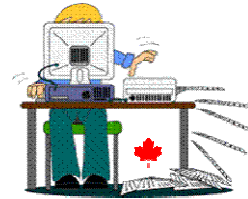


## Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry and research.

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

Compiled & Annotated by Barry R. Ashpole

"High tech" vs. "high touch": Scroll down to [Specialist Publications](#) and 'Work culture among healthcare personnel in a palliative medicine unit' (p.10), in *Palliative & Supportive Care*.

## Canada

Cultural sensitivity: Linguistic portrait of Canada

### Census shows rise of non-official tongues in Canadian homes

CTV NEWS | Online report – 24 October 2012 – The nation's official languages appear to be giving way to other tongues, the latest census data shows,<sup>1</sup> with one in five Canadians speaking a language other than English or French at home. From Cantonese to Swahili, about 6.6 million people reported speaking a non-official language at home. More than 200 different languages were identified. Tagalog – a Philippine-based language – showed the largest increase in popularity. <http://www.ctvnews.ca/canada/census-shows-rise-of-non-official-tongues-in-canadian-homes-1.1008443>

1. Statistics Canada, October 2012: <http://www.statcan.gc.ca/daily-quotidien/121024/dq121024a-eng.htm>

### [Specialist Publications](#)

Of related interest:

'End of life in residential care from the perspective of care aides' (p.7), in *Canadian Journal on Aging*.

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *Globe & Mail* – 25 October 2012 – '**Assisted suicide too risky, federal government argues in appeal against B.C. decisions.**' Ottawa is defending the law that prohibits assisted suicide as it appeals a decision from a British Columbia court, which concluded it is unconstitutional to prevent the sick and dying from asking a doctor to help them end their lives. <http://www.theglobeandmail.com/news/british-columbia/assisted-suicide-too-risky-federal-government-argues-in-appeal-against-bc-decision/article4673820/>

Noted in Media Watch, 13 August 2012:

- BRITISH COLUMBIA | *Vancouver Sun* – 11 August 2012 – '**Judge upholds Gloria Taylor's right to die.**' <http://www.vancouversun.com/health/Judge+upholds+Gloria+Taylor+right/7076196/story.html>

## U.S.A.

### **Many terminal cancer patients mistakenly believe a cure is possible**

MASSACHUSETTS | National Public Radio (Boston) – 25 October 2012 – Doctors are often called upon to deliver bad news to patients, and there isn't much that's worse than a diagnosis of an advanced-stage cancer for which there is no cure. But there's new evidence that a surprisingly large majority of patients who receive this news don't fully comprehend it, or perhaps willfully choose to ignore it. Almost three out of every four patients diagnosed with stage IV lung or colon cancer believe that chemotherapy can cure them of their disease, according to a survey of more than 1,100 cancer patients by the Dana-Farber Cancer Institute.<sup>1</sup> And yet for cancers diagnosed at that late of a stage, chemotherapy has been definitively shown to extend lifespan by only a few months at best. The survey ... also found that patients who rated their doctor as being a good communicator were more likely to hold mistaken beliefs about their prognosis. This indicates that some doctors may be trying to tell their patients what they think they want to hear, rather than the truth. <http://www.npr.org/blogs/health/2012/10/25/163572138/many-terminal-cancer-patients-mistakenly-believe-a-cure-is-possible>

1. 'Patients' expectations about effects of chemotherapy for advanced cancer,' *New England Journal of Medicine*, 2012;367(17):1616-1625. <http://www.nejm.org/doi/full/10.1056/NEJMoa1204410>

### **End-of-life system is needed in Wisconsin**

WISCONSIN | *Milwaukee Journal-Sentinel* – 25 October 2012 – This is a response to [a recent] *Journal-Sentinel* article.<sup>1</sup> The current status of advanced planning for end-of-life decisions is a system that is woefully lacking, and where tools exist, they are of limited utility. Autonomy is a fundamental bioethical principle: Patients have the right to make decisions affecting their health care, including deciding on the level and type of care they want. The principle of autonomy is no more important than in end-of-life decisions. These decisions should ultimately be made by the patient but clearly benefit from discussions with health care providers, family, religious leaders and others important in a patient's life. These decisions should reflect the individual's goals as guided by his or her personal values and beliefs. The Wisconsin Medical Society's Honoring Choices Wisconsin is in keeping with the importance of autonomy, and we fully support this. <http://www.jsonline.com/news/opinion/endoflife-system-is-needed-in-wisconsin-1b7br5c-175873421.html>

1. 'End-of-life medical care initiative prompts worries about abuse,' *Milwaukee Journal-Sentinel*, 16 October 2012 (noted in Media Watch, 22 October 2012). <http://www.jsonline.com/features/health/endoflife-medical-care-initiative-prompts-worries-about-abuse-pv71jc9-174491051.html>



