## 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.

## 22 August 2011 Edition | Issue #215



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

Compiled & Annotated by Barry R. Ashpole

Palliative care research: Scroll own to <u>Specialist Publications</u> and 'Experts: Palliative care can begin before the end' (p.8), published in the *Journal of Supportive Oncology*.

## Canada

## Going green: A look at Ontario's only natural burial site

ONTARIO | Metroland Media (Ajax) – 17 August 2011 – There are no tombstones, monuments, candles or geranium planters, just a meadow with tall grass and the odd blueberry bush or sunflower marking the final resting place of a loved one in Ontario's only natural burial site. The Cobourg Union Cemetery hosts the only space in Ontario designated for green burials. The natural site was created about three years ago and has 181 lots, though it can be expanded. So far about 10 people have been buried there and there are about 40 more people who have made arrangements. http://www.newsdurhamregion.com/news/article/183366

## Property tax exemption

## Extra funds will mean better care

ONTARIO | Sudbury Star – 17 August 2011 – Sudbury MPP [Member of the Provincial Parliament] Rick Bartolucci announced ... property tax exemptions and additional funds for Maison Vale Hospice. Leo Therrien, executive director ... said the tax exemption and additional funding will help ensure "excellent care for our residents and their families." The government is also adding \$320,000 in base funding from the North East Local Health Integration Network. http://www.thesudburystar.com/ArticleDispla v.aspx?e=3261558

**N.B.** Hospices across the province are now all officially property-tax exempt and are to get a 55% increase in base funding.

## **Specialist Publications**

Of particular interest:

'Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada,' (p.8), published in *Health & Social Care in the Community.* 



http://www.worldday.org/

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | CTV News 17 August 2011 'Assisted suicide lawsuit tossed in B.C. court.' A B.C. judge is encouraging two right-to-die groups to join forces after tossing out one of two lawsuits asking for changes to Canada's criminal code. A claim from the Farewell Foundation [for the Right to Die] ... will not be allowed to continue after B.C. Supreme Court Justice Lynn Smith ruled ... that the group does not have public interest standing to pursue the case.¹ But the judge encouraged the foundation to apply for standing in a similar suit filed by the BC Civil Liberties Association.http://www.ctvbc.ctv.ca/servlet/an/local/CTVNews/20110817/bc assisted suicide fare well lawsuit 110817/20110817/?hub=BritishColumbiaHome
  - The judge ruled that the foundation did not have a strong enough case to challenge the law, saying anonymous members of the group must identify themselves in order to prove the law directly affects them.

From Media Watch dated 4 July 2011:

BRITISH COLUMBIA | The Province – 29 June 2011 – 'Grandma wants to die with dignity.' The B.C. Civil Liberties Association filed suit to force B.C. to allow doctors to legally help terminally ill people commit suicide. http://www.theprovince.com/news/Grandma+wants+with+dignity/5021752/story.html

## U.S.A.

## Harsh lessons late in life

MASSACHUSETTS | *Boston Herald* (OpEd) – 20 August 2011 – Sure enough, despite Medicare and a good supplemental health insurance policy ... [my mother's] expenses outran her income from Social Security. Moreover, as she moved through the many stages of care, the costs mounted sometimes merely because of a puzzling inability among various caregivers to communicate with one another. For example, at the assisted living facility, the nurse was in the dark about even fundamental aspects of her treatment at the hospital. Sometimes it seemed as if the cardiologist was calling the shots on care, and then at other times, the gerontologist seemed to be in charge. Whenever my mother was transferred from one facility to another, so much was lost in translation and transition that we felt we were starting all over. The failure to communicate, as Paul Newman called it in 'Cool Hand Luke,' sometimes resulted in more frequent hospitalizations, longer stays in the hospital and unnecessary duplication of laboratory tests. http://www.bostonherald.com/news/opinion/op\_ed/view/2011\_0820harsh\_lessons\_late\_in\_life/

