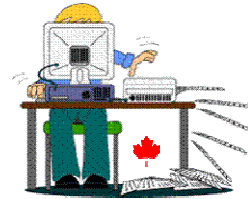


## Media Watch...

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.

2 July 2012 Edition | Issue #260



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

Compiled & Annotated by Barry R. Ashpole

The transition experiences of young people with palliative care needs: Scroll down to [International](#) and 'Young people with terminal illnesses deprived of support, report warns' (p.5), published in the U.K.'s *Children & Young People Now*.

## Canada

### Funding issues in end-of-life care

#### Residential hospice avoids shutdown

ONTARIO | *Ottawa Citizen* – 29 June 2012 – Ottawa's only residential hospice ... has merged with another palliative-care service and narrowly avoided shutting down. Hospice at May Court was on the verge of closing because of financial trouble. However, in agreeing to join forces with Friends of Hospice, another grassroots charity ... the May Court has given both groups a more secure place at a time when an aging population is increasing the demand for end-of-life care. In recent years, the May Court, which has 10 residential hospice beds and a range of day programs ... has had trouble balancing its budget as provincial funding and fundraising proceeds have levelled off. For fiscal 2011-2012, the May Court accumulated a \$300,000 deficit on a \$3.5-million budget as costs continued to outpace revenues. The organization ended up balancing its budget with a bailout from the Ontario government.

<http://www.ottawacitizen.com/health/Residential+hospice+avoids+shutdown/6858538/story.html>

### Specialist Publications

Of particular interest:

'The importance of discussing end-of-life options' (p.6), published in *BC Medical Journal*.

'Canadian rural-urban differences in end-of-life care setting transitions' (p.8), published in *Global Journal of Health Science*.

### 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>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *Ottawa Citizen* (OpEd) – 28 June 2012 – '**Canadian doctors wrestling with issues around medically assisted suicide.**' Canada's top medical journal reignited the euthanasia debate this week with an editorial urging a national "therapeutic homicide" discussion in Canada.<sup>1</sup> Meanwhile, the nation's biggest doctors' group has begun privately surveying its 75,000 members on their attitudes towards end-of-life care, including euthanasia and doctor-assisted suicide. <http://www.ottawacitizen.com/news/Canadian+doctors+wrestling+with+issues+around+medically+assisted+suicide/6856935/story.html>

1. 'Choosing when and how to die: Are we ready to perform therapeutic homicide?' *Canadian Medical Association Journal*, 25 June 2012. <http://www.cmaj.ca/content/early/2012/06/25/cmaj.120961.1>

## U.S.A.

### Can house calls cut health costs?

MASSACHUSETTS | *Boston Globe* – 1 July 2012 – [Daniel] Oates is a Boston Medical Center geriatrician who makes house calls, part of a cadre of physicians nationwide who serve a growing need of homebound seniors. He believes home visits provide more personalized, consistent care to people who might not otherwise see a doctor and can prevent hospitalizations or delay a move to a nursing home. Now the Centers for Medicare & Medicaid Services, in a program created under the newly-affirmed Affordable Care Act, is looking at the Boston program and 15 others to see whether they also can save money. <http://bostonglobe.com/lifestyle/health-wellness/2012/07/01/can-house-calls-cut-health-care-costs-house-calls-boston-medical-center-program-testing-home-care-for-homebound-seniors/s6jidObrL7oC43IkTDK8dL/story.html>

### Connecticut allows some inmates to go to nursing home

CONNECTICUT | Associated Press – 30 June 2012 – Connecticut's sickest state prison inmates will be released and moved to a nursing home early next year in an effort that state officials say will save millions of dollars in health care costs. As part of its wide-ranging state budget legislation signed into law in June, state lawmakers gave Correction Commissioner Leo Arnone the discretion to release severely incapacitated inmates from custody for "palliative and end-of-life" care. <http://www.sfgate.com/news/article/Conn-allows-some-inmates-to-go-to-nursing-home-3675642.php>