### 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>

## Michigan legislation requiring hospital disclosure of refuse-to-treat policy

*NATIONAL REVIEW* | Online OpEd – 23 October 2012 – Futile Care Theory (aka medical futility) permits doctors and/or hospital bioethics committees to unilaterally withdraw wanted life-sustaining treatment based on cost and/or quality of life. This isn't because the treatments don't or won't work – e.g., physiological futility – which should never have to be provided. To the contrary, they are refused precisely because they are working by maintaining the patient's life. In other words, it is really the patient being declared futile (qualitative futility). Some states have granted hospitals such legal authority, most particularly, Texas. Other state statutes tend to be more vague (such as in California). Regardless of state law, many hospitals

have created internal futile care protocols, unknown to patients. Now legislation has been filed in Michigan to require disclosure of such policies to patients upon request. <http://www.nationalreview.com/human-exceptionalism/331446/mi-legislation-requiring-hospital-disclosure-refuse-treat-policy#>

### Specialist Publications

'Stealing on insensibly: End of life politics in the U.S.' (p.7), in *Health Economics, Policy & Law*.

Noted in Media Watch, 27 August 2012:

- *HEC FORUM* | Published online – 19 August 2012 – **'Institutional futility policies are inherently unfair.'** <http://www.springerlink.com/content/q033k26474v2m877/>

## Conscious or not? Brain responses bring scientists closer to making a diagnosis in the brain-damaged

*DISCOVER MAGAZINE* | Online report – 22 October 2012 – When a brain-damaged person seems unresponsive, the uncertainty is excruciating. Is the person in a vegetative state, awake but not conscious, or are they minimally conscious, still retaining some shreds of awareness? <http://blogs.discovermagazine.com/80beats/2012/10/22/conscious-or-not-brain-responses-bring-scientists-closer-to-making-a-diagnosis-in-the-brain-damaged/>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE ATLANTIC* | Published online – 25 October 2012 – **'Physician-assisted suicide is not progressive.'** When cast as a rights issue, it's hard for progressives to resist [legalizing physician-assisted suicide]. But "the right to die" is just a slogan. No civil right to commit suicide exists in any social compact. Human beings have a biologically imposed *obligation* to die; and, as [French philosopher] Jean Paul Sartre reminded us, suicide is always an option. However, even if a civic right to suicide did exist, *suicide* and *assisted suicide* are very different things. Suicide might be a purely private act; but *physician-assisted suicide* involves two people, one of whom is trained, certified, licensed, and compensated by society. <http://www.theatlantic.com/health/archive/2012/10/physician-assisted-suicide-is-not-progressive/264091/>
- MASSACHUSETTS | Radio Boston – 23 October 2012 – **'The ethical conflict doctors face on physician-assisted suicide.'** Ravi Parikh is a fourth-year student at Harvard Medical School and the multiple medical associations he belongs to are sending out contrasting opinions on ... a ballot initiative Massachusetts voters will decide [on 6 November]: 'Should a licensed physician be able to prescribe medication, at a terminally ill patient's request, to end that patient's life?' The American Medical Association and the Massachusetts Medical Society say no. In contrast, the American Medical Student Association supports it. Is there a generational shift when it comes to doctors' attitudes about physician assisted suicide? <http://radioboston.wbur.org/2012/10/23/physician-assisted-suicide>

## International

### **They're patients not prisoners**

U.K. | *County Press* (Newport) – 26 October 2012 – As one of the few prisons in the country with its own hospital, Her Majesty's Prisons Isle of Wight is leading the way in providing good quality healthcare. An inspection earlier this year by health watchdog, the Care Quality Commission, found services were meeting all essential standards of quality and safety, and prisoners were treated with respect. Many prisoners had nothing but praise for the healthcare on offer, provided by the Isle of Wight National Health Trust (NHS) and that meets 28 of 31 performance targets, and they told inspectors the services were the best they had experienced. All good news, right? In reality it's not that simple, partly because prison healthcare is such a controversial issue. As head of prison healthcare Richard Knowles explained: "The truth is some people think prisoners don't deserve good quality healthcare. But prisoners are punished by being deprived of their liberty, not by removing

everything else that makes them a human being. Everyone deserves access to good healthcare." It is also better for society in the long term – healthy prisoners are less likely to re-offend on release, and less likely to burden the NHS.

