# 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

Place of death: Scroll down to <u>Specialist Publications</u> and 'No place like the hospital' (p.9), published in the *Journal of Pain & Symptom Management.* 

# <u>Canada</u>

# Cost of aging population on health care 'overblown'

BRITISH COLUMBIA | CBC News – 29 August 2011 – Fears that Canada's aging population could lead to soaring health-care costs may be greatly exaggerated, say researchers, who suggest that the predicted "grey tsunami" may turn out to be more like a "grey glacier." Two studies by health economists at the University of British Columbia say other factors are driving up health-care costs – primarily the growing use of specialists, increasing diagnostic tests for the elderly and higher consumption of ever more costly drugs.<sup>1,2</sup> Both studies found that the *percapita* cost of health care rose, even after adjusting for inflation and population changes. They concluded that neither the sharpest rise in cost nor the larger share of the increase was driven by the aging population, but by factors that can be controlled by health-care providers or policy-makers. <u>http://www.cbc.ca/news/health/story/2011/08/29/grey-tsunami-aging-population.html</u>

- HEALTHCARE POLICY, 2011;7(1):68-79. 'Population aging and the determinants of healthcare expenditures: The case of hospital, medical and pharmaceutical care in British Columbia, 1996 to 2006.' There is a gap between rhetoric and reality concerning healthcare expenditures and population aging. <u>http://www.longwoods.com/content/22525</u>
- HEALTHCARE POLICY, 2011;7(1):41-54. 'Diagnosing senescence: Contributions to physician expenditure increases in British Columbia, 1996/97 to 2005/06.' Physician services in Canada present a puzzle with major implications for access to and costs of medical care, as well as for physician supply policy. <u>http://www.longwoods.com/content/22527</u>

From Media Watch dated 9 May 2011:

 BRITISH COLUMBIA | *Times Colonist* (Victoria) – 2 May 2011 – 'University of Victoria study challenges notion of "grey tsunami" swamping health care system.' The persistent belief that the increasing size of our older population will overwhelm Canada's health care system is not true. The rising cost of high-tech, acute care is what's really behind steadily increasing health costs. http://www.timescolonist.com/health/UVic+study+challenges+notion+grey+tsunami+swamping+hea lth+care+system/4712960/story.html

# Assisted (or facilitated) death

Representative sample of recent news media coverage:

 QUEBEC | Montreal Gazette – 1 September 2011 – 'Quebec ALS sufferer seeks right to end her own life.' A Trois Rivières woman is resuming the crusade of Sue Rodriguez nearly 20 years later, pleading for help to end her life. Ginette Leblanc, 47, suffers from Lou Gehrig's disease – the same illness that led B.C.'s Rodriguez to challenge the federal law against assisted suicide in 1993. http://www.montrealgazette.com/news/Quebec+sufferer+seeks+right+life/5337336/story.html

**N.B.** Sue Rodriguez was diagnosed in 1991 with amyotrophic lateral sclerosis. In 1993, the Supreme Court of Canada dismissed an appeal by Rodriguez in which she challenged the validity of the Criminal Code, which prohibited an assisted suicide, under the Canadian Charter of Rights & Freedoms. Sue Rodriguez committed suicide with the assistance of a physician on 12 February 1994. The death was investigated by police, but no criminal charge was laid.

Available is **'Assisted (or Facilitated) Death: The Debate in Canada,'** which summarizes notable developments (as reported in past issues of Media Watch) – highlighting also those in other countries – that inform discussion of the issue in Canada. Contact information at foot of (p.12). **Specialist Publications** 

Of particular interest:

'Lessons from beyond Europe: Reflections on the evolution of palliative care research and policy in Canada' (p.9), published in the *Journal of Pain & Symptom Management.* 

