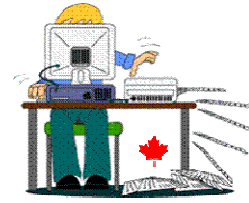


## Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010 ©

Compiled & Annotated by Barry R. Ashpole

More in their own words: Scroll down to [Specialist Publications](#) and 'Experiences of patients with serious illness at an urban public hospital' (p.7) published in the *Journal of Palliative Medicine*.

## Canada

### Palliative care falls short: Experts

ONTARIO | *Hamilton Spectator* – 24 June 2010 – Julie Darnay, director of the local [Hamilton Niagara Haldimand Brant] Hospice Palliative Care Network, said [at a recent workshop on palliative care that] a provincial palliative care policy is critical because more people in Ontario are approaching old age and medical advancements keep prolonging life. "It's like the Titanic headed toward the iceberg" [Darnay observed]. Ontario's 14 palliative care networks and a provincial coalition are currently working on recommendations to be released in August for a provincial policy, she said.  
<http://www.thespec.com/News/Local/article/795306>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *Calgary Herald* (OpEd) – 27 June 2010 – **'When doctors kill instead of heal.'** Perhaps Dutch health officials are now going to learn how to spell "slippery slope." The Dutch health ministry has launched an inquiry into the law which sets out the guidelines for euthanasia to be performed in the Netherlands, now that a 13% increase in cases in one year has been duly noted.  
<http://www.calgaryherald.com/health/When+doctors+kill+instead+heal/3207897/story.html>

**N.B.** 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 the foot of p.11.

### Specialist Publications

Of particular interest:

**'A protocol for determining differences in consistency and depth of palliative care service provision across community sites.'** Scroll down to p.6 for the findings of a study conducted in British Columbia and published in *Health & Social Care in the Community*.

**'Negotiating responsibility for treatment decisions in cancer care.'** Scroll down to p.9 for the findings of a study conducted in Ontario and published in *Social Science & Medicine*.

## U.S.A.

### **Man who renewed vows with wife of 72 years dies at hospice in Anderson**

SOUTH CAROLINA | *Independent Mail* (Anderson County) – 26 June 2010 – Vernon McAlister, whose South Carolina love story and 72-year marriage to his wife, Sue, captured hearts around the world, died Friday evening at the Hospice of the Upstate in Anderson, with the woman he loved by his side. He was 92. The McAlisters renewed their wedding vows on June 13 ... with a simple ceremony at the Rainey Hospice House. They did it because Vernon McAlister had a dream this month that his wife was waiting for him to marry her again. And he fought to live so that he could. <http://www.independentmail.com/news/2010/jun/26/man-who-renewed-vows-wife-72-years-dies-hospice-an/>

### **Overtreatment of terminal illnesses prolongs suffering of many, costs nation billions**

ASSOCIATED PRESS | Newswire article – 25 June 2010 – The doctors finally let Rosaria Vandenberg go home. For the first time in months, she was able to touch her 2-year-old daughter who had been afraid of the tubes and machines in the hospital. The little girl climbed up onto her mother's bed, surrounded by family photos, toys and the comfort of home. They shared one last tender moment together before Vandenberg slipped back into unconsciousness. Vandenberg, 32, died the next day. That precious time at home could have come sooner if the family had known how to talk about alternatives to aggressive treatment, said Vandenberg's sister-in-law, Alexandra Drane. [http://www.postbulletin.com/newsmanager/templates/localnews\\_story.asp?z=10&a=458665](http://www.postbulletin.com/newsmanager/templates/localnews_story.asp?z=10&a=458665)

### **Critically ill patients' wishes should be doctor's orders**

FLORIDA STATE UNIVERSITY CENTER | Press release – 23 June 2010 – Living wills and advance directives often don't ensure that dying patients receive the kind of medical care they want – or don't want – to receive. Now an effort being coordinated by the Center for Innovative Collaboration in Medicine & Law at the Florida State University College of Medicine hopes to improve communication and produce a clear set of medical orders for a dying patient's care. "One of the problems that frequently occur is that people get treated much more aggressively than they would want to be treated," said Marshall Kapp, director of Florida State's medicine and law center. <http://www.newswise.com/articles/florida-state-university-center-critically-ill-patients-wishes-should-be-doctor-s-orders>

**N.B.** Scroll down to [Specialist Publications](#) and '**Negotiating responsibility for treatment decisions in cancer care**' (p.9) published in *Social Science & Medicine*.

