Barriers to effective and empathetic communications: Scroll down to Specialist Publications and ‘Exploring oral literacy in communication with hospice caregivers’ (p.13), in Journal of Pain & Symptom Management.

Canada

Hospices struggle to meet demand

The value of end-of-life care

ONTARIO | CBC News (Commentary) – 28 March 2013 – A Canadian senate study in 2000 found that hospices in Canada can only meet about 15% of the demand of our aging population.1,2 [See sidebar, right] And, government funding has not grown as fast as demand. As a Canadian living in the U.S., I often quietly give thanks for the Canadian health-care system. A modest-income family, we never once had to worry whether health insurance would cover a necessary drug or another hospital stay the way so many Americans do. But the truth is there are not enough Hospice Renfrews in Ontario or in Canada.3 The ones that do exist do so thanks in large part to the kindness of their community. Hospice Renfrew relies on private donations for 50% of its operating budget. Volunteers play a key role… I wish Hospice Renfrew quality care for every Canadian family that needs it. I urge a national conversation about whether we can afford it and whether we can afford to ignore the need. http://www.cbc.ca/news/canada/ottawa/story/2013/03/28/ottawa-bonner-end-of-life-care.html

Other landmark articles, reports on end-of-life care in Canada


Cont


**Province introduces plan to improve end-of-life care**

BRITISH COLUMBIA | 1130 News (Vancouver) – 25 March 2013 – Dying-with-dignity is the goal of a new plan by the province to improve end-of-life care. The provinces health minister thinks it could also be the remedy to the euthanasia debate. The province doesn’t have a position on physician-assisted suicide, and Margaret MacDiarmid is reluctant to share her views on the issue. “As a care provider, if I went back into that world, I don’t believe that I would personally participate in euthanasia.” But she feels good end-of-life care helps people die with dignity. “When patients and their families feel that people in BC have good access to good high-quality end-of-life care, when they know their symptoms are going to be well-managed so that their comfortable, then a lot of that debate really quiets down.” [http://www.news1130.com/2013/03/25/bc-introduces-plan-to-improve-end-of-life-care/](http://www.news1130.com/2013/03/25/bc-introduces-plan-to-improve-end-of-life-care/)

**Specialist Publications**

'Among neighbors: An ethnographic account of responsibilities in rural palliative care' (p.15), findings of a study conducted in four rural communities in Western Canada, in *Palliative & Supportive Care*.

**Of related interest:**

- BRITISH COLUMBIA | *Times-Colonist* (Vancouver) – 29 March 2013 – ‘**Hospice is a good investment.**’ Hospice and palliative care are similar, except that hospice focuses on bringing comfort and peace of mind to those who are terminally ill or dying, while palliative care can involve patients who are undergoing treatment for curable illnesses or those living with chronic diseases, as well as patients who are nearing the end of life. The province’s initiative is a sign of how far palliative and hospice care have come. Dave Traynor, manager of communications for the Victoria Hospice and Palliative Care Foundation, says that 30 years ago, hospice care was more or less a fringe movement. [http://www.timescolonist.com/opinion/editorials/editorial-hospice-is-a-good-investment-1.100024](http://www.timescolonist.com/opinion/editorials/editorial-hospice-is-a-good-investment-1.100024)

- BRITISH COLUMBIA | *Comox Valley Record* (Courtenay) – 27 March 2013 – ‘**Comox Valley wonders where its end-of-life funding is.**’ Where’s the funding for end-of-life care in the Comox Valley? The Comox Valley Hospice Society has been asking this question for years, but after the Health Ministry’s announcement this week of millions for hospice care in the Lower Mainland, the society is asking the question with renewed vigour. Residents have been advocating for residential hospice beds for over six years, yet there are still zero dedicated hospice palliative care beds. [http://www.comoxvalleyrecord.com/news/200335711.html](http://www.comoxvalleyrecord.com/news/200335711.html)

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**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](http://www.ipcrc.net/barry-r-ashpole.php)
**U.S.A.**

**Inmates comfort other dying prisoners at South Woods**

NEW JERSEY | *The Daily Journal* (Vineland) – 31 March 2013 – [Andrew] Woodrow is not a typical hospice volunteer. He’s an confessed murderer, a man who strangled his wife and mother-in-law following an argument in their Sewell trailer in 1989. Woodrow is serving a 30-year sentence in South Woods State Prison, where he works each day with Thomas as part of a unique program that trains inmates as caregivers and then matches them with other prisoners who are terminally ill. Most of the inmate caregivers are “lifers,” serving lengthy sentences for crimes like murder or armed robbery. The palliative care program at South Woods now has 25 prisoners who serve as caregivers, according to Joann Anderson, a social worker at the prison who is in charge of the program. To be chosen for training as a caregiver for terminally ill patients, an inmate must not have violated any prison rules for at least a year. Any violation of prison rules is grounds for immediate expulsion from the program, Anderson said. Drug and sex offenders are not permitted to participate. Inmates in the program still must perform their regular work details at the prison. [Link](http://www.thedailyjournal.com/article/20130401/NEWS01/304010022?nclick_check=1)