<http://www.iwcp.co.uk/news/wight-living/theyre-patients-not-prisoners-46701.aspx>

#### **Extract from *County Press* article**

The 18-bed prison hospital, opened at the Albany site three years ago, is able to deal with the bulk of healthcare complaints, from chronic long-term conditions, including diabetes, asthma and heart conditions, to physical injuries and mental health problems. It even provides end-of-life care to terminally ill prisoners and has a serene garden, created by prisoners with a King's Fund grant.

### **Dying dementia victims deprived of dignity at end**

U.K. | *Express* – 25 October 2012 – A man with dementia who died after being left in agony for 11 days with a dislocated shoulder was just one of thousands of sufferers treated without dignity at the end of their lives, a report claims.<sup>1</sup> Hospital and care home staff have been accused of allowing patients to die in pain, as well as being rude and uncaring to them in their final days. It is believed the patient who suffered for 11 days in a care home before he died, had been seen by five doctors – but none had examined him thoroughly. The Alzheimer's Society report ... revealed complaints from relatives about their loved ones going unchanged and left to sit for hours in their faeces and urine. Others patients were reportedly changed but staff paid little attention to their privacy, failing to cover them up when they were being undressed. Researchers

found nearly 4% of relatives of dementia sufferers said their loved ones were never treated with dignity by hospital nurses, while 25% said they were only treated with dignity some of the time. There are [an estimated] 850,000 people with dementia in the U.K., a number set to rise to a million within a decade. <http://www.express.co.uk/posts/view/354230/Dying-dementia-victims-deprived-of-dignity-at-end>

#### **Specialist Publications**

**'The experience of providing end-of-life care to a relative with advanced dementia: An integrative literature review'** (p.9), in *Palliative & Supportive Care*.

1. 'My Life Until the End: Dying Well with Dementia,' Alzheimer's Society, October 2012. [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1537](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537)

Of related interest:

- U.K. | ITV News – 25 October 2012 – '**£50 million dementia care pledge.**' The Health Secretary will outline details on his pledge ... to help hospitals and care homes create more dementia-friendly environments. It comes as the Alzheimer's Society warns that sufferers should plan end-of-life care. <http://www.itv.com/news/story/2012-10-24/health-secretary-jeremy-hunt-dementia-alzheimers/>

Representative sample of articles on dementia and end-of-life care noted in recent issues of Media Watch:

- *BRITISH JOURNAL OF NURSING*, 2012;21(12): 723-727. '**A tormented death: End-of-life care for people with dementia.**' <http://www.internurse.com/cgi-bin/go.pl/library/abstract.html?uid=92656>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Published online – 18 July 2012 – '**Providing quality palliative care in end-stage Alzheimer disease.**' <http://ajh.sagepub.com/content/early/2012/07/16/1049909112453644.abstract>
- *AMERICAN JOURNAL OF ALZHEIMER'S DISEASE & OTHER DEMENTIAS* | Published online – 31 January 2012 – '**Palliative care for advanced dementia: Pilot project in two nursing homes.**' <http://aja.sagepub.com/content/early/2012/01/04/1533317511432732.abstract>

### **Old people's final wishes remain unfulfilled by poor planning**

U.K. | *Guardian* – 22 October 2012 – A questionnaire carried out as part of the national bereavement survey recently found that, of those who expressed a preference, 71% of respondents wanted to die at home but only 21% actually managed to do so.<sup>1</sup> For many older people, these important last wishes remain unfulfilled – and often needlessly so. Extra-care housing is one model that should help greater numbers of older people die at home, according to their wishes. There is already mounting evidence to support the claim that extra-care housing offers a "home for life," but qualitative work suggests that there is still a way to go before this is achieved for extra care residents. One of the most difficult aspects of planning end-of-life care is to start a conversation about dying. This lack of planning, however, can mean that an older person's ultimate wish to die at home remains unfulfilled. Extra care housing can enable residents to live later life to the full, allowing conversations about the end of life and determining a resident's wishes to become an extension of their broader life goals. <http://www.guardian.co.uk/housing-network/2012/oct/22/dying-home-extra-care-housing?newsfeed=true>

1. 'National Bereavement Survey, 2011,' Office for National Statistics, July 2012 (noted in Media Watch, 9 July 2012). Key Findings & Summary: [http://www.ons.gov.uk/ons/dcp171778\\_269914.pdf](http://www.ons.gov.uk/ons/dcp171778_269914.pdf)

#### **[Media Watch posted on Palliative Care Network-e Website](#)**

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

#### **[Quotable Quotes](#)**

*Our society and mainstream American culture have never grappled with the fundamental fact of mortality; therefore, we do not know what to expect or what is possible. When someone we love is diagnosed with a life-threatening condition, the worst thing we can imagine is that he or she might die. The sobering fact is that there are worse things than having someone you love die. Most basic, there is having the person you love die badly, suffering as he or she dies. Worse still is realizing later on that much of his or her suffering was unnecessary.* Ira Byock, Director of Palliative Medicine at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire, and Professor at Dartmouth Medical School

