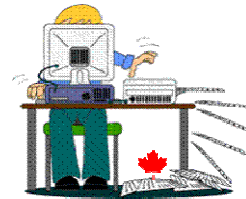


## Media Watch...

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.

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Compiled & Annotated by Barry R. Ashpole

Pain and symptom management: Scroll down to [Specialist Publications](#) and 'New tool "valid and reliable" to assess pain in non-communicative patients' (p.10), published in the *University of Maryland News*.

## Canada

### Technology in home care

#### **Alberta program allows seniors to remain at home longer**

ALBERTA | *Edmonton Journal* – 10 February 2011 – Seniors in Grande Prairie and Medicine Hat will test new technology designed to allow them to remain in their homes rather than move to continuing care centres. The new technology, rolled out through existing provincial home-care programs with \$1.9 million in funding, will include items such as a stove guard that turns off the stove if someone with a chronic illness falls asleep while some is cooking. The guard is equipped with a sensor that can detect if there is no motion nearby, indicating the person may have nodded off or fallen to the floor. Once the stove shuts off, someone in a centralized call centre will be notified, then contact the client through a two-way voice system to see if the client is safe or needs additional help. A flexible bed mat the size of a cookie sheet lets caregivers know if their loved one has woken up, since the mat has pressure sensors. The caregiver – no longer required to stand watch over someone who may sleep late due to dementia – can carry on with daily chores then check on the person when notified to help the patient who may be disoriented and likely to fall. One medication monitoring system is equipped with both a sensor-trigger system and a camera that sends a video clip to family members – in the next room, next province or anywhere in the world – who can then watch to ensure their relative has taken the proper dose at the right time. Other technology includes magnetic door sensors that send an e-mail, text message or cell phone message to caregivers if someone with dementia wanders out in the night. <http://www.edmontonjournal.com/news/Alberta+hoping+keep+seniors+home+longer/4259213/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/>

## Poll: Canadians fear cost of looking after family member

ONTARIO | News 1130 (Ottawa) – 8 February 2011 – The Canadian Cancer Society says more federal cash is needed for family caregivers. A new poll shows 88% of Canadians fear they would financially suffer if they had to look after a sick family member. The society's director of public issues Dan Demers says most people can't afford to take an unpaid leave from work. "As the society ages and more people are spending longer with illnesses and primarily at home, we're very concerned families will be expected to pay that financial cost," he points out. Studies show a patient's health and quality of life are better when they're able to stay at home. The society is calling for improvements to the Compassionate Care Benefit,<sup>1</sup> which is administered by the federal employment insurance program. <http://www.news1130.com/news/local/article/180982--poll-canadians-fear-cost-of-looking-after-family-member>

1. Compassionate Care Benefit website: [http://www.servicecanada.gc.ca/eng/ei/types/compassionate\\_care.shtml](http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml)

From Media Watch dated 7 February 2011:

- ONTARIO | *Toronto Sun* – 4 February 2011 – **'Canadians not ready for elderly parents: Study.'** A Leger survey commissioned by home-care provider We Care Home Health Services found 64% of Canadians say caring for an elder would be overwhelming as they try to balance their own lives. <http://www.torontosun.com/news/canada/2011/02/03/17138696.html>

From Media Watch dated 30 August 2010:

- CTV NEWS | Online report – 26 August 2010 – **'Many struggle to provide care to aging seniors: Study.'** Two new related studies from the Canadian Institute for Health Information found that one in six people providing informal care to seniors is experiencing some kind of distress. <http://www.ctv.ca/CTVNews/Health/20100826/caregivers-seniors-100826/>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *Victoria Times Colonist* (OpEd) – 11 February 2011 – **'Time to discuss the right to die.'** Thanks to modern medicine, we have the ability to extend lives for decades. That does not necessarily mean we should -and perhaps we should not require people to stick around either. No matter what, it's time for a debate about our right, if we have one, to make the final decision. <http://www.timescolonist.com/news/Time+discuss+right/4263889/story.html>