### More visits from hospice may allow death at home

REUTERS | Online report – 28 June 2012 – Very ill patients who prefer to die at home are more likely to do so if they get frequent visits from hospice nurses and doctors, according to a new report.<sup>1</sup> The findings highlight the importance of hospices, which provide specialized care to very sick or terminally ill patients and offer them the opportunity to remain at home if they want to. "Frankly, it's one of the things hospices offer that hospitals can't," said Dr. David Casarett, chief medical officer at the Penn-Wissahickon Hospice at the University of Pennsylvania in Philadelphia. "People want to be home," he told Reuters Health. "That's where they feel comfortable and it's a matter of dignity." <http://www.chicagotribune.com/health/sns-rt-us-hospice-deathsbre85r1ji-20120628,0,4320809.story>

1. 'Which hospice patients with cancer are able to die in the setting of their choice? Results of a retrospective cohort study,' *Journal of Clinical Oncology*, published online 25 June 2012. <http://jco.ascopubs.org/content/early/2012/06/20/JCO.2011.41.5711.abstract>

## Supreme Court ruling

### **The Affordable Care Act survived: Now focus on coverage and cutting costs**

STATE OF WASHINGTON | *Seattle Times* (OpEd) – 28 June 2012 – The U.S. Supreme Court changed the national discussion with its decision to uphold most of the Affordable Care Act. Time and energy spent debating medical-insurance coverage must now focus not only on providing care but also containing costs. The latter is urgent because soaring health-care costs are the No. 1 threat to economic prosperity and government treasuries. The law did not address enough substantial reforms to rein them in. Politicians on both sides of the aisle must accept the decision and move ahead. Republicans should put a lid on the prattle about repeal. President Obama and Democrats get a few scant moments of gloating about their policy triumph, then they must deliver on deeper commitments imposed by their achievement. Broad medical coverage will benefit tens of millions of Americans. Their access to prenatal care, preventive medicine, discounted drugs and basic access to medical treatment will save money. At the same time, the Obama administration and the infrastructure being established in states across America must find ways to rein in costs. [http://seattletimes.nwsourc.com/html/editorials/2018554893\\_edit29affordablecare.html](http://seattletimes.nwsourc.com/html/editorials/2018554893_edit29affordablecare.html)

Of related interest:

- CALIFORNIA | *Los Angeles Times* – 25 June 2012 – **'Sarah Palin's 'death panel' claim rises from the grave.'** It worked so well in 2009 as a way of marshaling opposition to President Obama's healthcare reform law that Sarah Palin has revived her widely debunked claim that the law will create "death panels" to determine which citizens are worthy of healthcare. In a Facebook® post timed to take advantage of the widespread focus on the Supreme Court's expected ruling on the Affordable Care & Patient Protection Act later this week, Palin wrote, "I reiterate what I wrote in my first post on this topic nearly three years ago. I stand by everything I wrote in that warning to my fellow Americans because what was true then is true now, and it will remain true as we hear what the Supreme Court has to say." In 2009, Palin conjured the image of faceless government drones wielding life-and-death power over helpless patients. <http://www.latimes.com/news/politics/la-pn-sarah-palins-death-panel-claim-rises-from-the-grave-20120625,0,7057615.story>

### **Helpful hands on life's last segregated journey**

GEORGIA (Madison) | *New York Times* – 23 June 2012 – When a black person dies in one of the rural counties around here, chances are the body will end up in the hands of Charles Menendez. First, he offers a little prayer and asks the person on the table to help him make the job go smoothly. Then he gets down to work, embalming the body like an old-school craftsman. "You don't want the family to touch Grandmama and feel it cold and hard," he said. "You want flexibility in the skin. The idea is to leave a good memory picture for them." All of his cases are black. They always have been. If Sunday remains the most segregated day in the South, funerals remain the most segregated business. In the same way that generations of tradition dictate the churches people attend, the races tend to bury their own. <http://www.nytimes.com/2012/06/24/us/funerals-remain-a-segregated-business-in-the-south.html>

