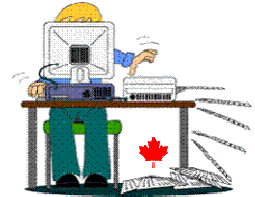


## Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

**Terminology and language of end-of-life care: Scroll down to [Specialist Publications](#) and 'Does it matter what you call it? A randomized trial of language used to describe palliative care services' (p.11), in *Supportive Care in Cancer*.**

## Canada

### End-of-life decision-making

#### **New research raises ethical questions over helping those in "vegetative" state**

ONTARIO | Global News (Toronto) – 15 August 2013 – While a Canadian man has been in vegetative state for 12 years following a car accident, neuroscientists at the University of Western Ontario say they've communicated with the man by concentrating on a string of "yes" or "no" questions. He's one of three brain injury victims the researchers have tried to reach out to. Their next steps are to consider how many more patients may be "trapped" in their bodies and if this technology could provide autonomy to these patients in making health decisions. It's uncharted territory in communicating with unresponsive patients – and with this breakthrough comes many questions, experts say. "If in fact you can reach in and have some kind of communication then I would argue we have an ethical obligation to be really, honestly checking in with those patients and allowing those patients to weigh in on their own end-of-life decisions," Dr. Kerry Bowman told Global News. He's a bioethicist and professor at the University of Toronto, specializing in end-of-life decision-making. <http://globalnews.ca/news/782601/new-research-raises-ethical-questions-over-helping-those-in-vegetative-state/>

Noted in Media Watch, 4 March 2013, #295 (p.12):

- *REVISTA DE BIOÉTICA Y DERECHO*, 2013;27(1):13-27. **'Distinguish patients in a vegetative state from the minimally conscious state: Moral and legal dilemmas.'** Research ... findings make all the more urgent the familiar moral and legal dilemmas arising in connection with persons in these "reduced" states, because in debating whether these persons have a will, we have to take into account the possibility that they may have "glimpses of consciousness." English language article: [http://www.ub.edu/fildt/revista/pdf/rbyd27\\_art-zullo.pdf](http://www.ub.edu/fildt/revista/pdf/rbyd27_art-zullo.pdf)

Noted in Media Watch, 18 February 2013, #293 (p.5):

- *AMERICAN JOURNAL OF BIOETHICS: NEUROSCIENCE*, 2013;4(1):46-51. **'Communicating with the minimally conscious: Ethical implications in end-of-life care.'** This article addresses ethical implications of the possibility of communication with minimally conscious patients. <http://www.tandfonline.com/doi/abs/10.1080/21507740.2012.740142>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *The Edmonton Journal* – 16 August 2013 – '**Canada's "parliament of medicine" set to debate end-of-life care.**' The incoming president of the Canadian Medical Association [CMA] says the time may have come for the powerful doctors' group to revisit its stance on euthanasia. Dr. Louis Hugo Francescutti says more doctors appear ready to have the same frank conversation many Canadians are being forced to have, as baby boomers watch their parents' end-of-life struggles, and consider their own future. The organization officially opposes euthanasia and doctor-assisted suicide in a policy that has not been updated since 2007. But every policy is a snapshot of the thinking of the time, says Francescutti, the Edmonton emergency physician who assumes the helm of the CMA at the group's annual council meeting. <http://www.edmontonjournal.com/health/Canada+parliament+medicine+debate+life+care/8798233/story.html>

Noted in Media Watch, 12 August 2013, #318 (p.2):

- *THE NATIONAL POST* | Online – 5 August 2013 – '**Only one in four doctors would help terminally ill patients end their lives if practice was legal in Canada.**' Only 25% of the nation's doctors would be willing to help terminally ill patients end their lives if the practice of doctor-assisted suicide were legalized, a survey by Canada's biggest doctors' group suggests. <http://news.nationalpost.com/2013/08/05/only-one-in-four-doctors-would-help-terminally-ill-patients-end-their-lives-if-practice-was-legal-in-canada/>

