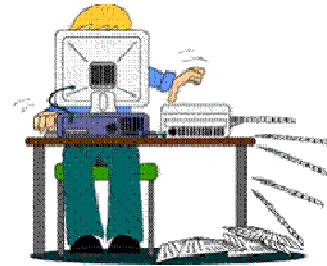


## Media Watch

...is distributed weekly to colleagues active or with 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 inform discussion and encourage further inquiry. Following is an annotated listing of recent articles, reports, etc., with links to the original source.

## 29 December Edition | Issue #77



Compilation of Media Watch 2008 ©

**Compiled & Annotated by Barry R. Ashpole**

**Hospice volunteers – roles and boundaries:  
Scroll down to [Journals](#) and 'Ethical issues for hospice volunteers.'**

## Canada: National

### **Compassion Care Benefit (for family caregivers): Entitlement**

GOVERNMENT OF CANADA | Online posting – accessed 26 December 2008 – A posting (on the Services Canada website) gives two examples of applications for the Compassionate Care Benefit that were denied. <http://srv130.services.gc.ca/indexjurisprudence/summaryissue-eng.aspx?issuesn=2156&level=2&desc=risk%20of%20death>

From Media Watch (Parliamentary Notes) dated 12.08.08.

- Bill C-217, a Private Member's Bill, proposes amendments to the Employment Insurance Act and the Canada Labour Code, extending the Compassionate Care Benefit to one year paid leave: [http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Parl=40&Ses=1&Mode=1&Pub=Bill&Doc=C-217\\_1&File=24](http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Parl=40&Ses=1&Mode=1&Pub=Bill&Doc=C-217_1&File=24)

**N.B.** The Manitoba provincial government recently introduced a Primary Caregiver Tax Credit, which will take effect for the 2009 tax year. The credit is worth up to \$85/month to a maximum of \$1,020/year.

### **Palliative care is a rural medicine issue**

*CANADIAN JOURNAL OF RURAL MEDICINE*, 2008;13(3):139-40. Canada's aging population is on the rise, resulting in a greater demand for palliative care services. This is particularly pronounced in rural communities. Specifically, demographic trends such as the increasing number of people relocating to rural areas upon retirement and the process of aging-in-place in such communities are amplifying the need for palliative care in these settings. At the same time, defining elements of health service provision in Canada, including the lack of tertiary and some forms of secondary care in rural settings, has decreased the capacity to provide quality palliative care in non-urban areas. <http://www.cma.ca/multimedia/staticContent/HTML/N0/I2/cjrm/vol-13/issue-3/pdf/pg139.pdf>

## Canada: Provinces

### Patient-physician communication

#### **Language barriers lead to health barriers: study**

ONTARIO | CBC News – 24 December 2008 – A new study on health care and language indicates that immigrants in Canada's largest city may not be getting the care they need. According to the study, published in the current issue of the *Canadian Journal of Public Health*, language is an enormous barrier for many newcomers, especially when it comes to communication between health-care providers and patients. The report says that in some instances, the language barrier is preventing patients from understanding their treatment options. <http://www.cbc.ca/health/story/2008/12/24/health-language.html>

Of related interest:

- U.S. (Yale University press release): '**Lost in translation – many hospital physicians not using interpreters: study.**' <http://opa.yale.edu/news/article.aspx?id=6301>
- 1. *Journal of General Internal Medicine* (online edition accessed 27 December 2008). 'Getting by: Underuse of interpreters by resident physicians.' <http://www.citeulike.org/article/3810953>

## U.S.A.

#### **Vermont leads the nation in palliative care**

VERMONT | *Bennington Banner* – 27 December 2008 – Vermont has been given the nation's highest score in terms of access to palliative care programs in a recent report from the Center to Advance Palliative Care. The state received the only perfect score in the report ... based on data from the American Hospital Association. [http://www.benningtonbanner.com/ci\\_11319286](http://www.benningtonbanner.com/ci_11319286)