From Media Watch dated 12 April 2010:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 9 April 2010 – '**Ask a different question, get a different answer: Why living wills are poor guides to care preferences at the end of life.**' Living wills have a poor record of directing care at the end of life, as a copious literature attests. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2009.0311>

### **Hospice patients aid in research**

*NEW YORK TIMES* | Online report – 23 June 2010 – About 11 a.m. on 19 May, Dr. Thomas Beach, a pathologist at Banner Sun Health Research Institute in Sun City, Arizona, stood in front of a long metal table, wearing gloves and an apron, and held up the brain of Patient 36 in an Avid Radiopharmaceuticals study. He was about to perform a brain autopsy as part of a study asking if Avid's new scans were accurately showing Alzheimer plaque. Avid's study required results from 35 patients and the company enrolled 145 hospice patients. They agreed to be scanned before they died and then have their brains examined after death to see if the Avid system worked. <http://www.nytimes.com/2010/06/24/health/research/24scansside.html>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CONNECTICUT | *New Haven Register* – 26 June 2010 – **'No appeal sought in assisted-suicide suit.'** The plaintiffs in a lawsuit challenging Connecticut's assisted-suicide law will not appeal a judge's decision dismissing the case. Two Connecticut doctors wanted a ruling ensuring that providing medication to end a patient's life would not result in prosecution. <http://www.nhregister.com/articles/2010/06/26/news/aa3ctsucideend062610.txt>
- OREGON | Associated Press – 25 June 2010 – **'Death with Dignity House doc loses license.'** A Portland psychiatrist who plans to open a home for terminally ill patients seeking to kill themselves has had his license suspended by medical regulators. <http://www.kgw.com/news/local/Medical-board-suspends-license-over-Death-with-Dignity-house-97167914.html>

## International

### Coroner's ruling 'may affect pain relief for dying'

U.K. (NORTHERN IRELAND) | *Belfast Telegraph* – 25 June 2010 – A health trust's barrister has warned that a ruling by Northern Ireland's top coroner may inhibit doctors from using morphine to relieve the pain of dying patients. The South Eastern Trust said it may bring a legal challenge against the findings of John Leckey, who said morphine intoxicity was a factor in the 2007 death of 56-year-old Anne Aitchison, who had terminal lung disease. A spokeswoman said: "The trust is considering the coroner's formulation as to the cause of death and will be considering whether or not to challenge these findings." <http://www.belfasttelegraph.co.uk/news/local-national/coronerrsquos-ruling-lsquomay-affect-pain-relief-for-dyingrsquo-14855248.html>

### Data analysis to support palliative care needs assessment for children and young people in London

U.K. | London Health Observatory report – 23 June 2010 – In 2004-2008 there were around 250 deaths each year of London residents aged 0-19 from causes likely to have required palliative care. Only 15% of the child deaths analysed occurred at home with the majority occurring in hospital. The death rate from causes likely to have required palliative care was nearly twice as high for children and young people living in deprived areas as for those living in the least deprived parts of London. <http://www.lho.org.uk/Download/Public/16175/1/Palliative%20care%20-%20children%20and%20young%20people%20needs%20assessment.pdf>

Of related interest:

- U.K. | BBC News – 26 June 2010 – **'Cambridgeshire children's hospice cited as role model.'** A children's hospice ... that develops palliative care projects across East Anglia has been cited as a role model for others. <http://news.bbc.co.uk/2/hi/england/cambridgeshire/10423984.stm>

