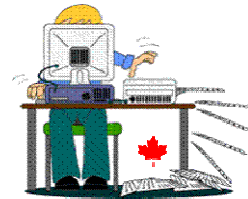


## Media Watch...

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.

4 April 2011 Edition | Issue #195



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

Compiled & Annotated by Barry R. Ashpole

Consumer engagement in end-of-life issues: Scroll down to [U.S.A.](#) and 'New report outlines progress made and issues call to action' (p.4), published by the National Hospice & Palliative Care Organization.

## Canada

### Weighing the merits of 'never-say-die' oncology

ONTARIO | *National Post* – 31 March 2011 – Konrad Fassbender remembers clearly the airport waiting room conversation he had with a grieving colleague, whose adult daughter had just died of breast cancer. The father lamented their final hours together were tainted by the medical team's vigorous attempts to keep the woman alive. "He said, 'Those buggers were poking and prodding her with needles the day before she died,'" recalled Prof. Fassbender... "He was very bitter about that." A growing body of thought suggests such assertive treatment is, in fact, often inappropriate for patients facing imminent death from cancer or other terminal diseases. A new Ontario study reveals, however, that cancer patients are increasingly undergoing emergency department treatment, chemotherapy and other "aggressive" care in the last few weeks of their lives.<sup>1</sup> Close to one in four patients studied received potentially aggressive care in their last month... Care of all kinds in the last months of life generally costs the health-care system billions of dollars a year, other research has suggested. The oncologist who led the Ontario study, Dr. Craig Earle ... said

hospice beds and palliative services in patients' homes are often not available. He and other experts advocate new government spending on palliative care, designed to lessen pain and discomfort and address psychological and spiritual issues for patients whose illness can no longer be treated. Resources are not the only issue... <http://www.nationalpost.com/news/Weighing+merits+never+oncology/4531556/story.html>

#### Correctol Cancer Association of Canada

#### **Extract from *Weighing Quality of Life in Cancer National Survey* (March/April 2011)**

When asked what they would spend their time doing if they only had a few more weeks to live ... 44% of respondents said they would spend that time seeking options in hopes of survival, and 35% of respondents specifically mentioned they would seek out options that may prolong life and prevent the cancer from progressing. [http://www.newswire.ca/en/releases/mmnr/smr/PDF/Weighing\\_Quality\\_of\\_Life\\_in\\_Cancer\\_Survey\\_Report.pdf](http://www.newswire.ca/en/releases/mmnr/smr/PDF/Weighing_Quality_of_Life_in_Cancer_Survey_Report.pdf)

Cont.

1. **'Trends in aggressiveness of end-of-Life cancer care in the universal health care system of Ontario, Canada,'** *Journal of Clinical Oncology*, online article, 14 March 2011. Among 227,161 patients, 22.4% experienced at least one incident of potentially aggressive EOL [end of life] cancer care. <http://jco.ascopubs.org/content/early/2011/03/14/JCO.2010.31.9897.abstract>

**N.B.** The authors of the study noted that aggressiveness of cancer care near the the end of life is increasing over time in Ontario, although overall rates were lower than in the U.S. Article noted in Media Watch dated 21 March 2011.

#### Withholding and withdrawing life-sustaining treatment

#### **Debate on death continues**

MANITOBA | *Winnipeg Free Press* (OpEd) – 29 March 2011 – The debate over who has the right to decide when to withhold or withdraw life-support to a patient proved too hot for politicians last week. The Winnipeg Regional Health Authority [WRHA] asked the government to appoint a panel to arbitrate disputes between doctors and patients' loved ones,<sup>1</sup> but Health Minister Theresa Oswald said this is a matter best kept inside hospital walls. The WRHA's fallback, then, is to devise responsive mediation services to keep such conflicts out of the courts. Conflicts over sustaining life – or prolonging a death – rarely make their way into headlines. In 2008, the Orthodox Jewish family of Samuel Golubchuk went to court to prevent Grace Hospital from taking their father, in the midst of multiple organ failure, off life-support. Mr. Golubchuk died before a judge ultimately ruled on the issue. It was the third such court case Manitoba has witnessed in recent years, and none has settled the central question of who, finally, gets the say. The health authority last week released a paper that accepts the [Manitoba] College of Physician & Surgeons' [MCPS] own conditions for doctors to withhold or withdraw life-sustaining treatment from the very ill.<sup>2</sup> Its controversial "minimum goal" for intervening with life-support is that a patient must have, or have the ability to regain, a sense of their self and environment. Critics argue this "wobbly" goal ignores the fact that self-awareness is a philosophical rather than medical concept. <http://www.winnipegfreepress.com/opinion/editorials/debate-on-death-continues-118825994.html>