#### **Medicaid-only patients to no longer receive hospice benefit**

SOUTH CAROLINA | *Post & Courier* – 24 December 2008 – Sick people who would prefer to die at home or in a hospice will have to remain in the regular health care system after Medicaid eliminates its hospice benefit in 2009. Critics of the decision say desperate families will be forced to turn to more expensive and invasive treatment in emergency rooms and intensive care units. Department of Health & Human Services, the state agency responsible for Medicaid, announced last week that hospice coverage will be limited to beneficiaries who are also eligible for Medicare. That phrasing is confusing to people, said Tamra West with The Carolinas Center for Hospice & End of Life Care, which represents more than 100 hospice providers in North and South Carolina. Basically, any Medicaid-only patient will no longer receive the hospice benefit, she said. [http://www.charleston.net/news/2008/dec/24/some\\_will\\_be\\_denied\\_hospice66053/](http://www.charleston.net/news/2008/dec/24/some_will_be_denied_hospice66053/)

- South Carolina (*Independent-Mail*): '**Cost-cutting measure will cost more in the end.**' <http://www.independentmail.com/news/2008/dec/28/cost-cutting-measure-will-cost-more-end/>
- Florida (News Chief): '**Save Medicaid hospice benefit (in Florida).**' [http://www.newschief.com/article/20081225/NEWS/812250304/1011/LIVING?Title=Save\\_Medicaid\\_hospice\\_benefit](http://www.newschief.com/article/20081225/NEWS/812250304/1011/LIVING?Title=Save_Medicaid_hospice_benefit)

### **Back Issues of Media Watch**

Back issues of Media Watch are held on file for a limited time and available on request.

## Patient's right to know

### **Not all nursing home records accessible**

FLORIDA | WCTV – 23 December 2008 – The Florida Supreme Court released an opinion saying nursing homes are not health care facilities and thus, they're not covered by the State's Patient's Right to Know Amendment. The high court explained "Chapter 400 of the Florida Statutes, which regulates nursing homes, consistently used the term "resident," not "patient" to refer to nursing home occupants. It goes on to say that the court finds this distinction between use of the terms "residents" and "patients" persuasive ... but, some attorneys say it's not that simple ... especially when trying to explain the law to elderly clients. <http://www.wctv.tv/news/headlines/36673064.html>

### **On the power of hope in medicine**

ILLINOIS | *Chicago Tribune* – 23 December 2008 – "No patient should ever leave a visit with a physician without a sense of hope." This important reminder comes from Dr. Catherine DeAngelis, editor of the *Journal of the American Medical Association (JAMA)*, and her husband Dr. James Harris, of Johns Hopkins University School of Medicine.<sup>1</sup> Their editorial (in the current issue of *JAMA*) is a reassertion of the crucial importance of the doctor-patient relationship and the value of the humanistic tradition in medicine. Hope comes when patients feel "something can be done for their illness; that they will be actively involved in their treatment; or (with) knowledge that hospice care may provide solace for their last days if their illness is terminal." But that's not all. Hope arises when a physician looks into a patient's face and a human connection is established. And hope happens when a patient feels free to talk and a provider listens carefully, the authors say. In that sense, hope means we are not alone with illness. We have a knowledgeable ally, a physician, on the journey with us. <http://newsblogs.chicagotribune.com/triage/2008/12/on-the-power-of.html>

1. *Journal of the American Medical Association*, 2008;300(24):2919-2920. 'The power of hope.'  
<http://jama.ama-assn.org/cgi/content/extract/300/24/2919>

### **Dogs used to comfort palliative care patients**

PENNSYLVANIA | WPXI.com – 22 December 2008 – One of the most popular visitors to the University of Pittsburgh Medical Center's palliative care floor is a three-year old Rottweiler named Duke. Duke and his owner, Regis Orkwis, visit patients once a week. Dr. Susan Hunt, a palliative care specialist, started the palliative pet therapy program at the center in 2006 with just one dog; it has now grown to include five dogs. <http://www.wpxi.com/news/18336698/detail.html>

### **Don't wait for palliative plan**

TEXAS | *Dallas Morning News* (letter to the editor regarding the newspaper's *At the Edge of Life* series)<sup>1</sup> – 21 December 2008 – As a social worker in health care for over 38 years, I have seen firsthand the suffering of patients and families due to a lack of education on the part of too many medical professionals and families about quality of life rather than quantity of life. I personally experienced it when my father was hospitalized more than four years ago and I had to argue with the medical staff to respect his advance directives. I could not get him out of the hospital and into hospice care quickly enough. He died peacefully and comfortably three weeks later. I have long been an advocate of everyone having that very important discussion about death with their families ... and completing advance directives, not waiting until they are ill or have been in an accident. <http://dallasmorningviewsblog.dallasnews.com/archives/2008/12/at-the-edge-of.html>

