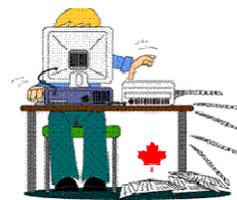


Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

Community policy, development and resourcing: Scroll down to [Specialist Publications](#) and 'Circles of care: Should community development redefine the practice of palliative care?' (p.7), in *BMJ Supportive & Palliative Care*.

Canada

Making Albertans more aware they have quality end-of-life care

ALBERTA | *The Edmonton Journal* (Letter) – 14 March 2013 – We at the Palliative Care Institute would like to comment on a population survey conducted in Alberta on the right to hastened death.¹ Based on the University of Alberta's Population Research Laboratory's annual 2010 health-care survey, 72.6% of the 1,203 respondents polled said yes to the question: Should dying adults be able to request and get help from others to end their life early; in other words, this is a request for assisted suicide? This compares with an earlier, more comprehensive peer-reviewed 1995 study done in Alberta of a similar size that also included 179 physicians, and 62 patients with terminal cancer, the latter agreeing to face-to-face interviews. A slight majority of the general public and the terminally ill patients ... agreed with the legalization of euthanasia and assisted suicide, while most physicians (61% to 94%) opposed it. The two studies suggest that over the past decade and a half there has been a slight trend toward support of hastened death in Alberta. We agree with the recent study that public perception should continue to be examined. However, as researchers and clinicians associated with the

institute, we remain concerned about whether the public adequately understands that quality and integrated hospice and palliative care services are available in Alberta. <http://www.edmontonjournal.com/Featured+letter+Making+Albertans+more+aware+they+have+quality+life+care/8100696/story.html>

Confusion between assisted or facilitated death and other end-of-life decisions

Authors of an article in a 2007 edition of the *Canadian Journal of Public Health* observed that public opinion polls on assisted or facilitated death should be interpreted in the light of the wording of the question.¹ The authors observed that education of the population on end-of-life decisions would be an important prerequisite to engage in public debate concerning the decriminalisation of assisted or facilitated death. **BRA**

1. 'Confusion between euthanasia and other end-of-life decisions: Influences on public opinion polls,' *Canadian Journal of Public Health*, 2007;98(3):235-238. <http://journal.cpha.ca/index.php/cjph/article/view/820/820>

Cont.

Noted in Media Watch, 11 March 2013:

- ALBERTA | *The Calgary Sun* – 7 March 2013 – **'Most Albertans support assisted suicide: Study.'** A peer-reviewed study conducted by researchers at the University of Alberta found 77.4% of the 1,203 Albertans studied agreed with the right to a hastened death.¹
<http://www.calgarysun.com/2013/03/06/most-albertans-support-assisted-suicide-study>

1. 'The public's viewpoint on the right to hastened death in Alberta, Canada...,' *Health & Social Care in the Community*, 6 December 2012. [Noted in Media Watch, 10 December 2012]
<http://onlinelibrary.wiley.com/doi/10.1111/hsc.12007/abstract>

Elder and end-of-life care

"We're living longer, not better": Average Canadian will spend more than a decade suffering from serious illness

THE NATIONAL POST | Online – 14 March 2013 – The good news is that medical and public-health advances have brought about dramatic improvements in life expectancy over the last decades. The bad news ... is that much of that gained time is lived under the burden of serious illness. The average Canadian will spend more than a decade of his or her life dealing with diseases such as diabetes, high blood pressure or cancer, concludes the Public Health Agency of Canada in a report that underlines the downside of surviving longer. While women live on average to almost 84 years, for instance, their average healthy, disease-free longevity is just 72 years, according to the analysis, billed as the first of its kind in this country. It is no secret that chronic disease affects people's quality of life, but such calculations provide a graphic illustration of the impact, and should help drive changes in health policy and individual lifestyles, said Susan Bondy, a University of Toronto epidemiology professor. "We're living longer, but not necessarily living better," said Prof. Bondy, who

was not involved in the study. "We have turned things that used to be fatal into chronic disorders.... We do have better life expectancy, but it has not been matched in terms of quality of life or absence of disability in those later years." Average lifetimes have climbed steadily in the last century, from 61 for Canadian women in 1920 to 66 in 1940, and 79 in 1980... The agency bills the report on "health-adjusted life expectancy" as the first in a series of such studies and a baseline to measure progress in future.
<http://life.nationalpost.com/2013/03/14/were-living-longer-not-better-average-canadian-will-spend-more-than-a-decade-suffering-from-serious-illness/>

Extract from *The National Post* article

"We're living longer, but not necessarily living better. We have turned things that used to be fatal into chronic disorders..."