## Patient death pathway 'based on guesswork'

U.K. | *Telegraph* – 22 October 2012 – The Liverpool Care Pathway [LCP] is aimed at providing a comfortable death for patients in their last days and hours by not subjecting them to futile treatments, but many fear it is being used inappropriately and has become "self-fulfilling." Campaigners have criticised a consensus statement signed by 22 organisations in support of the pathway, which said it was good medical practice and did not hasten death.<sup>1</sup> In their response to the agreement, the group opposing the pathway ... argued that it was fatally flawed. There was no scientific basis underpinning the prognoses that patients were dying, they said. "It is self-evident that stopping fluids whilst giving narcotics and sedatives hastens death," the group said in a statement. The group also pointed out that the latest pathway audit showed that just 16% of patients had fluids continued on the pathway and none had fluids started. "The median time to death on the LCP is now 29 hours," the group said. "Statistics show that even patients with terminal cancer and a poor prognosis may survive months or more if not put on the LCP." They add: "The fact is that there is no scientific evidence to support the diagnosis of impending death and there are no published criteria that allow this diagnosis to be made in an evidence-based manner. <http://www.telegraph.co.uk/health/healthnews/9626610/Patient-death-pathway-based-on-guesswork.html>

### Doctors not told to hasten deaths, says health secretary Alex Neil

U.K. (SCOTLAND) | *Scotsman* – 27 October 2012 – [Scotland's] Health secretary Alex Neil has vowed not to ask doctors to hit targets for the number of patients who die on the controversial LCP, after it emerged hospitals in England were being given financial incentives to do so. <http://www.scotsman.com/news/health/doctors-not-told-to-hasten-deaths-says-health-secretary-alex-neil-1-2601486>

### Probe into use of 'death pathway' by National Health Service [NHS]

U.K. | *Telegraph* – 26 October 2012 – The NHS is coordinating a probe into the Liverpool Care Pathway after concerns were raised over its misuse. <http://www.telegraph.co.uk/health/healthnews/9635878/Probe-into-use-of-death-pathway-by-NHS.html>

### Doctors to launch investigation into Liverpool Care Pathway

U.K. | *Telegraph* – 24 October 2012 – The Association for Palliative Medicine, representing over 1,000 doctors working in hospices and specialist palliative care units throughout the country, is to carry out research to see if the Liverpool Care Pathway is operating as a "euthanasia pathway." <http://www.telegraph.co.uk/health/healthnews/9630194/Doctors-to-launch-investigation-into-Liverpool-Care-Pathway.html>

1. 'Consensus statement: Liverpool Care Pathway for the Dying Patient,' National Council for Palliative Care, 25 September 2012 (noted in Media Watch, 1 October 2012). <http://www.ncpc.org.uk/sites/default/files/user/LCP%20Consensus%20Statement.pdf>

**N.B.** Several articles published in recent months on the LCP are noted in Media Watch, 22 October 2012 (p.6).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | *The Age* – 25 October 2012 – '**GPs reluctant to euthanize patients.**' More than 200 Australian doctors have banded together to call for law reform on voluntary euthanasia, but few of them would want to administer a fatal drug dose, the organisation's spokesman says. Robert Marr, a GP in Sydney, said he was unable to think of any member of Doctors for Voluntary Euthanasia Choice who would want to be responsible for the death of a patient wanting to die. He said critics of euthanasia focused on this reluctance and raised the issue of the possible traumatic outcomes for doctors. <http://www.theage.com.au/national/health/gps-reluctant-to-euthanise-patients-20121024-285q3.html>

Cont.

- AUSTRALIA (NEW SOUTH WALES) | *Sydney Morning Herald* – 23 October 2012 – 'Euthanasia is just a bridge too far.' A spokesman for the Deputy Premier and New South Wales Nationals leader, Andrew Stoner, confirmed that Nationals MPs will be allowed a conscience vote on any euthanasia bill brought before the Parliament. <http://www.smh.com.au/opinion/political-news/euthanasia-is-just-a-bridge-too-far-20121022-281i9.html>

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

### **End of life in residential care from the perspective of care aides**

*CANADIAN JOURNAL ON AGING* | Published online – 23 October 2012 – The authors explored contextual features shaping end-of-life (EOL) care in residential care facilities by drawing on the perspectives of resident care aides (RCAs). RCAs characterized EOL care as "providing comfort," including physical and emotional comfort. Concerns with time and workload challenges dominated accounts and generated guilt, sadness, and frustration. RCAs tried to "find the time" by taking it from themselves or other residents, and by relying on the commitment of co-workers and on families. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8719315>