### U.S. survey

#### **Family caregivers have poorer health**

UNITED PRESS INTERNATIONAL | Online report – 8 February 2011 – U.S. adults who are employed full time and care for an elderly or disabled family member suffer poorer health than non-caregivers, a survey indicates. The survey indicates caregivers, who represent 16% of the full-time workforce, have a physical health index score of 77.4 versus 83 among non-caregivers. Six percent of caregivers employed full time are ages 18-29, 22% are ages 30-44, 65% are ages 45-64 and 6% are age 65 and older. However, working Americans ages 18-29 suffer the physical effects of caregiving more than any other group, followed closely by those ages 30-44. [http://www.upi.com/Health\\_News/2011/02/08/Poll-Family-caregivers-have-poorer-health/UPI-75451297218088/](http://www.upi.com/Health_News/2011/02/08/Poll-Family-caregivers-have-poorer-health/UPI-75451297218088/)

### **Of related interest:**

Scroll down to [Specialist Publications](#) and **'Psychosocial aspects of caregiving: Perceptions of cancer patients and family caregivers,'** published in *Supportive Care in Cancer*, and **'End-of-life caregiving trajectories,'** published in *Clinical Nursing Research* (p.10).

**N.B.** Scroll down to [Worth Repeating](#) and **'Palliative care for families: Remembering the hidden patients'** (p.11), published in the *Canadian Journal of Psychiatry*

## U.S.A.

### **End of life in group homes: Some guidance**

PENNSYLVANIA | *Inquirer* (Pennsylvania) – 14 February 2011 – Abigail Sandler has fought for clearer rules on who calls the shots when a group-home resident becomes deathly ill ever since her mentally disabled sister got sick ... setting off a conflict between the home's administrators and her family. Sandler says her sister Aimee's group home ... balked at the decision of Aimee's uncle, her legal guardian, not to insert a feeding tube. Aimee had stopped eating, and two doctors said she was terminally ill. The case was a messy one – Aimee actually had an undiagnosed, treatable problem – but Sandler says it raised questions of who has the legal upper hand if families disagree with care providers, who often have sought all-out medical care for their intellectually disabled charges. Last month, the state issued a statement ... meant to clarify how Pennsylvania laws affect decision-making for group-home residents near death who can't make choices. [http://www.philly.com/philly/entertainment/20110214\\_End\\_of\\_life\\_in\\_group\\_homes\\_Some\\_guidance.html](http://www.philly.com/philly/entertainment/20110214_End_of_life_in_group_homes_Some_guidance.html)

### **When writing a will, leave loved ones your moral, spiritual wealth**

NORTH CAROLINA | *The Star* (Shelby) – 8 February 2011 – What do you treasure most in life? Probably, it is not your bank account or your car. It is probably your family and friends. Do they know that? Do they know what you value? Your morals? The guiding principles of your life? Would you like to give them a gift that will last long after the car they have inherited is rusted or grandpa's pocket watch has ceased to run? A 2006 study of wealth transfer shows that both baby boomers and their elders are more concerned about emotional issues regarding inheritance and family heirlooms than they are about money. <http://www.shelbystar.com/news/probably-53329-life-car.html>

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

Representative sample of recent news media coverage:

- MONTANA | KFBB TV News (Great Falls) – 10 February 2011 – **'Physician-assisted suicide bill tabled by lawmakers.'** Senate Bill 167 would set up rules and protections for physicians who honor their terminally ill patients end of life decisions. The bill ... failed by a vote of seven to five, with the motion to table the bill passing seven to five. <http://www.kfbb.com/news/local/Physician-Assisted-Suicide-Bill-Tabled-by-Lawmakers-115819274.html>
- HAWAII | *Star Advertiser* (Honolulu) – 8 February 2011 – **'Assisted suicide bill stalls.'** After citing numerous examples of loved ones who outlived a doctor's terminal diagnosis or of their own victory over suicidal depression, opponents of a proposal to legalize physician-assisted suicide in Hawaii applauded as a Senate committee defeated the measure last night. The Senate Health Committee heard more than 4½ hours of often-emotional public testimony before voting 4-0 to hold the bill in committee. [http://www.staradvertiser.com/news/hawaii/news/20110208\\_Assisted\\_suicide\\_bill\\_stalls.html](http://www.staradvertiser.com/news/hawaii/news/20110208_Assisted_suicide_bill_stalls.html)



#### Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers.