1. *Withholding/Withdrawing Life-Sustaining Treatment, WRHA Board Working Group Report*, December, 2010. <http://www.wrha.mb.ca/healthinfo/reports/files/EndOfLife-BoardReport.pdf>
2. *Withholding & Withdrawing Life-Sustaining Treatment*, College of Physicians & Surgeons of Manitoba, Statement No. 1602, 2008. <http://www.bioethics.ca/statement.pdf>

From Media Watch dated 28 March 2011:

- MANITOBA | *Winnipeg Free Press* – 25 March 2011 – **'End-of-life reports call for better education.'** The Winnipeg Regional Health Authority released two reports ... on the sensitive issue of end-of-life care. <http://www.winnipegfreepress.com/breakingnews/WRHAs-end-of-life-reports-call-for-better-education-118653749.html>

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

#### **Centers for Medicare & Medicaid Services implements new law on hospice, home health**

*LONG TERM CARE NEWS* | Online report – 4 April 2011 – The Centers for Medicare & Medicaid Services [CMS] has begun implementing a new law that requires physicians to meet face-to-face with individuals looking to be certified for Medicare home health services and Medicare hospice services. While the law went into effect 1 January under the Affordable Care Act, CMS allowed a three-month delay to give struggling agencies more time. The rule requires the healthcare professionals who make certification decisions to provide documentation saying they met with the patient in person. <http://www.mcknights.com/cms-implements-new-law-on-hospice-home-health/article/199830/>

## Hampton Veterans Affairs hospital increases hospice care training after report faults response to dying man

VIRGINIA | *Daily Reporter* (Hampton) – 1 April 2011 – The Hampton Veterans Affairs Medical Center has increased training for employees after a report faulted its response to a man who was dying of cancer. [The] Office of Inspector General at the Department of Veterans Affairs says the hospital missed numerous opportunities to start hospice care for the man, who wasn't identified. <http://www.greenfieldreporter.com/view/story/6710b0ff4a874208be19da026cd90a83/VA--VA-Hospice-Care/>

## Lawsuits aren't improving nursing home care: Study

U.S. NEWS & WORLD REPORT | Online report – 30 March 2011 – High-quality nursing homes get sued almost as often as low-quality nursing homes, a new study shows.<sup>1</sup> Researchers say the finding illustrates that litigation, or the threat of litigation, doesn't lead to improvements in patient care. Nor does it appear that better nursing homes are rewarded for superior care in terms of fewer lawsuits. <http://health.usnews.com/health-news/family-health/boomer-health/articles/2011/03/30/lawsuits-arent-improving-nursing-home-care-study>

1. 'Relationship between quality of care and negligence litigation in nursing homes,' *New England Journal of Medicine*, 2011;364(13):1243-1250. In this analysis of a large national [U.S.] sample of nursing homes, those rated as having more deficiencies in quality of care were more likely to have malpractice claims brought against them; however, the difference was modest. <http://www.nejm.org/doi/full/10.1056/NEJMsa1009336>

## Idaho Senate passes end-of-life conscience bill over seniors' objections

IDAHO | *Spokesman-Review* (Boise) – 29 March 2011 – The Idaho Senate sent Governor Butch Otter a measure ... that's opposed by seniors and the AARP [American Association for retired Persons], making a narrow change to the state's "conscience law," which lets health care providers refuse to provide end-of-life care that violates the provider's conscience. The conscience law ... allows any health care provider to refuse to provide any type of treatment that violates the provider's conscience, if it has to do with abortion, emergency contraception, stem-cell research or end-of-life care. <http://www.spokesman.com/stories/2011/mar/29/idaho-senate-passes-end-life-conscience-bill-over/>

### Media Watch Online

The weekly report can be accessed at several websites, among them:

#### **Canada**

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation Services: <http://www.hpconnection.ca/newsletter/inthenews.html>

Ontario | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm>  
(Scroll down to 'Newsletters/Media Updates')

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

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

#### **International**

Global | Palliative Care Network Community: <http://www.pcn-e.com/community/search/?tag=Media+Watch>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm>

## Consumer engagement in end-of-life issues

### **New report outlines progress made and issues call to action**

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online report – 29 March 2011 – *Private Conversations & Public Discourse* is a call to action that encourages – and provides a framework for – a national agenda for consumer engagement in end-of-life issues. The report points to both real and perceived barriers in people seeking quality care when facing a serious or life-limiting illness. One such example is the common misconception that a patient and doctor have "given up" when they elect hospice. Research has shown that hospice and palliative care improve quality of life and family caregiver satisfaction; and in some cases, patient lives longer than if more conventional "curative" treatments were chosen. [http://www.caringinfo.org/files/public/PrivateConversations and PublicDiscourse.pdf](http://www.caringinfo.org/files/public/PrivateConversations%20and%20PublicDiscourse.pdf)

#### **Extract from *Private Conversations & Public Discourse***

Individuals need to talk about and document their wishes.