**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.16.

**A Texas Senate bill would revise the State's end-of-life procedure**

TEXAS | *The New York Times* – 30 March 2013 – State law allows physicians to discontinue treatment they deem medically futile. If a physician's decision to end treatment contradicts the patient's advance directive or the judgment of the patient's surrogates, state law gives patients or their families 10 days to find another provider and appeal the doctor's decision to a hospital ethics committee. Advocacy groups that identify as “pro-life” say existing law does not go far enough to protect the interests of patients or their families. But they are divided on how legislators should change it. While support in the Legislature's upper chamber seems to be coalescing around Senate Bill 303, which would tweak the process, some support bills that would bar doctors or hospital ethics committees from making the final decision to end treatment. The bill would alter the existing dispute process by extending the time frame for finding an alternate provider to 14 days... [Link](http://www.nytimes.com/2013/03/31/health/state-senate-bill-would-revise-end-of-life-procedure.html?_r=0)

**Why more patients should blog about illness and death**

NATIONAL PUBLIC RADIO | Online – 28 March 2013 – We share so many milestones now through social media. And that includes health: A [sic] 2010 survey ... found that 23% of the users of social networking sites have followed their friends' personal health experiences on Facebook.¹ So is it any surprise that the outer reaches of our social networks now also deliver us intimate stories of dying? Palliative care experts, who specialize in improving the quality of life for people with a life-threatening illness, say all this blogging and sharing about illness is helping to open up the conversation about death that we so often avoid. "As more people tell their story of dying with a terminal illness, we're seeing a change in how we look at illness and mortality," says Christian Sinclair, national hospice medical director at Gentiva Health Services. Blogging empowers patients to talk about illness outside the typical frame of "the battle," Sinclair says, and reading the stories helps family members, too. [Link](http://www.npr.org/blogs/health/2013/03/26/175383540/why-more-patients-should-blog-about-illness-and-death)

¹. 'Social network sites are popular, but used only sparingly for health updates and queries.' Pew Research Center’s Internet & American Life Project, 12 May 2011. [Link](http://www.pewinternet.org/Reports/2011/Social-Life-of-Health-Info/Part-1/Section-2.aspx)
Choosing life or a better death: Hospice under scrutiny

CALIFORNIA | KPBS News (San Diego) – 27 March 2013 – A young mother with two children is dying of leukemia. The doctors say there is no way to cure the disease, but she wants to live as long as possible. Transfusions – hundreds of dollars per treatment – might give her a little more time. But the woman is in hospice, the kind of care meant to shepherd the critically ill into a pain free death, not prolong life. What to do? Dr. Charles Lewis, who has treated thousands of dying patients over the past 20 years as the former Medical Director of the San Diego Hospice Inpatient Center, remembers this case. And the discussion at the center's ethics committee. "If we don't do any more transfusions she'll die a little sooner," Lewis recalls of the meeting. "Should we be giving these transfusions, we're keeping her alive." Some on the committee suggested hospice stop the transfusions."Which one of you is going to go in and tell her?" Lewis asked. "Complete silence." The woman lived another two weeks. She received the transfusions until she died. Cases like this one come up repeatedly in end-of-life treatments and they frame important questions: How much care should hospices provide and at what cost? Should dying patients have to choose between hospice care and expensive treatments that could make them feel better and even prolong life?  


Drop in hospital death rates may mean more Americans dying at home

CBS NEWS | Online – 27 March 2013 – Most Americans would rather die at home than in a hospital, according to patient surveys. Now, a new study suggests more and more people getting their wish.¹ Researchers at the National Center for Health Statistics studied the deaths of patients admitted to a sampling of U.S. hospitals. They determined that hospital deaths accounted for 29% of U.S. deaths in 2010, down from more than 32% in 2000. The number of inpatient hospital deaths dropped 8% over the decade study period from 776,000 deaths in 2000 to 715,000 in 2010. During that time, the number of total hospitalizations increased 11%. Patients who died in the hospital had longer average hospital stays than all patients. About one quarter of hospital deaths in 2010 occurred in adults aged 85 and older, which was consistent throughout the decade. Meanwhile, other reports indicate deaths in the home grew from 23% to 27% over the decade. Deaths in nursing homes held steady at around 21%. CDC officials said the growing availability of hospice care may be one factor for fewer hospital deaths.  


Specialist Publications

'Methods for improving the quality of palliative care delivery: A systematic review' (p.8), in American Journal of Hospice & Palliative Medicine.

'Palliative care legislation proposes $44 million in education fellowships for nurses' (p.15), in McKnight's Long Term Care News & Assisted Living.