1. *Edge of Life* webpage with links to the articles in the series:  
<http://www.dallasnews.com/sharedcontent/dws/spe/2008/edgeoflife/>

## International

### **Free home care plan for elderly across Hampshire**

U.K. | This is Hampshire – 29 December 2008 – Elderly people ... are to get free home care for up to eight weeks under an ambitious plan council chiefs say will transform adult social services. [http://www.thisishampshire.net/news/hampshirenews/4005815.Free\\_home\\_care\\_plan\\_for\\_elderly\\_across\\_Hampshire/](http://www.thisishampshire.net/news/hampshirenews/4005815.Free_home_care_plan_for_elderly_across_Hampshire/)

### **National Health Service to offer more drugs for cancer treatment**

U.K. | *The Guardian* – 26 December 2008 – The National Health Service drugs watchdog is to take a more flexible approach to the issuing of treatments which can prolong the life of people with terminal illnesses. Professor Sir Michael Rawlins, chairman of the National Institute for Clinical Excellence, said guidelines to be published next week would extend the range of cancer treatments available on the NHS. <http://www.guardian.co.uk/society/2008/dec/26/nhs>

### **The Suicide Tourist**

#### **End of life care issues**

U.K. | *Harrogate Advertiser* (editorial) – 24 December 2008 – Following the broadcast of *The Suicide Tourist*, a documentary featuring the last days of Yorkshire motor neurone disease sufferer Craig Ewert's life ... people ... are uncomfortable about the televising of such a private moment and have strong feelings about the rights and wrongs of filming. And this is completely understandable. But it is important that we don't let this debate overshadow the many other issues that were highlighted by the broadcast. Much of the coverage seemed to advocate control of the time of death as the only important hallmark of a "good death." This presumption is simply untrue. It is perfectly possible for a person to have a 'good death' without having control over the precise time that it occurs. <http://www.harrogateadvertiser.net/letters/End-of-life-care-issues.4817170.jp>

From Media Watch dated 12.15.08.

- Canada (CBC News): **'Britain in uproar over Canadian documentary on assisted suicide.'** <http://www.cbc.ca/health/story/2008/12/10/suicide-documentary.html>

#### **Long term care: Unannounced visits report card**

AUSTRALIA | Australian Labour Party press release – 22 December 2008 – The Australian Government today released a report card on the unannounced visits conducted by the Aged Care Standards & Accreditation Agency for the last six months. The Government is undertaking a record 7,000 visits – including 3,000 unannounced visits – by the Agency to ensure proper care, including nutrition and hydration. These protections complement the extension of police checks to all nursing home staff that comes into effect 1 January 2009. So far, the Agency has conducted a record 1,796 unannounced visits between 1 July and 15 December 2008. There are currently 15 nursing homes out of a total of nearly 3,000 aged care homes around Australia under sanction. Nine of those nursing homes were identified through direct or indirect result of unannounced visits. <http://www.alp.org.au/media/1208/msagei221.php>

Of related interest:

- World Health Organization (Regional Office for Europe): **'Home care in Europe. The solid facts.'** [http://www.euro.who.int/InformationSources/Publications/Catalogue/20081103\\_2](http://www.euro.who.int/InformationSources/Publications/Catalogue/20081103_2)

## 79% of (U.K.) nurses say 'No' to assisted suicide

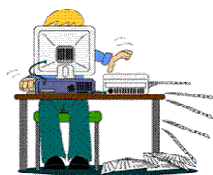
U.K. | Nurses.co.uk (press release) – 22 December 2008 – A survey shows that only 20.9% of nurses think that assisted suicide should be legalised in the U.K. Recent high profile cases of citizens opting for assisted suicide in clinics overseas raises the question of whether it should be legalised. European countries such as Switzerland, Netherlands, Belgium and Luxembourg allow assisted suicide ... and there are growing calls in other European countries, including the U.K., to follow suit. [http://www.responsesource.com/releases/rel\\_display.php?relid=LLigQ](http://www.responsesource.com/releases/rel_display.php?relid=LLigQ)