Health care providers need to initiate honest, timely and culturally-relevant discussions with those they care for.

Policy makers need to eliminate barriers that prevent timely access to hospice and palliative care.

The media needs to help demystify dying and help normalize the experience for society.

Of related interest:

- NEW JERSEY | *The Record* – 4 April 2011 – **'Hospital breaking the cycle for terminally ill.'** They show up in the nation's emergency rooms every day: patients terminally ill from cancer or battling chronic heart failure, in pain or short of breath and feeling scared. They are admitted by overwhelmed ER doctors, stabilized and sent home after a few days. Then the terrible cycle begins again. St. Joseph's Regional Medical Center is trying to stop this revolving door by giving patients alternatives to aggressive care, a practice that also ends unnecessary admissions. [http://www.northjersey.com/news/health/119164764\\_Hospital\\_breaking\\_the\\_cycle\\_for\\_terminally\\_ill.html](http://www.northjersey.com/news/health/119164764_Hospital_breaking_the_cycle_for_terminally_ill.html)
- VERMONT PUBLIC RADIO | Online report – 29 March 2011 – **'Many doctors still focus more on cure than managing pain.'** Patients hearing about palliative care for the first time can get a little scared about implications that it spells the beginning of the end of life. A barrier to wider acceptance of the approach isn't patients' resistance but foot-dragging by doctors. <http://www.vpr.net/npr/134949536/>
- HOSPITAL REVIEW (U.S.) | Online report – 28 March 2011 – **'Palliative care still not covered, despite successes.'** Despite studies showing the cost-effectiveness of palliative care, insurers typically don't reimburse hospitals for it, except for doctor visits and care related to hospice, according to a report by the *Washington Post*.<sup>1</sup> <http://www.beckershospitalreview.com/hospital-financial-and-business-news/palliative-care-still-not-covered-despite-successes.html>
  1. **'Hospitals increasingly offer palliative care,'** *Washington Post*, 28 March 2011. In a recent survey, only 24% of people said they were familiar with the term. Palliative care isn't nearly as well known as, say, hospice care; in fact, people often confuse the two. [http://www.washingtonpost.com/national/hospitals-increasingly-offer-palliative-care/2011/03/24/AFuFAeqB\\_story.html](http://www.washingtonpost.com/national/hospitals-increasingly-offer-palliative-care/2011/03/24/AFuFAeqB_story.html)

#### **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/>

## In 43% of U.S. families, one sibling is responsible for care of parents

SENIOR HOUSING NEWS | Online report – 29 March 2011 – Research conducted by the Home Instead Senior Care network found that 46% of family caregivers say their relationships with siblings have deteriorated from an unwillingness to provide help. Making decisions together, dividing the workload and teamwork are the three key factors to overcoming family conflict, according to the organization's research. <http://seniorhousingnews.com/2011/03/29/in-43-of-u-s-families-one-sibling-is-responsible-for-care-of-parents/>

## International

### Respecting a patient's wishes at the end of their life

AUSTRALIA | *The Age* (OpEd) – 3 April 2011 – Doctors are hard-wired to save lives, wrote Dr. William Silvester.<sup>1</sup> But when a patient is chronically ill, and suffering from an incurable condition, should doctors do all they can to extend life? Dr. Silvester, director of Respecting Patient Choices at Austin Heath [Victoria], has come to question whether aggressive medical intervention is always the right way to proceed. His thoughtful article about the need to respect what a patient wants struck a chord with many readers, who have welcomed this gentler approach to patient care. Over the past 10 years, the Austin, along with other hospitals and nursing homes around Australia, has developed programs to learn how patients would wish to be treated at the end of their lives. "Advanced care planning" asks patients what they would want – or not want – if they become too sick to tell the doctor themselves. Dr. Silvester says, doctors and nurses are trained to have "these sensitive, personal and, let's face it, confronting discussions." "It isn't something you get taught at university; it is a skill most of us have to consciously work on," he says. Adding to the difficulty is that many patients have not had these discussions with their own families. Dr. Silvester says a patient's wishes should come before the wishes of their relatives ... "treacherous terrain" for doctors, who can be pressured by families to

### Specialist Publications

Of particular interest:

**'The hospice caregiver support project: Providing support to reduce caregiver stress'** (p.11), published in the *Journal of Palliative Medicine*.