Of related interest:

- *MACLEAN'S MAGAZINE* | Online – 15 March 2013 – **'Provinces, territories may expand home care to deal with aging population.'** <http://www2.macleans.ca/2013/03/15/provinces-territories-may-expand-home-care-to-deal-with-aging-population/>

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>



U.S.A.

Boomers poised to reinvent end-of-life care

FLORIDA | *The Herald-Tribune* (Sarasota) – 16 March 2013 – For millions of baby boomers 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? This can be a terrifying topic, considering the data — which inspired a controversial effort to reform our nation's health care system that will play out for years to come. This cohort of 78 million Americans ... is expected to double or even triple the nation's cases of chronic diseases such as diabetes, Alzheimer's and heart failure. The 48-to-66-year-olds who will transform Florida's retirement scene for the next four or five decades ... have so far displayed a characteristically diverse approach to their health care futures. <http://www.heraldtribune.com/article/20130316/ARTICLE/130319694>

Family caregivers' contracts under scrutiny in legislation

FLORIDA | *The Tampa Bay Times* – 16 March 2013 – Love and duty led [Patty] Wallace two years ago to take in her widowed mother, who suffers from dementia. But Wallace, 61, worries she may one day have to put her mother in a nursing home. To prepare for that possibility, she did something that she never expected: She signed a contract with her mother. Wallace gets \$2,000 a month from her mother, a former factory worker who had less than \$60,000 once she sold her home. The "personal services contract" is a legal way for her mother to redistribute her assets so she would qualify for Medicaid coverage should she go into a nursing home. It's also a way to compensate her daughter, her sole caregiver. "For somebody to say I'm doing this for the money, come spend a week with me," said Wallace. "I'm too tired to think about the money." But state officials say they've seen wealthier families abuse the system and are asking the Legislature to rein in the contracts. <http://blogs.tampabay.com/news/health/family-caregivers-contracts-under-scrutiny-in-legislation/2109442>

Noted in Media Watch, 9 January 2012:

- *QUALITATIVE SOCIOLOGY* | Online – 24 December 2011 – '**Caught between love and money: The experiences of paid family caregivers.**' This paper considers the experiences of family home care providers, paid an hourly wage by California's In Home Supportive Services program... <http://www.springerlink.com/content/d25461886w842065/>

Noted in Media Watch, 22 December 2008:

- *CANADIAN JOURNAL OF ELDER CARE* | Online – 15 December 2008 – '**Formalizing the informal: Family care agreements in Canada and the U.S.**' Family caregiving agreements are increasingly being used to formalize the responsibilities that family caregivers undertake when providing in-home assistance for their older relatives. Under such agreements, each party can be better off because of the bargain that these agreements represent. <http://www.bcli.org/cjel/projects/formalizing-informal-family-care-agreements-canada-and-united-states>

Give patients end-of-life options

CNN NEWS | Online – 15 March 2013 – We must have publicly reported data on the degree in which our health care system delivers on the promise of patient centered care -- that health care providers are informing patients and their families of the expected prognosis and treatment options, helping them in making these difficult decisions, and that patients are provided the right care at the right time, in the right place, and consistent with their informed wishes. We must hold our health care system accountable to the goal that medical decisions should reflect patient informed goals and values. <http://www.cnn.com/2013/03/15/opinion/teno-end-of-life-care/index.html>

Families may gain from observing CPR

THE NEW YORK TIMES | Online – 14 March 2013 – It seems counterintuitive: allowing family members of deathly ill patients to watch while doctors try to restart the patients' hearts. Wouldn't it be traumatic for the family to see? Couldn't it be distracting for the doctors? But a new study, the largest rigorous trial on this issue to date, has found that family members who observed resuscitation efforts were significantly less likely to experience symptoms of post-traumatic stress, anxiety and depression than family members who did not.¹ The results ... applied regardless of whether the patient survived; most did not, since frequently patients in such dire condition cannot be saved. The study, which involved 570 people in France whose family members were treated by emergency medical teams at home, also found that the presence of relatives did not

affect the results of cardiopulmonary resuscitation, did not increase stress on physicians or other members of the medical teams, and did not result in legal claims. <http://www.nytimes.com/2013/03/14/health/visiting-cpr-benefits-patients-families-study-finds.html?ref=health&r=0>

Extract from *The New York Times* article

Witnessing CPR, say some emergency medicine experts and family members, can demystify a seemingly frightening process, provide reassurance that everything has been done to try to save the patient, and offer closure for relatives wanting to be with loved ones until the very last moment. It also shows relatives why reviving someone in cardiac arrest is much less likely than people assume from watching television.