# <u>U.S.A.</u>

### For many Americans, caregiving a long-distance burden

*U.S. NEWS & WORLD REPORT* | Online report – 31 August 2011 – Caring for a parent or relative in the same zip code can be hard enough, but long-distance caregiving, which is becoming more common in an increasingly mobile society, brings with it added burdens. By 2012, an estimated 14 million Americans will be long-distance caregivers, so many that some even have new names: "seagulls" and "pigeons." These terms refer to family members who alight for short periods of time, make a mess for local caregivers and fly out. What they don't take into account are the pain, isolation and hassles that long-distance caregivers are dealing with on their own. "They have unique issues," said Polly Mazanec, lead author of a paper appearing in a recent issue of *Oncology Nursing Forum.*<sup>1</sup> http://health.usnews.com/health-news/family-health/cancer/articles/2011/08/31/for-many-americans-caregiving-a-long-distance-burden

1. 'Experiences of distance caregivers of parents ...' *Oncology Nursing Forum*, 2011;38(3):307-313. <u>http://ons.metapress.com/content/lq33u02r116t47h7/?p=2f0aac453a05406ebf7e304a171b0408&pi</u> <u>=2</u>

#### <u>Trends in hospice</u>

# Patients choose hospice care

INDIANA | *The Republic* (Columbus) – 30 August 2011 – Hospice admissions have remained steady in recent years [according to Hospice of South Central Indiana], but families are turning to the 15-county agency for a much shorter period of time. Six years ago, patients received hospice care for an average of 34 days. Today, that's dropped to 16 days, matching a nationwide trend, despite the availability of coverage by Medicare and private insurance plans. Hospice President Sandy Carmichael and her staff have launched a new education campaign on the agency's care and services. "We want people to know we're here not just for crisis intervention at the very end." http://www.therepublic.com/view/local\_story/Patients\_choose\_hospice\_care\_1314676536/

Cont.

Of related interest:

 PENNSYLVANIA | NewsWorks (Public Media Service) – 31 December 2011 – 'Advocates push for more access to palliative care in Pennsylvania.' In Pennsylvania, in the past three years alone, the percentage of medium and large hospitals with [palliative care] teams has risen from 54 to 67%. Still, advocates and some lawmakers say pain management and emotional support for those with serious or terminal illnesses and their caregivers are still not accessible enough. <u>http://www.newsworks.org/index.php/homepage-feature/item/25826-advocates-push-for-moreaccess-to-palliative-care-in-pa-&Itemid=1</u>

#### Declining life-sustaining treatment

#### Right to choose fatal fast is tested

NEW MEXICO | Seattle Times (Washington State) – 30 August 2011 – Armond & Dorothy Rudolph feared a lingering decline and prolonged suffering in their old age, so they joined an organization that supports the right to end life when illness or pain becomes overwhelming. They attended meetings and drafted advance directives declining life-sustaining treatment in the case of fatal and irreversible illness. They gave their children literature on the subject and discussed their plans with them. But years later, when the couple finally opted for an exit from this life, it all fell apart. After the Rudolphs began refusing nourishment, the assisted living facility ... in which they lived tried to evict them. When the family balked, the managers called 911 and tried to have the elderly couple transported to a hospital. The Rudolphs did leave the facility, and they died in a rented house surrounded by their children and cared for by hospice workers. Now their case has become a rallying point for those who support self-determination at the end of life, and ... raised thorny questions about the rights of residents in assisted living facilities and society's ...

unease with hastening death. Nobody knows how many people choose to end their lives this way. But a survey of hospice nurses in Oregon, published in *The New England Journal of Medicine* in 2003<sup>1</sup> ... found that most of their terminally ill patients who deliberately refused food and fluids had "a good death," with low levels of pain or suffering.<u>http://seattletimes.nwsource.com/ht</u> ml/health/2016058768 fatalfast30.html

 'Nurses' experiences with hospice patients who refuse food and fluids to hasten death,' *New England Journal of Medicine*, published online 24 July 2003. <u>http://www.nejm.org/doi/full/10.1056/NE</u> <u>JMsa035086</u>

# **Specialist Publications**

Of particular interest:

'Effect of palliative care services on the aggressiveness of end-of-life care in the Veteran's Affairs cancer population' (p.9), published in the *Journal of Palliative Medicine*.