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
American Civil Liberties Union says faith-based hospitals jeopardize reproductive, end-of-life care

WASHINGTON STATE | The Columbian (Clark County) – 24 March 2013 – Hospitals are supposed to be places of healing, but Washington's hospitals are becoming places of conflict between religion and government over health care services. The state's American Civil Liberties Union [ACLU] is questioning whether health care regulatory agencies and public hospital districts should grant approval to faith-based hospitals – primarily Catholic – that don't offer reproductive and end-of-life services that are widely available at secular hospitals. In some rural areas of the state, the ACLU says, hospital consolidations and mergers could leave communities only with Catholic hospitals which refuse, based on Catholic religious beliefs, to provide such services. [http://www.columbian.com/news/2013/mar/24/ACLU-faith-based-hospitals-jeopardize-care/]

Noted in Media Watch, 21 March 2011:


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**Media Watch: Editorial Practice**

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

**Distribution**

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1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

**Something Missed or Overlooked?**

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

Eco-friendly farewells

Six feet greener

U.K. | The Economist – 30 March 2013 – unlike one of the national parks it resembles, Hinton Park [Dorset] has some 6,000 people buried there. It is one of over 260 eco-friendly burial sites in Britain. The ways that Britons choose to have their bodies disposed of after death are changing markedly. In 1960 only 35% of all funerals involved cremation; now 74% of them do. Less space in churchyards, the rising costs of funerals and the declining number of Christians have all contributed. http://www.economist.com/news/britain/21574514-unfunerals-help-environment-are-taking-six-feet-greener

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

We need to refocus end of life care as a health priority

U.K. | The Guardian – 26 March 2013 – An ageing population, ongoing pressures on public spending, the Francis report and current National Health Service reforms mean that now is a good time to think about how to refocus care for people who are dying. As the number of people dying and the proportions of those who have multiple morbidities increase, so the need to rethink end of life care becomes more urgent. In rethinking such care, we are now aided by a growing evidence base, which gives us a clear picture of what people want and what they get from end of life care. 'Death & Dying' brings together data previously published elsewhere, much of which is available via the Marie Curie End of Life Care Atlas. The Atlas has been developed to help Clinical Commissioning Groups and others identify gaps and differences of experiences across all end of life care services. It enables commissioners to see how their area compares, to address unmet needs and improve care for all. 'Death & Dying' draws on published data from the Atlas, the ‘VOICES Survey of the Bereaved People,’ the Nuffield Trust’s reports on clinical care at the end of life and the independent evaluation of the Marie Curie Nursing Service. What is new is the analysis that explores what this evidence tells us about current services and needs. http://www.guardian.co.uk/healthcare-network/2013/mar/26/rethink-end-life-care-health-priority

Specialist Publications


Social isolation 'increases death risk in older people'

U.K. | BBC News – 25 March 2013 – Social isolation is associated with a higher risk of death in older people regardless of whether they consider themselves lonely. A study of 6,500 U.K. men and women aged over 52 found that being isolated from family and friends was linked with a 26% higher death risk over seven years.\(^1\) Whether or not participants felt lonely did not alter the impact of social isolation on health. [The charity] Age U.K. says cuts to services for older people are compounding the problem. It is not the first time that loneliness and social isolation has been linked with poor health. But researchers wanted to find out if it was the emotional aspect of feeling lonely that was having an impact or the reality of having little social contact. Those who were socially isolated – that is had little or no contact with friends or family – were more likely to be older and unmarried and have long-standing illnesses limiting their mobility, such as lung disease and arthritis. People who described themselves as feeling lonely were more likely to be female and have a wider range of health conditions, including depression.

http://www.bbc.co.uk/news/health-21929197

Specialist Publications

'A longitudinal study of end-of-life preferences of terminally-ill people who live alone' (p.12), in Health & Social Care in the Community.

Media Watch Online

Asia

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

Australia

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

Canada

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

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

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

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

Europe

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

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb90c

International


PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch
1. ‘Social isolation, loneliness, and all-cause mortality in older men and women,’ Proceedings of the National Academy of Sciences of the United States of America, online, 25 March 2013. http://www.pnas.org/content/early/2013/03/19/1219686110.abstract?sid=e494e753-cbe1-46a4-bf73-9046f7ba6e7c

Noted in Media Watch, 25 June 2012:


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

Methods for improving the quality of palliative care delivery: A systematic review

AMERICAN JOURNAL OF HOSPICE & MEDICINE | Online – 26 March 2013 – The effectiveness for improving the outcomes across palliative care domains remains unclear. The authors conducted a systematic review of different types of quality improvement interventions relevant to palliative care. A minority have succeeded in improving the quality of palliative care delivery. More studies are needed on specific quality improvement types, including organizational change and multiple types of interventions. http://ajh.sagepub.com/content/early/2013/03/21/1049909113482039.abstract

Hospice patient evacuation: A case for using a checklist for safe disaster response

AMERICAN JOURNAL OF HOSPICE & MEDICINE | Online – 26 March 2013 – This study was conducted to provide lessons learned from the experience of a small, rural hospice care organization to an actual crisis that required evacuation of the facility. A process improvement framework using the emergency response certification guidelines was used to first provide details of the incident, second analyze the effectiveness of disaster planning and response to an actual crisis, and third discuss the post event review, lessons learned, and process improvement. http://ajh.sagepub.com/content/early/2013/03/21/1049909113481401.abstract