do everything to prolong life. <http://www.theage.com.au/opinion/editorial/respecting-a-patients-wishes-at-the-end-of-their-life-20110402-1csc1.html>

1. **'A good death,'** *The Sunday Age*, 20 March 2011. William Silvester knows better than most that dying with dignity is as important as living with it. <http://www.theage.com.au/victoria/a-good-death-20110319-1c1d8.html>

### **This man is dying and, as a sign of new times in palliative care, he's decided how he will go**

AUSTRALIA | *The Age* (OpEd) – 3 April 2011 – Ron and Jo Lennox have a familiarity with death. Jo saw a lot of it in 39 years of nursing, and she sat in a small room with her father for three days as he slowly but gently passed away after a series of strokes. Over a two-year period in the mid-1990s, Ron lost his brother, mother, sister and former wife. After years driving trucks, he spent seven more in aged-care facilities, looking after people at the end of their days. He's stared down four heart attacks in the past decade. So death doesn't frighten them – "billions have done it before us," says Ron. It's the dying. Or dying badly. More particularly, dying on someone else's terms. <http://www.theage.com.au/national/this-man-is-dying-and-as-a-sign-of-new-times-in-palliative-care-hes-decided-how-he-will-go-20110402-1cslc.html>

## D-day as hospice ends lengthy link with National Health Service

U.K. | *Sutton Coldfield Observer* – 1 April 2011 – As of today John Taylor Hospice ... which was set up more than 100 years ago, will cease to be under the control of Birmingham East & North ... PCT [Primary Care Trust], and instead will be run by an independent body set up by staff and supporters. The change marks the end of months of hard work for the staff, who last year were told that a change in Government funding meant they could no longer have the financial support of the PCT. There were fears that the only way to protect the future of the hospice, which serves more than 400,000 people, would be to sell it to the private sector or have its facilities merged with another service provider. <http://www.thisissuttoncoldfield.co.uk/news/D-day-hospice-ends-lengthy-link-NHS/article-3397004-detail/article.html>

## Talking about death is not always best

U.K. | *The Guardian* (OpEd) – 31 March 2011 – Where once death and dying were taboos that must never be mentioned, now it seems they are subjects that must always be talked about upfront and brought out into the open. But, say you have a 20-year-old just diagnosed with a terminal illness, who not only doesn't want to talk about it, but isn't even yet in a position to know what is happening to them? They may have been told they can't be cured, but is it really surprising if they can't really take it in? Jaw jaw isn't necessarily always the best thing. Why is it we seem to have to move so swiftly from one standard response to another? Now after every major disaster, counsellors rush in, although the evidence seems to be that such early input is as likely to be unhelpful as helpful, often keeping people stuck in their difficulties. Yet there seems to be the same pressure to get people to open up about their impending death, as though this just has to be a "good thing." But regardless of their age, many people don't want to talk about dying; they seem focused instead on doing the most with the living they have got left. A palliative care social worker said, "Perhaps the moral here should be whatever works for each of us is what's right." <http://www.guardian.co.uk/society/joepublic/2011/mar/31/talking-about-death-not-always-best>

## The costly business of dying

U.K. | *The Guardian* – 28 March 2011 – In the last six years, funeral costs in the U.K. have risen by 50%. The U.S. National Funeral Directors Association says a funeral costs, on average, about \$8,000 (£5,000). There are a lot of funerals that go into quintuple digits; a coffin alone can cost upwards of \$10,000 (£6,200), with a myriad of padding and hidden costs thrown in. Refrigeration. Embalming. Casketing. Preparation of the body. Viewing. Compensation for religious officiants. Flowers. Vaults. Grave liners. Gaskets and seals. Grave markers. Opening the grave. Closing the grave. Opening the vault. Closing the vault. The grave, or cremation. Transport. Administrative fees. Facility rental. Honorariums. Funeral directors suggest this is the result of increased regulation, causing higher consumer costs as funeral homes pass on their operating expenses. The truth is much less savory. <http://www.guardian.co.uk/commentisfree/2011/mar/28/business-dying-funeral>

### Sea burials to hit peak of 1,000 in Beijing

CHINA | *Asia One* – 30 March 2011 – Officials at the Beijing Funeral Ritual Service Center ... attributed the increase [in sea burial] to greater public awareness and subsidies offered by the government. Since 1994, ceremonies have been held for more than 7,000 Beijingers. <http://news.asiaone.com/News/Latest%2BNews/Asia/Story/A1Story20110330-270875.html>