# 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>

#### Following a death

#### Families skeptical as Arlington tries to repair trust

VIRGINIA | NPR Radio News - 29 August 2011 - For years, Arlington National Cemetery has been defined by honor. Presidents are buried there. The crew of the space shuttle Challenger. And thousands of men and women who served in the military. But Barbara Tye doesn't have the same sense of honor she once had. After her family had her little brother, Army Staff Sqt. Michael Somers, disinterred she found out he had been buried in the wrong place. After reports last year revealed mishandling of remains at the cemetery, military officials are now working to reconcile the burial records of the 330,000 people laid to rest there. The cemetery faces a joint criminal probe by the Army and the FBI. Congress has also ordered an accounting by the end of the year.http://www.npr.org/2011/08/29/1400379 88/families-skeptical-as-arlington-tries-torepair-trust

# Daughter mourned her mother at the wrong grave for two decades after cemetery blunder

U.K. | *Daily Mail* – 30 August 2011 – A grieving daughter has spoken of her distress after discovering that she had been mourning at the wrong grave for 17 years. Bungling cemetery staff told Catherine Haywood that her mother's ashes had been buried 500 yards away from where they actually were. And Catherine only realised the error last month, when she wanted to scatter her father's ashes along with her mother's. <u>http://www.dailymail.co.uk/news/article-2031734/Daughter-mourned-mother-wronggrave-TWO-DECADES-cemeteryblunder.html?ito=feeds-newsxml</u>

Of related interest:

 CALIFORNIA | Oakland Tribune – 30 August 2011 – 'Dividing up a life.' Regardless whether the death is expected, dividing a loved one's possessions can be one of the most painful – or rewarding – experiences a family can go through. There are no hard or fast rules for how and when it should be done, and many people dread the thought of going through it. http://www.insidebayarea.com/trivalleyherald/ci 18782222

#### 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

# **International**

#### The National Health Service has rooms for improvement in end of life care

U.K. | The Guardian - 1 September 2011 -The environments in which patients are cared for can make a real difference to their overall health and well being. In the case of palliative care patients, good quality and sympathetic environments can provide a sense of reassurance at a time of high stress. But despite the good progress that has been made in improving care and choice for people at the end of their lives since the publication of the national strategy in 2008, more can be done. The King's Fund's ... Environments for Care at end of life, on improving the environment in which people are dying, their relatives and the bereaved in hospitals, highlights that there is still reluctance to discuss these important aspects of care. There is also an absence in taking them fully into consideration when planning services. <u>http://www.guardian.co.uk/healthcare-</u><u>network/2011/sep/01/nhs-rooms-</u> improvement-end-life-care

# Hospital rooms for end of life care – before and after

U.K. | *The Guardian* – 1 September 2011 – How two trusts, South Staffordshire & Shropshire Healthcare and Southend University Hospital, have enhanced the environment for palliative care. <u>http://www.guardian.co.uk/healthcare-</u> <u>network/gallery/2011/sep/01/hospital-rooms-end-</u> <u>life-care</u>

From Media Watch dated 29 August 2011:

 KING'S FUND (U.K.) | Online report – 23 August 2011 – 'Environments for care at the end of life: The King's Fund's Enhancing the Healing Environment [EHE] Programme 2008-2010.' This publication describes projects in 19 NHS [National Health Service] trusts and one prison that took part in schemes to improve the environment of care at the end of life. It describes the broader EHE programme. <u>http://www.kingsfund.org.uk/publications/ehe\_care\_environment.html</u>

#### ICU doctor wants more elderly to die at home

AUSTRALIA (NEW SOUTH WALES) | *The Australian* – 30 August 2011 – A leading intensivecare specialist has warned that too many terminally ill people are dying painful, traumatic deaths in hospital, hooked up to machines and prodded by doctors, when most want to die peacefully at home. University of New South Wales professor of intensive care Ken Hillman told *The Australian* the expensive health system "conveyor belt" on which the majority of elderly people died in hospital intensive-care units needed to be stopped. "Someone has to stop this conveyor belt of home to ambulance to emergency department to ICU to death," said Professor Hillman, who practises at Liverpool Hospital's busy ICU in Sydney's southwest. "In ICU, you're surrounded by well-meaning strangers ... and we're doing all sorts of painful things to people. We always try to provide pain relief, but we stick catheters in lungs, veins, arteries ... and you're hooked up to breathing machines, liver-cleansing machines." Professor Hillman ... said society needed to accept that modern medicine, while capable of great things, could not stop ageing or dying. http://www.theaustralian.com.au/national-affairs/health/icu-doctor-wants-more-elderly-to-die-athome/story-fn59nokw-1226125907793