## International

### Supporting Australians to Live Well at the End of Life

#### **National palliative care strategy released**

AUSTRALIA | [Federal] Department of Health & Ageing – 10 February 2011 – The release of the updated National Palliative Care Strategy will help ensure a nationally consistent and coordinated approach to the delivery of palliative care services across Australia. *Supporting Australians to Live Well at the End of Life* provides the key framework for delivering palliative care services in Australia.<sup>1</sup> The National Palliative Care Strategy, originally developed and endorsed by the Australian Health Ministers' Advisory Council in 2000, has guided service planning and policy development in palliative care over the past decade. It has been updated in partnership with state and territory governments and key stakeholders to ensure it accurately reflects current policies and practices. <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr11-mb-mb020.htm>

1. *Supporting Australians to Live Well at the End of Life*, Department of Health & Ageing, February 2010. [http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/\\$File/NationalPalliativeCareStrategy.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/$File/NationalPalliativeCareStrategy.pdf)

Of related interest:

- U.K. | *Eulogy Magazine* – 7 February 2011 – '**End of life: Rethinking palliative care.**' Last week an illuminating episode of Dr. Mark Porter's BBC Radio 4 series Case Notes revealed the less familiar faces of palliative care [see below]. When we think of hospices, 'cancer,' 'terminal,' 'death' and 'dying' are perhaps the immediate connotations. We find it difficult to visualise the place where someone might spend their final few weeks or even days. The reality presented by Dr. Porter's broadcast from St. Joseph's ... is quite different. So what makes the care offered at St. Joseph's special? <http://www.eulogymagazine.co.uk/article/ofinterest/detail/id/92>

From Media Watch dated 7 February 2011:

- U.K. | BBC Radio 4 – 1 February 2011 – '**Case notes: End of life.**' As a nation, we don't tend to dwell on the nitty gritty detail of care we might want when we're dying. It's a topic many tend to approach only when required and then might not know what questions to ask, or what support may be on offer. <http://www.bbc.co.uk/programmes/b00y2f1c>

#### **First-ever pain management initiative in The Gambia, Kenya and Malawi**

FOUNDATION FOR HOSPICES IN SUB-SAHARAN AFRICA (FHSSA) | Press release – 9 February 2011 – The FHSSA and the African Palliative Care Association are partnering to improve pain management among palliative care patients receiving care in hospitals in The Gambia, Kenya and Malawi. These three countries were selected because they each have well-established national palliative care organizations, strong clinical leadership, and success with related projects. <http://www.prnewswire.com/news-releases/fhssa-and-the-african-palliative-care-association-launch-the-first-ever-pain-management-initiative-in-the-gambia-kenya-and-malawi-115638824.html>

#### Editorial

##### **What Africa has to teach the U.S. about hospice and palliative care**

*JOURNAL OF PALLIATIVE MEDICINE*, 2011; 14(2):129-131. Hospice in Africa does not seem to have the elitism and separatism that characterized many of our programs in the early hospice movement in the U.S. Instead, there is a great sense of collaboration and partnership with all components of the existing health system, as fragile and tenuous as some of them are. This posture of bringing added value as a mutually respected partner is one of the strongest impressions I have of the African hospice movement and how hospices relate to their communities. <http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2010.9732>

## Patients with better palliative care live longer, research finds

*IRISH TIMES* | Online report – 8 February 2011 – The Irish Association for Palliative Care has described as "very significant" the findings of new research on seriously ill patients seeking support. Patients who avail of earlier palliative care can live longer and enjoy a better quality of life, according to the research published last year in the *New England Journal of Medicine*.<sup>1</sup> The study of people newly diagnosed with metastatic non-small cell lung cancer involved randomly assigning them into two groups. One group received "standard oncologic care" for their serious condition while the other got the same, but were also given early palliative care referral. After 12 weeks, researchers found that the group with

palliative care involvement had experienced a better quality of life, and recorded a lower incidence of depressive symptoms.  
<http://www.irishtimes.com/newspaper/health/2011/0208/1224289253898.html>

### Specialist Publications

Of particular interest:

**'Managing patients with advanced cancer: The benefits of early referral for palliative care'** (p.8), published in the *Medical Journal of Australia*.