### **A new instrument to assess the needs of parents whose children died in the pediatric intensive care unit**

*CRITICAL CARE MEDICINE*, 2012;40(11):3050-3057. [In a cross-sectional survey] the Bereaved Parent Needs Assessment demonstrated reliability and validity to assess the needs of bereaved parents. Meeting parents' needs around the time of their child's death may promote adjustment to loss. [http://journals.lww.com/ccmjournal/Abstract/2012/11000/The\\_Bereaved\\_Parent\\_Needs\\_Assessment\\_A\\_new.16.aspx](http://journals.lww.com/ccmjournal/Abstract/2012/11000/The_Bereaved_Parent_Needs_Assessment_A_new.16.aspx)

### **Stealing on insensibly: End of life politics in the U.S.**

*HEALTH ECONOMICS, POLICY & LAW*, 2012;7(4):467-483. Because the U.S. often seems (and seems eager to present itself as) the home of the technological imperative and of determination to brand all challenges to it in end-of-life care as a descent into death panels, the prospects look unpromising for progress in U.S. public policies that would expand the range of choices of medical treatments available to individuals preparing for death. Beneath this obdurate and intermittently hysterical surface, however, the diffusion across U.S. states and communities of living wills, advanced directives, palliative care, hospice services and debates about assisted suicide is gradually strengthening not so much 'personal autonomy' as the authority, cultural and formal, of individuals and their loved ones not merely to shape but to lead the inevitably 'social' conversations on which decisions about care at

the end of life depend. In short, the nation appears to be (in terms taken from John Donne's meditations on death) 'stealing on insensibly' – making incremental progress toward the replacement of clinical and other types of dogma with end-of-life options that honor the preferences of the dying.

<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8722112&fulltextType=RA&fileId=S1744133112000254>

This issue of *Health Economics, Policy & Law* includes several articles pertaining to end-of-life care. Topics range from the cost of and access to end-of-life care (EOLC), to the cost of prolonging life. There is also a comparative overview of EOLC in the U.S. and U.K. Contents pages: <http://journals.cambridge.org/action/displayJournal?jid=HEP>

1. The 'Peak-End Rule' put forward by psychologist postulated that "we judge our past experiences almost entirely on how they were at their peak (pleasant or unpleasant) and how they ended. Virtually all other information appears to be discarded, including net pleasantness or unpleasantness and how long the experience lasted."

## How haematological cancer nurses experience the threat of patients' mortality

*JOURNAL OF ADVANCED NURSING*, 2012;68(10):2175-2184. The major findings [of this study] emphasized nurses' internal conflict related to their simultaneous need to help patients fight their disease and to prepare them for the possibility of letting go. The authors used the terms 'letting go,' not to reflect nurses' intents to abandon life but to release patients from perceived norms of the 'curative culture.' Nurses experienced 'bursting the bubble of hope' by circumstances not in their control, and were often not certain whether or not to respond and how to respond to the distress of patients and families about death and dying. When feeling reassured of meeting patients' and families' expectations, nurses enabled patients and families to let go when further treatment was futile, prevented technological intrusions, and helped patients have 'easier' deaths. Results suggest enhancing nurses' capacity to negotiate more effectively the contradictory clinical tasks of fighting disease and preparing patients for the end of life. In this regard, nurses may minimize patients' distress by providing opportunities for them to share their fears and have them validated. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2648.2011.05902.x/abstract>

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2012;18(10):471. '**Shifting dying trajectories: Integrating self-management and palliative care.**' [http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=94904;article=IJPN\\_18\\_10\\_471](http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=94904;article=IJPN_18_10_471)

## Initiating palliative care conversations: Lessons from Jewish bioethics

*JOURNAL OF SUPPORTIVE ONCOLOGY* | Published online – 22 October 2012 – What are the ethical responsibilities of the medical staff (doctors, nurses, social workers, and chaplains) regarding the preservation of meaningful life for their patients who are approaching the end of life? In particular, what is the staff's ethical responsibility to initiate a conversation with their patient regarding palliative care? By subjecting traditional Jewish teachings to an ethical analysis and then exploring the underlying universal principles, the authors will suggest a general ethical duty to inform patients of the different care options, especially in a manner that preserves hope. The principle that we can derive from Jewish bioethics teaches that the medical staff has a responsibility to help our patients live in a way that is consistent with how they understand their task or responsibility in life. For some patients, the best way to preserve a meaningful life in which they can fulfill their sense of purpose in the time that remains is to focus on palliation. For this reason, although palliative and supportive care are provided from the time of diagnosis, it is critical we make sure our patients realize that they have the opportunity to make a decision between either pursuing additional active treatments or choosing to focus primarily on palliative therapies to maximize quality of life. The Jewish tradition and our experience in spiritual care suggest the importance of helping patients preserve hope while, simultaneously, honestly acknowledging their situation. Staff members can play a vital role in helping patients make the most of this new period of their lives. <http://www.sciencedirect.com/science/article/pii/S154467941200170X>