Of related interest:

AUSTRALIA (NEW SOUTH WALES) | *The Australian* – 30 August 2011 – **'In-care age on the rise as more resist moving.'** New figures released by the Australian Institute for Health & Welfare [AIHW] show the ageing of the population has pushed up demand for nursing home care and inhome care, with national aged-care spending up almost 10% in the past year to \$11 billion. Higher demand in the past decade caused a 23% rise in people living permanently in residential aged care, says the AIHW report. <a href="http://www.theaustralian.com.au/national-affairs/health/in-care-age-on-the-rise-as-more-resist-moving/story-fn59nokw-1226125911217">http://www.theaustralian.com.au/national-affairs/health/in-care-age-on-the-rise-as-more-resist-moving/story-fn59nokw-1226125911217</a>

# National Health Service training on 'do not resuscitate' orders must not be cut, says doctor

U.K. | The Guardian - 30 August 2011 -National Health Service training in making "do not resuscitate" orders and communicating them to patients and families must not fall victim to spending cuts, according to a senior doctor who provides professional guidance on the issue. Jasmeet Soar, chair of the Resuscitation Council, said that while the existing framework governing the use of such orders in England did not need changing, there was room for improvement in explaining the issues. The Royal College of Nursing also called for a public education drive on the complexities of end-of-life decisions. Their pleas came after The Guardian revealed that the husband of a patient had launched legal action against Addenbrooke's hospital in Cambridge and the health secretary, Andrew Lansley,<sup>1</sup> alleging illegal use of such orders

and seeking to force the government in England to follow Scotland by having a national policy on the use of "do not attempt cardiopulmonary resuscitation" orders. David Tracey claims doctors twice put such orders in his wife Janet's medical notes, cancelling the first after she objected to it, only to put in a second three days later without her consent or any discussion with her.<u>http://www.guardian.co.uk/society/2011/</u> aug/30/nhs-training-do-not-resuscitate

- 'Do not resuscitate: Final word is with medical staff, whatever patient feels,' *The Guardian*, 26 August 2011 (noted in Media Watch dated 29 August 2011). <u>http://www.guardian.co.uk/society/2011/</u> aug/26/do-not-resuscitate-medicalpatient
- U.K. | The Guardian 29 August 2011 'Patient Concern demands national policy on 'do not resuscitate' orders.' A patients' rights group ... Patient Concern wants legally enforceable regulations to ensure the orders are added to patients' medical notes only with their consent or, if they are not mentally competent, the permission of their family or lawyer. Guidance would not be enough. <u>http://www.guardian.co.uk/society/2011/aug/29/do-not-resuscitate-regulation-janet-tracey</u>

#### Funding hospice

#### Hospice relief a cut too far

U.K. | News & Star (Carlisle) - 30 August 2011 - Argue the importance of one charity over another and you step perilously onto very thin ice. Each has its own supporters, loyal volunteers and grateful users of services provided outside the private and public sectors. A tough call for local authorities then. Budgeting painfully for spending cuts, it was inevitable councils would look again at help given to charities through rates relief – a bone of contention with some commercial concerns. But it's hard to make a case for treating all local charities in exactly the same way when one of them is a hospice, offering specialist care for the terminally ill - care the NHS [National Health Service] couldn't take on, even in boom years. Eden Valley Hospice is an indispensable care provider, on which communities in Carlisle and beyond rely. It depends on donations for 80% of more than £3m a year needed to function. The Department of Health, mindful of its crucial work, chips in around 20%. Care for the terminally ill, dying and life-threatened children is what a civilised community offers willingly. Are we really ready to endanger that?http://www.newsandstar.co.uk/opinion/our-view/hospicerelief-a-cut-too-far-1.873146?referrerPath=opinion/