## U.S.A.

### A good death: How boomers will change the world a final time

*TIME* | Online – 14 August 2013 – Surely the world has heard enough of the Baby Boomers, who have dominated the political, cultural and economic landscape for six decades. But a generation that has refused to go quietly into any life stage will, it seems, be heard from one final time on the biggest issue of them all: how to die. For eons, folks grew old, endured the symptoms, and died when it was their time – according to God's will, some would say, even if it involved fighting through lingering illness, pain and suffering, or years of mental or physical incapacitation. A "good" death was about having lived long enough to see grandchildren, put one's affairs in order, and pass away surrounded by a loving family. Boomers don't

see it that way ... a good death is more about a good life. When they can't have that any longer, it's time to pull the plug. This will be the first generation to broadly eschew painful life-extending procedures and make the most of palliative care to live better in fewer days, and then die with dignity. <http://business.time.com/2013/08/14/a-good-death-how-boomers-will-change-the-world-a-final-time/>

#### Specialist Publications

'Few states meet palliative care benchmark' (p.7), in *Family Practice News*.

Noted in Media Watch, 18 March 2013, #297 (p.3):

- FLORIDA | *The Herald-Tribune* (Sarasota) – 16 March 2013 – '**Boomers poised to reinvent end-of-life care.**' For millions ... who witness their parents' journey through a medical maze of unprecedented complexity and cost, it's a question that comes up sooner or later: How will I grow old and die? <http://www.heraldtribune.com/article/20130316/ARTICLE/130319694>

## Medicine's most important teachers

*THE ATLANTIC* | Online – 12 August 2013 – This month and next, almost 20,000 U.S. students will be reporting for their first day of medical school. Guiding them through this process are almost 150,000 faculty members, many holding MD or PhD degrees, often boasting decades of experience in patient care, research, and teaching. At this time it's worth remembering, though, that our most important medical educators never went to medical or nursing school. They are patients, the people for whom medical students are learning to care. As ... William Osler once said, medical education at its best "begins with the patient, continues with the patient, and ends with the patient." In other words, no matter how knowledgeable and skilled our medical school faculty members, medical education centers less on what the teachers seek to teach than on what patients need future physicians to learn. As in warfare no battle plan ever survives initial contact with the enemy, so in

medical education no educational blueprint supersedes contact with the patient. <http://www.theatlantic.com/health/archive/2013/08/medicines-most-important-teachers/278573/>

### Extract from *The Atlantic* article

If we are fortunate, sometimes important lessons flow through us, but they originate in the patient. Borrowing from Socrates, we are but medical education's midwives, doing what we can to impart knowledge, but knowing full well that the patients are the ones who really bring it to life.

### [Specialist Publications](#)

**"It's not all doom and gloom": Perceptions of medical students talking to hospice patients'** (p.10), in *Journal of Palliative Medicine*.

## [International](#)

### End-of-life care in Australia

#### **"Dummies guide" recommended in plan to break taboos around death**

AUSTRALIA (AUSTRALIAN CAPITAL TERRITORY [ACT]) | *The Canberra Times* – 13 August 2013 – The ACT government has been advised to develop a "dummies guide to death" and an education program for children and adults about end-of-life issues. A report on end-of-life planning ... also calls for law reforms to make advanced care planning simpler and less daunting. The ACT Local Hospital Network Council report says Canberrans are largely unaware of advanced care plans and how to guide decisions about care at the end of their life – "management of death should be a public health issue" and recommends a government campaign to increase awareness of what end of life means, when it might start and to "counter the myth that medicine can

save people all the time." It calls on the government to normalise discussion about death and end-of-life planning by offering education and information at schools, universities, workplaces and GPs' practices. <http://www.canberratimes.com.au/act-news/dummies-guide-recommended-in-plan-to-break-taboos-around-death-20130812-2rsp2.html>

### [Specialist Publications](#)

**'Australian health policy and end-of-life care for people with chronic disease: An analysis'** (p.7), in *Health Policy*.

Cont.