### FHSSA and NASW collaborate in response to needs in sub-Saharan Africa

FOUNDATION FOR HOSPICES IN SUB-SAHARAN AFRICA (FHSSA) | Press release – 21 June 2010 – In 2008 alone there were an estimated two million AIDS-related deaths in sub-Saharan Africa. In many countries in this region there is little or no access to adequate pain medication, little or no access to hospice and palliative care, and desperate situations of suffering, stigma, poverty, and isolation. This is particularly acute for women and children. [The U.S.-based] FHSSA and the [U.S.] National Association of Social Workers have come together to share resources and information that may be potentially helpful to the other, to those providing care, and to individuals and families in sub-Saharan Africa suffering from HIV/AIDS, cancer, and other life-limiting illnesses. <http://www.fhssa.org/i4a/pages/index.cfm?pageID=3549>

## Charity begins at home to help town's unpaid carers

U.K. | *Shrewsbury Chronicle* – 17 June 2010 – Despite carers saving the U.K. economy £87 billion annually by relieving pressure on health and social services, they are often left feeling isolated and lonely, missing out on opportunities others take for granted. But in Shrewsbury a small, young charity, with a national remit, is delivering a programme to offer free support to unpaid carers.

<http://www.shrewsburychronicle.com/2010/06/17/charity-begins-at-home-to-help-towns-unpaid-carers/>

### Specialist Publications

Of particular interest:

**'Home-based family caregiving at the end of life.'** Scroll down to p.8 for a comprehensive review of published literature by authors based in Australia, Canada and the U.K., published in *Palliative Medicine*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | ABC News – 28 June 2010 – **'Voluntary euthanasia bill to get another run.'** The Tasmanian Government is hoping its voluntary euthanasia legislation will be ready by the end of next year. <http://www.abc.net.au/news/stories/2010/06/28/2938987.htm>
- CZECH | Angus Reid Global Monitor – 26 June 2010 – **'Most Czechs agree with euthanasia.'** Most people in the Czech Republic support the practice of euthanasia, according to a poll. 61% of respondents share this point of view, down one point since May 2009. [http://www.angus-reid.com/polls/view/35684/most\\_czechs\\_agree\\_with\\_euthanasia](http://www.angus-reid.com/polls/view/35684/most_czechs_agree_with_euthanasia)
- U.K. | *Daily Telegraph* (OpEd) – 26 June 2010 – **'Assisted suicide: How the new guidelines are applied.'** Aiding or abetting another person's death was made punishable by 14 years' imprisonment in England and Wales under the 1961 Suicide Act. <http://www.telegraph.co.uk/news/uknews/law-and-order/7854829/Assisted-suicide-how-the-new-guidelines-are-applied.html>
- GERMANY | *Deutsche Welle* – 25 June 2010 – **'German court rules in favor of passive assisted suicide.'** Germany's Federal Court of Justice has ruled that assisted suicide is legal in certain cases. The ruling is based on a case involving a terminally-ill coma patient whose daughter attempted to cut her feeding tube. <http://www.dw-world.de/dw/article/0,,5730366,00.html>
- U.K. | BBC News – 25 June 2010 – **'No prosecution for right-to-die doctor.'** A former GP and right-to-die campaigner who took a man to a euthanasia group in Switzerland will not be prosecuted. Director of Public Prosecutions Keir Starmer said while there was enough evidence to prosecute, it would not be in the public interest. <http://news.bbc.co.uk/2/hi/uk/10414767.stm>
- SWITZERLAND | *Daily Telegraph* (U.K.) – 24 June 2010 – **'Dignitas founder is multi-millionaire.'** The founder of the assisted suicide group Dignitas has become a multi-millionaire since setting up the self help group, a new report [by the respected Swiss newspaper *Beobachter*] claims. <http://www.telegraph.co.uk/news/worldnews/europe/switzerland/7851615/Dignitas-founder-is-multi-millionaire.html>
- THE NETHERLANDS | *Sydney Morning Herald* (Australia) – 22 June 2010 – **'Dutch hold inquiry as number of euthanasia cases continues to rise.'** A total of 2636 ... people were killed by euthanasia in 2009, with 80% of cases involving people dying at home after their doctors administered a lethal dose of drugs. This compares with 2331 reported deaths in 2008. The increase in cases has prompted the Dutch Health Ministry to open an inquiry into the law. <http://www.smh.com.au/world/dutch-hold-inquiry-as-number-of-euthanasia-cases-continues-to-rise-20100621-ys85.html>