1. 'Family presence during cardiopulmonary resuscitation,' *New England Journal of Medicine*, 14 March 2013. http://www.nejm.org/doi/full/10.1056/NEJMoa1203366?query=featured_home

Cont. next page

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

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.

Of related interest:

- ILLINOIS | *The Paris Beacon-News* – 14 March 2013 – **'New uniform do-not-resuscitate advance directive form available: Citizens now have more options in treatment level.'** The new Illinois Department of Public Health (IDH) form adds a greater level of specificity when it comes to decisions about cardiopulmonary resuscitation (CPR) and life support measures including being intubated, placed on a ventilator and fed through a tube. The new form meets requirements to nationally be considered a physician orders for life-sustaining treatment form. http://www.parisbeacon.com/news/article_23b3a780-8d03-11e2-b527-0019bb2963f4.html
- *THE NEW YORK TIMES* | Online – 14 March 2013 – **'New data to consider in DNR decisions.'** ...only 18 to 20% of older patients in hospitals who suffer cardiac arrest end up leaving the hospital alive. But that is an improvement from years past, when survival rates were even more abysmal. What has not been clear is what happened to older hospital patients who left the hospital after a cardiac arrest. A new study gives some answers.¹<http://newoldage.blogs.nytimes.com/2013/03/14/healthy-rate-of-survival-for-elderly-saved-by-cpr/?ref=health>

Worth Repeating

'Cardiopulmonary resuscitation on television – miracles and misinformation' (p.13), in *New England Journal of Medicine*.

1. 'Long-term outcomes in elderly survivors of in-hospital cardiac arrest,' *The New England Journal of Medicine*, 14 March 2013. <http://www.nejm.org/doi/full/10.1056/NEJMoa1200657>

International

End-of-life care in India

State government comes up with palliative care policy

INDIA (MAHARASHTRA) | *The Indian Express* (New Delhi) – 13 March 2013 – The Maharashtra public health department has come up with a policy for providing palliative care to people who suffer from life-limiting diseases ... besides elderly citizens. The palliative care unit at Tata Memorial Hospital (TMH) had been collaborating with the state government to draw up a draft policy. "The level of palliative care in the state is quite low and people first need to be sensitised to the need of palliative treatment. At TMH, 70% of patients come from outside the state making a strong infrastructure important. Apart from availability of essential medicines, psychological and emotional support for patients is equally important," said Dr. Maryann Muckaden, of the department of palliative care at TMH. There are barely five palliative care units in Mumbai, the busiest being the one at TMH which gets over 3,000 adult and 300 children a year. The other units are mostly hospices. Estimates show that only 3% of needy patients actually receive palliative care. <http://www.indianexpress.com/news/state-government-comes-up-with-palliative-care-policy/1087167/>

Noted in Media Watch, 15 October 2012:

- INDIA | *The Hindustan Times* (New Delhi) – 14 October 2012 – **'Morphine law hurting palliative care.'** <http://www.hindustantimes.com/India-news/Mumbai/Morphine-law-hurting-palliative-care/Article1-944374.aspx>

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/owner/MediaWatch>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- INDIA | *Business Standard* (New Delhi) – 15 March 2013 – '**Law Commission bats for comprehensive law on passive euthanasia.**' The Law Commission has come out in support of a Supreme Court judgement allowing withdrawal of life-support measures of a dying patient with certain safeguards, saying it is "not objectionable" from legal and constitutional angles. In its report on "passive euthanasia," the panel recommended that government evolve a comprehensive law in this regard. The report, presented to the government in August 2012, was tabled in Parliament today. http://www.business-standard.com/article/pti-stories/law-commission-bats-for-comprehensive-law-on-passive-euthanasia-113031400414_1.html
- AUSTRALIA (TASMANIA) | *The Mercury* (Hobart) – 13 March 2013 – '**Euthanasia laws spark debate.**' More than 300 submissions have been received by the State government to discuss Premier Lara Giddings' and Tasmanian Greens leader Nick McKim's proposed voluntary assisted dying legislation. The new laws, to be debated in parliament this year, would make Tasmania the first state in Australia to give advanced terminally ill patients the opportunity to take their own lives. http://www.themercury.com.au/article/2013/03/13/374452_tasmania-news.html