YouTube poor source of palliative information

THE ONCOLOGY REPORT | Online – 28 March 2013 – Just 28% of 468 videos sampled from YouTube were rated as having useful information on palliative care, hospice, or end of life, while 72% were considered poor quality. Unfortunately, the poor information is getting much more exposure: Poor-quality videos averaged about 28,056,711 million hits, compared with only about 11,808 hits for the good-quality videos, Benjamin Getter, said at the recent annual meeting of the American Academy of Hospice & Palliative Medicine. One reason may be the sheer volume of videos and that patients are likely to use filters or broad search terms such as “palliative care” or “pain.” YouTube queues up videos containing those words based on viewer count, so when view counts are low, videos get pushed back further on search results page. “Studies have shown that whether it's Google or YouTube, the distance you will go looking for your information decreases exponentially,” he said. “The third page of Google might as well not exist.” Dr. Getter and Dr. Wesam Aziz, palliative medicine fellows at the University of Texas Health Science Center in San Antonio, identified the 468 YouTube videos by relevance and view count search strategies, and independently categorized them as useful, misleading, or personal experience. Videos creators fell into one of five categories: health care institutions, media/news organizations, hospices, universities, and individuals. http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/youtube-poor-source-of-palliative-information/0f389aa553f58b79ad9116f90d935667.html
Palliative care is everyone’s business, including pharmacists

AMERICAN JOURNAL OF PHARMACEUTICAL EDUCATION, 2013;77(2):21. An increasing burden of chronic disease and an aging population bring growing demands for palliative care, seeing it expand beyond end-of-life cancer care to a broad practice that is independent of diagnosis. To meet this social need, strategies have been implemented at individual and population levels to integrate principles of palliative care across disciplines and care settings, promoting palliative care as “everyone’s business.” Concurrent to changes in palliative care, primary health reform has resulted in more patients being cared for and dying in their home or community-based facility. Pharmacists care for patients with palliative needs from the beginning of their career, making the principles of palliative care an essential component of a robust pharmacy education.

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3602845/

Noted in Media Watch, 13 August 2012:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 9 August 2012 – 'End-of-life and palliative care education in U.S. pharmacy schools.' Guidelines and standards regarding end-of-life issues for pharmacy schools are being addressed, thus today's pharmacists should be better prepared to relate to patients with terminal illnesses and their families... http://ajh.sagepub.com/content/early/2012/08/06/1049909112457011.abstract

Noted in Media Watch, 24 January 2011:

- JOURNAL OF PALLIATIVE MEDICINE, 2011;14(1):7-11. "Where is the community pharmacist?" Active involvement in the palliative care team is not reflected in the community setting, despite the community pharmacist being one of the most accessible professionals in the community... http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0369

How do GPs identify a need for palliative care in their patients? An interview study

BMC FAMILY PRACTICE | Online – 25 March 2013 – GPs [i.e., study participants] reported that a combination of several signals, often subtle and not explicit, made them identify a need for palliative care: signals from patients (increasing care dependency and not recuperating after intercurrent diseases) and signals from relatives or reports from medical specialists. GPs reported differences in how they identified a need for palliative care in cancer patients versus those with other diseases. In cancer patients, the need for palliative care was often relatively clear because of a relatively strict demarcation between the curative and palliative phase. However, in patients with e.g., COPD or in the very old, GPs' awareness of palliative care needs often arises gradually, relatively late in the disease trajectory. GPs consider the diagnosis of a life-threatening illness as a key point in the disease trajectory.http://www.biomedcentral.com/content/pdf/1471-2296-14-42.pdf

Care vs. care – "biomedical" and "holistic" worldviews of palliative care

EUROPEAN JOURNAL OF INTEGRATIVE MEDICINE | Online – 22 March 2013 – Scarce information has been collected regarding how the construct of palliative care is conceptualised from the physicians’ perspective. The components of the two worldviews of palliative care are outlined, highlighting the tension that exists between a holistic worldview focused on social connectedness and “total care” of a person, and a biomedical worldview focused on control and mastery of disease. Profiles are constructed of the salient features differentiating holistic and bio-medical worldviews. Physicians who habitually organise their knowledge and perceptions of clinical reality according to each of these two worldviews (bio-medical, holistic), appear to be having distinctly different experiences of their clinical reality – as reflected linguistically in how they describe it. http://www.sciencedirect.com/science/article/pii/S1876382013000383

Cont.
Noted in Media Watch, 3 September 2012:

- **BRITISH JOURNAL OF GENERAL PRACTICE, 2012;62(602):e625-e631.** 'Early identification of palliative care patients in general practice: Development of RADboud indicators for PAlliative Care Needs (RADPAC).’ RADPAC is the first tool developed from a combination of scientific evidence and practice experience that can help GPs identify patients with congestive heart failure, chronic obstructive pulmonary or cancer in need of palliative care. http://www.ingentaconnect.com/content/rcgp/bjgp/2012/00000062/00000602/art00033

Of related interest:

- **JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS EDINBURGH, 2013;43(1):24-8.** 'Are newly qualified doctors prepared to provide supportive and end-of-life care? A survey of Foundation Year 1 doctors and consultants.' Newly qualified doctors [i.e., study participants] were not adequately prepared to deliver generalist palliative care and lacked first-hand experience of end-of-life issues. http://www.rcpe.ac.uk/journal/issue/journal_43_1/bowden.pdf

