia rose by 13% last year to 4,188, according to the five regional committees charged with ensuring the legal conditions for assisted suicide are met. Euthanasia requests have risen steadily since 2006 when 1,923 people applied for assisted suicide. Researchers have been unable to determine why the number of cases is rising; they suspect it is due to greater acceptance of euthanasia by both patients and doctors. A large majority of last year's requests came from people with cancer – 3,251. In 42 cases, people with dementia were involved and 13 had severe psychiatric problems. http://www.dutchnews.nl/news/archives/2013/09/euthanasia_requests_rose_in_20.php



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

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

To be truly alive: Motivation among prison inmate hospice volunteers and the transformative process of end-of-Life peer care service

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 September 2013 – Some U.S. prisons are meeting the growing need for end-of-life care through inmate volunteer programs, yet knowledge of the motivations of inmate caregivers is underdeveloped. This study explored the motivations of inmate hospice volunteers from across Louisiana State... Participants expressed complex motivations; Inter-related themes on personal growth, social responsibility and ethical service to vulnerable peers suggested inmate caregivers experience an underlying process of personal and social transformation, from hospice as a source of positive self-identity to peer-caregiving as a foundation for community. Better understanding of inmate caregiver motivations and processes will help prisons devise effective and sustainable end of life peer-care programs. http://ajh.sagepub.com/content/early/2013/09/25/1049909113506035.abstract

> **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.15.

Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis

BRITISH JOURNAL OF GENERAL PRACTICE, 2013;63(615):e657-e668. This review focuses on conversations about end-of-life care with frail and older people who have no main overriding diagnosis who are estimated to account for around 40% of deaths. While a significant minority of frail older individuals would find them unwelcome, the majority would appreciate the chance to discuss end-of-life care, yet most do not have this opportunity. Attitudes to the timing of these discussions were variable, but most perceived the risk of leaving them too late. Most doctors believed it was their professional responsibility to initiate discussions, but felt limited by time pressures and the absence of a precipitating event. A range of barriers were identified: the reluctance of family members to discuss end-of-life care; the passive expectation that someone else would decide on an individual's behalf; and, significant uncertainty concerning future illness and decline. http://www.ingentaconnect.com/content/rcgp/bjgp/2013/00000063/00000615/art00033

Of related interest:

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 23 September 2013 – **'The value of sharing treatment decision making with patients: Expecting too much?'** The growing emphasis on patient-centered care is increasing the demand on physicians' time and effort to more fully engage patients and their families in treatment decision making. Thus, it is important to understand the potential effects of shared decision making (SDM) with patients on the outcomes of clinical encounters. Shared decision making is being strongly promoted for several reasons. First, it is the ethical responsibility of clinicians to facilitate patient involvement in treatment decision making because patients and their families are ultimately subjected to the outcomes of these decisions. Second, there is evidence that more engaged patients are more informed, more likely to fully deliberate about the risks and benefits between different treatment options, and ultimately more satisfied with the clinical encounter. The objectives of SDM are to fully inform patients and their families about treatment options, including the trade-offs between risk and benefits, and to incorporate patient values and preferences into treatment decisions. http://jama.jamanetwork.com/article.aspx?articleid=1741778

Palliative care in low- and medium-resource countries

CANCER JOURNAL, 2013;19(5):410-413. Low- and medium-resource countries are facing a significant increase in the incidence of non-communicable diseases such as cancer. Unfortunately, the majority of patients with cancer present with advanced disease, and disease-directed treatment may be unlikely to be effective and/or not available. Globally, there will be a growing need for palliative care services. There has been significant progress in the provision and integration of palliative care into the health care policy and systems. Nonetheless, palliative care services vary significantly between regions of the world and also between countries in the same region. Some common barriers to care include the lack of a trained workforce to provide palliative care, lack of availability of opioids or the restriction of their use, cultural attitudes of physicians and patients, and also funding. Despite these challenges, there are examples of low- and medium-resource countries that are providing excellent palliative care that is being integrated into the health care system and the cancer care continuum. This article provides an overview of the progress in providing palliative care in low- and medium-resource countries. In addition, more specific information is provided on palliative care in low-resource countries in Latin America, Asia, and Africa. http://journals.lww.com/journalppo/Abstract/2013/09000/Palliative_Care_in_Low__and_Medium_Resource.7.aspx

Of related interest:

- *PALLIATIVE CARE & MEDICINE* | Online – 30 August 2013 – **'Discussion of risk in palliative care as personal experience in two countries.'** The end of life care that palliation suits well has many issues that need to be addressed. The risks of premature or late withdrawal of life saving interventions are the least of the problems encountered. The curative care model that has been the expensive and more futile variety of end-of-life care is being superseded slowly by Dame Cicely Saunders and her colleagues simple mantra, that one should not die in pain and one should not die alone. Occasionally, the providers are suspected of hastening the death, by attending to deep anxiety and pain, and reducing the quantity of life, by giving medication that turns the patient inward and away from desire to eat, drink and communicate. http://www.omicsgroup.org/journals/discussion-of-risk-in-palliative-care-as-personal-experience-in-two-countries-2165-7386.1000155.pdf

- *RESEARCH & THEORY FOR NURSING PRACTICE*, 2013;27(2):95-114. **'Comfort measures: A concept analysis.'** For the comfort work of nurses to be recognized, nurses must be able to identify and delineate key attributes of comfort measures. Four main themes of attributes for comfort measures were identified in this analysis. Comfort measures involve an active, strategic process including elements of "stepping in" and "stepping back," are both simple and complex, move from a physical to a holistic perspective, and are a part of supportive care. http://www.ingentaconnect.com/content/springer/rtnp/2013/00000027/00000002/art00004

Restoring humanity in health and social care – some suggestions

CLINICAL ETHICS | Online – 26 September 2013 – This paper ... argues that the ethical requirement for humanity in health care is obvious and needs little ethical analysis – the problem is to get the results of ethical reflection, ordinary humanity and everyday common sense, into everyday behaviour. The author offers some suggestions that might help to achieve this aim and bring back the human face of health and social care. These suggestions concern organisational structural changes (including "humanity objectives" in appraisal and reward schemes); individual attitudes (including self assessment of their own humanity in their work by all health and social care workers – "does my own practice manifest a human face?"); and a possible research agenda (and a concomitant effort to remind all health care research funders that "humanity is an integral component of medical, health and care research." The author proposes a standing high level "humanity task force" to implement and oversee Health Education England's recent "humanity mandate." http://cet.sagepub.com/content/early/2013/09/18/1477750913502618.abstract

Cont.

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 September 2013 – **'"Isn't there anything more you can do?" When empathic statements work, and when they don't.'** The query, "Isn't there anything more you can do?" represents a classic informational question with an emotional subtext. In our previous work we have emphasized the value of noticing the emotional cue implicit in this question, and responding with an empathic statement. Yet responding explicitly to patients' emotions is not the best initial communication strategy for all patients. In this paper we discuss four different opening communication strategies – verbalize empathy, exchange information, contain chaos, respect searching – for patients who ask, "Isn't there anything more you can do?" http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0193

Is prolonged mechanical ventilation of cancer patients futile?

CRITICAL CARE | Online – 20 September 2013 – The issue of limiting life-sustaining treatments for intensive care unit (ICU) patients is complex. The ethical principles applied by ICU staff when making treatment-limitation decisions must comply with the law of their country. Until 2011, the law in Taiwan prohibited the withdrawal of mechanical ventilation. Consequently, patients with severe underlying diseases could receive prolonged mechanical ventilation. In [a recently published] study conducted in patients with cancer in Taiwan, continuous mechanical ventilation for more than 21 days was associated with poor outcomes, particularly in the subgroups of patients with metastases, lung cancer, or liver cancer. These results highlight the need for appropriate legislation regarding the withdrawal of life-sustaining treatments in patients, especially those for whom no effective cancer treatments are available. http://ccforum.com/content/17/5/189/abstract

Media Watch: Editorial Practice

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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.

What do hospital mortality rates tell us about quality of care?

EMERGENCY MEDICINE JOURNAL | Online – 23 September 2013 – Hospital mortality rates could be useful indicators of quality of care, but careful statistical analysis is required to avoid erroneously attributing variation in mortality to differences in health care when it is actually due to differences in case mix. The summary hospital mortality indicator is currently used by the English National Health Service. It adjusts mortality rates up to 30 days after discharge for patient age, sex, type of admission, year of discharge, co-morbidity, deprivation and diagnosis. Such risk-adjustment methods have been used to identify poor performance ... but their use is subject to a number of limitations. Studies exploring whether variation in risk-adjusted mortality can be explained by variation in healthcare have reached conflicting conclusions. Furthermore, concerns have been raised that the proportion of preventable deaths among hospital admissions is too small to produce a reliable "signal" in risk-adjusted mortality rates. This provides hospital managers, regulators and clinicians with a considerable dilemma. Variation in mortality rates cannot be ignored, as they might indicate unacceptable variation in healthcare and avoidable mortality, but they also cannot be reliably used to judge the quality of healthcare, based on current evidence. http://emj.bmj.com/content/early/2013/09/23/emermed-2013-203022.abstract