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

### **[U.K.] General Medical Council guidance on end of life care**

*BRITISH MEDICAL JOURNAL* | Online editorial – 22 June 2010 – The recently published guidance from the General Medical Council (GMC) on end of life care comes into force on 1 July 2010 and commands the attention of all doctors in the U.K. by emphasizing that failure to comply will place registration at risk. Change became essential following the Mental Capacity Act 2005 and after reviews reported how patients with terminal illness are denied informed choice regarding the remainder of their life and the manner in which they die. Doctors have been seeking advice from the GMC on these difficulties and should reasonably expect the regulatory body to provide unequivocal guidance on optimal care and how professional censure can be avoided.

[http://www.bmj.com/cgi/content/extract/340/jun22\\_2/c3231](http://www.bmj.com/cgi/content/extract/340/jun22_2/c3231)

From Media Watch dated 24 May 2010:

- *BRITISH MEDICAL JOURNAL* | Online report – 20 May 2010 – **'Doctors should avoid making assumptions about patients' choices at the end of life.'** The General Medical Council [GMC] has issued comprehensive new guidance for doctors on end of life care, including advice on how to decide whether to attempt cardiopulmonary resuscitation (CPR), and when to withhold or withdraw artificial nutrition and hydration.  
[http://www.bmj.com/cgi/content/extract/340/may20\\_1/c2609](http://www.bmj.com/cgi/content/extract/340/may20_1/c2609)

### **"Moving swiftly on..."**

### **Psychological support provided by district nurses to patients with palliative care needs**

*CANCER NURSING* | Online article – 17 June 2010 – In this study, district nurses described assessing and meeting patients' psychological needs informally through "chatting." Observation of practice, however, revealed avoidance behaviors when faced with patients' psychological concerns, exemplified by the statement "moving swiftly

on," which was one district nurse's response to a patient's overt distress. District nurses have a potentially important role in assessing and meeting cancer patients' psychological needs, but appear to lack confidence and skills.

[http://journals.lww.com/cancernursingonline/Abstract/publishahead/Moving\\_Swiftly\\_On\\_Psychological\\_Support.99878.aspx](http://journals.lww.com/cancernursingonline/Abstract/publishahead/Moving_Swiftly_On_Psychological_Support.99878.aspx)

### **Media Watch: Editorial Practice**

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

### **Distribution**

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### **Links to Sources**

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### **Something Missed or Overlooked?**

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

## Improve Palliative Care in the ICU Project

### **Models for structuring a clinical initiative to enhance palliative care in the intensive care unit**

*CRITICAL CARE MEDICINE* | Online article – 18 June 2010 – There are two main models for intensive care unit-palliative care integration: 1) the "consultative model," which focuses on increasing the involvement and effectiveness of palliative care consultants in the care of intensive care unit patients and their families, particularly those patients identified as at highest risk for poor outcomes; and, 2) the "integrative model," which seeks to embed palliative care principles and interventions into daily practice by the intensive care unit team for all patients and families facing critical illness. These models are not mutually exclusive but rather represent the ends of a spectrum of approaches. Choosing an overall approach from among these models should be one of the earliest steps in planning an intensive care unit-palliative care initiative.