#### **Specialist Publications**

Of particular interest:

'Home care in Europe: A systematic literature review' (p.7), publish by *BMC Health Services Research.* 

# **Quotable Quotes**

If you tell the truth, you don't have to remember anything. Samuel Langhorne Clemens (Mark Twain) [1835-1910]

# Sri Lanka, Thailand to adopt Kerala model in palliative care

ASIA | *Times of India* – 29 August 2011 – Kozhikode based Institute of Palliative Medicine [IPM] that has been spearheading the palliative care movement in the state will help developing countries like Sri Lanka, Thailand, Ethiopia and Seashell Island [*sic*]<sup>1</sup> to adopt Kerala model of cost-effective community-based palliative care system. The IPM – the only World Health Organisation collaborating centre in the developing countries – has already held first round of discussion with the Sri Lankan government to include palliative care in its health control programme. In Thailand, IPM will work in collaboration with Khon Khen University and the National Research University. <u>http://articles.timesofindia.indiatimes.com/2011-08-</u>29/kozhikode/29940820 1 palliative-care-kerala-model-countries

1. Palliative Care Project for the Seychelles: <u>http://www.hospicecare.com/news/04-06/regional-reports.html</u>

From Media Watch dated 29 August 2011:

INDIA | Business Standard (New Delhi) – 25 August 2011 – 'Kerala healthcare model may be copied nationwide.' A discussion note, prepared by the India office of the World Health Organisation [WHO] and the health ministry, identified Kerala as the country's only state that has a palliative care policy in line with WHO's public health approach in this area. <a href="http://www.business-standard.com/india/news/kerala-healthcare-model-may-be-copied-nationwide/446965/">http://www.business-standard.com/india/news/kerala-healthcare-model-may-be-copied-nationwide/446965/</a>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

 BULGARIA | The Echo (Sofia) – 1 September 2011 – 'Bulgarian MPs reject proposed euthanasia law.' Euthanasia of terminally ill people will not be allowed in Bulgaria, after members of Parliament voted on 1 September 2011 to reject a draft law by socialist MP Lyuben Kornezov. http://www.sofiaecho.com/2011/09/01/1148746 bulgarian-mps-reject-proposed-euthanasia-law

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

#### Home care in Europe: A systematic literature review

BMC HEALTH SERVICES RESEARCH | Online article – Home care systems appeared to differ both between and within countries. The papers included [in this literature search], however, provided only a limited picture of home care. Many studies only focused on one aspect of the home care system and international comparative studies were rare. Furthermore, little information emerged on home care financing and on home care in general in Eastern Europe. This review clearly shows the need for more scientific publications on home care, especially studies comparing countries. A comprehensive and more complete insight into the state of home care in Europe requires the gathering of information using a uniform framework and methodology. http://www.biomedcentral.com/content/pdf/1472-6963-11-207.pdf

Of related interest:

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2011;17(8):398-404. 'Challenges in home-based palliative care in Norway: A qualitative study of spouses' experiences.' Issues around patients' preferred place of care and death are taking greater precedence of late. However, little is known about patients' and carers' experiences of palliative care in the home setting. This study explored carers' views of what determines the quality of home care at the end of life. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=85939;article=IJPN 17 8 398 404

### American College of Surgeons eases the pain of providing palliative care

BULLETIN OF THE AMERICAN COLLEGE OF SURGEONS | Online article – Accessed 2 September 2011 – In keeping with its mission of patient advocacy, the American College of Surgeons has taken steps in recent years to train surgeons in the safe, effective, and compassionate delivery of palliative care. Examples include forming panels to examine the issues involved, releasing statements on end-of-life care, presenting and cosponsoring symposia on the subject, and publishing educational materials for use in surgical training programs. http://www.facs.org/fellows\_info/bulletin/2011/schneidman0911.pdf

# Participatory knowledge exchange to support palliative care in Chile: Lessons learned through global health research

*CANADIAN JOURNAL OF NURSING RESEARCH*, 2011;43(3):16-37. The authors designed a ... qualitative research study to develop a collaborative partnership between palliative care practitioners in Canada and in Chile. The research goal was to support the provision of palliative care in vulnerable settings through a participatory knowledge exchange process using qualitative and participatory methodologies. The study involved an inter-professional palliative care team from a primary health care centre in Chile and 5 adults receiving palliative care and their relatives. http://www.ingentaconnect.com/content/mcgill/cjnr/2011/0000043/0000003/art00003