- International Association for Hospice & Palliative Care (IAHPC News, 2008;9(12)): '**Assisted suicide and euthanasia should not be practiced in palliative care units.**'  
<http://www.hospicecare.com/news/08/12/aom.html>
- **N.B.** A review of an article published in the *Journal of Palliative Medicine*, 2008;11(8):1074-1076.  
<http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2008.0093>
- Germany (Deutsche Welle): '**German police stop controversial suicide counsellor.**'  
<http://www.dw-world.de/dw/article/0,,3908333,00.html>
- Germany (United Press International): 'German court clears euthanasia doctors.'  
[http://www.upi.com/Top\\_News/2008/12/23/German\\_court\\_clears\\_euthanasia\\_docs/UPI-46571230058513/](http://www.upi.com/Top_News/2008/12/23/German_court_clears_euthanasia_docs/UPI-46571230058513/)
- Italy (Life Site News): '**European Court refuses to intervene to save Italian 'Terri Schiavo.'**'  
<http://www.lifesitenews.com/ldn/2008/dec/08122302.html>
- South Korea (Bosa): '**Legislation of death with dignity, new Korean funeral system.**'  
[http://www.bosa.co.kr/umap/nzine\\_view.asp?nzine\\_PK=1830](http://www.bosa.co.kr/umap/nzine_view.asp?nzine_PK=1830)
- U.K. (*Inverness Courier*, Scotland): '**Legalising euthanasia needs careful thought.**'  
[http://www.inverness-courier.co.uk/news/fullstory.php/aid/8305/Legalising\\_euthanasia\\_needs\\_careful\\_thought.html](http://www.inverness-courier.co.uk/news/fullstory.php/aid/8305/Legalising_euthanasia_needs_careful_thought.html)
- U.K. (*Press & Journal*, Scotland): '**Debate on legalising assisted suicide.**'  
<http://www.pressandjournal.co.uk/Article.aspx/1003976?UserKey>

### Quotable Quotes

*How people die remains in the memories of those who live on.*  
Dame Cecily Saunders, 'Pain and impending death,' in *Textbook of Pain*, 1989.

### 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 workshops for frontline care providers.

## Journal Articles

### **The use of pediatric advance directives: A tool for palliative care physicians**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 2009;25(6):427-430. Although laws such as the Patient Self-Determination Act encourage individuals to address their end-of-life treatment preferences using advance directives, the wishes of children have traditionally been ignored or, perhaps even worse, overruled. Given that there is a substantial body of research indicating that children are capable of making mature decisions when faced with terminal illness, the author proposes granting minors, especially older minors, the right to participate in making end-of-life decisions. Children who complete advance directives benefit in multiple ways. Adopting this approach could benefit patients by demonstrating respect for patient autonomy and informing parents and providers that the minor may be ready to stop aggressive treatment.

<http://ajh.sagepub.com/cgi/content/abstract/25/6/427>

From Media Watch dated 11.10.08.

- Canadian Paediatric Society (press release): **'Provinces should recognize the wishes of children and youth with life-threatening illnesses, advise paediatricians.'**  
<http://www.cps.ca/english/Media/NewsReleases/2008/LifeThreateningIllnesses.htm>

Of related interest:

- *International Journal of Palliative Nursing*, 2008;14(12):596-601. **'Children affected by genetic conditions in end-of-life care.'** [http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=32064;article=IJPN\\_14\\_12\\_596\\_601](http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=32064;article=IJPN_14_12_596_601)

### **Ethical issues for hospice volunteers**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 2009;25(6):458-462. Health care professionals usually receive professional education in ethics, but the half million hospice volunteers in the U.S. may receive only brief training that is limited to confidentiality and the volunteer role. The purpose of this study was to explore ethical issues hospice volunteers confront in their work. Interviews with 39 hospice volunteers were conducted, audio recorded, transcribed, and analyzed using qualitative methods. Prominent themes were dilemmas about gifts, patient care and family concerns, issues related to volunteer roles and boundaries, and issues surrounding suicide and hastening death. Suggestions for training include discussions of ethics after initial training once volunteers had confronted ethical issues, with special emphasis on strategies for negotiating their uneasy role positioned between health care professional and friend. <http://ajh.sagepub.com/cgi/content/abstract/25/6/458>

### **Surrogate decision-makers' perspectives on discussing prognosis in the face of uncertainty**

*AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE*, 2009;179:48-53. The authors sought to understand surrogate decision makers' views regarding whether physicians should discuss prognosis in the face of uncertainty. Eighty-seven percent of surrogates wanted physicians to discuss an uncertain prognosis. They identified five main reasons for this, including surrogates' belief that prognostic uncertainty is unavoidable, that physicians are their only source for prognostic information, and that discussing prognostic uncertainty leaves room for realistic hope, increases surrogates' trust in the physician, and signals a need to prepare for possible bereavement. Twelve percent of surrogates felt that discussions about an uncertain prognosis should be avoided. The main explanation was that it is not worth the potential emotional distress if the prognostications are incorrect. <http://ajrccm.atsjournals.org/cgi/content/abstract/179/1/48>