*Living to the end - palliative care for an ageing population*



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

October 13 2012

## International

### **How has palliative care agenda been promoted in Africa?**

AFRICA | *Weekend Observer* (Mbabane, Swaziland) – 30 June 2012 – As the disease burden is great in Africa palliative care has been considered as the main cornerstone to improving the quality of life for those living with the life limiting condition. By 2008 an estimated 22 million people in Sub-Saharan Africa were living with the HIV/AIDS virus, with 1.9 million new infections reported in that year alone. There were an estimated 7.6 million new cancer cases and six million related deaths in Africa by 2007. These numbers are expected to increase dramatically in the years ahead. There is growing concern that as people's lifestyle, nutritional preference and non-sedentary work pattern the continent changes, Africa may experience an increase in the incidence of chronic life limiting diseases. <http://www.observer.org.sz/index.php?news=40331>

### **Scandal of €22m hospice lying idle**

IRELAND | *Herald* (Dublin) – 28 June 2012 – This state-of-the-art hospice that cost €22m to build is lying empty because of a funding shortfall. The hold-up in opening the 24-bed facility was today described as a "tragedy." The hospice ... cannot get a commitment for money from health chiefs. <http://www.herald.ie/news/scandal-of-22m-hospice-lying-idle-3152846.html>

### **Paupers' funerals "set to rise"**

U.K. | Dying Matters – Accessed 28 June 2012 – The number of so-called 'paupers' funerals' is set to rise in the as the disparity between the rising cost of funerals and the state contribution puts increasing pressure on an already stretched system, warns a new study.<sup>1</sup> The study ... contends the Funeral Payment scheme, intended to contribute to the cost of funerals for the most vulnerable in society, is failing to meet mounting demand. The situation is set to get worse as the cost of funerals increases against a backdrop of economic austerity and a burgeoning older population, the report's authors warn. Almost half of the 69,000 applications were rejected last year. Survey respondents were often left feeling confused, frustrated and with a sense of social shame when applying for assistance. <http://www.dyingmatters.org/news/paupers-funerals-set-rise>

1. 'Cost of Dying Special Report: "Affording a funeral," University of Bath and Sun Life Direct, June 2012. [http://www.sunlifedirect.co.uk/uploadedFiles/Content/Site\\_Build/About\\_Sun\\_Life\\_Direct/News\(1\)/SF%20Funeral%20Payment%20Research%20-%2020220612.pdf](http://www.sunlifedirect.co.uk/uploadedFiles/Content/Site_Build/About_Sun_Life_Direct/News(1)/SF%20Funeral%20Payment%20Research%20-%2020220612.pdf)

### **End-of-life planning could cut health bill**

IRISH TIMES | Online report – 27 June 2012 – A lack of planning for the end of life, by patients and their families, costs the health service "a lot of money" and gives people "a lot of heartache," according to an expert on emergency medicine in Ireland. Dr. Una Geary, of Ireland's emergency medicine programme ... said, many elderly people coming into emergency departments were being medicated and kept alive with no prospect of recovery, and the cost of this had to be addressed. Professor Matthew Cooke, national clinical director for urgent and emergency care at the British department of health, agreed. "How many times have we here found we are the first doctor to actually come out and talk to a family about their loved one's end of life? An extra 20 minutes spent compassionately talking to the family saves days, if not weeks, of costly, futile care." He said everyone should be able to say where and how they would like to die. "We should not let people get to the end under the fluorescent lights of an intensive care unit. Dr. Geary said it was about ensuring the patient got the "best-quality palliative care, when the time comes, that is needed." There was a need for more end-of-life planning and work was being done on improving this here. <http://www.irishtimes.com/newspaper/ireland/2012/0628/1224318891450.html>

## Young people with terminal illnesses deprived of support, report warns

U.K. | *Children & Young People Now* – 27 June 2012 – Teenagers with terminal illnesses are missing out on support because of a lack of coordination between children's and adult services, a report into palliative care for young people has warned.<sup>1</sup> The report ... argues 16-and 17-year-olds currently face a "cliff edge" when they cease to be the responsibility of children's services and move over to adult care. This is because planning for young people's transition between services often takes place too late, and some services are restricted to either under-16s or over-18s, the report says. "On leaving the comprehensive care offered by children's services, they will often have to deal with and establish important relationships with a range of agencies and professionals," the report states. "The result can be gaps in services or fewer or less appropriate services. All this happens at a time when young people's needs may be greatest, as many chronic progressive conditions now reach a crisis during late adolescence and young adulthood. The costs of bad transition for young people can include greater illness, adverse social and educational outcomes, and even earlier death. <http://www.cypnow.co.uk/cyp/news/1073729/young-people-terminal-illnesses-deprived-support-report-warns>