Of related interest:

- *JOURNAL OF NURSING EDUCATION & PRACTICE*, 2013;3(2):120-125. '**End of life care pedagogy, death attitudes, and knowing participation in change.**' End of life care continues to be an area of glaring concern in health care. In addition, literature points to continued inconsistencies in end of life care education for those in the health professions, despite accumulating studies which suggest that preparation is needed to care for those who are dying and their loved ones. Some research findings suggest that there is a relationship between perceptions of preparedness and ability to provide care at the end of life and the nurse's professional and perhaps personal quality of life. <http://www.sciedu.ca/journal/index.php/jnep/article/view/1175>

Cont.



- *NEW ENGLAND JOURNAL OF MEDICINE*, 2012;367(17):1651-1652. **'Talking with patients about dying.'** Self-deception is a valuable personal coping tool. It allows us to aspire to significance, strive for new knowledge, and yearn to make a lasting contribution to the world despite the certainty of our inevitable end. Indeed, no arduous task would ever be undertaken if we were unable to exaggerate the benefits we expect from it and underestimate the difficulty of its accomplishment. <http://www.nejm.org/doi/full/10.1056/NEJMe1211160>
- *NORTH AMERICAN JOURNAL OF SCIENCES* | Published online – 5 October 2012 – **'Reporting of 'knowledge/awareness': A systematic review and quantitative analysis of research publications in palliative care journals.'** <http://www.najs.us/>

### Palliative care in India

#### **End of life issues in the intensive care units**

*MEDICAL JOURNAL ARMED FORCES INDIA* | Published online – 24 October 2012 – A structured discussion of End-of-Life (EOL) issues is a relatively new phenomenon in India. Personal beliefs, cultural and religious influences, peer, family and societal pressures affect EOL decisions. Indian law does not provide sanction to contentious issues such as do-not-resuscitate (DNR) orders, living wills, and euthanasia. Finally, published data on EOL decisions in Indian ICUs is lacking. What is needed is a prospective determination of which patients will benefit from aggressive management and life-support. A consensus regarding the concept of Medical Futility is necessary to give impetus to further discussion on more advanced policies including ideas such as Managed Care to restrict unnecessary health care costs, euthanasia, the principle of withhold and/or withdraw, ethical and moral guidelines that would govern decisions regarding futile treatment, informed consent to EOL decisions and do-not-resuscitate orders. This review examines the above concepts as practiced worldwide and looks at some landmark judgments that have shaped current Indian policy, as well as raising talking points for possible legislative intervention in the field. [http://www.mjafi.net/article/S0377-1237\(12\)00163-3/abstract](http://www.mjafi.net/article/S0377-1237(12)00163-3/abstract)

#### **Multivariate analysis of countries' government and health-care system influences on opioid availability for cancer pain relief and palliative care: More than a function of human development**

*PALLIATIVE MEDICINE* | Published online – 26 October 2012 – Study findings demonstrate that a limited number of predictor variables characterizing a country's government and health-care system infrastructure can explain its opioid consumption level, with the greatest influence being very high Human Development Index [HDI]. However, HDI is not the most policy-relevant factor, and this finding should be reconciled against the reality that many countries with low or medium HDI have succeeded in creating and sustaining a health-care system to strengthen cancer pain care and palliative care, including through the appropriate use of essential prescription opioids. <http://pmj.sagepub.com/content/early/2012/10/25/0269216312461973.abstract>

#### **The experience of providing end-of-life care to a relative with advanced dementia: An integrative literature review**

*PALLIATIVE & SUPPORTIVE CARE* | Published online – 23 October 2012 – Ten studies were identified that specifically addressed the experience of family caregivers providing end-of-life care to a relative with advanced dementia. Common themes of these studies included: 1) the experience of grief; 2) guilt and burden with decision making; 3) how symptoms of depression may or may not be resolved with death of the care receiver; 4) how caregivers respond to the end-stage of dementia; and, 5) expressed needs of family caregivers. It is evident from this literature review that much remains to be done to conceptualize the experience of end-of-life caregiving in dementia. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8724776&fulltextType=RA&fileId=S1478951512000831>