Noted in Media Watch, 11 March 2013, #296 (p.4):

- AUSTRALIAN ASSOCIATED PRESS | Online – 4 March 2013 – **'Dying let down by health system: Report.'** Chronic disease accounts for more than half of Australian deaths, but scant attention is paid to the support a patient needs as their condition slowly deteriorates.<sup>1</sup>  
<http://au.news.yahoo.com/latest/a/-/latest/16292553/dying-let-down-by-health-system-report/>

1. 'Meeting end-of-life care needs for people with chronic disease: Palliative care is not enough,' *Medical Journal of Australia*, 2013;198(4):186-187. What should a system that successfully combines interventional and palliative approaches look like?  
<https://www.mja.com.au/journal/2013/198/4/meeting-end-life-care-needs-people-chronic-disease-palliative-care-not-enough>

## Why palliative care is a human right

AFRICA (RWANDA) | *The New Times* (Kigali) – 10 August 2013 – The need for worldwide palliative care coverage has never been greater. As the incidence of non-communicable diseases like cancer is rising in resource-limited settings, the need for palliative care alongside curative treatment is also growing. Basic symptom control and holistic support are not expensive and do not require highly specialised personnel, but are often lacking even where health structures and home based care programmes are in place. Inadequate drug supplies are partly to blame, but equally important, also lack of basic understanding of palliative care amongst healthcare providers at all levels, a lack of confidence in communication skills and as well a lack of knowledge of symptom control techniques. All of these may compound the inadequate procurement of the needed palliative care drugs. For these reasons communities and health workers can be overwhelmed by palliative care needs that they do not feel equipped to meet.  
<http://allafrica.com/stories/201308120501.html>

Noted in Media Watch, 11 February 2013, #291 (pp.10-11):

- *PALLIATIVE MEDICINE*, 2013; 27(2):101-102. **'The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care.'** The European Association for Palliative Care, the International Association for Hospice & Palliative Care, the World Palliative Care Alliance, and Human Rights Watch have formulated 'The Prague Charter for Palliative Care as a Human Right.'  
<http://pmj.sagepub.com/content/27/2/101.full>

### Additional articles on palliative care as a human right noted in past issues of Media Watch

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 January 2013 – **'The Lisbon Challenge: Acknowledging palliative care as a human right.'** It has been argued failure to provide palliative care for patients facing severe pain could constitute cruel, inhuman, or degrading treatment. Yet governments of many countries worldwide have still not acknowledged a human right to access palliative care for all those who need it. [Noted in Media Watch, 4 February 2013, #291 (p.7)]  
<http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0394>

### In Canada

*EDUCATIONAL GERONTOLOGY*, 2013;39(4): 241-249. **'Hospice palliative care as a human right in Canada.'** This paper describes numerous barriers that currently exist including, but not limited to, barriers from geographic location, prognosis, ageism, and constraints from the Canadian medical system that have resulted in unequal access to a patchwork of services. [Noted in Media Watch, 4 February 2013, #291 (p.7)]  
<http://www.tandfonline.com/doi/abs/10.1080/03601277.2013.750930>

*MCGILL JOURNAL OF LAW & HEALTH*, 2011; 5(1):106-160. **'Palliative care: An enforceable Canadian human right?'** The authors of this article lay out a series of approaches for establishing an enforceable human right to palliative care in Canada. They first examine international human rights instruments to which Canada is a signatory, and conclude that they offer limited assistance to palliative care advocates. [Noted in Media Watch, 26 September 2011, #220 (p.9)]  
<http://mjlh.mcgill.ca/pdfs/vol5-1/MJLH%20Vol%20V..%20No.%201%20-%20Shariff.pdf>

Cont.