1. *NEW ENGLAND JOURNAL OF MEDICINE* | Online article – 18 August 2010 – **'Early palliative care for patients with metastatic non-small-cell lung cancer.'** As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life, but longer survival. <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>

**N.B.** Noted in Media Watch dated 23 August 2010.

## Families cutting funeral costs, survey reveals

U.K. | *Guardian* – 8 February 2011 – The average funeral cost in the U.K. fell last year as bereaved families cut optional extras such as limousines and flowers, according to a new survey which also warns that many struggle to cover all the expenses. The survey reveals cremation costs have risen by 5.4% and burial costs 7%, making a burial £800 more expensive, on average, than cremation. <http://www.guardian.co.uk/money/2011/feb/08/families-cutting-funeral-costs>

### 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>

## Palliative Care Policy for Kerala

### **Palliative clinic at medical college**

INDIA | *The Hindu* – 6 February 2011 – The Government Medical College Hospital ... [in Kerala] has finally got its first clinic in palliative medicine. Though, in 2008, Kerala had emerged as a model for the rest of the country by being the first State to formulate a palliative-care policy, one of the main declarations in the policy that palliative clinics will be started in all government medical college hospitals has remained on paper. It has been announced that palliative care will be integrated into primary health care and that primary health centres will be equipped with palliative clinics. Palliative clinics are now functioning in a small way in a few government hospitals. Pallium India, which has been doing a lot of work in the community in the field of palliative care, had offered in 2008 to start free clinics at medical colleges wherever hospital administrations

were willing to allow it to do so.

<http://www.thehindu.com/todays-paper/tp-national/tp-kerala/article1161352.ece>

#### **From Media Watch dated 10 January 2011**

##### **A model to treat the dying that could be rolled out in other nations**

INDIA | BBC 4 – 6 January 2011 – One of the most sophisticated systems of palliative care in the developing world has been established in the Indian state of Kerala. The grassroots movement to create a much-valued and effective palliative care system in Kerala has been called a silent revolution. [http://www.bbc.co.uk/iplayer/episode/b00wr9v8/Crossing\\_Continents\\_Palliative\\_Care\\_in\\_India/](http://www.bbc.co.uk/iplayer/episode/b00wr9v8/Crossing_Continents_Palliative_Care_in_India/)

Of related interest:

- INDIA | *Indian Express* – 14 February 2011 – **'Palliative care body to draw national policy.'** The Indian Association of Palliative Care has named a committee to formulate a national policy for it. The four-member committee is expected to submit its first draft within three months. <http://www.indianexpress.com/news/palliative-care-body-to-draw-national-policy/749747/>
- INDIA | *Times of India* – 13 February 2011 – **'Awareness on palliative care poor: Survey.'** People in general tend to concentrate more on cure and not care for a terminally ill patient, a pilot survey ... has revealed. The survey ... shows that only 18% of the people are aware of palliative care, medical care or treatment that concentrates on reducing the severity of the disease symptoms, rather than striving to stop, delay or reverse the progression of the disease itself or provide a cure. <http://timesofindia.indiatimes.com/city/delhi/Awareness-on-palliative-care-poor-Survey/articleshow/7488661.cms>

**N.B.** India rated 40th in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

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

### **Boundary issues for hospice palliative care volunteers: When to say "yes" and when to say "no"**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 10 February 2011 – Hospice palliative care volunteers from two community-based hospice programs responded to a ... Boundary Issues Questionnaire. Volunteers were asked to indicate whether or not they considered each item (e.g., "lend personal belongings to a patient or family," "agree to be a patient's power of attorney," "attend/go into a patient's medical appointment") to be something they should not do and to indicate whether or not they have ever done it. On the basis

Cont.