**Doctors, dying children and religious parents: Dialogue or demonization?**

**CLINICAL ETHICS, 2013;8(1):2-4.** A recent article..., which received wide media coverage, raised the possibility that children are being "subjected to torture" due to the "fervent or fundamentalist views" of their parents. However, the quality of argument in that article was inadequate to sustain such a radical thesis. There was no engagement with the perspectives of different religious traditions about end-of-life care. Instead the authors invoked practices such as male infant circumcision which are wholly irrelevant to the end-of-life theme. There were serious failings in relation to core principles of social and epidemiological research practice: the study based its conclusion on a sample of only six cases and failed to consider even the more obvious confounding features. Rather than demonizing the religious beliefs of parents there should be recognition of the need for mutual respect, dialogue based on an "expert-expert relationship" and collaboration based on "shared understanding." http://ce.rsmjournals.com/content/8/1/2.short

Noted in Media Watch, 2 April 2012:

- **JOURNAL OF MEDICAL ETHICS | Online – 30 March 2012 –** 'Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?' Not infrequently ... religious claims used by families to challenge cessation of aggressive therapies considered futile and burdensome by a wide range of medical and lay people. While it is vital to support families in such challenging times, the authors are increasingly concerned that deeply held belief in religion, especially with more fundamentalist religions, leads to children being subjected to burdensome care in expectation of 'miraculous' intervention. http://jme.bmj.com/content/early/2012/03/08/medethics-2011-100104.abstract

**Obtaining consent for organ donation from a competent ICU patient who does not want to live anymore and who is dependent on life-sustaining treatment: Ethically feasible?**

**CLINICAL ETHICS, 2013;8(1):29-33.** The authors anticipate a further decline of patients who eventually will become brain dead. The intensive care unit (ICU) is considered a last resort for patients with severe and multiple organ dysfunction. Patients with primary central nervous system failure constitute the largest group of patients in which life-sustaining treatment is withdrawn. Almost all these patients are unconscious at the moment physicians decide to withhold and withdraw life-sustaining measures. Sometimes, however competent ICU patients state that they do not want to live anymore because of the severity of their illness or the poor prognosis and ask for withdrawal of life-sustaining measures like mechanical ventilation. Do we consider the unconscious patient as potential organ donor before withdrawal of mechanical ventilation? http://ce.rsmjournals.com/content/8/1/29.short
Noted in Media Watch, 4 February 2013:

- **JOURNAL OF MEDICAL ETHICS** | Online – 26 January 2013 – 'Honouring the donor: In death and in life.' Elective ventilation is ventilation – not to save a patient's life, but with the expectation that s/he will die – in the hope that organs can be retrieved in the best possible state. [http://jme.bmj.com/content/early/2013/01/25/medethicsU2012U101159.abstract](http://jme.bmj.com/content/early/2013/01/25/medethicsU2012U101159.abstract)

Noted in Media Watch, 9 July 2012:

- **END OF LIFE JOURNAL, 2012;2(2). 'The barriers to organ and tissue donation in palliative care.'** Discussions about organ/tissue donation are now expected to become part of end-of-life care discussions, when appropriate. It is commonly perceived that terminally ill people are not eligible to donate their organs/ tissues. However, that is not the case. [http://endoflifejournal.stchristophers.org.uk/clinicalUreview/theUbarriersUtoUorganUandUtissueUdonationUinUpalliativeUcare](http://endoflifejournal.stchristophers.org.uk/clinicalUreview/theUbarriersUtoUorganUandUtissueUdonationUinUpalliativeUcare)

Remembering the past and envisioning the future in bereaved adults with and without complicated grief

**CLINICAL PSYCHOLOGICAL SCIENCE** | Online – 18 March 2013 – Complicated grief (CG) is associated with impairment in the ability to retrieve specific autobiographical memories. However, previous research suggests that this impairment may not occur for memories related to the deceased. Individuals with CG [i.e., study participants] were no less specific than bereaved comparison subjects when generating events that included the deceased. However, they did exhibit difficulty recalling specific past events and imagining specific future events that did not include the deceased. [http://cpx.sagepub.com/content/early/2013/03/14/2167702613476027.abstract](http://cpx.sagepub.com/content/early/2013/03/14/2167702613476027.abstract)

Hospital variation and temporal trends in palliative and end-of-life care in the ICU

**CRITICAL CARE MEDICINE** | Online – 20 March 2013 – In this retrospective cohort study of ... the authors found significant inter-hospital variation in ratings and delivery of palliative care, consistent with prior studies showing variation in intensity of care at the end of life. They did not find evidence of temporal changes in most aspects of palliative care, family satisfaction, or nurse/family ratings of the quality of dying. With the possible exception of pain assessment, there is little evidence that the quality of palliative care has improved over the time period studied. [http://journals.lww.com/ccmjournal/Abstract/publishahead/Hospital_Variation_and_Temporal_Trends_in.97882.aspx](http://journals.lww.com/ccmjournal/Abstract/publishahead/Hospital_Variation_and_Temporal_Trends_in.97882.aspx)

Of related interest:


Advance care planning and interpersonal relationships: A two-way street

**FAMILY PRACTICE, 2013;3092):219-226.** Advance care planning (ACP) was seen (by study participants) as having both positive and negative impacts on interpersonal relationships. It was thought to enhance family relationships, help resolve conflicts between families and health professionals, and improve trust and understanding between patients and health professionals. Negatively, it could take the family's attention away from patient care. The link between ACP and interpersonal relationships was perceived to be bidirectional – the nature of interpersonal relationship that patients have with their families and health professionals has a profound impact on what form of ACP is likely to be useful. [http://fampra.oxfordjournals.org/content/30/2/219.abstract](http://fampra.oxfordjournals.org/content/30/2/219.abstract)
A longitudinal study of end-of-life preferences of terminally-ill people who live alone