1. 'Don't let me down: Ensuring a good transition for young people with palliative care needs,' Marie Curie Cancer Care & Together for Short Lives, June 2012. <http://www.mariecurie.org.uk/Documents/press-and-media/News-Comment/Dont-Let-Me-Down.pdf>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Independent* – 27 June 2012 – **'BMA rejects assisted suicide move as one delegate likens it to murder.'** Doctors ... rejected calls to take a neutral stance on assisted suicide. Medics at the British Medical Association's (BMA) annual conference ... reiterated their opposition to assisted dying, with one delegate likening it to murder. Members of the BMA voted down proposals for the organisation to take a neutral stance. Doctors speaking at the conference cautioned that a change in position would send the wrong message. <http://www.independent.co.uk/life-style/health-and-families/health-news/bma-rejects-assisted-suicide-move-as-one-delegate-likens-it-to-murder-7893118.html>

From Media Watch, 18 June 2012:

- U.K. | *Daily Mail* – 14 June 2012 – **'End opposition to assisted dying and move to position of neutrality, doctors are told.'** <http://www.dailymail.co.uk/news/article-2159030/End-opposition-assisted-dying-position-neutrality-doctors-told.html?ito=feeds-newsxml>
- AUSTRALIAN (TASMANIA) | *The Examiner* (Launceston) – 25 June 2012 – **'Assisted death debate reignited.'** A discussion paper outlining the pros and cons of different right-to-die laws from overseas is expected to be released within the next few weeks. The feedback will inform a private members bill Premier Lara Giddings and Tasmanian Greens leader Nick McKim will introduce later this year. <http://www.examiner.com.au/news/local/news/politics/assisted-death-debate-reignited/2601105.aspx?src=rss>



### 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>

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

### The importance of discussing end-of-life options

*BC MEDICAL JOURNAL*, 2012;54(6):292-293. There are many reasons for physician reluctance to discuss end of life and possibilities of withholding or withdrawing therapies: lack of training in having the conversation; lack of awareness of what palliative therapies and services can do and how to access them; lack of expertise in other co-morbidities and their prognosis; and, perception that they are consulting on one aspect of the patient's care and that someone else is considering the overall situation with a good understanding of the patient's values and preferences. With the increase in discussion about euthanasia, there has also been confusion around the ethical principles of withholding and withdrawing care. Any treatment that we offer should be medically indicated and based on the clinical situation and knowledge of the patient's values and preferences. A treatment may be withheld or not initiated if it is not medically indicated. While we are not obliged to offer treatments, it is always helpful for the family to understand why that treatment is not being offered. If the treatment is medically indicated the patient or substitute decision-maker who has an understanding of the benefits and risks of this and other options can make an informed decision. [http://www.bcmj.org/sites/default/files/BCMJ\\_54\\_Vol6\\_cohp.pdf](http://www.bcmj.org/sites/default/files/BCMJ_54_Vol6_cohp.pdf)

Of related interest:

- *BMC PALLIATIVE CARE* | Online article – 27 June 2012 – **'The ACA training programme to improve communication between general practitioners and their palliative care patients: Development and applicability.'** The 'ACA training programme' focuses on *Availability* of the GP for the patient, *Current issues* that should be raised by the GP, and *Anticipating* various scenarios. Results indicate the ACA training programme to be applicable to GPs and GP Trainees. <http://www.biomedcentral.com/content/pdf/1472-684X-11-9.pdf>
- *JOURNAL OF AGING & HEALTH* | Online article – 27 June 2012 – **'Racial and ethnic differences in advance care planning: Identifying subgroup patterns and obstacles.'** [In this study] Latinos are less likely than Whites to discuss preferences and to have a living will, although the latter gap is fully accounted for by education. Asians are less likely than Whites to have discussions, but more likely to have living wills. Black-White differences emerge only among low socioeconomic status subgroups. <http://jah.sagepub.com/content/early/2012/06/25/0898264312449185.abstract?rss=1>