of the responses, the authors distinguished between "definite boundary issues" (things volunteers should never do, for example, "accept money from a patient or family"), "potential boundary issues" (things volunteers should stop and think twice about doing, for example, "accept a gift from a patient or family"), and "questionable boundary issues" (things volunteers should be aware of doing, for example, "give your home phone number to a patient or family"). The implications of these findings for training volunteers are discussed and the need for clear and unambiguous organizational policies and procedures to preserve boundaries is stressed. Without clear policies, etc., community-based hospice programs may be putting themselves at legal risk.  
<http://ajh.sagepub.com/content/early/2011/02/08/1049909110397926.abstract>

### **Palliative and terminal care at home as portrayed in Dutch newspapers in 2009 compared to 2000**

*EUROPEAN JOURNAL OF GENERAL PRACTICE* | Online article – 10 February 2011 – Terminal care at home is receiving increased attention from the Dutch media, which is relevant for primary care providers. In the year 2000, the framing of articles in regional newspapers appeared to be predominantly consumer-oriented (66%) and in national newspapers predominantly contextual (63%). The moral judgment in the regional articles was predominantly positive (66%), in the national newspapers predominantly negative (58%). In 2009, articles in regional and national newspapers were categorized mainly as consumer-oriented (73% and 55%, respectively), and new themes appeared, i.e. self-care and

medical topics. For moral judgment, again regional articles were mainly positive (76%) and national articles were mainly negative (39%) and neutral (31%).  
<http://informahealthcare.com/doi/abs/10.3109/13814788.2010.549224>

#### **Extract from *European Journal of General Practice***

Health care providers should realize that the portrayal of palliative and terminal care at home may differ depending on the type of newspaper – regional or national.

### **Hospice care in Chinese culture: A challenge to home care professionals**

*HOME HEALTH CARE MANAGEMENT PRACTICE*, 2011;23(1):67-68. Issues of traditional Chinese views of death and dying, open disclosure of diagnostic information with patient, misconceptions about hospice care, filial responsibility, and family involvement in decision making may lead to disadvantages in accessing appropriate hospice services. Introducing the option of hospice care to a dying person and their families in a culturally sensitive manner requires an understanding of Chinese beliefs and values. <http://hhc.sagepub.com/content/23/1/67.extract>

**N.B.** Chinese culture and apparent conflicting attitudes within the local Chinese community towards dying and death surfaced in recent months in Vancouver, Canada, over a controversial proposal to build a hospice on the campus of the University of British Columbia. A representative sample of the media coverage is noted in the issues of Media Watch dated 17, 24 and 31 January 2011.

### **Children and grief: But what about the children?**

*HOME HEALTHCARE NURSE*, 2011;29(2):67-77. For anyone who has ever lost a loved one, you know too well the devastation and raw emotions that can accompany the grief process. Now imagine you are 3, 7, 13, or 17 years of age trying to understand why your mom, dad, sibling, grandparent, or best friend has died. Children's grief is like a fierce storm at sea, bringing devastation that lasts long after the funeral and burial are over. Many children struggle to come to terms with their grief for years after the death. It is important to be aware of the child's developmental age because this greatly influences the child's perception and understanding of death. [http://journals.lww.com/homehealthcarenurseonline/Fulltext/2011/02000/Children\\_and\\_Grief\\_But\\_What\\_About\\_the\\_Children\\_4.aspx](http://journals.lww.com/homehealthcarenurseonline/Fulltext/2011/02000/Children_and_Grief_But_What_About_the_Children_4.aspx)

## **Palliative care in amyotrophic lateral sclerosis: Review of current international guidelines and initiatives**

*JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY* | Online article – 5 February 2011 – Despite an international consensus that ALS [amyotrophic lateral sclerosis] management should adopt a multidisciplinary approach, integration of palliative care ... varies considerably across health care systems. Late referral to palliative services in ALS is not uncommon and may impact negatively on the quality of life of ALS patients and their caregivers. However, common themes and principles of engagement can be identified across different jurisdictions, and measurement systems have been established that can assess the impact of palliative care intervention. <http://jnnp.bmj.com/content/early/2011/02/04/jnnp.2010.232637.abstract?sid=2fb2379c-b7d2-419d-8a3b-bf6f757148c3>