Noted in Media Watch, 8 November 2010, #174 (p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 November 2010 – **'Hospital mortality rates: How is palliative care taken into account?'** Using mortality rates to measure hospital quality presumes hospital deaths are medical failures. Palliative care and hospice leaders need to educate themselves and hospital administrators about the extent to which mortality rates take end-of-life care into account. http://www.jpsmjournal.com/article/S0885-3924(10)00654-8/abstract

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Online – 24 September 2013 – **'Statistics behind the headlines: Are you 45% more likely to die in a U.K. hospital rather than a U.S.' hospital?'** On 11 September Channel 4 News carried lengthy and uncritical coverage of ... [research] ... comparing hospital mortality in seven Western countries between 2004 and 2012.[1] The headline claims were that English "health service patients are 45% more likely to die in hospital than in the US," which was the leading (and only named) country of the seven being compared. http://www.bmj.com/content/347/bmj.f5775

    1. 'National Health Service hospital death rates among worst, new study finds,' BBC Channel 4 News, 11 September 2013. http://www.channel4.com/news/nhs-hospital-death-rates-among-worst-new-study-finds

It is not where you die, but who is with you when you die: Evolving palliative care practices among Marshall Islanders in Hawaii

HAWAII JOURNAL OF MEDICINE & PUBLIC HEALTH, 2013;72(9):72. A "good death" was defined [by study participants] as "peaceful and pain free," occurring naturally with avoidance of artificial life prolongation. Factors associated with a "good death" included gathering of family to absolve conflicts, and proper and timely cultural practices such as Ilomej (wake) and Eorak (post-burial memorial service). Dying at home is the norm among people living in the Marshall Islands. After migrating to Hawaii, having family present at the time of death was more important than the actual locale of death. Factors associated with "bad deaths" included young age, active suffering, accidents, suicides, or "black magic/curses," lack of timely burial or proper burial site. Barriers included mortuary fees, cost of transporting bodies, U.S. government policies, and wait times for death certificates. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3764590/

Cont.

Of related interest:

- *JOURNAL OF GERONTOLOGY: SERIES B* | Online – 21 September 2013 – **'Feeling lonely versus being alone: Loneliness and social support among recently bereaved persons.'** Both loneliness and social support declined over the first year and a half of bereavement [among study participants]. Greater social support was associated with lower levels of loneliness overall, but the receipt of social support did not modify one's expression of loneliness over time. Loneliness was more highly correlated with support from friends than family. http://psychsocgerontology.oxfordjournals.org/content/early/2013/09/21/geronb.gbt075.abstract

Pediatric palliative care for youth with HIV/AIDS: Systematic review of the literature

HIV/AIDS, 2013;5:165-179. There have been few empirically based studies evaluating palliative care and medical decision-making in youth with HIV. What was available tended to focus on physical aspects of care... Future research should focus on ... evaluating the psychological, social, ethical, and cultural aspects of care, while investigating the needs of all stakeholders, patients, families, and health care providers. http://www.dovepress.com/pediatric-palliative-care-for-youth-with-hivaids-systematic-review-of--peer-reviewed-article-HIV

Of related interest:

- *JOURNAL OF PEDIATRIC HEALTH CARE* | Online – 20 September 2013 – '**Coverage of palliative and hospice care for pediatric patients with a life-limiting illness: A policy brief.'** No abstract available. http://www.jpedhc.org/article/S0891-5245(13)00228-9/abstract

The future of the Medicare home health program

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 26 September 2013 –The Medicare home health benefit is a prominent national policy supporting older Americans at home and provides for visiting nurse and therapist services from home health agencies (HHAs). In 2012, Medicare spent $18.2 billion on HHAs; 3.5 million beneficiaries received care. Home health can help struggling patients get support in the community and can enable successful transitions home from institutional care. However, numerous concerns have been raised about the home health benefit, including fraud, geographic variation in utilization, and poor coordination with primary medical care. This uncertainty is untimely, as more than 70 million adults will join Medicare between 2011 and 2030 with the hope of receiving care at home. It is time to develop a stronger home health option. http://jama.jamanetwork.com/article.aspx?articleid=1742539