## Short lives, troubling questions

ILLINOIS | Chicago Tribune – 18 August 2011 – The agonizing decisions began even before they were born. Kameron and Kaydon Hayes were joined at the chest. They shared a liver and a defective heart. If their mother elected to continue her pregnancy, they were likely to be stillborn or to live less than a day. Each day they survived would require aggressive, and expensive, intervention. The prognosis was unyieldingly poor. Their mother was determined to give them a chance, and their medical team did everything it could. The twins spent their entire lives – 16 months, 11 days – at the University of Illinois Medical Center at Chicago, where they died last Thursday. The bill for their medical care: \$5.6 million. It was an extraordinary case, but the issues it raised are increasingly familiar. How much should be done, and at what cost, to prolong a life? Medical advances present doctors with that dilemma every day, whether they deal with critically ill infants or adults with end-stage cancer. When does the cost outweigh the medical benefit, and who decides? <a href="http://www.chicagotribune.com/news/opinion/editorials/ct-edit-twins-20110818,0,2528437.story">http://www.chicagotribune.com/news/opinion/editorials/ct-edit-twins-20110818,0,2528437.story</a>

Cont.

From Media Watch dated 11 July 2011:

- U.S. NEWS & WORLD REPORT | Online report 5 July 2011 'Medical futility trend seen in neonatal deaths.' Most deaths that occur in neonatal intensive care units at U.S. hospitals are due to withdrawal of life support and the withholding of lifesaving measures, a new study reveals. http://health.usnews.com/health-news/managing-your-healthcare/healthcare/articles/2011/07/05/medical-futility-trend-seen-in-neonatal-deaths
  - 'How infants die in the neonatal intensive care unit,' Archives of Pediatrics & Adolescent Medicine, 2011; 165(7):630-634. http://archpedi.ama-assn.org/cgi/content/abstract/165/7/630

## Medicare end-of-life counseling: A matter of choice

HEALTH POLICY OUTLOOK (American Enterprise Institute for Public Policy Research) | Online article - Accessed 17 August 2011 – Medicare spends a considerable amount of money on beneficiaries in their last year of life. This is often thought to be an issue of cost versus the intensity of care that end-of-life patients should receive. This way of framing the debate, however, overstates the importance of end-of-life spending, which is quantitatively modest compared to an everincreasing Medicare budget. More salient is whether patients are receiving end-of-life care that matches their values and beliefs. Unfortunately, the evidence suggests that Medicare's tendency toward providing endof-life care in a hospital inpatient setting is at odds with the preferences of patients. http://www.aei.org/docLib/HPO-2011-08-No-7-q.pdf

## Highlights of Health Policy Outlook article

Reducing end-of-life costs will do little to curb the growth in Medicare spending overall. But end-of-life care provision should be reformed to match the values of patients, many of whom lack the tools to make informed decisions about end-of-life care.

Medicare's incentive structure rewards providers who "do more" but not providers who spend more time counseling patients or eliciting their end-of-life treatment preferences.

Medicare should compensate physicians for providing end-of-life care counseling. Such a physician-centered approach stands in contrast to payer-centric approaches that attempt to allocate care according to rigid cost-effectiveness criteria.

USA TODAY | Online report – 15 August 2011 – 'Hospice lobbyists battle over Medicare payment system.' For-profit hospice organizations have spent more than \$1million ... lobbying to prevent Medicare from reducing payments to try to curb the soaring cost of hospice care. Trade groups representing hospice companies have formed the Hospice Action Network, which has enlisted at least four lobbying firms. <a href="http://www.usatoday.com/news/washington/2011-08-15-hospices-medicare-lobbying\_n.htm">http://www.usatoday.com/news/washington/2011-08-15-hospices-medicare-lobbying\_n.htm</a>

## Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

## Bill would expand hospice care to more state residents

MASSACHUSETTS | *Taunton Daily Gazette* – 15 August 2011 – More terminally ill people covered by the state's low-income health insurance plans could be eligible for hospice coverage, making their end of life care a little more comfortable, under a bill recently filed by a handful of top lawmakers. Out of the 1.3 million MassHealth recipients, approximately 1 million are already entitled to hospice care as part of their plans, but the proposed law would extend coverage to people with more limited plans. Last week, lawmakers sent the bill expanding hospice care ... to the Joint Committee on Health Care Financing. The idea to extend hospice care to more MassHealth recipients stems from a year-long legislative and expert panel formed to study end-of-life care in Massachusetts. http://www.tauntongazette.com/state\_news/x919533215/Bill-would-expand-hospice-care-to-more-state-residents