## Prevalence of undertreatment in cancer pain: A review of published literature

*ANNALS OF ONCOLOGY*, 2008;19(12):1985-1991. Pain is a major health care problem for patients with cancer: despite the existence of guidelines for cancer pain management, undertreatment is a widespread problem. Pain Management Indexes (PMIs) evaluate the congruence between the patient's reported level of pain and the intensity/strength of the analgesic therapy. Among the 44 studies identified, 26 studies used the PMI as proposed by Cleeland. The range of negative PMI varied from 8% to 82% with a weighted mean value of 43%. In multivariate analyses, factors associated with negative PMI were date of publication before 2001, provenance from Europe or Asia, and countries with a gross national income per capita <\$40 000/year and a care setting not specific for cancer. Age was not a significant predictor for undertreatment. Nearly one of two patients with cancer pain is undertreated.

<http://annonc.oxfordjournals.org/cgi/content/abstract/19/12/1985>

Of related interest:

- *British Medical Journal*, 2008;337:a3104 (24 December 2008). '**Morphine remains gold standard in breakthrough cancer pain.**' [http://www.bmj.com/cgi/content/extract/337/dec24\\_1/a3104](http://www.bmj.com/cgi/content/extract/337/dec24_1/a3104)
- *Journal of Clinical Oncology*, 10.1200/JCO.2008.17.1660 (22 December 2008). '**Is pain intensity a predictor of the complexity of cancer pain management?**' <http://jco.ascopubs.org/cgi/content/short/JCO.2008.17.1660v1?rss=1>
- *Palliative Medicine*, 2008;22(8):895-903. '**Pain assessment tools in palliative care: an urgent need for consensus.**' <http://pmj.sagepub.com/cgi/content/abstract/22/8/895>

## Setting up home-based palliative care in countries with limited resources

*ANNALS OF ONCOLOGY*, 2008;19(12):2061-2066. The provision of palliative care and opioids is difficult to ensure in remote areas in low- and middle-income countries. The authors describe the set up of a home-care program in Sarawak (the Malaysian part of the Borneo Island), where half the population lives in villages that are difficult to access. The program has been sustainable and cost efficient, serving 936 patients in 2006. Results show that pain medication can be provided even in remote areas with effective organization and empowerment of nurses, who were the most important determinants for the set up of this program. Education of family was also a key aspect. The authors believe that the experience gained in Sarawak may help other regions with low or middle resources in the set up of their palliative care program, especially for their remote rural population. <http://annonc.oxfordjournals.org/cgi/content/abstract/19/12/2061>

Of related interest:

- Ukraine (America.gov): '**U.S. specialists bring palliative care training to Ukraine.**' <http://www.america.gov/st/foraid-english/2008/December/20081224095535AKIlennoCcM0.5508081.html>

## Palliative care for people with severe persistent mental illness: A review of the literature

*CANADIAN JOURNAL OF PSYCHIATRY*, 2008;53(11):725-736. A systematic overview of the literature on palliative care for people with severe persistent mental illness (SPMI) was conducted to inform clinical practice, research, and education. Empirical studies and non-empirical papers were included. Few empirical studies exist. There is even less information about the palliative care needs of, or the nature of palliative care provided to, people with SPMI. Mental health, primary care, and palliative care providers need to partner with people who have SPMI in developing and providing palliative care. The field of palliative care for people with SPMI is wide open and in need of methodologically sound studies that will help define the issues that exist for this vulnerable population. Recognizing the similarities between mental health and palliative care should lead to collaborative ventures and discussions in an attempt to address common and parallel issues. <http://publications.cpa-apc.org/media.php?mid=702&xwm=true>