## Conflict between "high tech" and "high touch"

### **Work culture among healthcare personnel in a palliative medicine unit**

*PALLIATIVE & SUPPORTIVE CARE* | Published online – 23 October 2012 – Understanding and assessing health care personnel's work culture in palliative care is important, as a conflict between "high tech" and "high touch" is present. Implementing necessary changes in behavior and procedures may imply a profound challenge, because of this conflict. The aim of this study was to explore the work culture at a palliative medicine unit (PMU). Healthcare personnel at a PMU in Norway comprising physicians, nurses, physiotherapists, and others filled in a questionnaire about their perception of the work culture at the unit. The Systematizing Person-Group Relations method was used for gathering data and for the analyses. The method seeks to explore which aspects dominate the particular work culture, identifying challenges, limitations, and opportunities. The healthcare personnel working at the PMU had significantly higher scores than the "Norwegian Norm" in both vectors in the "Withdrawal" dimension and significant lower scores in both vectors in the "Synergy," "Control," and "Dependence" dimensions. Healthcare personnel at the PMU have a significantly different perception of their work culture than do staff in "well-functioning or-

ganizations" in several dimensions. The low score in the "Synergy" and "Control" dimensions indicate lack of engagement and constructive goal orientation behavior, and not being in a position to change their behavior. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8724773&fulltextType=RA&fileId=S1478951512000818>

#### **Ageing with telecare: Care or coercion in austerity?**

*SOCIOLOGY OF HEALTH & ILLNESS* | Published online – 25 October 2012 – Drawing on European-funded research the author's argue that home-monitoring based telecare has the potential to coerce older people unless we are able to recognise and respect a range of responses including non-use and 'misuse' in daily practice. The authors propose that re-imagining the aims of telecare and redesigning systems to allow for creative engagement with technologies and the co-production of care relations would help to avoid the application of coercive forms of care technology in times of austerity. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-9566.2012.01530.x/abstract>

## Coping with death and loss

### **Confucian perspectives and the use of rituals**

*PASTORAL PSYCHOLOGY*, 2012;61(5-6):1037-1049. All of us must personally face and experience death and loss. Death and loss are sad events in our lives. But people living in different cultures and religions all have their own methods of coping. Chinese Confucianism has its own system and has evolved a set of mourning and burial ceremonies which have common characteristics. These mourning and burial ceremonies emphasize filial piety and the use of rituals as effective methods of coping with death. These beliefs and practices have deep meaning for the psychology of religion. They provide comfort and stimulate people to reflect on and promote spirituality. Through these interactions between relatives and ritualized behavior, Chinese find effective methods of coping with death and loss in culture. The mourning and burial ceremonies of Confucianism give the participants a comprehensive religious experience and personality integration so that their spirituality can be cultivated. <http://www.springerlink.com/content/d8310r2820r4l154/>

Of related interest:

- *JOURNAL OF NURSING MANAGEMENT* | Published online – 20 October 2012 – 'A health services framework of spiritual care.' <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2834.2012.01482.x/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

## Using palliative care in progressive neuromuscular disease to maximize quality of life

*PHYSICAL MEDICINE & REHABILITATION CLINICS OF NORTH AMERICA* | Published online – 19 October 2012 – This article discusses the role of palliative care in the treatment pathway of patients with progressive neuromuscular disease (NDM), including amyotrophic lateral sclerosis and Duchenne muscular dystrophy (DMD). People with severe NMDs like DMD are now living much longer, well in to adulthood. This makes them suitable for the medical model of palliative care. Yet palliative medicine is a new area, especially for "adults" with DMD. Strategies for identifying the most effective modalities to alleviate suffering in patients with an NMD receiving palliative services and creating best practice standards in pain and symptom management for this patient population are discussed. [http://www.pmr.theclinics.com/article/S1047-9651\(12\)00066-6/abstract](http://www.pmr.theclinics.com/article/S1047-9651(12)00066-6/abstract)

### End-of-life care in South Australia

## Watch your words! The challenges of law around the end of life

*PRACTICAL ETHICS* | Published online – 23 October 2012 – Here in South Australia last week, a bill has been proposed to clarify the legal status of advance directives. One very small part of that bill involves a modification to an older palliative care act. The modification corrects an ambiguity in wording in the earlier act. The ambiguity is subtle. However, that choice of words has had major consequences for seriously ill children and adults in South Australia and for health practitioners. It is a salutary reminder of how hard it is to enact good laws in the area of end of life, and how easily such laws can make things worse rather than better. The Consent to Medical Treatment & Palliative Care Act was passed in 1995. The act clarified who could make decisions. It also set out to protect dying patients from having burdensome and futile treatments, and to protect health practitioners who consulted with family members and stopped treatment that would merely prolong the dying process. Sounds OK doesn't it? If the patient is dying and they (or their family on their behalf) do not want life-support treatment that offers no potential benefit, then that treatment should be stopped. But the phrase "in the absence of an express direction ... to the contrary... no duty" appears to imply that if the patient or family did object, that health practitioners do have a duty to provide treatment. <http://blog.practicaethics.ox.ac.uk/2012/10/watch-your-words-the-challenges-of-law-around-the-end-of-life/>