### Greener approaches helping make the Tomb Sweeping holiday cleaner

TAIWAN | *Focus Taiwan* – 2 April 2011 – Taiwanese are adopting greener ways to pay tribute to their ancestors during the Tomb Sweeping Festival, a sign of the country's growing environmental awareness. [http://focustaiwan.tw/ShowNews/WebNews\\_Detail.aspx?Type=aLIV&ID=201104020014](http://focustaiwan.tw/ShowNews/WebNews_Detail.aspx?Type=aLIV&ID=201104020014)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | *The Advertiser* (Adelaide) – 4 April 2011 – '**Strong support among Christians for euthanasia.**' The public policy research organisation [The Australia Institute] found that of 1300 people polled, including non-Christians, 75% supported doctors being able to legally assist in euthanasia. <http://www.adelaidenow.com.au/strong-support-among-christians-for-euthanasia/story-e6frea6u-1226032969786>

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

### Transitions to palliative care in acute hospitals in England: Qualitative study

*BRITISH MEDICAL JOURNAL* | Online article – 29 March 2011 – Participants [in this qualitative study] identified that a structured transition to a palliative care approach of the type advocated in U.K. policy guidance is seldom evident in acute hospital settings. In particular they reported that prognosis is not routinely discussed with inpatients. Achieving consensus among the clinical team about transition to palliative care was seen as fundamental to the transition being effected; however, this was thought to be insufficiently achieved in practice. Secondary care professionals reported that discussions about adopting a palliative care approach to patient management were not often held with

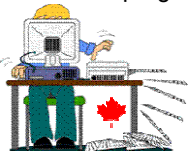
patients; primary care professionals confirmed that patients were often discharged from hospital with "false hope" of cure because this information had not been conveyed. <http://www.bmj.com/content/342/bmj.d1773>

#### Extract from *British Medical Journal*

Key barriers to ensuring a smooth transition to palliative care included the difficulty of "standing back" in an acute hospital situation, professional hierarchies that limited the ability of junior medical and nursing staff to input into decisions on care, and poor communication.

Of related interest:

- *BRITISH JOURNAL OF GENERAL PRACTICE*, 2011;61(585):e167-e172. '**Facilitators and barriers for GP-patient communication in palliative care: A qualitative study among GPs, patients, and end-of-life consultants.**' Barriers reported by both GPs and end-of-life consultants were: difficulty in dealing with former doctors' delay and strong demands from patients' relatives. <http://www.ingentaconnect.com/content/rcgp/bjgp/2011/00000061/00000585/art00005>
- *GIORNALE ITALIANO DI MEDICINA DEL LAVORO ED ERGONOMIA*, 2011;33(1):A41-A46. '**Knowledge and expectations of patients in palliative care: Issues regarding communication with people affected by life-threatening diseases.**' Different social norms influence the type and amount of information transmitted to palliative care patients. In Italy disclosure rate is low and medical decisions are often mediated by the family since communication of diagnosis and prognosis is viewed as harmful and brutal. [http://gimle.fsm.it/33/1s\\_psi/06.pdf](http://gimle.fsm.it/33/1s_psi/06.pdf)



#### 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.

## Prolonged grief proposed as mental disorder

CANADIAN MEDICAL ASSOCIATION  
JOURNAL | Online article – 29 March 2011  
– In the field of mental health, the line between well and ill is not always clear. But that line can pretty much disappear, taking "well" along with it, when a new diagnosis appears in the *Diagnostic & Statistical Manual of Mental Disorders* (DSM). What was once an emotion becomes a symptom. What was once something to be endured becomes something to be treated. This may soon be the case for people who grieve intensely for prolonged periods. The next edition of the manual ... [in 2013] ... is likely to contain a new entry called bereavement-related disorder.  
<http://www.cmaj.ca/earlyreleases/29mar11/prolonged-grief-proposed-as-mental-disorder.dtl>

From Media Watch dated 7 March 2011:

- *THE MCGILL DAILY* (University of McGill, Montreal, Quebec, Canada) | Online article – 3 March 2011 – **'To medicalize mourning.'** While many psychiatrists believe that pathological grief has long deserved a place in diagnostic nomenclature, its potential

inclusion as a mental disorder has great implications for how we understand and negotiate a fundamental human experience: the death of a loved one.  
<http://www.mcgilldaily.com/2011/03/to-medicalize-mourning/>