#### **Parent-clinician communication intervention during end-of-life decision making for children with incurable cancer**

*JOURNAL OF PALLIATIVE MEDICINE* | Online article – 25 June 2012 – In this single-site study, the authors evaluated the feasibility of a parent-clinician communication intervention designed to: identify parents' rationale for the phase I, do-not-resuscitate (DNR), or terminal care decision made on behalf of their child with incurable cancer; identify their definition of being a good parent to their ill child; and, provide this information to the child's clinicians in time to be of use in the family's care. The communication intervention was feasible within hours of decision making, was acceptable and beneficial without harm to participating parents, and was acceptable and useful to clinicians in their care of families. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0006>

### Continuous deep sedation at the end of life and the 'natural death' hypothesis

*BIOETHICS*, 2012;26(6):329-336. The authors focus on what they call the 'natural death' hypothesis ... that acceptance of CDS [continuous deep sedation] has spread rapidly because death after CDS can be perceived as a 'natural' death by medical practitioners, patients' relatives and patients. The authors attempt to show that the label 'natural' cannot be unproblematically applied to the nature of this end-of-life practice. They argue that the labeling of death following CDS as 'natural' death is related to a complex set of mechanisms which facilitate the use of this practice. However, their criticism does not preclude the view that CDS may be clinically and ethically justified in many cases. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2010.01861.x/abstract>

## Oncology and palliative care

### **Effect of integrated palliative care on the quality of end-of-life care**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online article – 29 June 2012 – To examine the impact of oncologist awareness of palliative care (PC), the intervention of the PC team (PCT) and multidisciplinary decision-making on three quality indicators of end-of-life (EOL) care. [In this study] 11%) patients died at home, 9% in an intensive care unit or ER, and 49% in an acute care hospital; 36% patients visited the ER in last month of life and 14% received chemotherapy in last 14 days of life. Only the OPM [onco-palliative meeting] independently decreases the odds of receiving chemotherapy in last 14 days of life and of dying in an acute care setting. PCT intervention did not independently improve any indicators. Among patients seen by the PCT, early PCT intervention had no impact on indicators, whereas the OPM reduced the odds of persistent chemotherapy in the last 14 days of life. <http://spcare.bmj.com/content/early/2012/06/29/bmjspcare-2011-000157.abstract>

## Nursing perspectives on end-of-life care

### **Oncology nurses' narratives about ethical dilemmas and prognosis-related communication in advanced cancer patients**

*CANCER NURSING* | Online article – 21 June 2012 – [In this study] the most frequently reported ethical dilemmas encompassed uncertainties and barriers to truth telling, familial and cultural conflict and futility. Physician-nurse teams were considered optimal for delivering prognosis-related information. Nurses offered strategies for facilitating these communications. They also expressed the need for more education about how to engage in prognosis-related discussions and for better methods for relaying this information among team members to avoid "working in the dark." [http://journals.lww.com/cancernursingonline/Abstract/publishahead/Oncology\\_Nurses\\_Narratives\\_About\\_Ethical\\_Dilemmas.99703.aspx](http://journals.lww.com/cancernursingonline/Abstract/publishahead/Oncology_Nurses_Narratives_About_Ethical_Dilemmas.99703.aspx)