Of related interest:

- *AMERICAN MEDICAL NEWS* | Online report – 29 October 2012 – '**Clearing up confusion on advance directives.**' Misunderstandings among physicians about living wills, advance directives and do-not-resuscitate orders are common, according to research and medical experts. A series of surveys by QuantiaMD, an online physician learning collaborative, found that nearly half of health professionals misunderstood the components of living wills. Ninety percent of those surveyed were physicians. <http://www.ama-assn.org/amednews/2012/10/29/prsa1029.htm>

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *PALLIATIVE MEDICINE* | Published online – 26 October 2012 – '**Similarities and differences between continuous sedation until death and euthanasia – professional caregivers' attitudes and experiences: A focus group study.**' Although the differences and similarities between continuous sedation until death and euthanasia were not specifically addressed in the questions addressed in the focus groups, it emerged as an important theme in the participants' accounts. Many caregivers elaborated on the differences between both practices, particularly with regard to patients' preferences and requests, decision-making and physicians' intentions. However, some stated that the distinction between the two sometimes becomes blurred, especially when the sedating medication is increased disproportionately or when sedation is used for patients with a longer life expectancy. <http://pmj.sagepub.com/content/early/2012/10/25/0269216312462272.abstract>

Cont.

- *PALLIATIVE MEDICINE* | Published online – 26 October 2012 – '**Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives and treating physicians in The Netherlands.**' A patient's request for euthanasia entails a complex process that demands emotional work by all participants. It is characterised by an intensive period of sharing information, relationship building and negotiation in order to reach agreement. The authors hypothesise that making decisions about euthanasia demands a proactive approach towards participants' preferences and values regarding end of life, towards the needs of relatives, towards the burden placed on physicians and a careful attention to shared decision-making. <http://pmj.sagepub.com/content/early/2012/10/25/0269216312463259.abstract>
- *PULSE* (U.K.) | Online report – 25 October 2012 – '**GPs asked to provide patients with medical reports for Dignitas.**' GPs are facing demands from patients for copies of medical reports to support them in assisted suicide – but have been warned by the General Medical Council (GMC) that this could lead to criminal prosecution. Doctors are required to provide access to a patient's records under the Data Protection Act 1998 if a 'subject access request' has been made. However, new GMC draft guidance for fitness-to-practise decision-makers, due to be published later this year, advises it is a criminal offence for doctors to encourage or assist a person to commit or attempt suicide. <http://www.pulsetoday.co.uk/gps-facing-assisted-suicide-demands/20000658.article>

### Media Watch Online

#### **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>

#### **U.S.A.**

Prison Terminal: <http://www.prisonterminal.com/news%20media%20watch.html>

#### **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>

#### **Asia**

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'What's New: Reading List Update')

#### **International**

Australasian Palliative International Link: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Media Watch')

Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

International Palliative Care Resource Center: <http://www.ipccr.net/archive-global-palliative-care-news.php>

## Worth Repeating

### **Integration of palliative care throughout HIV disease**

*LANCET INFECTIOUS DISEASES*, 2012; 12(7):571-575. People with HIV have a high burden of pain and physical, psychological, and social difficulties that can be managed effectively with palliative care. However, most individuals do not have access to this type of care. Palliative care is holistic patient centred management of life-limiting progressive disorders and is recognised by WHO as an essential element of HIV care, from diagnosis to end of life. Historically, palliative care and HIV care were linked closely, but misconceptions divide the two disciplines today. Palliative care can augment patients' outcomes and boost adherence to antiretroviral treatments and life expectancy. In much of the world, services providing palliative care are isolated, and most individuals in need have no access to this care. The commitment to provide palliative care for all

people with HIV can be fulfilled if clinical workers are trained in this therapeutic approach and if care is delivered at community level, with support for family caregivers. [http://www.thelancet.com/journals/laninf/article/PIIS1473-3099\(12\)70085-3/fulltext](http://www.thelancet.com/journals/laninf/article/PIIS1473-3099(12)70085-3/fulltext)

World Aids Day 1 December 2012



*Getting to zero. Zero new HIV infections. Zero discrimination. Zero AIDS related deaths.*

### 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 tool or change document.

### Distribution

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

### Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

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

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