**N.B.** This issue of Media Watch lists several articles on this topic.

### Health care professionals' grief after the death of a child

*PAEDIATRICS & CHILD HEALTH*, 2011; 16(4):213-216. The level of grief experienced by health care professionals (HPs) [i.e., participants in this cross-sectional study] after a memorable death was intense. There was no significant association between ... [an] HP being a parent, having received palliative care training or the length of his/her relationship with the child and family. Seventy per cent of HPs spoke with their colleagues after the death of a child and 48% with family and friends. Many participants (37%) believed that this social support helped them the most.  
[http://www.pulsus.com/journals/abstract.jsp?sCurrPg=abstract&jnlKy=5&atlKy=10029&isuKy=972&isArt=t&fromfold=Current Issue](http://www.pulsus.com/journals/abstract.jsp?sCurrPg=abstract&jnlKy=5&atlKy=10029&isuKy=972&isArt=t&fromfold=Current+Issue)

## Paediatric palliative care

### Caring for children dying from cancer at home: A qualitative study of the experience of primary care practitioners

*FAMILY PRACTICE* | Online article – 22 March 2011 – GPs [i.e., participants in this study] had minimal input into the preceding care of children undergoing treatment for cancer but sought to re-establish their role at the child's transition to palliative care. GPs felt they had a role to play and could add value to this phase of care, highlighted their continuing role with the child's family and acknowledged that they had gained from the experience of contributing. However, lack of specialist knowledge and uncertainty about their role within the team made this more challenging. In contrast, community nurses were routinely involved in both active treatment and palliation care phases. There was little evidence of collaboration between the specialist and primary care professionals involved. There was considerable variation in out-of-hours provision across cases. Engaging primary care practitioners needs to be more actively anticipated and negotiated at the transition to palliation. Variation in out of hours care is another cause for concern. Enhancing inter-professional collaboration and planning during both active and palliative care phases may help. <http://fampra.oxfordjournals.org/content/early/2011/03/22/fampra.cmr007.abstract>



Of related interest

- *KAISER HEALTH NEWS* | Online video – 28 March 2011 – **'Special needs, special care: Palliative care helps families navigate unfamiliar medical terrain.'** Joanne Wolfe, palliative care director of Children's Hospital Boston, talks about her approach to helping children live with serious or life-limiting illness and how many need an interdisciplinary approach to care to make sense of the maze of medical treatment. <http://www.kaiserhealthnews.org/Multimedia/2011/March/032811-Palliative-Care.aspx>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 25 March 2011 – **'Care goals and decisions for children referred to a pediatric palliative care program.'** Children with complex, life-limiting conditions and their families referred to a palliative care service commonly verbalize goals related to health maintenance and independence. Anticipating this expectation may foster communication and improve patient care. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0450>

#### **Canadian Paediatric Society**

#### **Withholding and withdrawing artificial nutrition and hydration**

*PAEDIATRICS & CHILD HEALTH*, 2011; 16(4):241-244. Decisions regarding artificial nutrition and hydration (ANH) ... should be considered in the individual context of the child's overall plan of care. The purpose of the present practice point is to provide guidance for Canadian paediatric health care practitioners regarding when withholding or withdrawing ANH may be an ethically permissible option as part of a palliative care plan and to briefly address some pragmatic considerations. <http://www.pulsus.com/journals/abstract.jsp?sCurrPg=abstract&jnlKy=5&atKy=10034&isuKy=972&isArt=t&fromfold=Curent Issue>

#### **End of life care in ICU: A practical guide**

*JOURNAL OF INTENSIVE CARE MEDICINE* | Online article – 24 March 2011 – The purpose of this manuscript is to provide a practical guide to EOL [end of life] management for all bedside practitioners. The manuscript outlines not all but some fundamentally important ethical concepts and provides helpful rules and steps on end-of-life management based on my own personal experience and practice. Moreover, nowhere in the rigorous training of critical care or hospitalist physicians do we teach the procedure for removal of life-sustaining measures. Like any other procedure in medicine, it requires preparation, implementation and conclusion, as well as supervision and repetition to become proficient. Therefore, at the conclusion of this paper, an attempt is made to correct this lack of training by providing such outline and a guide. <http://jic.sagepub.com/content/early/2011/02/13/0885066610392697.abstract>

From past issues of Media Watch:

Representative sample of articles, reports, etc., on ICU in the context of care for patient's living with a life-threatening illness:

- *CRITICAL CARE MEDICINE*, 2010;38(8):1623-1629. **'A history of resolving conflicts over end-of-life care in intensive care units in the U.S.'** Conflict ... is relatively rare because most families and physicians agree about how patients should be treated. Nevertheless, conflict still exists over some patients whose families insist on care that physicians consider inappropriate and hence inadvisable, and over other patients whose families object to care that physicians prefer to provide. [http://journals.lww.com/ccmjournal/Abstract/2010/08000/A\\_history\\_of\\_resolving\\_conflicts\\_over\\_end\\_of\\_life.1.aspx](http://journals.lww.com/ccmjournal/Abstract/2010/08000/A_history_of_resolving_conflicts_over_end_of_life.1.aspx)

Cont.