Of related interest:

- AFRICA (NIGERIA) | *The Nigerian Observer* – 16 August 2013 – '**Perils of operating palliative care in Nigeria.**' A country of about 160 million people, 36 States and 774 Local Government Areas, palliative care in Nigeria is disheartening given that in 1996 a small number of Nigerians initiated a crusade for palliative care. There are only two centres across the country where services to victims of chronic ailments like cancer, HIV/AIDS and renal failures, are being rendered ... the Palliative Care Initiative (Ibadan), and Hospice Nigeria (Lagos). <http://nigerianobservernews.com/16082013/features/features4.html>

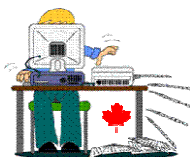
### [Specialist Publications \(e.g., in-print and online journal articles, reports, etc.\)](#)

#### **The influence of the family in conceptions of personhood in the palliative care setting in Singapore and its influence upon decision making**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 August 2013 – Conceptions of personhood are critical to the preservation of dignity and quality of life key to a good death and pivotal to the provision of patient centred care. Increasingly there is speculation that this role may be wider still. It has been posited that it is Confucian inspired conceptions of personhood replete with its "dualistic" view of personhood that sees family members as part of the individual's personhood that predispose to the prevailing practices of collusion and the trumping of patient autonomy. In a nation where family centric decision making still dominates end of life decision making, the need to appropriately conceptualise local conceptions of personhood are clear. <http://ajh.sagepub.com/content/early/2013/08/13/1049909113500136.abstract>

Of related interest:

- *THE PERMANENTE JOURNAL*, 2013;17(3):23-27. '**Non-beneficial treatment and conflict resolution: Building consensus.**' The authors established a fair and explicit non-beneficial treatment and conflict resolution policy at their medical center ... designed to help acknowledge and respect both patients and clinicians involved in treatment planning and decision making. <http://www.thepermanentejournal.org/files/Summer2013/NonbeneficialTreatment.pdf>



#### [Barry R. Ashpole](#)

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

#### [Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.12.

## Bereavement and the role of religious and cultural factors

*BEREAVEMENT CARE* | Online – 7 August 2013 – The authors give an overview of some of the key dimensions of variation in cultural and religious rituals during the immediate period after a death and in the longer term, in order to inform service delivery in multi-cultural societies. For each area they give examples of different customs, and consider their functions and possible impact. Dimensions considered in the immediate period after bereavement are: the time and space given to formal rituals, expression of feelings, assertion of status and disposal of the body. In the longer term, the authors look at variations in remembering the deceased and in continuing bonds. Throughout they consider the interplay between individual responses and the person's cultural and religious context ... to provide an accessible introduction for practitioners new to working with bereavement and provide a succinct reference point for more experienced bereavement workers. <http://www.tandfonline.com/doi/abs/10.1080/02682621.2013.812828#.UgojedJwomY>

Of related interest:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 6 August 2013 – '**Prolonged grievers: A qualitative evaluation of a support group intervention.**' The aim of this project was to study prolonged grievers psychosocial processes and experience during participation in a group intervention and 6-8 weeks after discontinuation. This study gives insight into prolonged grievers' thinking, which is valuable knowledge. Rather than assuming that all individuals suffering from prolonged grief need the same treatment, we suggest that there should be a range of different therapies. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8968278>

## Modelling the landscape of palliative care for people with dementia: A European mixed methods study

*BMC PALLIATIVE CARE* | Online – 12 August 2013 – Palliative care for people with dementia is often sub-optimal. This is partly because of the challenging nature of dementia itself, and partly because of system failings that are particularly salient in primary care and community services. There is a need to systematize palliative care for people with dementia, to clarify where changes in practice could be made. The [authors'] proposed model includes features deemed important for the systematisation of palliative care for people with dementia. These are: the division of labour amongst practitioners of different disciplines; the structure and function of care planning; the management of rising risk and increasing complexity; boundaries between disease-modifying treatment and palliative care and between palliative and end-of-life care; and the process of bereavement. The co-design approach to developing a generic model of palliative care for people with dementia has placed the person needing palliative care within a landscape of services and professional disciplines. <http://www.biomedcentral.com/content/pdf/1472-684X-12-30.pdf>

Noted in Media Watch, 12 August 2013, #318 (p.9):

- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 7 August 2013 – '**Improving the end of life for people with dementia living in a care home...**' This small non-randomized study is the first end-of-life care in dementia intervention to report an increase in family satisfaction with a reduction in hospital deaths. This is promising but requires evaluation in diverse care homes. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8968126&fulltextType=RA&fileId=S1041610213001221>

Noted in Media Watch, 8 July 2013, #313 (p.10):

- *PALLIATIVE MEDICINE* | Online – 4 July 2013 – '**White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care.**' The authors provide the first definition of palliative care in dementia ... [and] ... a framework to provide guidance for clinical practice, policy and research. 64 experts from 23 countries evaluated a set of 11 domains and 57 recommendations. <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>



## Justice, mercy, and the terminally ill prisoner

*CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS*, 2013;22(4):382-388. American society continues to struggle with the administration of criminal justice in the context of an aging prison population that now confronts profound physical infirmity, mental disorders of advanced age such as dementia, and terminal illness. The classical theories of punishment – retribution, rehabilitation, deterrence, and incapacitation – appear to leave no moral space for addressing the infirmities of age and for offering compassion for the sick and dying, particularly because the exponential increase in the prison population and vindictive moral sentiments that dominate societal views of offenders have virtually expunged rehabilitation from the pantheon of classical theories. As one commentator has observed, "the criminal justice system has taken on a very cold edge." <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8971217&fulltextType=RA&fileId=S0963180113000236>

**N.B.** Articles and reports focused on the provision and delivery of end-of-life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.12.

### End-of-life care in the U.S.

#### **Few states meet palliative care benchmark**

*FAMILY PRACTICE NEWS* | Online – 16 August 2013 – Only four states have effective strategies in place to improve access to and knowledge of palliative care services, the American Cancer Society Cancer Action Network [ACS CAN] reports.<sup>1</sup> The ACS CAN awarded top scores ... to Connecticut, Maryland, Massachusetts, and Rhode Island using a scoring system that combines grades from the Center to Advance Palliative Care's national palliative care report card with actions on model legislation.<sup>2</sup> The four states passed laws "this session that focus on improving patient quality of life through palliative care," the ACS CAN noted, with Maryland finally crossing "the finish line with a palliative care bill after a 3-year effort." The six states on the low end of the scoring range ... were Alabama, Alaska, Arkansas, Delaware, Mississippi, and Oklahoma. <http://www.familypracticenews.com/news/practice-trends/single-article/few-states-meet-palliative-care-benchmark/aa99a285c2ba1f770ae419fa55d66f20.html>

1. *How do you measure up? A Progress Report on State Legislative Activity to Reduce Cancer Incidence and Mortality*, American Cancer Society Cancer Action Network, August 2013. <http://www.acscan.org/content/wp-content/uploads/2013/08/HDYMU-2013.pdf>
2. *America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals*, Center to Advance Palliative Care, May 2011. [Noted in Media Watch, 19 September 2011, #219 (p.9)] <http://reportcard.capc.org/pdf/state-by-state-report-card.pdf>

#### **Australian health policy and end-of-life care for people with chronic disease: An analysis**

*HEALTH POLICY* | Online – 13 August 2013 – The key policy areas impacting directly on end-of-life-care are related to chronic disease, palliative care and, increasingly, aged care. This paper describes the outcomes of an audit of Australian chronic disease and end-of-life/palliative care policies. The authors identified that chronic disease health policies/strategies demonstrate a focus on prevention, early intervention and management, with scant recognition of end-of-life care needs. The majority assume that a referral to palliative care will address end-of-life care needs for people with, chronic disease. By contrast, palliative care policies recognise the need for the incorporation of a palliative approach into advanced chronic disease care, but there are few connections between these two policy areas. Whilst palliative care policies intersect with carer and advance care planning, policies, chronic disease policy does not. Key concerns requiring consideration when developing policy in this area are discussed and possible policy options identified. <http://www.sciencedirect.com/science/article/pii/S0168851013002145>