### Patient autonomy and the twenty-first century physician

*THE HASTINGS REPORT*, 2011;41(5):3. Daniel Groll suggests new ways to understand old tensions between autonomy and paternalism.<sup>1</sup> He categorizes disagreements between doctors and patients in four ways ... [and] shows that physicians can offer non-medical recommendations without violating patient autonomy. This simple concept sometimes gets lost in spirited defenses of autonomy that view doctors as inordinately powerful and patients as inordinately susceptible to authority. <u>http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5492</u>

 'What health care providers know: A taxonomy of clinical disagreement,' *The Hastings Report*, 2011;41(5):27-36. Some assume that respecting patient autonomy means clinicians should refrain from expressing opinions about what's in a patient's best interests. But depending on the kind of medical decision the patient is making, a clinician may have expertise vital to the patient's best interests... <u>http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5503</u>

#### End-of-life care and barriers for female inmates

JOURNAL OF OBSTETRIC, GYNECOLOGIC, & NEONATAL NURSING, 2011;40(4):477-485. The number of female inmates is growing, and their average age is increasing. As a result, endof-life care is situated in a highly restrictive environment with a focus on security rather than comfort. The authors describe the need for and potential barriers to humane care and provide care strategies that can be useful in a complex organizational system. Frontline workers such as nurses who understand the balance between care and control must promote change in the women's prison system. <u>http://onlinelibrary.wiley.com/doi/10.1111/j.1552-</u> 6909.2011.01260.x/abstract

#### 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. <u>http://www.pcn-e.com/community/pg/file/world/world/</u>

### No place like the hospital

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 2 September 2011 – A case is presented in which a patient dying of irreversible small bowel obstruction from metastatic cancer insisted on remaining in the acute care hospital for care when alternative sites of care, including a skilled nursing facility and residential hospice, were available to her and covered by her health insurance plan. The ethical issues raised by this case are discussed from the perspective of the patient, the clinical team, the hospital, and the insurance company. Over the past decade, hospital-based palliative care consultation and general inpatient hospice care have sought to improve the quality of dying in the hospital. To the extent that such efforts have been successful, they may result in increasing demand for the hospital as the site for terminal care in the future. <a href="http://www.jpsmjournal.com/article/S0885-3924(11)00380-0/abstract">http://www.jpsmjournal.com/article/S0885-3924(11)00380-0/abstract</a>

Of related interest:

 BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – 25 August 2011 – 'Opinions of patients with cancer on the relative importance of place of death in the context of a 'good death." Place of death is undoubtedly an important factor in achieving a good death for some patients and carers. However, for others a home death is either unimportant or to be avoided. http://spcare.bmj.com/content/early/2011/08/25/bmjspcare-2011-000041.abstract

# Lessons from beyond Europe: Reflections on the evolution of palliative care research and policy in Canada

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 29 August 2011 – In Canada, the aging population with a rising incidence of chronic diseases – and thus more complex care needs – is putting significant pressure on the health care system, long-term care system, and family caregivers. Ten years ago, the Government of Canada appointed Canada's first Minister with Special Responsibility for Palliative Care. During that time, the federal government developed significant public policy goals for palliative care, including the Canadian Strategy for Palliative and End-of-Life Care. This strategy led to many policy improvements, particularly in the areas of research and data collection, education for health care professionals, and support for caregivers. In 2007, the Secretariat within the federal government supporting the Canadian strategy was defunded and disbanded. Four years later, progress in improving palliative care for Canadians has slowed. This article reviews some of the successes of palliative care policy and research in Canada and outlines several lessons to be learned for other jurisdictions developing public policy for palliative care. <u>http://www.jpsmjournal.com/article/S0885-3924(11)00379-4/abstract</u>

# Effect of palliative care services on the aggressiveness of end-of-life care in the Veteran's Affairs cancer population