Cont. next page

### **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.
2. Links often remain active, however, for only a limited period of time.
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.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 27 June 2012 – **'Critical care nurses' perception of barriers and supportive behaviors in end-of-life care.'** Barriers to providing EOL [end-of-life care] care were related to intensive care environment, family members, nurses' knowledge and skills, physicians' attitudes and treatment policy. Possible help to providing EOL care involved nurses' support to each other, patient and family-centered care, and families' support. <http://ajh.sagepub.com/content/early/2012/06/13/1049909112450067.abstract>
- *JOURNAL OF EMERGENCY NURSING* | Online article – 25 June 2012 – **"Emergency nurses' suggestions for improving end-of-life care obstacles.'** Five major themes and four minor themes were identified. The major themes were increasing the amount of time ED nurses have to care for dying patients, allowing family presence during resuscitation, providing comfortable patient rooms, providing privacy, and providing family grief rooms. [http://www.jenonline.org/article/S0099-1767\(12\)00112-2/abstract](http://www.jenonline.org/article/S0099-1767(12)00112-2/abstract)
- *NURSING TIMES* | Online report – 27 June 2012 – **'End-of-life discharge nurses 'are effective.'** Teesside University has found that introducing an end-of-life discharge sister gives more patients the freedom to spend their final moments away from hospital. <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/end-of-life-discharge-nurses-are-effective/5046425.article>

### **Canadian rural-urban differences in end-of-life care setting transitions**

*GLOBAL JOURNAL OF HEALTH SCIENCE*, 2012;4(5):1-13. [In this study] moving from place to place for needed care in the last year of life was identified as common and concerning for rural people and their families, with three data themes developing: a) needed care in the last year of life is scattered across many places; b) travelling is very difficult for terminally-ill persons and their caregivers; and, c) local rural services are minimal. These findings indicate planning is needed to avoid unnecessary end-of-life care setting transitions and to make needed moves for essential services in the last year of life less costly, stressful, and socially disruptive for rural people and their families. <http://www.ccsenet.org/journal/index.php/gjhs/article/viewFile/17521/12109>

**N.B.** See Media Watch, 30 April 2012 (p.8-9) for a listing of articles, reports, etc., on the provision and delivery of end-of-life care in the rural setting.

### **Integration of health and social care: A case of learning and knowledge management**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online article – 28 June 2012 – This paper considers integration of health and social care as an exercise in learning and knowledge management (KM). Integration assembles diverse actors and organisations in a collective effort to design and deliver new service models underpinned by multidisciplinary working and generic practice. Learning and KM are integral to this process. A critical review of the literature is undertaken to identify theoretical insights and models in this field, albeit grounded mainly in a private sector context. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2012.01076.x/abstract>

### **Maintaining integrity in the face of death**

*INTERNATIONAL JOURNAL OF NURSING STUDIES*, 2012;49(6):718-726. This study found that preferences and wishes for future care and treatment were not the main concern of people with cancer; rather, any concerns for the future were about the social aspects of death. A theory 'maintaining integrity in the face of death' is proposed. This theory purports that patients with advanced lung cancer and their families focus on acting and talking as 'normal' to help them balance living in the present whilst facing death. Participants talked about their experiences of facing death whilst striving to live in the present. Planning for one's own dying and eventual death was not something that people with lung cancer reported having discussed, except when, out of concern for their families, practical arrangements needed to be made following death. [http://www.journalofnursingstudies.com/article/S0020-7489\(11\)00466-4/abstract](http://www.journalofnursingstudies.com/article/S0020-7489(11)00466-4/abstract)



## Advancing theory of family conflict at the end of life: A hospice case study

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 25 June 2012 – Although conflict is a common occurrence for families involved in caregiving for a dying family member, it has not been examined in the hospice context. The purpose of this study was to advance theory of family conflict at the end of life through replication and expansion of a case study involving professional perspectives in the context of a managed care program for low-income elders with advanced chronic disease in their last six months of life, by exploring the perceptions of professionals and family caregivers experiencing conflict in the hospice context.

[http://www.jpsmjournal.com/article/S0885-3924\(12\)00151-0/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00151-0/abstract)