## Policy analysis: Palliative care in Ireland

*HEALTH POLICY* | Online – 8 August 2013 – In 2001 Ireland became one of the first nations to publish a dedicated national palliative care policy. This paper uses the "policy analysis triangle" as a framework to examine what the policy entailed, where the key ideas originated, why the policy process was activated, who were the key actors, and what were the main consequences. Although palliative care provision expanded following publication, priorities that were unaddressed or not fully embraced on the national policy agenda are identified. The factors underlying areas of non-fulfilment of policy are then discussed. In particular, the analysis highlights that policy initiatives in a relatively new field of healthcare face a trade-off between ambition and feasibility. Key policy goals could not be realised given the large resource commitments required; the competition for resources from other, better-established healthcare sectors; and challenges in expanding workforce and capacity. Additionally, the inherently cross-sectoral nature of palliative care complicated the co-ordination of support for the policy. Policy initiatives in emerging fields such as palliative care should address carefully feasibility and support in their conception and implementation. <http://www.sciencedirect.com/science/article/pii/S0168851013002054>

Noted in Media Watch, 15 July 2013, #314 (p.8):

- *IRISH MEDICAL NEWS* | Online – 12 July 2013 – '**Inequity crises in hospice care.**' The 2001 report of the National Advisory Committee on Palliative Care found that there was "wide variation in the type and level of service provision within each health board area," and it made a number of recommendations to "ensure the equitable delivery of palliative care services in all health board areas." Again, in 2009, a Health Services Executive report found there was "a wide regional and intra-regional variation in the availability of specialist palliative care in a specialist inpatient unit." In 2013 ... a new publication from the Irish Hospice Foundation has revealed there has been little progress in relation to the availability of inpatient hospice beds. [http://www.imn.ie/index.php?option=com\\_content&view=article&id=5314:inequity-crisis-in-hospice-care&catid=57:clinical-news&Itemid=3](http://www.imn.ie/index.php?option=com_content&view=article&id=5314:inequity-crisis-in-hospice-care&catid=57:clinical-news&Itemid=3)

## The critical role of caregivers in achieving patient-centered care

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2013;310(6):575-576. Achieving high-quality, cost-effective medical care remains an elusive goal of the U.S. health care system, but there is widespread agreement that patient-centered care will be a key ingredient. Yet for frail elders and patients with advanced illness, many of whom have multiple chronic diseases, patient-centered care is impossible without caregiver involvement. Although advocacy groups ... have long endorsed attention to family members and prominent research organizations ... mention families in their research agendas, the critical role of caregivers deserves considerably more attention from clinicians. <http://jama.jamanetwork.com/article.aspx?articleid=1715921>

Of related interest:

- *MEDICAL DECISION MAKING* | Online – 13 August 2013 – '**Providing informal care in terminal illness: An analysis of preferences for support using a discrete choice experiment.**' The trend for terminally ill patients to receive much of their end-of-life care at home necessitates the design of services to facilitate this. Care at home also requires that informal care be provided by family members and friends. This study investigated informal carers' preferences for support services to aid the development of end-of-life health care services. <http://mdm.sagepub.com/content/early/2013/08/13/0272989X13500719.abstract>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 5 August 2013 – '**Pain relief, spiritual needs, and family support: Three central areas in intercultural palliative care.**' Many dying patients wish to be cared for at home by their families, but as the patient often has complex needs, the family may not be able to cope with the patient's care. Formal education and in-service programs are needed for healthcare providers, together with empirical studies regarding how to achieve more culturally appropriate care in intercultural palliative practice. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8962998>



## **An instrumental variables approach to post-acute care nursing home quality: Is there a dime's worth of evidence that continuing care retirement communities provide higher quality?**