JOURNAL OF PALLIATIVE MEDICINE | Online article – 30 August 2011 – The authors' objective was to observe the aggressiveness of cancer care near the EOL [end of life] among Veterans Affairs cancer patients before and after the institution of a PCS team. We also assessed the time taken prior to death to initiate a PCS [palliative care services] consultation and its effect on the aggressiveness of cancer care near the EOL. In the last 30 days of life, compared to 2002, patients in 2008 had a higher incidence of: chemotherapy administration, more than one hospital admission, more than 14 days of hospital stay, intensive care unit admissions, and in-hospital deaths. Patients with timely PCS consults in 2008 appeared to have a lower incidence of: chemotherapy administration, more than one hospital admission, more than 14-day hospital stays, intensive care unit admissions, and deaths in the hospital. Timely PCS consults were associated with earlier and more frequent hospice referral. http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0131

Cont.

From Media Watch dated 18 April 2011:

 U.S. | New York Times – 11 April 2011 – 'Hospital care at life's end: A disparity.' At the end of life, people with chronic diseases like cancer get more aggressive medical care in the New York area than anyplace else in the country, continuing a trend going back decades, according to a report by researchers [at the Dartmouth Institute for Health Policy & Clinical Practice, Dartmouth College, New Hampshire] <u>http://www.nytimes.com/2011/04/12/nyregion/12hospitals.html</u>

From Media Watch dated 4 April 2011:

 CANADA | National Post – 31 March 2011 – 'Weighing the merits of 'never-say-die' oncology.' A new Ontario study reveals ... that cancer patients are increasingly undergoing emergency department treatment, chemotherapy and other "aggressive" care in the last few weeks of their lives. <u>http://www.nationalpost.com/news/Weighing+merits+never+oncology/4531556/story.html</u>

From Media Watch dated 21 March 2011:

 JOURNAL OF CLINICAL ONCOLOGY | Online article – 14 March 2011 – 'Trends in the aggressiveness of end-of-life cancer care in the universal health care system of Ontario, Canada.' Aggressiveness of cancer care near the EOL is increasing ... although overall rates were lower than in the U.S. <u>http://jco.ascopubs.org/content/early/2011/03/14/JCO.2010.31.9897.abstract</u>

From Media Watch dated 23 August 2010:

NEW ENGLAND JOURNAL OF MEDICINE | Online article – 18 August 2010 – 'Early palliative care for patients with metastatic non-small-cell lung cancer.' ... early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life, but longer survival. <a href="http://www.nejm.org/doi/full/10.1056/NEJMoa1000678">http://www.nejm.org/doi/full/10.1056/NEJMoa1000678</a>

#### **REM** sleep could prompt life-saving decisions

*NEW SCENTIST* | Online article – 1 September 2011 – The brain waves associated with sleep and dreaming could be helpful for distinguishing between people in a persistent vegetative state and those who are minimally conscious – a distinction that could seal the fate of the individual. The minimally conscious state, persistent vegetative state and coma are all disorders of consciousness caused by severe brain damage. Minimally conscious individuals tend to have better outcomes than vegetative individuals, but distinguishing between them is difficult and misdiagnosis is common. Getting it wrong can sometimes mean that a person who might otherwise recover has their life-support machine switched off. Researchers at the University of Liège in Belgium ... report that minimally conscious patients respond to sounds, whereas vegetative patients do not. The team has now found more evidence that some brain function is preserved in the minimally conscious state. <u>http://www.newscientist.com/article/dn20856-rem-</u> sleep-could-prompt-lifesaving-decisions.html

Of related interest:

 CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 29 August 2011 – 'Mortality associated with withdrawal of life-sustaining therapy for patients with severe traumatic brain injury: A Canadian multicentre cohort study.' Considering the high proportion of early deaths associated with the withdrawal of life-sustaining therapy and the limited accuracy of current prognostic indicators, caution should be used regarding early withdrawal of life-sustaining therapy following severe traumatic brain injury. http://www.cmaj.ca/content/early/2011/0 8/29/cmaj.101786