From Media Watch dated 30 August 2010:

- AUSTRALIA | *The Record* – 24 August 2010 – **'Is there any 'frightening' disease palliative care can't deal with?'** Motor Neuron Disease, known as Lou Gehrig's disease [or amyotrophic lateral sclerosis (ALS)] ... is often more frightening than cancer for those who have it and their loved ones. [http://www.therecord.com.au/site/index.php?option=com\\_content&task=view&id=1929&Itemid=30](http://www.therecord.com.au/site/index.php?option=com_content&task=view&id=1929&Itemid=30)

From Media Watch dated 7 June 2010:

- *AMYOTROPHIC LATERAL SCLEROSIS* | Online article – 17 March 2010 – **'Meaning in life in patients with amyotrophic lateral sclerosis.'** The aim of this study was to investigate 'meaning in life' in patients with amyotrophic lateral sclerosis and compare the findings with a ... sample of the German population. <http://informahealthcare.com/doi/abs/10.3109/17482961003692604>

## **The measurement of spirituality in palliative care and the content of tools validated cross-culturally: A systematic review**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 10 February 2011 – Despite the need to assess spiritual outcomes in palliative care, little is known about the properties of the tools currently used to do so. In addition, measures of spirituality have been criticized in the literature for cultural bias, and it is unclear which tools have been validated cross-culturally. [In this systematic review] ... one hundred ninety-one articles were identified, yielding 85 tools. Fifty different tools had been reported in research studies; however, 30 of these had not been validated in palliative care populations. Thirty-eight tools met Criterion 1: general multi-dimensional measures, functional measures, and substantive measures. Nine measures met Criterion 2; these used spiritual concepts relating to six themes: beliefs, practices, and experiences; relationships; spiritual resources; outlook on life/self; outlook on death/dying; and indicators of spiritual well-being. A conceptual model of spirituality is presented on the basis of the content analysis. [http://www.jpsmjournal.com/article/S0885-3924\(11\)00010-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(11)00010-8/abstract)

## **Managing patients with advanced cancer: The benefits of early referral for palliative care**

*MEDICAL JOURNAL OF AUSTRALIA*, 2011;194(3):107-108. The results of the two studies discussed here provide the best evidence yet for the multiple benefits of early referral to palliative care services in the care of patients with advanced, incurable cancer. They show that early referral can improve all measurable outcomes for patients by as much as, or more than, new and expensive treatments. Further, they show that early referral can help patients and carers better understand and choose between their treatment options near the end of life, reducing futile use of finite medical resources, debilitating treatments such as continuing cycles of chemotherapy in very advanced stages of illness, and acute in-hospital interventions at the end of life. [http://www.mja.com.au/public/issues/194\\_03\\_070211/hai11104\\_fm.html](http://www.mja.com.au/public/issues/194_03_070211/hai11104_fm.html)

Cont.



Of related interest:

- *HEALTH POLICY NEWSLETTER* (Jefferson University Hospitals, Pennsylvania) | Online article – Accessed 8 February 2011 – '**Utilization of palliative care: Providers still hinder access.**' The Jefferson Palliative Care Service investigated end-of-life care for hospitalized patients with lung cancer and found barriers to palliative care access typical of those reported elsewhere in the U.S. Confusion about the difference between palliative care and hospice is at the heart of the matter. <http://jdc.jefferson.edu/cgi/viewcontent.cgi?article=1714&context=hpn>