*JOURNAL OF HEALTH ECONOMICS* | Online – 9 August 2013 – For the affluent elderly, continuing care retirement communities (CCRCs) have become a popular option for long term care and other health care needs related to aging. While CCRCs have experienced significant growth [in the U.S.] over the last few decades, very little is known about the quality of care CCRCs provide. This paper is the first to rigorously study CCRCs on a national scale and the only study that focuses on nursing home quality. Using a national sample from 2005, the authors determine if the quality of post-acute care provided by CCRC nursing homes is superior to traditional nursing homes. To mimic randomization of patients, instrumental variables analysis is used with relative distance as an exclusion restriction to handle the endogeneity of the type of facility where care is provided. After adjusting for endogeneity, the authors find that CCRC nursing homes provide post-acute care quality that is similar or lower to traditional nursing homes, depending on the quality measure. <http://www.sciencedirect.com/science/article/pii/S0167629613000933>

Noted in Media Watch, 12 August 2013, #318 (p.2):

- U.S. (FLORIDA) | CBS Evening News (Tallahassee) – 9 August 2013 – **'Eleven states get failing grades for nursing home care.'** For the first time, a new report states which do a good job of caring for seniors and which fail to ensure that they won't be neglected or abused. [http://www.cbsnews.com/8301-18563\\_162-57597944/eleven-states-get-failing-grades-for-nursing-home-care/](http://www.cbsnews.com/8301-18563_162-57597944/eleven-states-get-failing-grades-for-nursing-home-care/)
- 1. 'Nursing Home Report Cards,' Families for Better Care, August 2013. <http://nursinghomereportcards.com/>

### **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 and research tool.

### **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**

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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.

## **"It's not all doom and gloom": Perceptions of medical students talking to hospice patients**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 August 2013 – End-of-life care has become a priority in medical education internationally. A previous study of hospice patients and staff regarding medical students teaching in a hospice showed positive responses from patients and hospice staff. However concern was expressed by some staff regarding medical students' welfare, contributing to gatekeeping by professionals. Studies have shown that medical students feel underprepared to care for the dying by the time they qualify. Although students [i.e., study participants] expressed some anxieties prior to their hospice visit about meeting patients who were near the end of life, they felt that the overall experience, and the time spent with patients in particular, provided valuable learning about palliative care and preparation for caring for dying patients. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0036>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 August 2013 – **'The utility of reflective writing after a palliative care experience: Can we assess medical students' professionalism?'** Exposure to palliative care, an often deeply moving clinical experience, is an optimal trigger for rich student reflection, and students' reflective writings can be explored for professional attitudes. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0462>

## **Two therapeutic approaches for palliative care patients experiencing death anxiety**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 6 August 2013 – Evidenced-based psychotherapies are not well researched for palliative care patients experiencing unrelenting anxiety about dying, even less research is focused on young adult palliative care patients with death anxiety. This study suggests that palliative care patients expressing death anxiety may benefit from either ACT [acceptance and commitment therapy] or CT [cognitive therapy] for death anxiety, however, future research is needed to explore the usefulness of each approach. Findings of this study support the theory that ACT and CT are viewed to have a similar session impact in the palliative care population. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8966339>

Of related interest:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 5 August 2013 – **'Midwifing distress at end of life: Missed opportunities?'** Birth and death are rites of passage, and preparation is important. Palliative care clinicians describe end of life as a meaningful stage of life filled with opportunity and mystery. However, in palliative care, we have a tendency to overlook dying as a means of spiritual awakening, and there is little understanding, and little or no demand, among palliative care patients, or in the broader culture, to learn the skills of dying. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8962995>

## **Understanding communication among health care professionals regarding death and dying in pediatrics**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 6 August 2013 – In this analysis of a survey conducted in a tertiary care teaching children's hospital health care professionals who felt comfortable discussing options for end-of-life care with colleagues also felt more comfortable: initiating a discussion regarding a child's impending death with his/her family, discussing options for terminal care with a family, discussing death with families from a variety of ethnic/cultural backgrounds, guiding parents in developmentally age-appropriate discussions of death with their children, identifying and seeking advice from a professional role model regarding management concerns, or interacting with a family following the death of a child. Among all three disciplines, physicians were more likely to initiate discussions with regards to a child's impending death. Health care professionals that received formal grief and bereavement training were more comfortable discussing death. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8966345>

Cont.