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 27 March 2013 – As a home death seems to be the perceived ideal, terminally ill people who live alone are at a disadvantage in terms of their place of care and death and little is known about their end-of-life preferences. This study aimed at eliciting patient preferences for their place of care and death longitudinally at two points during their illness trajectory, and reporting on the extent they were able to achieve their place of choice or congruence between preferred and actual place of death. The results indicated that preferences were in favour of either a home or hospice death, with more preferring home as a place of death rather than a place of care. However, overall congruence between preferred and actual place of death was between 53% and 41% dependent on whether it was based on first or second visit preferences respectively. This is the first longitudinal study to elicit the end-of-life preferences of terminally ill people who live alone. As home may not be the preferred location for dying for many patients (nearly half of the patients in this study), ability to die in the place of choice needs to be looked at as a possible indicator of meeting patient needs or as a quality measure in end-of-life care.  

Noted in Media Watch, 16 July 2012:

- *HEALTH SOCIAL CARE IN THE COMMUNITY* | Online – 14 July 2012 – ‘Do models of care designed for terminally ill ‘home alone’ people improve their end-of-life experience? A patient perspective.’ This article describes the experiences of terminally ill ‘home alone’ people using one of two models of care aimed at maintaining participants’ need for independent living, focusing on the effect of these two models of care on their physical, social and emotional needs.  

Respecting autonomy in the end-of-life care of people with intellectual disabilities: A qualitative multiple-case study

*JOURNAL OF INTELLECTUAL DISABILITY RESEARCH* | Online – 19 March 2013 – Respect for autonomy in the end-of-life care of people with intellectual disabilities (ID) was mainly reflected in helping the person with ID familiarise with three transitions: new information on the diagnosis and prognosis, changing care needs and wishes, and important decisions that were at stake. In respecting autonomy, relatives and caregivers encountered several challenges. These concerned ascertaining information needs, communicating about illness and death, inexperience in end-of-life care, eliciting current and hidden last wishes, the dependence of people with ID and conflicting wishes. Several qualities were important for respecting autonomy: attention to information needs, connecting, recognising end-of-life care needs, giving space to show wishes and preferences, and discussing dilemmas. If caregivers and professionals embrace autonomy as a relational construct, attained through an open, active and reflective attitude, and have more access to knowledge about communication and how to identify end-of-life care needs, this could lead to improved respect for the ID persons’ autonomy at the end of life.  

Noted in Media Watch, 4 February 2013:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE,* 2013;20(1):48-50. 'Palliative Care for People with Learning Disabilities Network.' How people with ID are supported at the end of life is dependent on the place people with intellectual disabilities have in society and their level of integration; on the training and attitudes of those who provide care for people with intellectual disabilities; and on the availability of palliative care services for the general population.  
http://www.eapcnet.eu/LinkClick.aspx?fileticket=8Plz1FAom1k%3d&tabid=1622

Cont.
Noted in Media Watch, 26 November 2012:

- **AMERICAN JOURNAL ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES, 2012; 117(6):509-532.** 'Unique and universal barriers: Hospice care for aging adults with intellectual disability.' This article presents a review of the literature ... underscoring the multiple challenges and the importance of a more collaborative approach between hospice and palliative care workers with people with ID, their families, and other important stakeholders. [http://www.aaidjournals.org/doi/abs/10.1352/1944-7558-117.6.509](http://www.aaidjournals.org/doi/abs/10.1352/1944-7558-117.6.509)

**Continuous sedation until death: Therapeutically and ethically acceptable**

**JOURNAL OF MEDICAL COLLEGES OF PLA, 2013;28(1):32-34.** If a patient is dying and still suffering great pain, what is the least harmful alternative? Here we prefer continuous sedation until death (CSD). CSD differs from physician-assisted death (PAD) in many aspects. Firstly, CSD is not used to shorten life or cause death, but instead its intention is to relieve suffering. Secondly, once CSD is associated with a reduction in or suspension of food intake, the duration of sedation is too short to have an impact on survival rate. Thirdly, CSD is titrated while PAD is often overdosed. Fourthly, the sanctity of life could be maintained since sedation is used as a means of quelling suffering. [http://www.sciencedirect.com/science/article/pii/S1000194813600131](http://www.sciencedirect.com/science/article/pii/S1000194813600131)

**Experimental philosophy, clinical intentions, and evaluative judgement**

**CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS, 2013;22(2):126-135.** ...in the debate over palliative sedation for terminally ill patients, it is often said that it is permissible for a clinician to administer a potentially lethal dose of pain medication. This idea – that it can be permissible to bring about a foreseen but unintended effect (the patient's death), although it would not be permissible to intend to bring about this same effect – is central to the principle of double effect, which has found expression in both the law and the professional codes of medical organizations. [http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8862243](http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8862243)