 Patient Centered Care & Human Mortality: The Urgency of Health System Reforms to Ensure Respect for Patients' Wishes and Accountability for Excellence in Care, Report & Recommendations of the Massachusetts Expert Panel on End of Life Care, 2010 (noted in Media Watch 28 March 2011). http://www.mass.gov/lhqcc/docs/expert\_panel/final\_expert\_panel\_report.pdf

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ MASSACHUSETTS | Patriot Ledger (Quincy) – 20 August 2011 – 'Massachusetts voters facing right-to-die showdown.' The proposal to legalize assisted suicide for some terminally ill patients is likely to ignite a lot of debate. It was a controversial enough subject that 643 Patriot Ledger readers chimed in on a website questionnaire. Nearly three-quarters – 474 – said they would vote in favor of such a referendum. The proposed law would permit patients "with a terminal disease that will cause death within six months" to obtain drugs to "end his or her life in a humane and dignified manner." <a href="http://www.patriotledger.com/news/state\_news/x1510868140/Massachusetts-voters-facing-right-to-die-showdown">http://www.patriotledger.com/news/state\_news/x1510868140/Massachusetts-voters-facing-right-to-die-showdown</a>

## International

#### How dead is dead?

## Sometimes, those who have died seem more alive than those who have not

U.K. | The Economist – 20 August 2011 – In general, people are pretty good at differentiating between the quick and the dead. Modern medicine, however, has created a third option, the persistent vegetative state. People in such a state have serious brain damage as a result of an accident or stroke. This often means they have no hope of regaining consciousness. Yet because parts of their brains that run activities such as breathing are intact, their vital functions can be sustained indefinitely. When, if ever, to withdraw medical support from such people, and thus let them die, is always a traumatic decision. It depends in part, though, on how the fully alive view the mental capacities of the vegetative—an area that has not been investigated much. To fill that gap Kurt Gray of the University of Maryland, and Annie Knickman and Dan Wegner of Harvard University, conducted an experiment designed to ascertain just how people perceive those in a persistent vegetative state. <a href="http://www.economist.com/node/21526321">http://www.economist.com/node/21526321</a>

From Media Watch dated 8 August 2011:

 COGNITION | Online article – 27 July 2011 – 'More dead than dead: Perceptions of persons in the persistent vegetative state.' Patients in persistent vegetative state (PVS) may be biologically alive, but these experiments indicate that people see PVS as a state curiously more dead than dead. <a href="http://www.sciencedirect.com/science/article/pii/S0010027711001752">http://www.sciencedirect.com/science/article/pii/S0010027711001752</a>

## Team-up to double end-of-life care in people's homes in Surrey

U.K. | Redhill, Reigate & Horley Life – 19 August 2010 – Marie Curie Cancer Care will be working alongside Surrey Community Health and Central Surrey Health to increase the amount of end-of-life care the charity provides to Surrey people in their own homes. The project ... will be building on a successful pilot scheme... The next stage ... will continue to integrate with community nursing services, and work closely with hospices across the county, to support local people of any diagnosis in the last weeks of life. The county-wide 24/7 ... service ... will increase nursing care for people at home during the day and night, allowing more people to die in their place of choice. <a href="http://www.redhillandreigatelife.co.uk/news/localnews/9203251.Team\_up\_to\_double\_end\_of\_life\_care\_in\_people\_s\_homes\_in\_Surrey/">http://www.redhillandreigatelife.co.uk/news/localnews/9203251.Team\_up\_to\_double\_end\_of\_life\_care\_in\_people\_s\_homes\_in\_Surrey/</a>