- *CRITICAL CARE MEDICINE* | Online article – 18 June 2010 – '**Models for structuring a clinical initiative to enhance palliative care in the intensive care unit.**' There are two main models for ICU-palliative care integration: 1) the "consultative model," which focuses on increasing the involvement and effectiveness of palliative care consultants in the care of intensive care unit patients and their families, particularly those patients identified as at highest risk for poor outcomes; and, 2) the "integrative model," which seeks to embed palliative care principles and interventions into daily practice by the intensive care team for all patients and families facing critical illness. [http://journals.lww.com/ccmjournal/Abstract/publishahead/Models\\_for\\_structuring\\_a\\_clinical\\_initiative\\_to.98673.aspx](http://journals.lww.com/ccmjournal/Abstract/publishahead/Models_for_structuring_a_clinical_initiative_to.98673.aspx)
- *PHILADELPHIA INQUIRER* | Pennsylvania (U.S.A.) – 17 October 2010 – '**Finding more balance in decision making at the end of life.**' About 2.4 million Americans die every year, an estimated 400,000 in an intensive care unit. Most Americans don't want an ICU death, but many start down a path of aggressive medicine that takes them there. Some doctors say they themselves are partly to blame. [http://www.philly.com/inquirer/front\\_page/20101017\\_Medical\\_challenge\\_Finding\\_more\\_balance\\_in\\_decision\\_making\\_at\\_the\\_end\\_of\\_life.html](http://www.philly.com/inquirer/front_page/20101017_Medical_challenge_Finding_more_balance_in_decision_making_at_the_end_of_life.html)

**Where is the evidence for pain, suffering, and relief – can narrative help fill the void?**

*JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2011;25(1):25-28. Eighty percent of global population has no access to pain relief or to palliative care. International organizations have repeatedly pointed out that access to pain relief and palliative care are basic human rights. Ignorance, callous indifference, and barriers to availability of essential medicines are among the reasons for such needless pain. Experience from Uganda and from Kerala in India has shown that such suffering can be relieved at minimal cost. People in pain and suffering do not have the ability to raise their voice against the injustice. The needless suffering needs to be brought to global attention. Narratives can help fill the gap. In addition to acting as cathartic to people who have suffered, narratives help professionals and concerned individuals by improving self-awareness and awareness of the patients' perspective. <http://informahealthcare.com/doi/abs/10.3109/15360288.2010.549937>

Of related interest:

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2011; 25(1):50-60. '**Critical summaries of innovations in palliative care pharmacotherapy.**' Timely and important studies are reviewed and commentaries provided by leading palliative care clinicians. <http://informahealthcare.com/doi/abs/10.3109/15360288.2010.549550>

**Asociación Latinoamericana de Cuidados Paliativos**

**Opioid analgesic availability in Latin American and Caribbean countries**

The Asociación Latinoamericana de Cuidados Paliativos (Latin American Association for Palliative Care (ALCP)) offers an on-line resource with regional information on opioid analgesics. The goal of this project is to disseminate clear and accessible information on opioid analgesic availability in most of the Latin American and Caribbean countries. It is hosted on the ALCP website that displays visual and text information on the formulation and strengths of available opioid analgesics.<sup>1</sup> The project was developed with the support of the U.S. Cancer Pain Relief Committee and the Open Society Institute.

Latin American Association for Palliative Care: <http://www.cuidadospaliativos.org/>

ALCP database-driven flash map: <http://www.cuidadospaliativos.org/article.php?id=54>

1. Ryan K, De Lima L, Maurer M. 'Disponibilidad de Opioides en Latinoamérica' in *Uso de Opioides para el Tratamiento del Dolor: Manual para Latinoamérica*. Patricia Bonilla, Liliana De Lima, Paola Díaz, Marta Ximena Leon, Marcela González (eds). IAHPCC Press: Houston, 2011.

**Acknowledgement:** This information in translation was kindly provided by Dr. Roberto Wenk, Director, Programa Argentino de Medicina Paliativa of the Fundacion FEMEBA, Buenos Aires.