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

Hardships of end-of-life care with court-appointed guardians

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 15 March 2013 – In the U.S., the court-appointed guardians do not have the ability to make decisions regarding end-of-life (EOL) care for their clients. Additionally, the process of initiating EOL care measures can be slow and cumbersome, despite an existing process of getting approval for such care. This process has the potential to prolong suffering and delay imperative decisions. This article reviews the hardships that patients, court-appointed guardians, and health care staff endure while moving through the oppressive process of obtaining EOL care orders through the court. This article also proposes ways of tuning up the laws, regulations, and communications to make it easier and faster to obtain orders regarding EOL care to preserve the dignity of our patients and loved ones. <http://ajh.sagepub.com/content/early/2013/03/01/1049909113481100.abstract>

Understanding hospital admissions close to the end of life (ACE) study

BMC HEALTH SERVICES RESEARCH | Online – 11 March 2013 – Palliative care is a policy priority internationally. In England, policymakers are seeking to develop high quality care for all by focusing on reducing the number of patients who die in acute hospitals. It is argued that reducing 'inappropriate' hospital admissions will lead to an improvement in the quality of care and provide cost savings. Yet, what is meant by an 'inappropriate' admission is unclear and is unlikely to be shared by all stakeholders. The decision process that leads to hospital admission is often challenging, particularly when patients are frail and elderly. The ACE study re-opens the idea of 'inappropriate' hospital admissions close to the end of life.

The authors explore how decisions that result in inpatient admissions close to death are made and valued from the perspective of the decision-maker, and consider the implications ... for current policy and practice. <http://www.biomedcentral.com/content/pdf/1472-6963-13-89.pdf>

Extract from *BMC Health Services Research* article

...what is meant by an 'inappropriate' admission is unclear and is unlikely to be shared by all stakeholders.

Cont.

Noted in Media Watch, 14 January 2013:

- *PALLIATIVE MEDICINE* | Online – 7 January 2013 – **'The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care providers.'** Reasons for inappropriate admissions were identified: family carers being unable to cope, the 'rescue culture' of modern medicine, the financing and availability of community services and practice within aged residential care. <http://pmj.sagepub.com/content/early/2013/01/04/0269216312469263.abstract>

The Vulnerable Elders Survey and its prognostic relationship to survival in an older community-based palliative population

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 12 March 2013 – Frailty denotes a vulnerability to poor outcomes and is a common risk factor for mortality in older persons. The Vulnerable Elders Survey (VES) is an easy to administer validated screening tool to detect a frail population. Assessment of frailty has the potential to aid in prognostication for the older community dwelling palliative population. This study seeks to evaluate the relationship of the VES to prognosis in this population. In this study, the VES demonstrated high rates of vulnerability and has the potential to improve the accuracy of prognosis in older palliative community dwelling patients. <http://spcare.bmj.com/content/early/2013/03/12/bmjspcare-2012-000386.abstract>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 12 March 2013 – **'Predicting palliative care needs and mortality in end stage renal disease: Use of an at-risk register.'** Patients with chronic kidney disease and a reduced life expectancy can be accurately identified by a multi-disciplinary team using the surprise trigger question with a relatively high sensitivity and specificity. <http://spcare.bmj.com/content/early/2013/03/12/bmjspcare-2011-000165.abstract>

Community policy, development and resourcing

Circles of care: Should community development redefine the practice of palliative care?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 5 March 2013 – Specialist palliative care, within hospices in particular, has historically led and set the standard for caring for patients at end of life. The focus of this care has been mostly for patients with cancer. More recently, health and social care services have been developing equality of care for all patients approaching end of life. This has mostly been done in the context of a service delivery approach to care whereby services have become increasingly expert in identifying health and social care need and meeting this need with professional services. This model of patient centred care, with the impeccable assessment and treatment of physical, social, psychological and spiritual need, predominantly worked well for the latter part of the 20th century. Over the last 13 years, however, there have been several international examples of community devel-

opment approaches to end of life care. The patient centred model of care has limitations when there is a fundamental lack of integrated community policy, development and resourcing. The authors propose a model of care which identifies a person with an illness at the centre of a network which includes inner and outer networks, communities and service delivery organisations. All of these are underpinned by policy development... <http://spcare.bmj.com/content/early/2013/03/05/bmjspcare-2012-000359.abstract>

Extract from *BMJ Supportive & Palliative Care* article

The patient centred model of care has limitations when there is a fundamental lack of integrated community policy, development and resourcing.