#### Of related interest:

- U.K. | BBC News 18 August 2011 'Leicestershire centre to improve end of life care.' Two organisations in Leicestershire have launched a new research centre, aimed at improving palliative care for people in the county. De Montfort University and LOROS [Leicestershire & Rutland Organisation for the Relief of Suffering], the Leicestershire and Rutland Hospice, have been working together to educate medical professionals in how to support people at the end of their lives. A report by the National Council for Palliative Care (NCPC) recently criticised the care available. http://www.bbc.co.uk/news/uk-england-leicestershire-14571863
  - 'No dress rehearsals: Four key priorities to ensure we get end of life care right first time,' National Council
    for Palliative Care and the Dying Matters Coalition, August 2011 (noted in Media Watch 15 August 2011).
     <a href="http://www.dyingmatters.org/news/ncpc-calls-new-deal-dying">http://www.dyingmatters.org/news/ncpc-calls-new-deal-dying</a>

## Supporting families of children with a life limiting illness

PALLIATIVE CARE AUSTRALIA | Online press release – 18 August 2011 – The Association has launched *Journeys – Palliative care for children and teenagers*, a resource designed to prepare and equip families caring for a child with a life limiting illness. *Journeys* is divided into four sections, reflective of the different stages and situations families face as their child's illness progresses. <a href="http://www.palliativecare.org.au/Portals/46/PCA%20media%20release%20-%20Journeys%20Launch%20-%2018th%20August%202011.pdf">http://www.palliativecare.org.au/Portals/46/PCA%20media%20release%20-%20Journeys%20Launch%20-%2018th%20August%202011.pdf</a>

From Media Watch dated 15 August 2011:

■ U.K. | CHILDREN'S HOSPICES U.K. & ASSOCIATION FOR CHILDREN'S PALLIATIVE CARE (ACT) – 8 August 2011 – 'Local square table learning and evaluation report.' The report ... captures the open and honest discussions between those who provide children's palliative care, those who use the services, and those who play a wider part in supporting children, young people and families. http://www.act.org.uk/news.asp?itemid=1154&itemTitle=Local+square+table+learning+and+evaluation+report&section=94&sectionTitle=News

From Media Watch dated 16 May 2011:

U.K. | ONMEDICA – 13 May 2011 – 'Guidance on palliative care for children.' The charity ACT ... has launched online Children's Palliative Care Handbook for GPs, a practical and emotional guide to support GPs as they care for children who need palliative care, and their families.http://www.onmedica.com/newsarticle.aspx?id=f852 a255-8fec-4a36-a8e0-9b050faf78ac

## Specialist Publications

Of particular interest:

'The need for increased access to pediatric hospice and palliative care,' (p.7), published in Dimensions of Critical Care Nursing, 2011; 30(5):231-235.

## Pupils discover more about hospice care

U.K. | Basingstoke Gazette (Hampshire) – 17 August 2011 – A few of the taboos attached to dying, hospice care and bereavement were tackled by youngsters from a Basingstoke school. They were participating in the Hawthorn Project which was created by The North Hampshire Palliative Care Service and St Michael's Hospice. The four-week effort involved palliative care patients and students at Everest Community College in Oxford Way, Popley. During this time, the students visited the hospice in Aldermaston Road and worked with patients to produce a colourful collage which will be displayed at their school. The group of students were the first in north Hampshire to take part in the project, which aimed to educate them about end-of-life care. <a href="http://www.basingstokegazette.co.uk/news/9199612.Pupils\_discover\_more\_about\_hospice\_care/">http://www.basingstokegazette.co.uk/news/9199612.Pupils\_discover\_more\_about\_hospice\_care/</a>

From Media Watch (Worth Repeating) dated 8 August 2011:

AUSTRALIA | TheAge.com.au – 14 February 2007 – 'Lesson in life and death: Pupils build dying teacher's coffin.' A Dutch primary school teacher dying of cancer is overseeing one last class project: her pupils are making her coffin. <a href="http://www.theage.com.au/news/world/lesson-in-life-and-death-pupils-build-dying-teachers-coffin/2007/02/13/1171128974213.html">http://www.theage.com.au/news/world/lesson-in-life-and-death-pupils-build-dying-teachers-coffin/2007/02/13/1171128974213.html</a>