### **The ethical and legal aspects of palliative sedation in severely brain injured patients: A French perspective**

*PHILOSOPHY, ETHICS & HUMANITIES IN MEDICINE* | Online article – 8 February 2011 – The issue of palliative sedation deserves particular attention in adults with serious brain injuries and in neonates with severe and irreversible brain lesions, who are unable to express pain or to state their wishes. In France, treatment limitation decisions for these patients are left to the physicians. Treatment-limitation decisions are made collegially, based on the presence of irreversible brain lesions responsible for chronic severe disorders of consciousness. Before these decisions are implemented, they are communicated to the relatives. Because the presence and severity of pain cannot be assessed in these patients, palliative analgesia and/or sedation should be administered. However, palliative sedation is a complex strategy that requires safeguards to prevent a drift toward hastening death or performing covert euthanasia. In addition to the law on

patients' rights at the end of life passed in France on April 22, 2005, a recent revision of Article 37 of the French code of medical ethics both acknowledges that treatment-limitation decisions and palliative sedation may be required in patients with severe brain injuries and provides legal and ethical safeguards against a shift towards euthanasia. <http://www.peh-med.com/content/pdf/1747-5341-6-4.pdf>

#### **Extract from *Philosophy, Ethics & Humanities in Medicine***

Legislation [in France] may hold value as a model for other countries where euthanasia is illegal and for countries such as Belgium and Netherlands where euthanasia is legal but not allowed in patients incapable of asking for euthanasia but in whom a treatment limitation decision has been made.

**N.B.** Articles, editorials, guidelines by professional bodies, etc., on the issue of palliative sedation have been featured in many past issues of Media Watch. A sample listing appears in the weekly report dated 17 January 2011 (p.8).

### **Association of British Clinical Diabetologists position statement on diabetes and end of life care**

*PRACTICAL DIABETES INTERNATIONAL*, 2011;28(1):26-27. As the population of the U.K. ages and the incidence of diabetes rises, more individuals will be reaching the end of their life with co-existent diabetes. In the words of Prof. J Saunders, diabetologist and ethicist: "Dying patients should receive care that offers comfort, dignity and freedom from distressing symptoms as far as these are possible." That includes those with diabetes for whom the aim should be to keep the blood glucose within a range which will avoid symptoms while reducing invasive tests, such as blood glucose monitoring, to a minimum. <http://onlinelibrary.wiley.com/doi/10.1002/pdi.1547/full>

From Media Watch dated 3 January 2011:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 31 December 2010 – '**An approach to diabetes mellitus in hospice and palliative medicine.**' The authors propose a specific framework to guide management in patients with diabetes and advanced disease who are relatively stable, experiencing impending death or organ failure, or actively dying. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0191>

## Psychosocial aspects of caregiving: Perceptions of cancer patients and family caregivers

*SUPPORTIVE CARE IN CANCER* | Online article – 6 February 2011 – Caregivers reported providing more help in dealing with feelings than patients endorsed needing. Caregivers were also more likely than patients to report the psychosocial aspects of caregiving were more difficult for them. Lastly, caregivers were more likely to report helping with logistical issues in comparison with patients expressing this need. Our results suggest that patients may underestimate how difficult caregivers perceive the psychosocial aspects of caregiving to be. Also, it seems that caregivers tend to take on the psychosocial aspects of caregiving, although patients do not tend to report this need. Caregiving needs were only minimally associated with demographic variables, as was participation in caregiving tasks. <http://www.ncbi.nlm.nih.gov/pubmed/21298291>

From Media Watch dated 31 January 2011:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 25 January 2011 – '**Exploring the dynamics of interdisciplinary palliative care teams in providing psychosocial care: "Everybody thinks that everybody can do it and they can't."**' Two ... themes emerged ... "Lack of clear role boundaries" and "Strategies for maintenance of role boundaries," which included: "claiming access to specialist expertise and knowledge" and "minimizing the knowledge of other professions and professionals." <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0229>

Of related interest:

- *CLINICAL NURSING RESEARCH*, 2011;20(1):7-24. '**End-of-life caregiving trajectories.**' The purpose of this study is to illustrate variations in caregiving trajectories as described by informal family caregivers providing end-of-life care. The unifying theme of end-of-life caregiving is "seeking normal" as family caregivers worked toward achieving a steady state, or sense of normal during their caregiving experiences. Distinct variations in the caregiving experience correspond to the death trajectory. Understanding caregiving trajectories that are manifest in typical cases encountered in clinical practice will guide nurses to better support informal caregivers as they traverse complex trajectories of end-of-life care. <http://cnr.sagepub.com/content/20/1/7.abstract>
- U.S. | University of Missouri-Columbia press release – 10 February 2011 – '**Study examines phenomenon of women caring for ex-husbands.**' The aging population, 65 years and older, includes nearly 3.8 million divorced men and women, according to the U.S. Census Bureau. Illnesses and end-of-life issues can be particularly difficult for singles without spouses or designated caregivers. A new study from the University of Missouri provides insight into the experiences of exes who care for their former spouses, offering support, assistance with daily tasks and management of health needs. [http://www.eurekalert.org/pub\\_releases/2011-02/uom-sep021011.php](http://www.eurekalert.org/pub_releases/2011-02/uom-sep021011.php)