Grief, depression, and the *DSM-5*

JOURNAL OF PSYCHIATRIC PRACTICE, 2013;19(5):386-396. Based on a review of the best available evidence and the importance of providing clinicians an opportunity to ensure patients and their families receive the appropriate diagnosis and the correct intervention without necessarily being constrained by a somewhat arbitrary two-month period of time, the *DSM-5* [*Diagnostic & Statistical Manual of Mental Disorders IV*] Task Force recommended eliminating the "bereavement exclusion" (BE) from the diagnosis of major depressive disorder. This article reviews the initial rationale for creating a BE in *DSM-III*, reasons for not carrying the BE into *DSM-5*, and sources of continued controversy. The authors argue removing the BE does not "medicalize" or "pathologize" grief, "stigmatize" bereaved persons, imply grief morphs into depression after two weeks, place any time limit on grieving or imply antidepressant medications should be prescribed. http://journals.lww.com/practicalpsychiatry/Abstract/2013/09000/Grief,_Depression,_and_the_DSM_5.5.aspx

N.B. Selected articles on the controversy surrounding *DSM-5* are noted in Media Watch, 13 May 2013, #305 (pp.4-5).

Accounting for personhood in palliative sedation

MEDICAL HUMANITIES | Online – 26 September 2013 – Application of sedation at the end of life has been fraught with ethical and clinical concerns, primarily focused on its potential to hasten death. However, in the face of clinical data that assuage most of these concerns, a new threat to this treatment of last resort has arisen. Concern now pivots on its effects on the personhood of the patient, underpinned by the manner in which personhood has been conceptualised. For many authors, it is consciousness that is seen to be the seat of personhood, thus its loss is seen to rob a patient of their moral and ethical worth, leaving them in a state that cannot ethically be differentiated from death. The author proffers an alternative to this view ... which dispels these concerns about sedation at the end of life. http://mh.bmj.com/content/early/2013/09/26/medhum-2013-010368.abstract

Noted in Media Watch, 11 March 2013, #296 (p.11):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 6 March 2013 – **'Moral differences in deep continuous palliative sedation and euthanasia.'** Some writers argue that there is an important moral dividing-line between palliative sedation and euthanasia, making the first acceptable and the latter not. The authors question this. A recent article has argued we are wrong on two accounts: first, we fail to account properly for the moral difference between continuous deep palliative sedation at the end of life and euthanasia, and, second, we fail to account properly for the difference between permanent loss of consciousness and death.[1] http://spcare.bmj.com/content/early/2013/03/06/bmjspcare-2012-000431.abstract

    1. 'Intention, procedure, outcome and personhood in palliative sedation and euthanasia,' *BMJ Supportive & Palliative Care*, 2012;2(1):9-11. http://spcare.bmj.com/content/2/1/9.abstract [Noted in Media Watch, 20 February 2012, #241 (p.7)]

Implications for carers of terminally ill patients dying at home

NURSING STANDARD, 2013;28(3):40-45. Most terminally ill patients will express a wish to die at home. To achieve this, patients rely on the support of family carers, who may experience emotional and health difficulties in providing such care, both before and after the death. Healthcare professionals can help to relieve the burden on family carers, and there is guidance available to direct GPs and other community healthcare professionals on providing good anticipatory palliative care for patients, and support for carers. This will increase the likelihood patients at the end of life will achieve a "good death" and family members will have a positive experience of care giving. http://rcnpublishing.com/doi/abs/10.7748/ns2013.09.28.3.40.e7651

Of related interest:

- *MEDICAL XPRESS* | Online – 24 September 2013 – **'Stepfamilies add to caregiver burden.'** Caregiving is always tough, but it's that much tougher when caregivers have to rely on family ties that are ambiguous, strained or virtually nonexistent, suggests a University of Michigan study.[1] http://medicalxpress.com/news/2013-09-stepfamilies-caregiver-burden.html

    1. 'Dementia caregiving in the context of late-life remarriage: Support networks, relationship quality, and well-being,' *Journal of Marriage & Family*, 2013;75(5):1149-1163. http://onlinelibrary.wiley.com/doi/10.1111/jomf.12059/abstract