Of related interest:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online article – 25 June 2012 – '**Exploring communication patterns among hospice nurses and family caregivers: A content analysis of in-home speech interactions.**' This study provides empirical support for best communication practices and may help ... [hospice nurses] ... better understand how specific communication patterns facilitate positive outcomes by supporting caregivers' own needs for interaction and self-expression. [http://journals.lww.com/jhpn/Abstract/publishahead/Exploring\\_Communication\\_Patterns\\_Among\\_Hospice.99989.aspx](http://journals.lww.com/jhpn/Abstract/publishahead/Exploring_Communication_Patterns_Among_Hospice.99989.aspx)
- *PSYCHO-ONCOLOGY* | Online article – 25 June 2012 – '**A systematic review of psychosocial interventions to improve cancer caregiver quality of life.**' Interventions targeting problem-solving and communication skills may ease the burdens related to patient care and role changes associated with care while improving caregiver's overall quality of life. Further research is needed to establish efficacy of interventions ... especially focusing on issues of caregiver retention, caregiver relationships to the cancer patient, and individual differences in caregiver experiences with different types of cancer. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3118/abstract>
- *SOCIOLOGY OF HEALTH & ILLNESS* | Online article – 28 June 2012 – '**The end of life and the family: hospice patients' views on dying as relational.**' The authors argue that family dynamics strongly influence individual experiences near death and that the focus on individual preferences and the management of disease in palliative care contexts must be augmented with sophisticated and nuanced understandings of the family context. They suggest that sociological conceptual explanations of shifts in social and family life, such as individualisation and ontological security, may also help us better understand the ways families approach and respond to the dying process. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-9566.2012.01497.x/abstract>

## Religiosity, spirituality, and end-of-life planning: A single-site survey of medical inpatients

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 25 June 2012 – Prior studies suggest that terminally ill patients who use religious coping are less likely to have advance directives and more likely to opt for heroic end-of-life measures. Yet, no study to date has examined whether end-of-life practices are associated with measures of religiosity and spirituality. The authors examined data from the University of Chicago Hospitalist Study, which gathers sociodemographic and clinical information from all consenting general internal medicine patients at the University of Chicago Medical Center. The sample population was predominantly African American (73%) and female (60%). In this population, 1.5% had advance directives and 10.4% had DNR [do not resuscitate] orders. Half (51%) of the patients had specified a decision maker. White patients were more likely than African American patients to have an advance directive and a DNR order. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00169-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00169-8/abstract)

Of related interest:

- *INTENSIVE CARE MEDICINE*, 2012;38(7):1126-1133. '**Are religion and religiosity important to end-of-life decisions and patient autonomy in the ICU?**' Health-care professionals, families and patients who are religious will frequently want more extensive treatment than unaffiliated individuals. <http://www.springerlink.com/content/d623164u51665725/>

## Compassion and vigilance: Investigators' strategies to manage ethical concerns in palliative and end-of-life research

*JOURNAL OF PALLIATIVE MEDICINE* | Online article – 25 June 2012 – Ethical concerns were identified as a potential barrier to advancing palliative and end-of-life science at the 2004 National Institutes of Health State of the Science Meeting. However, data are lacking about the nature of ethical concerns and strategies for balancing the need to advance science with human subjects protections. A qualitative case-study design was used to follow 43 end-of-life studies from proposal development through the review process and implementation. Investigator strategies fell into two broad categories: 1) Recruitment and consent strategies related to subject identification and enrollment; and 2) Protocol-related strategies related to the process of data collection. These strategies shared the overarching meta-themes of compassion, as evidenced by a heightened sensitivity to the needs of the population, coupled with vigilance, as evidenced by close attention to the possible effects of study participation on the participants' well-being, clinical care, and the needs of research staff. Ethical concerns have led to the development of compassionate and vigilant strategies designed to balance the potential for risk of harm with the need to advance the science of palliative and end-of-life care. These strategies can be used by investigators to address ethical concerns and minimize barriers to the development of palliative and end-of-life care science. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0515>

Cont. next page

### 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/news.htm> (Scroll down to 'International End of Life Roundup')

#### **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.ipcrc.net/archive-global-palliative-care-news.php>

Of related interest:

- *PALLIATIVE MEDICINE*, 2012;26(5):679-680. **'Quality indicators for palliative care: Debates and dilemmas.'** The purpose of this editorial is to draw together the debates about quality indicators for palliative care that have been highlighted in the lively blogs posted on the EAPC site since April 2012. The context to the debates that emerged was the opportunity to influence the World Health Assembly's adoption of a global health indicator for non-communicable diseases (NCDs) that focused on palliative care for the first time. This was not a stand-alone indicator, but one of 12 indicators that could provide the framework to influence health for the next decade or so. It is noteworthy that this is the first time that palliative care has received major attention in global health politics. <http://pmj.sagepub.com/content/26/5/679.extract>