**Exploring oral literacy in communication with hospice caregivers**

**JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 21 March 2013 –** Low oral literacy has been identified as a barrier to pain management for informal caregivers who receive verbal instructions on pain medication and pain protocols. Communication between team members and caregivers [i.e., study participants] averaged a fourth-grade level on the Flesch-Kincaid scale, indicating that communication was easy to understand. Reading ease was associated with caregiver understanding of and comfort with the pain management. Perceived barriers to caregiver pain management were lower when sessions had increased use of passive sentences, suggesting that passive voice was not an accurate indicator of language complexity. Caregiver understanding and comfort with administering pain medications and caregiver quality of life were negatively correlated with the dialogue pace. [http://www.ncbi.nlm.nih.gov/pubmed/23522518](http://www.ncbi.nlm.nih.gov/pubmed/23522518)

**Extract from Journal of Pain & Symptom Management article**

As the grade level of talk with caregivers and hospice teams increased, associated caregiver anxiety increased. Caregivers with higher anxiety also experienced greater difficulty in understanding pain medication and its management.

Cont.
Of related interest:


- **PATIENT EDUCATION & COUNSELING** | Online – 26 March 2013 – 'Physician eye contact and elder patient perceptions of understanding and adherence.' Using suggested framework for operationalizing eye contact elements, including verbally synchronous communication, may facilitate patient-centeredness and have positive implications for patient understanding and adherence. [http://www.sciencedirect.com/science/article/pii/S073839911300089X](http://www.sciencedirect.com/science/article/pii/S073839911300089X)

Noted in Media Watch, 11 February 2013:

- **JOURNAL OF THE AMERICAN GERIATRICS SOCIETY** | Online – 4 February 2013 – 'Literacy and race as risk factors for low rates of advance directives in older adults.' Literacy and race probably represent two separate but important causal pathways that need to be understood to improve how the healthcare system ascertains and protects individuals' advance care preferences. [http://onlinelibrary.wiley.com/doi/10.1111/jgs.12134/abstract](http://onlinelibrary.wiley.com/doi/10.1111/jgs.12134/abstract)

Noted in Media Watch, 16 April 2012:

- **RESEARCH IN NURSING & HEALTH** | Online – 10 April 2012 – 'Readability of hospice materials to prepare families for caregiving at the time of death.' The authors examined the readability of documents used by hospices to prepare families for caregiving at the time of death. Most (78%) included medical terms directly (46.2%) or indirectly (25.6%) explained in the text. Modification of hospice materials could improve families' comprehension of information... [http://onlinelibrary.wiley.com/doi/10.1002/nur.21477/abstract](http://onlinelibrary.wiley.com/doi/10.1002/nur.21477/abstract)

Noted in Media Watch, 3 May 2010:

- **BMC MEDICAL ETHICS** | Online – 25 April 2010 – 'Readability of state-sponsored advance directive forms in the U.S.' The readability of state government-sponsored advance directive forms exceeds ... the average reading skill level of most U.S. adults. Such forms may inhibit care planning and ... patient autonomy. [http://www.biomedcentral.com/content/pdf/1472-6939-11-6.pdf](http://www.biomedcentral.com/content/pdf/1472-6939-11-6.pdf)

An integrative review of sexual health issues in advanced incurable disease

**JOURNAL OF PALLIATIVE MEDICINE** | Online – 28 March 2013 – The sexual health needs of people with advanced incurable diseases are underexplored and under assessed by health care practitioners and under studied by researchers. The loss of sexual health can impact a person's overall quality of life and well-being. Studies regarding the sexual health of patients with life limiting illnesses are generally narrative reviews, expert opinions, or exploratory in nature. Of the 30 possibly relevant abstracts and titles identified, there was only one prospective or case control trial focusing on sexual health in this population thereby offering the practitioner little research evidence to inform clinical practice. Increasing our understanding of the sexual health needs of people facing the end of their lives is crucial if we are to conduct appropriate assessments and initiate relevant treatments. [http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0416](http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0416)

Noted in Media Watch, 27 September 2010:

- **NURSING STANDARD, 2010;24(52):35-39. 'Importance of sexual needs assessment in palliative care.'** Health professionals must address care in the social, psychological, spiritual and physical domains, yet no mention is made of the sexual domain. [http://nursingstandard.rcnpublishing.co.uk/resources/archive/GetArticleByld.asp?ArticleId=7954](http://nursingstandard.rcnpublishing.co.uk/resources/archive/GetArticleByld.asp?ArticleId=7954)
Under 'Worth Repeating' in the same issue of Media Watch:

- **ADVANCES IN CONTEMPORARY PALLIATIVE & SUPPORTIVE CARE, 2007;27(1):49-60.** "Let's talk about sex: Risky business for cancer and palliative care clinicians." Patient sexuality and intimacy is largely medicalised so that health professional discussions remain at the level of patient fertility, contraception, erectile or menopausal status. [http://www.atypon-link.com/EMP/doi/abs/10.5555/conu.2007.27.1.49](http://www.atypon-link.com/EMP/doi/abs/10.5555/conu.2007.27.1.49)