## The hospice caregiver support project: Providing support to reduce caregiver stress

*JOURNAL OF PALLIATIVE MEDICINE* | Online article – 25 March 2011 – The vast majority (80%) of care provided to hospice patients is given by informal and unpaid caregivers, who are often family members. They may be responsible for everything from management of the household and finances to medical and personal care. Providing this kind of care to a loved one at the end of life can contribute to increased stress, health problems, and decreased quality of life. The project results show that offering such services [hospice respite benefit] relieved caregiver stress, reduced use of respite, and reduced the number of respite days used. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0520>

## The sound of spiritual care: Music interventions in a palliative care setting

*JOURNAL OF PASTORAL CARE & COUNSELING*, 2011;65(1). The article describes how music has been integrated into spiritual and supportive care for palliative care patients at Brantford General Hospital (Ontario). Numerous case examples illustrate how a song or piece of music can play a vital role in the spiritual dimension of end of life care. The article expands the concept of the "living human document" by positing that a life story has an accompanying soundtrack: a musical memory and sensorial attunement that can be energized when music is offered at the bedside. <http://journals.sfu.ca/jpcp/index.php/jpcp/article/viewArticle/385>

Of related interest:

- *REVISTA DA ESCOLA DE ENFERMAGEM DA USP*, 2011;45(1):138-145. **'Music in human terminality: The family members' conceptions.'** Considering the deficit of leisure and the monotony of the home environment, using music contemplates the philosophical and humanitarian precepts of palliative care, thus being characterized as a complementary resource to nursing care, as besides being a communication resource, it improves the interpersonal relationship between patients and their families. [http://www.scielo.br/scielo.php?script=sci\\_abstract&pid=S0080-62342011000100019&lng=en&nrm=iso&tlng=en](http://www.scielo.br/scielo.php?script=sci_abstract&pid=S0080-62342011000100019&lng=en&nrm=iso&tlng=en)

### 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.

## **Authentic and congruent leadership providing excellent work environment in palliative care**

*LEADERSHIP IN HEALTH SERVICES* | Online article – 3 April 2011 – The purpose of this study was to describe the perceptions of registered nurses, enrolled nurses, and leaders (i.e., the first-line nurse manager) as to what characterises an excellent work environment in a palliative care unit and the involvement of leadership in that environment. According to the participants, the most important component at the palliative care unit was to accomplish the vision of good palliative care. Congruence in leadership, mature group functioning, adequate organisational structures and resources, and comprehensive and shared meaningfulness were all identified as essential components for fulfilling the vision. Finally, the study support authentic leadership as important for creating a good work environment. The authors suggest that such an authentic leadership involves providing the best care for patients while simultaneously ensuring the well-being of staff members. <http://www.emeraldinsight.com/journals.htm?articleid=1916809&show=abstract>

## **Assisted (or facilitated) death**

Representative sample of recent articles, etc:

- *NATIONAL CATHOLIC BIOETHICS QUARTERLY*, 2011;11(1):41-48. **'Double effect and U.S. Supreme Court reasoning.'** Chief Justice William Rehnquist, writing ... in *Vacco v. Quill*, introduced double-effect reasoning to identify the distinctions between palliative care and assisted suicide in an effort to uphold the constitutionality of the ban on assisted suicide in New York. <http://ncbcenter.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,9;journal,1,41;linkingpublicationresults,1:119988,1>
- *THE MEDICAL POST* | Online report – 28 March 2011 – **'Physicians clearly establish their views – in both camps as to 'What If...euthanasia became legal across Canada?'** The debate over euthanasia is predictably running red hot on the online pages of *The Medical Post*. What ... may shock many are the poll results, which currently show physicians are virtually evenly split on their thoughts towards legalizing the practice of euthanasia [52% against, 48% in favour]. <http://www.canadianhealthcarenetwork.ca/physicians/what-if/physicians-clearly-establish-their-views-in-both-camps-as-to-what-if-euthanasia-became-legal-across-canada-15070>

## **Worth Repeating**

### **Modern death: Taboo or not taboo?**

*SOCIOLOGY*, 1991;25(2):293-310. There has been a proliferation of literature on death – in the U.K. mainly journalistic and very recent, in the U.S. mainly scholarly and covering the past thirty years. This literature has created the conventional wisdom that death is the taboo of the twentieth century. The article asks: a) is death taboo? if so, in what sense?; b) if it is not taboo, then why the frequent announcements that it is? It is this second question that scholars have not previously attempted to incorporate into their theory. The strengths and weakness of the taboo thesis are reviewed. Six possible modifications/critiques are offered in an attempt to resolve the difficulties: 1) that there was a taboo, but it is now disintegrating; 2) that death is hidden rather than forbidden; 3) that the taboo is limited largely to the (influential) occupational groups of the media and of medicine; 4) that the loss of a coherent language for discussing death leads to conversational unease; 5) that all societies must both accept and deny death, so pundits are able to pick whatever examples fit their thesis; and, 6) that it is the modern individual, not modern society, that denies death. <http://soc.sagepub.com/content/25/2/293.short>

---

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

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