## How people who are dying or mourning engage with the arts

*MUSIC & ARTS IN ACTION*, 2012;4(1):73-98. Though death and loss are recognized as significant themes in fine and popular arts forms, we know virtually nothing about how people who themselves are dying or bereaved use the arts – unless they are practising artists or under therapeutic supervision. This article reviews how established artists have used death/loss themes in their work, along with the work of arts practitioners in palliative and bereavement care and the role of the arts in death education. These literatures tend to privilege the production of artworks over their consumption, and reveal the absence of research into the arts practices of lay people who are dying or grieving. The article advocates ethnographic research into lay practices, using the author's own personal experiences and observations to indicate the kind of findings that ethnography may produce, in particular the likely importance – at the end as in the rest of life – of meaningful arts consumption. The article suggests avenues for researching lay arts practices at the end of life, concluding with some ... implications for profes-

sional care of dying and bereaved people. <http://musicandartsinaction.net/index.php/maia/article/viewFile/dyingmourning/77>

### Resounding the great divide: Theorising music in everyday life at the end of life

*MORTALITY*, 2012;17(2):92-105. Music in contexts of death and dying is an important but often-overlooked aspect of music in everyday life. In this article the author develops an ecological perspective for end of life experience that takes account of the temporal-cultural complexity of being gravely ill and, by implication, being well. She concludes that music opens up opportunities for action and social relation at end of life. Music is a dynamic medium for the collective performance of what it means to be well or ill, and what it means (and can mean) to be alive, dying or dead. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.673375>

**N.B.** This issue of *Mortality* includes several articles on music, dying and death. Journal contents page: <http://www.tandfonline.com/toc/cmrt20/current>

Of related interest:

- *BRAIN, BEHAVIOR & IMMUNITY* | Online article – 23 June 2012 – **'When grief makes you sick: Bereavement induced systemic inflammation is a question of genotype.'** The results of this study suggest a possible mechanism for the increase in morbidity and mortality in the surviving spouse. <http://www.sciencedirect.com/science/article/pii/S0889159112001511?v=s5>
- *PSYCHO-ONCOLOGY* | Online article – 29 June 2012 – **'Healthcare utilization of bereaved relatives of patients who died from cancer: A national population-based study.'** Spousal bereavement because of cancer appears to influence healthcare utilization months before the loss and years after the loss. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3120/abstract>
- *QUALITY HEALTH RESEARCH* | Online article – 25 June 2012 – **'"Cycling around an emotional core of sadness": Emotion regulation in a couple after the loss of a child.'** The findings [of this study] suggest the presence of a dialectic tension between the need to be close to the deceased child and the need for distance from the pain of the loss, which was evidenced on both individual and relational levels. <http://qhr.sagepub.com/content/early/2012/06/27/1049732312449209.abstract>

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *YALE JOURNAL OF BIOLOGY & MEDICINE*, 2012;85(2):271-284. **'Debating death: Religion, politics, and the Oregon death with dignity act.'** This paper compares the public discussion that occurred in 1994 and during the Act's implementation in 1997 and examines these debates in relation to health care reform under the Obama administration. The author argues that the 1994 and 1997 Oregon PAS [physician-assisted suicide] campaigns and the ensuing public debate represent the culmination of a growing lack of deference to medical authority, concerns with the doctor-patient relationship, and a desire for increased patient autonomy over decisions during death. The public debate over PAS in Oregon underscored the conflicts among competing religious, political, and personal interests. More visible and widespread than any other American debate on PAS, the conflict in Oregon marked the beginning of the now nationwide problem of determining if and when a terminally ill person can choose to die. <http://www.ncbi.nlm.nih.gov/pubmed/22737056>

---

**Barry R. Ashpole**  
Beamsville, Ontario CANADA

'phone: 905.563.0044  
e-mail: [barryashpole@bellnet.ca](mailto:barryashpole@bellnet.ca)