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

**Palliative care legislation proposes $44 million in education fellowships for nurses**

*MCKNIGHT'S LONG TERM CARE NEWS & ASSISTED LIVING | Online – 26 March 2013 –* The Palliative Care and Hospice Education and Training Act ... would award funds and contracts to help educational institutions beef up their palliative care and hospice programs. It would also allocate more than $44 million in fellowship money annually through 2018 for advanced practice nurses and other healthcare professionals seeking advanced degrees. Recipients would then agree to work for five years providing palliative or hospice care in an educational, home, hospice or long-term care setting. [http://www.mcknights.com/palliative-care-legislation-proposes-44-million-in-education-fellowships-for-nurses/article/285988/#](http://www.mcknights.com/palliative-care-legislation-proposes-44-million-in-education-fellowships-for-nurses/article/285988/#)

**Among neighbors: An ethnographic account of responsibilities in rural palliative care**

*PALLIATIVE & SUPPORTIVE CARE | Online – 19 March 2013 –* Building high quality palliative care in rural areas must take into account the cultural dimensions of the rural context. Findings [of this study] provide important insights into the complex ways rurality influences understandings of responsibility in palliative care. Families, healthcare providers, and administrators work together in fluid ways to support high quality palliative care in their communities. However, the very fluidity of these responsibilities can also work against high quality care, and are easily disrupted by healthcare changes. Proposed healthcare policy and practice changes... should undergo a careful analysis of their potential impact on the longstanding negotiated responsibilities. [http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8869654](http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8869654)

Noted in Media Watch, 14 January 2013:

- **RURAL & REMOTE HEALTH | Online – 7 January 2013 –** 'Comparing the experiences of rural and urban family caregivers of the terminally ill.' Results of this study suggest that while there are commonalities to the caregiving experience regardless of setting, key differences also exist. Location is a factor to be considered when implementing palliative care programs and services. [http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=2250](http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=2250)

**N.B.** This issue of Media Watch (p.14) lists several articles noted in past issues of the weekly report on the provision and delivery of end-of-life care in rural areas. Also see Media Watch 30 April 2012 (p.8-9).

**Changing patterns in place of cancer death in England: A population-based study**

*PLOS MEDICINE | Online – Accessed 29 March 2013 –* Hospital remained the most common PoD [place of death] for patients with cancer in England (48%). Home and hospice deaths increased since 2005, oppositely mirroring reducing trends in hospital deaths. People who died from haematological cancer, who were single, widowed or divorced, and aged over 75 years, were less likely to die in home or hospice. There was little improvement in patients with lung cancer of dying in home or hospice. Marital status overtook age as the second most important factor associated with PoD, after cancer type. More efforts are needed to reduce hospital deaths. Health care facilities should be improved and enhanced to support the increased home and hospice deaths. [http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001410](http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001410)
Of related interest:

- **BRITISH MEDICAL JOURNAL** | Online – 21 March 2013 – "National Institute for Health & Care Excellence's end of life decision making scheme: Impact on population health." No abstract available. [http://www.bmj.com/content/346/bmj.f1363](http://www.bmj.com/content/346/bmj.f1363)

**Assisted (or facilitated) death**

Representative sample of recent articles, etc:

- **BRITISH MEDICAL BULLETIN** | Online – 26 March 2013 – "Euthanasia is not medical treatment." Advocates of euthanasia and assisted suicide give priority to the right to personal autonomy and avoid discussions of harmful impacts of these practices on medicine, law and society. Opponents give priority to respect for life and identify such harmful effects. These both require euthanasia to remain legally prohibited. Proposals are emerging that if society legalizes euthanasia it should not be mandated to physicians. The impact of characterizing euthanasia as 'medical treatment' on physicians' professional identity and on the institutions of medicine and law should be examined in jurisdictions where assisted suicide and euthanasia have been de-criminalized. [http://bmb.oxfordjournals.org/content/early/2013/03/26/bmb.l010t0.0abstract](http://bmb.oxfordjournals.org/content/early/2013/03/26/bmb.l010t0.0abstract)

- **CLINICAL ETHICS**, 2013;8(1):5-8. "From empathy to assisted dying: An argument." Assisted dying (AD) has not been legalized despite a number of presentations to parliament. It is necessary for doctors who support AD to justify themselves in the context of repeated legislative failure. [http://ce.rsmjournals.com/content/8/1/5.abstract](http://ce.rsmjournals.com/content/8/1/5.abstract)

- **SINGAPORE LAW WATCH** | Online – 20 March 2013 – "Euthanasia is a matter for Parliament." Chief Justice Sundaresh Menon has made it clear it is for Parliament to decide if voluntary euthanasia, or assisted suicide, is to be allowed in Singapore. But the choice is a complicated one, requiring plenty of debate. When he delivered the Singapore Medical Association's annual lecture "Euthanasia: a matter of life or death?" he highlighted the example of Singaporean lawyer Suzanne Chin to show that even science did not have all the answers. After she collapsed in Hong Kong in 2009, her family was informed she was brain dead. Her husband was advised to switch off the ventilator as there was no hope of recovery. Three days later, she revived. Eight days later she was discharged. "There are limits to what we know and what science can tell us," said Menon, who explained that issues relating to accelerated and assisted dying were profound, with so many deeply different views that no "categorical conclusion" might be reached. [http://www.singaporelawwatch.sg/slwc/headsnews/22222-euthanasia-is-a-matter-for-parliament-cj.html](http://www.singaporelawwatch.sg/slwc/headsnews/22222-euthanasia-is-a-matter-for-parliament-cj.html)


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