Cont.

Of related interest:

- *CANADIAN FAMILY PHYSICIAN*, 2013;59(3):243-245. **'Back to the future: Home-based primary care for older homebound Canadians.'** [Part 2] Although Canadian family physicians have moved away from housecalls ... Canada is well positioned to adopt the emerging modern model of home-based primary care. Recent political interest and successful local demonstration models have arisen and provincial governments to continue investing in the development and expansion of these programs. <http://www.cfp.ca/content/59/3/243.full.pdf+html>

N.B. Part 1: <http://www.cfp.ca/content/59/3/237.full.pdf+html>

- *HEALTH AFFAIRS*, 2013;32(3):544-551. **'Strong social support services, Such as transportation and help for caregivers, can lead to lower health care use and costs.'** A growing evidence base suggests services that address social factors with an impact on health ... must be integrated into new models of care if the Institute for Healthcare Improvement's Triple Aim is to be realized. <http://content.healthaffairs.org/content/32/3/544.abstract>

N.B. U.S. Institute for Healthcare Improvement's Triple Aim initiative:
<http://www.ih.org/offerings/Initiatives/TripleAim/Pages/default.aspx>

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2013;45(3):488-505. **'Delivery strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness...'** A single case conference added to current specialized community-based palliative care reduced hospitalizations and better maintained performance status. Comparatively, patient/caregiver education was less effective; GP education was not effective. [http://www.jpmsjournal.com/article/S0885-3924\(12\)00274-6/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00274-6/abstract)

"Nice idea. Pity about the practice."

The Liverpool Care Pathway [LCP]: What do specialists think?

BRITISH MEDICAL JOURNAL | Online – 7 March 2013 - The motivation and idea behind optimal palliation during the final days of a person's life is an acceptable concept to most health workers. It makes good medical sense and is the end of the continuum of good palliative care or even acute care. The idea of making someone comfortable and easing suffering sounds good. Relatives like to think their loved ones are at peace. This is the plan. There are a number of practical issues involved, not least of which is: Who will diagnose imminent death or dying? What internationally accepted criteria are used, or do such guidelines even exist? What evidence base is there that opiates and sedatives, plus or minus no nutrition or fluid, are good for anything except to hasten death? The differential diagnosis of "dying" is large with copious accounts of recoveries, and various syndromes such as "locked in," minimally conscious state, electrolyte abnormalities, and many more dying scenarios that recover and sometimes to full health. Before any invasive procedure a thorough

investigation is carried out, and likewise objective data are obtained before starting any treatment. Thorough assessment of the diagnosis of "dying" should also happen especially since the course of treatment being considered (LCP) will definitely confirm the diagnosis! Palliative care physicians acknowledge they cannot diagnose dying with any certainty and these are specialists in the area. Angels fear to tread type of idea, but junior trainees seem to have become expert at diagnosing "dying" according to reports. <http://www.bmj.com/content/346/bmj.f1184/rr/634874>

Extract from *British Medical Journal* article

Palliative care physicians acknowledge they cannot diagnose dying with any certainty and these are specialists in the area. Angels fear to tread type of idea, but junior trainees seem to have become expert at diagnosing "dying" according to reports.

Loss and separation

Interventions for spousal bereavement in the older adult: An evidence review

DEATH STUDIES | Online – 11 March 2013 – A search was performed to review publications over the last 20 years examining the effect of interventions on grieving processes for older bereaved spouses. Nine publications met inclusion criteria and were critically reviewed. Study designs, populations, and outcomes measured varied widely. All intervention types showed improvements in grief-related outcomes, but statistical significance of major measures between interventions and controls was absent in all but one study using a mind-body intervention. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2011.649941>

Of related interest:

- *ILLNESS, CRISIS & LOSS*, 2013;21(1):3-13. **'I'm not the man I was: Reflections on becoming a widower.'** This article focuses on the intertwined questions of profound loss, the search for meaning, and the impact of that search on the reshaping of identities. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,10;journal,1,73;linkingpublicationresults,1:103734,1>