#### Palliative care and hospice in advanced heart failure

*PROGRESS IN CARDIOVASCULAR DISEASES*, 2011;54(2):168-178. Despite a growing body of evidence ... palliative therapies remain underused in the treatment of advanced HF [heart failure]. Review of the literature reveals that although barriers to integrating palliative care are not fully understood, difficult prognostication combined with caregiver inexperience with end-of-life issues specific to advanced HF is likely to contribute. In this review, the author's outline the general need for palliative care in advanced HF, detail how palliative measures can be integrated into the care of those having this disease, and explore end-of-life issues specific to these patients. <a href="http://www.sciencedirect.com/science/article/pii/S0033062011000673">http://www.sciencedirect.com/science/article/pii/S0033062011000673</a>

From Media Watch dated 8 August 2011:

 CONGESTIVE HEART FAILURE | Online article – 1 August 2011 – 'Ethics in the treatment of advanced heart failure: Palliative care and end-of-life issues.' Planning for adverse events and the end of life, formulated as "preparedness planning," can be integrated into HF [heart failure] care early in illness. <u>http://onlinelibrary.wiley.com/doi/10.1111/j.1751-7133.2011.00245.x/abstract</u>

From Media Watch dated 7 March 2011:

JOURNAL OF CARDIAC FAILURE, 2011;17(3):231-252. 'Palliative care in advanced heart failure: An international review of the perspectives of recipients and health professionals on care provision.' Advanced HF patients report little discussion with health professionals about their clinical status and sense a lack of timely support to accommodate their evolving needs. Health professionals report poor multidisciplinary communication and lack confidence both in diagnosing advanced HF and in communicating a poor prognosis to those affected, affecting the provision of good-quality coordinated care. <a href="http://www.onlinejcf.com/article/S1071-9164(10)01144-9/abstract">http://www.onlinejcf.com/article/S1071-9164(10)01144-9/abstract</a>

#### 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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#### 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.

# Unsolicited written narratives as a methodological genre in terminal illness: Challenges and limitations

*QUALITATIVE HEALTH RESEARCH* | Online article – 29 August 2011 – Stories about illness have proven invaluable in helping health professionals understand illness experiences. Such narratives have traditionally been solicited by researchers through interviews and the collection of personal writings, including diaries. These approaches are, however, researcher driven; the impetus for the creation of the story comes from the researcher and not the narrator. In recent years there has been exponential growth in illness narratives created by individuals, of their own volition, and made available for others to read in print or as Internet accounts. The authors sought to determine whether it was possible to identify such material for use as research data. <a href="http://ghr.sagepub.com/content/early/2011/08/27/1049732311420737.abstract">http://ghr.sagepub.com/content/early/2011/08/27/1049732311420737.abstract</a>

From Media Watch dated 15 June 2009:

JOURNAL OF PALLIATIVE CARE, 2009;25(1):61-67. 'What is a good death?' The components
of good and bad deaths have not been well elucidated in the literature. Furthermore, the value of
using narratives in palliative care research has not been extensively explored. The authors invited
people involved in palliative care (patients, caregivers, physicians and nurses) to tell their stories of
good and bad deaths. <u>http://www.ncbi.nlm.nih.gov/pubmed/19445343</u>

# Worth Repeating

# Indigenous ethnic minorities and palliative care: Exploring the views of Irish Travellers and palliative care staff

PALLIATIVE MEDICINE, 2007;21(7):635-641. Indigenous people are among the ethnic minorities who encounter palliative care services. This research shows that Irish Travellers have little experience of specialist palliative care and that specialist palliative care providers have little knowledge or experience of Irish Travellers. Characteristics of Irish Travellers culture including the importance of hope, avoidance of open acknowledgment of death, the importance of family and the avoidance of the place of death (including moving away or burning caravans where death has occurred) challenge the provision of specialist palliative care. Individualisation of patient care, a feature of specialist palliative care can help staff provide appropriate care. http://pmj.sagepub.com/content/21/7/635.ab stract

Irish Travellers are a traditionally nomadic people of ethnic Irish origin, who maintain a separate language and set of traditions. They live predominantly in Ireland, the U.K. and the U.S.

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