## Stillborn babies buried on remote Donegal island remembered

IRISH TIMES | Online report – 15 August 2011 – More than 200 people travelled to a remote island off the coast of Donegal ... to remember more than 500 stillborn babies buried in a secret burial ground. The children, all born between the 18<sup>th</sup> and 19<sup>th</sup> centuries, could not be buried on consecrated ground because they had not been baptised. The memorial service took place after a campaign by local people to remember the children who were laid to rest on Oileán na Marbh (Isle of the Dead). http://www.irishtimes.com/newspaper/ireland/2011/0815/1224302451271.html

From Media Watch dated 2 February 2011:

■ IRISH TIMES | Online article – 2 February 2011 – 'They buried our baby for £5 and nothing more was said.' There are countless mass infant graves scattered around Ireland, left unmarked, unconsecrated and containing hundreds of bodies ... a legacy of Roman Catholic tradition, which stipulated babies who died before being baptised did not go to heaven, but to an in-between state known as limbo. http://www.irishtimes.com/newspaper/features/2011/0202/1224288760646.html

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | The Guardian 18 August 2011 'Assisted suicide could be 'legalised' in ground-breaking case.' A 46-year-old-man who wants to die after a stroke that left him almost completely paralysed is bringing a groundbreaking legal action that could effectively lead to the legalisation of assisted suicide in the U.K. <a href="http://www.guardian.co.uk/society/2011/aug/18/assisted-suicide-could-be-legalised">http://www.guardian.co.uk/society/2011/aug/18/assisted-suicide-could-be-legalised</a>
- U.K. | The Guardian 18 August 2011 'The law on assisted suicide.' Changes brought in by
  Director of Public Prosecutions in 2009 do not decriminalise the offence but set out factors making
  prosecution less likely. <a href="http://www.guardian.co.uk/society/2011/aug/18/the-law-on-assisted-suicide">http://www.guardian.co.uk/society/2011/aug/18/the-law-on-assisted-suicide</a>

## **Quotable Quotes**

Rory, needy child turned "protective parent," administering to his mother numerous drugs; helping her go to the lavatory, turning the tap on to preserve her dignity during the 20 minutes it takes, a wooden whistle rigged up so she can alert them when she has finished; carrying her diminished body, "frail, like an injured bird in a blanket." Rory Maclean, *Gift of Time: A family's diary of cancer (Telegraph Books, 2011)* 

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

## Recognizing dying in terminal illness

BRITISH JOURNAL OF HOSPITAL MEDICINE, 2011;72(8):446-450. Recognizing dying in terminally ill patients is a complex clinical skill. This article outlines the approach to the decision, common difficulties encountered in patients with both malignant and non-malignant disease, and a simple approach to considering the question 'Is this patient dying?' <a href="http://www.bjhm.co.uk/cgibin/go.pl/library/abstract.html?uid=85643">http://www.bjhm.co.uk/cgibin/go.pl/library/abstract.html?uid=85643</a>

## The need for increased access to pediatric hospice and palliative care

DIMENSIONS OF CRITICAL CARE NURSING, 2011;30(5):231-235. Pediatric hospice and palliative care continue to be an underutilized model of care. There is much confusion over the differences between hospice and palliative care [in the U.S.]. Nurses and physicians continue to need specialized training regarding end-of-life care and the pediatric population. Children and their families may needlessly be suffering during the dying process. Barriers exist that prevent its use among medical professionals; this article discusses ... barriers, and strategies to reduce them.http://journals.lww.com/dccnjournal/Abstract/2011/09000/The\_Need\_for\_Increased\_Access to Pediatric Hospice.1.aspx

From Media Watch dated 20 June 2011:

PALLIATIVE MEDICINE | Online article - 16 June 2011 - 'Factors associated with perceived barriers to pediatric palliative care: A survey of pediatricians in Florida and California.' The provision and uptake of pediatric palliative care continues to be plagued by barriers. Several studies have documented these barriers, but none have done so with a diverse sample ... or specifically about pediatric palliative care. None have investigated the factors associated with perceived barriers.http://pmj.sagepub.com/content/ early/2011/06/16/0269216311409085.ab stract

From Media Watch dated 7 March 2011:

INTERNAL MEDICINE NEWS | Online article – 4 March 2011 – 'Improving access to pediatric palliative care.' Stefan J. Friedrichsdorf has a list of "myths" about pediatric palliative care that he presents during lectures. Among them: that the death of a child in the U.S. is a rare event, that pediatric palliative care is just for children with cancer, and that care starts when treatment stops. <a href="http://www.internalmedicinenews.com/news/oncology-hematology/single-article/improving-access-to-pediatric-palliative-care/c1d363a8fa.html">http://www.internalmedicinenews.com/news/oncology-hematology/single-article/improving-access-to-pediatric-palliative-care/c1d363a8fa.html</a>

## The doctor's dilemma – What is "appropriate" care?

NEW ENGLAND JOURNAL OF MEDICINE | Online editorial – 18 August 2011 – Most physicians want to deliver "appropriate" care. Most want to practice "ethically." But the transformation of a small-scale professional service into a technologically complex sector that consumes more than 17% of the nation's gross domestic product makes it increasingly difficult to know what is "appropriate" and what is "ethical." When escalating health care expenditures threaten the solvency of the federal government and the viability of the U.S. economy, physicians are forced to re-examine the choices they make in caring for patients. How can a commitment to cost-effective care be reconciled with a fundamental principle of primacy of patient welfare?http://www.nejm.org/doi/full/10.1056/NEJ Mp1107283

## Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. http://www.pcn-e.com/community/pg/file/world/world/

# Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online article – 18 August 2011 – After more than a decade of concerted effort by policy-makers in Canada and elsewhere to encourage older adults to age at home, there is recognition that the ageing-in-place movement has had unintended negative consequences for family members who care for seniors. Although understanding about the concepts of caregiver burden and burnout is now quite developed, the broader socio-political context giving rise to these negative consequences for caregivers to individuals with dementia has not improved. If anything, the Canadian homecare policy environment has placed caregivers in more desperate circumstances. A fundamental reorientation towards caregivers and caregiver supports is necessary, beginning with viewing caregivers as a critical health human resource in a system that depends on their contributions in order to function. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2011.01025.x/abstract

#### Of related interest:

- PALLIATIVE & SUPPORTIVE CARE, 2011;9(3):251-262. 'Protection against perceptions of powerlessness and helplessness during palliative care: Family members' perspective.' [The findings of this Swedish study indicate that] protection against powerlessness and helplessness had been facilitated by a stable patient condition, the patient coping well, a trusting relationship with the patient, practical and emotional support from family and friends, access to palliative expertise, and staff support that was both individually-focused and cooperative.
  <a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8353997&fulltextType=RA&fileId=S1478951511000204">http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8353997&fulltextType=RA&fileId=S1478951511000204</a>
- PALLIATIVE & SUPPORTIVE CARE, 2011;9(3):263-271. 'Meeting needs of family members of persons with life-threatening illness: A support group program during ongoing palliative care.' The results indicate that the support group program could work as an acceptable and useful intervention for family members. The program was experienced to cover topics of immediate interest reflecting life close to severely ill persons. The structure ... was found to be inviting, offering an opportunity to establish relationships with other participants and the caring team in a warm atmosphere.
  http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8354000&fulltextType=RA&fileId=S1478951511000216

## Palliative care research

## Experts: Palliative care can begin before the end

JOURNAL OF SUPPORTIVE ONCOLOGY | Online report – 16 August 2011 – Palliative care, once limited to the last days before death, is ripe for research and essential to improving patient quality of life, according to speakers at a summit sponsored by the National Institute of Nursing Research and National Institutes of Health partners. According to several speakers at the meeting, putting the clinician back in the mix may mean changing the thinking about palliative care from something that begins in the last days of life to something started as early as a patient's first day of a cancer diagnosis, as well as making it easier for clinicians to explore palliative care strategies. <a href="http://jso.imng.com/single-view/experts-palliative-care-can-begin-before-the-end/4155306c72.html">http://jso.imng.com/single-view/experts-palliative-care-can-begin-before-the-end/4155306c72.html</a>