Noted in Media Watch, 26 March 2012:

- *CLINICAL PSYCHOLOGY* | Online – 20 March 2012 – **'Bereavement interventions, end-of-life cancer care, and spousal well-being...'** Patient end-of-life interventions may positively influence bereavement outcomes for spouses, but based on the available evidence, it is difficult to draw definitive conclusions about the effectiveness of bereavement group interventions for spouses of patients with cancer. <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-2850.2012.01275.x/abstract?userIsAuthenticated=false&deniedAccessCustomisedMessage=>

Learning from the public: Citizens describe the need to improve end-of-life care access, provision and recognition across Europe

EUROPEAN JOURNAL OF PUBLIC HEALTH | Online – 13 March 2013 – Despite ageing populations and increasing cancer deaths, many European countries lack national policies regarding palliative and end-of-life care. This research revealed two prominent themes: 1) a need for improved quality of end-of-life and palliative care, and access to this care for patients and families; and, 2) the recognition of the importance of death and dying, the cessation of treatments to extend life unnecessarily, and the need for holistic care to include comfort and support. The public ... are concerned about the prioritization of quantity of life over quality of life and they call for improved quality of end-of-life and palliative care for patients, especially for elderly patients, and families. To fulfil the urgent need for a policy response and to advance research and care, the authors suggest four solutions for European palliative and end-of-life care: 1) institute government-led national strategies; 2) protect regional research funding; 3) consider within- and between-country variance; and, 4) establish standards for training, education and service delivery. <http://eurpub.oxfordjournals.org/content/early/2013/03/13/eurpub.ckt029.abstract>

Of related interest:

- *BMC CANCER* | Online – 8 March 2013 – **'Burden to others' as a public concern in advanced cancer: A comparative survey in seven European countries.'** Pain was the top concern in all countries, from 34% participants (Italy) to 49% (Flanders). Burden was second in England, Germany, Italy, Portugal, and Spain. Breathlessness was second in Flanders and The Netherlands. Concern with burden was independently associated with age (70+ years), living alone and preferring quality rather than quantity of life. When imagining a last year of life with cancer, the public is not only concerned about medical problems but also about being a burden. <http://www.biomedcentral.com/content/pdf/1471-2407-13-105.pdf>

Pediatric palliative care

Tackling taboo topics: How to have effective advanced care planning discussions with adolescents and young adults with cancer

JAMA PEDIATRICS | Online – 11 March 2013 – How can we clinicians talk about important but scary topics with patients and their parents? More specifically, for adolescents and young adults with cancer, how can we best engage them in advanced care planning (ACP) in a timely manner, especially in light of the reluctance by patients, families, and clinicians to open up this conversation? These are important questions: if the disease advances and the adolescent or young adult patient is no longer able to participate in decision making, then the parents or other family members will be called on for guidance regarding the medical choices the patient would have made, providing a so-called substituted judgment on behalf of the patient. Yet, frequently parents and family members do not know in sufficient detail what the patient would have wanted. Discussions that would have clarified these issues are often avoided or postponed because they are often felt to be too scary, depressing, or daunting. Indeed, getting patients and families to have these con-

versations has been a major hurdle since ACP was first advocated more than 20 years ago. <http://archpedi.jamanetwork.com/article.aspx?articleid=1663077>

End-of-life care in pediatrics: Ethics, controversies, and optimizing the quality of death

PEDIATRIC CLINICS OF NORTH AMERICA | Online – 7 March 2013 – Hospitalized children constitute most annual pediatric deaths in the U.S. The details of "how-to" provide end-of-life (EOL) care are not consistently taught to staff and therefore the actual delivery of EOL care is often inconsistent and invariably negatively associated with the long-term mental health of both the patient's family and care providers. This review describes the pertinent aspects of EOL care in pediatrics. Finally, a framework to optimize the quality of death is described, which underscores the importance of synchrony between the care team and the family at the end of a child's life. [http://www.pediatric.theclinics.com/article/S0031-3955\(13\)00023-0/abstract](http://www.pediatric.theclinics.com/article/S0031-3955(13)00023-0/abstract)

Of related interest:

- *PEDIATRIC BLOOD & CANCER*, 2013;60(5):715-718. **'When silence is not golden: Engaging adolescents and young adults in discussions around end-of-life care choices.'** <http://onlinelibrary.wiley.com/doi/10.1002/pbc.24490/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Noted in Media Watch, 14 January 2013:

- U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES | National Institute of Mental Health – 7 January 2013 – **'Guide offers a blueprint for end-of-life conversation with youth.'**¹ <http://www.nimh.nih.gov/science-news/2013/guide-offers-a-blueprint-for-end-of-life-conversation-with-youth.shtml>

1. 'Voicing My CHOICES: A Planning Guide for Adolescents and Young Adults,' Aging with Dignity, October 2012. <http://www.agingwithdignity.org/forms/voicingmychoices.pdf>

Noted in Media Watch, 15 October 2012:

- *PEDIATRICS* | Online – 8 October 2012 – **'Allowing adolescents and young adults to plan their end-of-life care.'** Adolescents and young adults want to be able to choose and record: the kind of medical treatment they want and do not want, how they would like to be cared for, information for their family and friends to know, and how they would like to be remembered. <http://pediatrics.aappublications.org/content/early/2012/10/02/peds.2012-0663.abstract>

Do nurses who care for patients in palliative and end-of-life settings perform good self-care?

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2013;15(2):99-106. While attending national End-of-Life Nursing Education Consortium train-the-trainer courses, attendees have an opportunity to participate in a 1-hour self-care session, sharing personal stories of how they and their organizations participate in this care, admitting barriers in taking good care of themselves, and talking about the importance and challenges of finding balance in life. During a period of 13 months, 605 nurses who attended one of nine national End-of-Life Nursing Education Consortium courses responded to a survey about self-care that was developed by End-of-Life Nursing Education Consortium investigators and faculty. The nurses, who filled out the survey voluntarily, ranged in age from 22 to 78 years and had between 0 and 58 years of nursing experience. The respondents practiced in all types of healthcare settings from hospices to hospitals, skilled nursing facilities, schools of nursing, and in critical care, pediatrics, geriatrics, oncology, hospice, palliative care, and medical/surgical settings. The purpose of this article was to share the descriptions of self-care among End-of-Life Nursing Education Consortium-trained nurses. It is important that palliative care nurses practice self-care so they can, in turn, provide excellent care for others. http://journals.lww.com/jhpn/Abstract/2013/04000/Do_Nurses_Who_Care_for_Patients_in_Palliative_and.8.aspx

Of related interest:

- *ADVANCES IN PALLIATIVE MEDICINE* | Online – Accessed 17 March 2013 – '**Attachment styles and the ways of coping with stress in Polish nurses.**' Secure attachment styles are significant predictors of an ability to cope under difficult circumstances. On the other hand, distorted attachment styles create an unfavorable dynamic for dealing with stressful situations, consisting of destructive and ineffective behaviors. <http://www.advpm.eu/>

Noted in Media Watch, 20 June 2011:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 8 June 2011 – '**Work-life balancing: Challenges and strategies.**' <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0095>
- *NURSING ETHICS*, 2011;18(3):317-326. '**Burnout in palliative care: A systematic review.**' <http://nej.sagepub.com/content/18/3/317.abstract>

Physician-patient-companion communication and decision-making: A systematic review of triadic medical consultations

PATIENT EDUCATION & COUNSELING, 2013;91(1):3-13. Results indicated companions regularly attended consultations, were frequently perceived as helpful, and assumed a variety of roles. However, their involvement often raised challenges. Patients with increased need were more often accompanied. Some companion behaviours were felt to be more helpful (e.g., informational support) and less helpful (e.g., dominating/demanding behaviours), and preferences for involvement varied widely. Preliminary strategies for health professionals include: 1) encourage/involve companions; 2) highlight helpful companion behaviours; and, 3) clarify and agree upon role preferences of patient/companions. [http://www.pec-journal.com/article/S0738-3991\(12\)00455-7/abstract](http://www.pec-journal.com/article/S0738-3991(12)00455-7/abstract)

Of related interest:

- *SUPPORTIVE CARE IN CANCER* | Online – 14 march 2013 – '**Understanding how cancer patients actualise, relinquish, and reject advance care planning: implications for practice.**' <http://link.springer.com/article/10.1007/s00520-013-1779-6>

L'équipe mobile de soins palliatifs en service de neurologie: Présentation de deux groupes interdisciplinaires et pluriprofessionnels fruits d'un projet commun de diffusion de la démarche palliative et d'aide à la réflexion éthique