Palliative care experience of U.S. adult nephrology fellows: A national survey

RENAL FAILURE | Online – 24 September 2013 – Over two-thirds (72%) of the [nephrology] fellows [i.e., survey respondents] had no formal PC [palliative care] medicine rotation during their medical school. Half (53%) had no formal PC elective experience during residency. Although nearly 90% of the fellows had a division or department of PC medicine at their institution, only 46.9% had formal didactic PC medicine experience. Over 80% of the respondent's program did not offer formal clinical training or rotation in PC medicine during fellowship. While 90% of fellows felt most comfortable with either writing dialysis orders in the chronic outpatient unit, seeing an ICU consult or writing continuous dialysis orders in the ICU, only 35% of them felt most comfortable "not offering" dialysis to a patient in the ICU with multi-organ failure. Nearly one out of five fellows surveyed felt obligated to offer dialysis to every patient regardless of benefit. Over two-thirds (67%) of the respondents thought that a formal rotation in PC medicine during fellowship would be helpful to them. http://informahealthcare.com/doi/abs/10.3109/0886022X.2013.831718

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Media Watch Online

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://APHN.ORG/CATEGORY/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' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report)

Canada

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

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

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

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

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.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)

Selected articles on the provision of palliative care for patients with end-stage renal disease noted in past issues of Media Watch:

- *NEPHROLOGY DIALYSIS TRANSPLANTATION* | Online – 2 September 2010 – **'National survey of the current provision of specialist palliative care services for patients with end-stage renal disease.'** The majority specialist palliative care services accept end-stage renal disease patients, but limited numbers are referred. [Noted in Media Watch, 6 September 2010, #165 (p.11)] http://ndt.oxfordjournals.org/cgi/content/abstract/gfq530

- *CLINICAL JOURNAL OF THE AMERICAN SOCIETY NEPHROLOGY* | Online – 14 January 2010 – **'End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease.'** [Survey] participants reported relying on the nephrology staff for extensive end-of- life care needs not currently systematically integrated into their renal care, e.g., pain and symptom management, advance care planning, and psychosocial and spiritual support. Participants also had poor self-reported knowledge of palliative care options and of their illness trajectory. [Noted in Media Watch, 18 January 2010, #132 (p.5)] http://cjasn.asnjournals.org/content/5/2/195.abstract?sid=ffe4ad3e-bb66-4daa-bc3c-43a7330495b2

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *CANCER JOURNAL*, 2013;19(5):438-443. **'From the Euthanasia Society to Physician Orders for Life-Sustaining Treatment: End-of-life care in the U.S.'** Advances in medical care and increasing prevalence of non-communicable illnesses such as cardiovascular disease and cancer had raised concerns about respecting the patients' dying wishes as early as 1938, when the Euthanasia Society of America was formed. Many high-profile cases and landmark court decisions later, there are now several ways in which different states regulate the patients' end-of-life wishes. How these laws evolved, how seminal cases and medical and ethical advances helped shape the current state of end-of-life legislation, and how patients – especially those with cancer – began adopting various forms of advance directives is the topic of this article.http://journals.lww.com/journalppo/Abstract/2013/09000/From_the_Euthanasia_Society_to_Physician_Orders.11.aspx

Worth Repeating

What "best practice" could be in palliative care: An analysis of statements on practice and ethics expressed by the main health organizations

BMC PALLIATIVE CARE | Online – 7 January 2010 – The authors carried out an analysis of the statements on practice and ethics of palliative care expressed by the main health organizations to show which dimensions of end-of-life care are taken into consideration. Overall, 34 organizations were identified, 7 international, and 27 operating on the national level in four different countries (Australia, Canada, U.K. and the U.S.). Up to 56 documents were selected and analysed. Most ... are position statements. Relevant quotations from the documents were presented by "areas" and "sub-areas." In general, the "sub-areas" of symptoms control as well as those referring to relational and social issues are more widely covered by the documents than the "sub-areas" related to "preparation" and to "existential condition." Indeed, the consistency of end-of-life choices with the patient's wishes, as well as completion and meaningfulness at the end of life is given only a minor relevance. An integrated model of the best palliative care practice is generally lacking in the documents. http://www.biomedcentral.com/content/pdf/1472-684x-9-1.pdf

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Barry R. Ashpole **'phone: 519.837.8936**
Guelph, Ontario CANADA **e-mail: barryashpole@bell.net**