## Transitioning to end-of-life care in the intensive care unit

*CANCER NURSING*, 2008;31(6):478-484. Traditionally, the intensive care unit (ICU) has focused on reversal of life-threatening illness. Patients with incurable cancer admitted to the ICU present unique challenges for clinicians when these patients transition to end-of-life (EOL) care. A dimensional analysis of a single case study from a larger 30-case ethnographic study was used to explore the cancer patient's transition to EOL care in the ICU. Family members and clinicians had different expectations of care, which resulted in divergent treatment goals and desires for the patient, a 62-year-old woman with presumed pneumonia and underlying terminal glioblastoma multiforme. The attending physician and palliative care consultant unified family members' and clinicians' divergent goals and desires through a mediating process of probing the family about the patient's wishes. This process unified those involved and brought them to a place of acceptance. This case illustrates the turning point and rationale for the shift to EOL care in the ICU and the important role that communication plays in the transition. Understanding individual and family processes and family members' need for time to adjust to the transition to EOL is an essential element of practice within ICUs that increasingly manage terminally ill cancer patients. [http://www.nursingcenter.com/library/JournalArticle.asp?Article\\_ID=825375](http://www.nursingcenter.com/library/JournalArticle.asp?Article_ID=825375)

## Palliative care of the patient with advanced gynecologic cancer

e-MEDICINE | Online journal – 3 December 2008 – Cancer of the female genital tract is a significant cause of morbidity and mortality worldwide. In the U.S., ovarian cancer is the deadliest of gynecologic cancers, ranking fifth among all causes of cancer death in women. In countries where ... pap smear screening and treatment of cervical dysplasia are widely implemented, ovarian cancer is responsible for more cancer deaths each year than cancers of the uterine corpus and cervix combined. In the absence of effective screening and early intervention programs, cervical cancer is a much more common cause of gynecologic cancer morbidity and mortality. When potentially curative treatment options are unavailable or are ineffective, the clinical goal changes from cure to palliation. <http://emedicine.medscape.com/article/270646-overview>

## The use of palliative sedation for existential distress: A psychiatric perspective

*HARVARD REVIEW OF PSYCHIATRY*, 2008;16(6):339-51. This article introduces a structure for standardization in the ongoing debate about the application of palliative sedation for psychological and existential suffering at the end of life. The authors differentiate the phenomenon of existential distress from the more general one of existential suffering, defining existential distress as a special case of existential suffering that applies to persons with terminal illness. They introduce both a clinical classification system of existential distress based on proximity to expected death and a decision-making process for considering palliative sedation. <http://www.ncbi.nlm.nih.gov/pubmed/19085388?dopt=Abstract>

Of related interest:

- *American Journal of Hospice & Palliative Medicine*, 2009;25(6):492-495. **'High-dose Propofol drip for palliative sedation: A case report.'** <http://ajh.sagepub.com/cqi/content/abstract/25/6/492>

### [Links](#)

Please alert this office if you encounter any difficulty. Every effort will be made to find an alternative means of access. Alternatively, copy/paste the URL into the address bar of your browser. All links are confirmed as being active before Media Watch is distributed; they remain active, however, for only a limited period of time.

## **Agitation and delirium at the end of life**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2008;300(24):2898-2910. Delirium is the most common neuropsychiatric complication experienced by patients with advanced illness, occurring in up to 85% of patients in the last weeks of life. Using the case of Mr L, a 59-year-old man with metastatic lung cancer who developed an agitated delirium in the last week of life, we review the evaluation and management of delirium near the end of life. Although some studies have identified agitation as a central feature of delirium in 13% to 46% of patients, other studies have found up to 80% of patients near the end of life develop a hypoactive, non-agitated delirium. Both the agitated (hyperactive) and non-agitated (hypoactive) forms of delirium are harbingers of impending death and are associated with increased morbidity in patients who are terminally ill, causing distress for patients, family members, and staff. Delirium is a sign of significant physiological disturbance, usually involving multiple causes, including infection, organ failure, and medication adverse effects. Often these causes of delirium are not reversible in the dying patient, and this influences the outcomes of its management. Delirium can also significantly interfere with the recognition and control of other physical and psychological symptoms, such as pain. Unfortunately, delirium is often misdiagnosed or unrecognized and thus inappropriately treated or untreated in terminally ill patients. To manage delirium in terminally ill patients, clinicians must be able to diagnose it accurately, undertake appropriate assessment of underlying causes, and understand the benefits and risks of the available pharmacological and non-pharmacological interventions. <http://jama.ama-assn.org/cgi/content/short/300/24/2898>