('Mobile team of palliative care in a department of neurology: Value of two multidisciplinary and professional groups fruit of a joint distribution of the palliative approach and ethical support')

REVUE NEUROLOGIQUE | Online – 28 February 2013 – This article describes how a mobile team of palliative care and a department of neurology learned to cope with many complex end-of-life situations. After a brief introduction to inter-team cooperation, clinical work of the mobile team with patients and families and its cooperation with the neurology team are presented. The specificity of supportive care in neurology is also analyzed. Two interdisciplinary and multi-professional tools – the Palliative Care Resource Group and the Ethics Consultation Group – are described, with their activities and their goals. Specific cases illustrate some of the difficulties encountered in decision-making. <http://www.sciencedirect.com/science/article/pii/S0035378713000350>

N.B. French language article.

Media Watch Online

Asia

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

Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: <http://www.palliativecarewa.asn.au/news.php> (Scroll down to 'International palliative care news and journal articles')

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>

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>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BMC PALLIATIVE CARE* | Online – 13 March 2013 – '**De-tabooing dying control – a grounded theory study.**' De-tabooing dying control is an assumed secular process starting with open awareness contexts of dying half a century ago, and continuing with the growth of the palliative care movement and later euthanasia and physician assisted suicide legislation. <http://www.biomedcentral.com/content/pdf/1472-684X-12-13.pdf>
- *GP (U.K.)* | Online – 15 March 2013 – '**Medico-legal – new policy on assisted suicide.**' Following a House of Lords ruling in 2009, Keir Starmer QC, the director of public prosecutions (DPP), issued interim guidance clarifying grounds for prosecution of an individual aiding and abetting a suicide in contravention of the Suicide Act, 1961. In 2010, section 59 of the Coroners & Justice Act, 2009, came into force. This established a single offence of 'encouraging or assisting a suicide.' An offence is committed if the actions of the offender are deemed capable of encouraging or assisting the suicide, provided it was the offender's intention to do so. The potential ramifications for doctors became clear when the DPP published his finalised policy later the same year. One key feature in the revised policy was a new factor in favour of prosecution, namely that the offender was acting in the capacity of a medical doctor or other health-care professional and that the victim was in their care. Locked-in syndrome patient Tony Nicklinson died shortly after his application to the High Court to allow doctors to end his life without fear of prosecution was rejected, on the grounds that it would represent a major change in the law.¹ Mr. Nicklinson's widow is appealing the court's decision. The current situation puts doctors in a very difficult position. <http://www.gponline.com/Clinical/article/1174545/medico-legal-new-policy-assisted-suicide/>

1. U.K. | BBC News – 1 October 2012 – '**Tony Nicklinson right-to-die refused Court of Appeal hearing.**' <http://www.bbc.co.uk/news/uk-england-wiltshire-19797634>

Worth Repeating

Cardiopulmonary resuscitation on television – miracles and misinformation

NEW ENGLAND JOURNAL OF MEDICINE, 1996;334(24):1578-1582. Responsible, shared decision making on the part of physicians and patients about the potential use of cardiopulmonary resuscitation (CPR) requires patients who are educated about the procedure's risks and benefits. Television is an important source of information about CPR for patients. The authors analyzed how three popular television programs depict CPR. They watched all the episodes of the television programs 'ER' and 'Chicago Hope' during the 1994-1995 viewing season and 50 consecutive episodes of 'Rescue 911' broadcast over a three-month period in 1995. The authors identified all occurrences of CPR in each episode and recorded the causes of cardiac arrest, the identifiable demographic characteristics of the patients, the underlying illnesses, and the outcomes. There were 60 occurrences of CPR in the 97 television episodes – 31 on 'ER,' 11 on 'Chicago Hope,' and 18 on 'Rescue 911.' In the majority of cases, cardiac arrest was caused by trauma; only 28% were due to primary cardiac causes. Sixty-five percent of the cardiac arrests occurred in children, teenagers, or young adults. Seventy-five percent of the patients survived the immediate arrest, and 67% appeared to have survived to hospital discharge. The survival rates in the study are significantly higher than the most optimistic survival rates in the medical literature, and the portrayal of CPR on television may lead the viewing public to have an unrealistic impression of CPR and its chances for success. Physicians discussing the use of CPR with patients and families should be aware of the images of CPR depicted on television and the misperceptions these images may foster. <http://www.nejm.org/doi/pdf/10.1056/NEJM199606133342406>

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