## New tool "valid and reliable" to assess pain in non-communicative patients

*UNIVERSITY OF MARYLAND NEWS* (U.S.) | Online article – 8 February 2011 – A valid and reliable tool to assess acute pain in non-communicative patients has been developed by researchers at the University of Maryland School of Nursing. They say their tool addresses a tremendous need in medical care because patients who cannot self-report are at risk for under-treatment of pain, partly because assessing their pain has not always been consistent between practitioners. Tests of Multidimensional Objective Pain Assessment Tool on non-communicative hospice patients before and after nurses administered medication show that the patients' pain is lessened, says lead researcher Deborah McGuire, professor and director of the School's Developing Center of Excellence in Palliative Care Research & Oncology Graduate Program. <http://www.oea.umaryland.edu/communications/news/?ViewStatus=FullArticle&articleDetail=12015>

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *LEGAL STUDIES*, 2011;31(1):119-134. '**Informal legal change on assisted suicide: The policy for prosecutors.**' Following the House of Lords' decision in Purdy, the Director of Public Prosecutions issued an interim policy for prosecutors setting out the factors to be considered when deciding whether a prosecution in an assisted suicide case is in the public interest. This paper considers the interim policy, the subsequent public consultation and the resulting final policy. Key aspects of the policy are examined, including the condition of the victim, the decision to commit suicide and the role of organised or professional assistance. The inclusion of assisted suicides which take place within England and Wales makes the informal legal change realised by the policy more significant than was originally anticipated. <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-121X.2010.00184.x/abstract>

From Media Watch dated 24 January 2011:

- *BOSTON COLLEGE INTERNATIONAL & COMPARATIVE LAW REVIEW*, 2011;33(2):289-304. '**From "personal autonomy" to "death-on-demand": Will Purdy v. DPP [Director of Public Prosecutions] legalize assisted suicide in the U.K.?**' The author ... argues that the Purdy court's reasoning and the DPP's response to the decision paves the way for a gradual breakdown in restrictions on the practice. <http://lawdigitalcommons.bc.edu/cgi/viewcontent.cgi?article=1013&context=iclr>

## Worth Repeating

### Palliative care for families: Remembering the hidden patients

CANADIAN JOURNAL OF PSYCHIATRY, 2004;49(6):359-365. Families of patients receiving palliative care are profoundly affected by the challenges of the illness. They observe care that the patient receives, provide care for the patient, and receive support from health professionals in the form of information, counselling, or practical assistance. As they witness and participate in the patient's care, they judge the quality of care that the patient receives. They often see themselves as the patient's care advocates and may harbour regret and guilt if they believe that the patient did not have the best possible care. The illness experience profoundly affects family members' psychological and physical health; recognition of this has coined the term "hidden patients." This article briefly synthesizes empirical work that suggests how to best support families in a palliative care context. We discuss how to define the family, emphasizing a systems approach to

family care. The authors describe the impact of the illness on the family in terms of family members' health, family communication issues, psychological issues, needs for information, physical care demands, and family costs of caring.

<https://ww1.cpaapc.org/Publications/Archives/CJP/2004/june/kristjanson.pdf>

#### Clinical Implications

1. The impact of terminal illness on the family may have significant and enduring effects on the physical, mental, and financial well-being of family caregivers.
2. Family caregivers have unmet needs for information, support, and communication.
3. It is critical to monitor the needs and well-being of family caregivers and target those most in need with therapeutic interventions.

### 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.

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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

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

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

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