#### Of related interest:

PALLIATIVE MEDICINE | Online article – 'Designing and conducting randomized controlled trials in palliative care: A summary of discussions from the 2010 clinical research forum of the Australian Palliative Care Clinical Studies Collaborative.' Rigorous clinical research in palliative care is challenging but achievable. Trial participants are likely to have deteriorating performance status, co-morbidities and progressive disease. It is difficult to recruit patients, and attrition unrelated to the intervention being trialled is high. The aim of this paper is to highlight practical considerations from a forum held to discuss these issues by active palliative care clinical researchers. http://pmj.saqepub.com/content/early/2011/08/13/0269216311417036.abstract

### **Bereavement and depression**

Possible changes to the *Diagnostic & Statistical Manual of Mental Disorders*: A report from the Scientific Advisory Committee of the Association for Death Education & Counseling

OMEGA – JOURNAL OF DEATH & DYING, 2011;63(3):199-220. A proposed revision [to the manual] ... is to remove ... the exclusionary criterion and allow clinicians to diagnose a person with a major depressive episode within the early days and weeks following a death. The exclusionary criterion states that within the first two months of the onset of bereavement a person should not be diagnosed as having major depression unless certain symptoms not characteristic of a normal grief reaction are present. [The authors of the Committee's report] ... note these symptoms when discussing the exclusionary criterion. They identify the features that comprise the exclusionary criterion, examine reasons ... given for retaining and for eliminating the exclusionary criterion, offer extensive comments from experienced licensed clinicians about the issues involved, discuss diagnostic and treatment implications, and offer ... recommendations. <a href="http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,5;journal,1,250;linkingpublicationresults,1:300329,1;">http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,5;journal,1,250;linkingpublicationresults,1:300329,1;</a>

From Media Watch dated 7 March 2011:

THE McGILL DAILY (University of McGill, Montreal, Canada) | Online article – 3 March 2011 – 'To medicalize mourning.' Over the past 25 years in the Diagnostic & Statistical Manual of Mental Disorders (DSM) has expanded to allow room for a number of "new" disorders. Included in this growing group is "Complicated Grief," or "Prolonged Grief Disorder," which is being considered for a spot in the DSM, due out in 2013. <a href="http://www.mcgilldaily.com/2011/03/to-medicalize-mourning/">http://www.mcgilldaily.com/2011/03/to-medicalize-mourning/</a>

**N.B.** This issue of Media Watch lists several articles on the proposed change to DSM-IV. The manual is published by the American Psychiatric Association.

## **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.

## Inpatient palliative care consults and the probability of hospital readmission

THE PERMANENT JOURNAL, 2011;15(2):48-51. Many patients and their families have difficulty making decisions when confronted with complex medical problems. Often their expectations and hopes are beyond what medical science can deliver, and at times their desires seem to conflict with their treatment plans. Additionally, costly tests and treatments with little or no benefit are often explored. <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3140749/pdf/i1552-5775-15-2-48.pdf">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3140749/pdf/i1552-5775-15-2-48.pdf</a>

#### Of related interest:

JOURNAL OF NURSING & HEALTHCARE OF CHRONIC ILLNESS, 2011;3(3):165-173. 'End-of-life care in acute hospitals: An integrative literature review.' There is a need for research to investigate end-of-life care in the acute hospital setting. Care pathways are in use to varying degrees without validation, but implementation alone does not ensure quality end-of-life care. http://onlinelibrary.wiley.com/doi/10.1111/j.1752-9824.2011.01094.x/full

## **Worth Repeating**

## Humor, laughter, and happiness in the daily lives of recently bereaved spouses

OMEGA – JOURNAL OF DEATH & DYING, 2009;58(2):87-105. The positive psychology movement has created more interest in examining the potential value of experiencing positive emotions (e.g., humor, laughter, and happiness) during the course of bereavement. The authors found that most of the bereaved spouses rated humor and happiness as being very important in their daily lives and that they were also experiencing these emotions at higher levels than expected. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,5;journal,22,250;linkingpublicationresults,1:300329,1

## 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.hpcconnection.ca/newsletter/inthenews.html

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

## 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/pg/file/all/

International Palliative Care Resource Center: http://www.ipcrc.net/archive-global-palliative-care-news.php

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

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