Of related interest:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2013;67(3):291-303. '**Complicated grief in children: The perspectives of experienced professionals.**' Experienced clinicians and researchers worldwide responded to a survey consisting of both structured and open-ended questions on complicated grief in children. Analyses showed professionals struggled with defining complicated grief in children, although they agreed that the major defining aspects were intensity, duration, and longevity of reactions. They identified traumatic and delayed or inhibited grief as major types, and also agreed that adult criteria were inappropriate for children. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,5;journal,1,265;linkingpublicationresults,1:300329,1>

### **Does it matter what you call it? A randomized trial of language used to describe palliative care services**

*SUPPORTIVE CARE IN CANCER* | Online – 14 August 2013 – Integration of palliative care into oncology practice remains suboptimal. Misperceptions about the meaning of palliative care may negatively impact utilization. When compared to palliative care [in this study], the term supportive care was associated with better understanding, more favorable impressions, and higher future perceived need. There was no difference in outcomes between traditional and patient-centered descriptions. <http://link.springer.com/article/10.1007/s00520-013-1919-z>

Articles on defining end-of-life care noted in past issues of Media Watch:

- *THE ONCOLOGY REPORT* | Online – 10 April 2013 – '**Is the moniker "palliative care" too loaded?**' A survey of 169 patients with advanced cancer found those randomized to hear the term "supportive care" instead of "palliative care" rated their understanding, overall impressions and future perceived need for those services significantly higher. [Noted in Media Watch, 15 April 2013, #301 (pp.14-15)] <http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/what-s-in-a-name-is-the-moniker-palliative-care-too-loaded/15b05715fc83fdc88503a88bc9cbfc0e.html>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 11 January 2013 – '**Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process: A qualitative study.**' Although most [study participants] claimed that early referrals to the service are preferable, oncologists identified several challenges, related to the timing and communication with patients regarding the referral... [Noted in Media Watch, 14 January 2013, #288 (p.7)] <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814761&fulltextType=RA&fileId=S1478951512000685>
- *SUPPORTIVE CARE IN CANCER* | Online – 31 August 2012 – '**Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks.**' Commonly used terms such as "supportive care," "best supportive care," "palliative care," and "hospice care" were rarely and inconsistently defined in the palliative oncology literature. [Noted in Media Watch, 3 September 2012, #269 (p.7)] <http://link.springer.com/article/10.1007/s00520-012-1564-y>

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

Representative sample of recent articles, etc:

- *MEDICAL CARE* | Online – 6 August 2013 – '**Euthanasia and assisted suicide in selected European countries and U.S. States: Systematic literature review.**' Despite some common characteristics between countries, the authors found wide variation in the extent and specific characteristics of those who died an assisted death. [http://journals.lww.com/lww-medical-care/Abstract/publishahead/Euthanasia\\_and\\_Assisted\\_Suicide\\_in\\_Selected.99253.aspx](http://journals.lww.com/lww-medical-care/Abstract/publishahead/Euthanasia_and_Assisted_Suicide_in_Selected.99253.aspx)

## From the Archives: 1976

### **The problem of caring for the dying in a general hospital: The palliative care unit as a possible solution**

*CANADIAN MEDICAL ASSOCIATION JOURNAL*, 1976:115(2):119-121. The general hospital as a setting for terminal care has disturbing deficiencies: particularly, the medical, emotional and spiritual needs of the patients and their families are generally neglected. Consideration of the options for improving the situation led to the opening of the palliative care unit (PCU) at the Royal Victoria Hospital, Montreal, which is staffed by an interdisciplinary team with a positive and creative attitude to death and bereavement. The service comprises three areas of care – the PCU itself, a domiciliary service and a consultative service – as well as research, teaching and administrative functions. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1878558/pdf/canmedaj01484-0031.pdf>

#### Media Watch Online

##### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/](http://APHN.ORG/CATEGORY/MEDIA-WATCH/)

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

##### **Australia**

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

##### **Canada**

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

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

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/?s=ashpole>

##### **Europe**

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

##### **International**

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> (Scroll down to 'Aggregators' and Barry Ashpole and Media Watch)

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