## **Attitudes to end-of-life decisions in paediatric intensive care**

*NURSING ETHICS*, 2009;16(1):83-92. The aim of this study was to assess attitudes of intensive care nurses to selected ethical issues related to end-of-life decisions in paediatric intensive care units. A self-administered questionnaire was distributed in 2005 to intensive care nurses at two different scientific occasions in Turkey. Of the 155 intensive care nurse participants, 98% were women. Fifty-three percent of these had intensive care experience of more than four years. Most of the nurses failed to agree about withholding (65%) or withdrawing (60%) futile treatment. In addition, 68% agreed that intravenous nutrition must continue at all costs. In futile treatment cases, the nurses tended to leave the decision to parents or act maternalistically. The results showed that intensive care nurses could ignore essential ethical duties in end-of-life care. We suggest that it is necessary to educate Turkish intensive care nurses about ethical issues at the end of life. <http://nej.sagepub.com/cgi/content/abstract/16/1/83>

## **Nurses' experiences in caring for dying patients with profound learning disabilities**

*PALLIATIVE MEDICINE*, 2008;20(8):949-955. This qualitative study identifies areas of expertise and deficits in the specific knowledge and practical skills of nurses in the care of dying patients with profound learning disabilities in one National Health Service Primary Care Trust in the U.K. The authors have developed an observational checklist applicable to profound learning disability nursing to identify disease-related personality and physiological changes. Themes showed were "certainty of knowing" about disease-related changes in patients' habits and behaviour, and "uncertainty and ambiguity" in the patho-physiology of advanced diseases and disease progression. <http://pmj.sagepub.com/cgi/content/abstract/22/8/949>

### **Something Missed or Overlooked?**

If you come across a media report, journal article, etc., relevant to hospice palliative care or end-of-life issues not mentioned in this edition of Media Watch, please alert this office so that it can be included in a future issue of the weekly report. Thank you.

## **Qualitative culture study of paediatric palliative care**

*QUALITATIVE HEALTH RESEARCH*, 2009;19(1):5-16. While conducting a grounded theory study of Chinese-American and Mexican-American families' experiences in paediatric palliative care, we encountered a number of unanticipated challenges regarding project development, Institutional Review Boards, recruitment, data collection, and data analysis. In this article, the authors describe their experiences, strategies, and insights for the benefit of other researchers and clinicians in the field. <http://qhr.sagepub.com/cgi/content/abstract/19/1/5>

## **Arts & Entertainment**

### **Puppet theatre aims to cheer grieving children**

FLORIDA | *Ledger* (Lakeland) – 26 December 2008 – Children come to Good Shepherd Hospice's Bethany Center in Auburndale because they hurt. Someone precious to them – a parent, grandparent, sibling or other close relative – has died or is seriously ill. Sam McKendrick, 18, hasn't been in a hospice program as someone experiencing grief, but the Lakeland Boy Scout and his mother, Lisa, gained some insight into what grieving children experience when they attended a training program. He used that knowledge to create a puppet theatre ... a backdrop for princesses, unicorns, dragons and other characters who express through their words what those children sometimes can't. His mother, drawn into her son's project, wrote a play intended to remind children who come to Bethany for grief support that death can't take everything away from them. [http://www.theledger.com/article/20081226/NEWS/812260331/1410?Title=Puppet\\_Theater\\_Aims\\_to\\_Cheer\\_Grieving\\_Children](http://www.theledger.com/article/20081226/NEWS/812260331/1410?Title=Puppet_Theater_Aims_to_Cheer_Grieving_Children)

## **Worth Repeating**

### **Hospice referral decisions: The role of physicians**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 2004;21(3):196-202. In this study, the authors collected and evaluated the opinions of physicians in the Lowcountry of South Carolina (Berkeley, Charleston, and Dorchester counties) regarding their referrals to hospice programs and the extent of influence that their patients and families had on the decision. The research questionnaire was sent to 362 physicians who made referrals to hospice (53% response rate) and to 337 physicians who did not make referrals (40% response rate). Results revealed that medical doctors take the initiative in referrals. They felt that late referrals were due to reluctance on the part of the patient and the patient's family to admit that death was imminent. No differences were found in age, sex, medical specialty, percent of terminally ill patients per practice, or initiative taken. However, when the age and sex of physicians were evaluated, a statistically significant difference was found; females younger than 45 years of age were more likely to make referrals than younger males. Younger physicians were more likely to perceive that the family's reluctance to admit that death was near was a barrier to hospice referrals. <http://ajh.sagepub.com/cgi/content/short/21/3/196>

---

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

phone: 905.563.0044 / fax 905.563.0043  
e-mail: [baryashpole@bellnet.ca](mailto:baryashpole@bellnet.ca)