[http://journals.lww.com/ccmjjournal/Abstract/publishahead/Models\\_for\\_structuring\\_a\\_clinical\\_initiative\\_to.98673.aspx](http://journals.lww.com/ccmjjournal/Abstract/publishahead/Models_for_structuring_a_clinical_initiative_to.98673.aspx)

From Media Watch dated 21 June 2010:

- CENTER TO ADVANCE PALLIATIVE CARE | Press release – 16 June 2010 – **'New initiative to improve palliative care in the ICU.'** In a major national effort to integrate and improve palliative care in the ICU, the Center to Advance Palliative Care has launched The IPAL-ICU Project. <http://www.capc.org/news-and-events/releases/06-16-10>

### **A protocol for determining differences in consistency and depth of palliative care service provision across community sites**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online article – 16 June 2010 – In this study, the authors gathered both quantitative and spatial – or geographical – data to develop a composite picture that captures the extent, composition and depth of palliative care in the Canadian province of British Columbia (BC). The province is intensely urban in the southwest and is rural or remote in most of the remainder. [The authors calculated] three critical metrics: 1) the population served within 1 hour of palliative care facilities – and more critically those not served; 2) a matrix that determines access to in-home palliative care measured by both diversity of professionals as well as population served per palliative team member; and, 3) a ranking of palliative care services across the province based on physical accessibility as well as the extent of in-home care. <http://www3.interscience.wiley.com/journal/123531840/abstract>

From Media Watch dated 22 March 2010:

- ONTARIO | *Ottawa Citizen* – 21 March 2010 – **'Struggling to fulfil his final wish.'** Josina [has] tried in vain to find a palliative-care doctor to examine and treat her husband [Harold] in their home. There are two small groups of doctors known as the Community Palliative Care Network & Palliative Care Outreach, but they only have the time and resources to serve patients in the urban Ottawa area. <http://www.ottawacitizen.com/health/Struggling+fulfil+final+wish/2708233/story.html>

### **Diagnosing consciousness: Neuroimaging, law and the vegetative state**

*JOURNAL OF LAW, MEDICINE & ETHICS*, 2010;38(2):374-385. In this paper, the authors review recent neuroimaging investigations of disorders of consciousness and different disciplines' understanding of consciousness itself. They consider potential tests of consciousness, their legal significance, and how they map onto broader themes in U.S. statutory law pertaining to advance directives and surrogate decision-making. The authors discuss broader scientific, ethical, and legal issues associated with the advent of neuroimaging for disorders of consciousness and conclude with policy recommendations that could help to mitigate confusion in this realm.

<http://www3.interscience.wiley.com/journal/123550228/abstract?CRETRY=1&SRETRY=0>

"I'm sitting here by myself..."

## Experiences of patients with serious illness at an urban public hospital

*JOURNAL OF PALLIATIVE MEDICINE* | Online article – 23 June 2010 – [In this study] difficult events such as estrangement, homelessness, substance abuse, and imprisonment shaped patients' approaches to serious illness. This influence manifested in interpersonal relationships, conceptualizations of death and concerns about dying, and approaches to coping with end of life (EOL). Because patients lacked social support, providers played significant roles at EOL. Patients preferred honest communication with providers and sharing in medical decision-making. A prolonged dying process was feared more than sudden death. Concerns included pain, dying in the hospital, and feeling unwelcome in the hospital. Patients coped by advocating for their own care, engaging with religion/spirituality, and viewing illness as similar to past trauma. Participants suggested that providers listen to their concerns and requested accessible chaplaincy and home-based services. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2009.0352>

From Media Watch dated 21 June 2010:

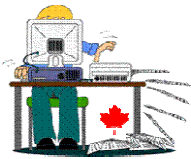
- *INTERNATIONAL JOURNAL OF SOCIAL WELFARE*, 2010;19(3):262-271. **'Palliative care patients' experiences of healthcare treatment.'** Palliative care patients often have long healthcare careers, which enables them to compare different professionals and services, thus offering a more powerful and complex analysis of patient experience than that obtainable from analysis of complaints or satisfaction surveys. <http://www3.interscience.wiley.com/journal/122394414/abstract>

## Staff perceptions of essential prerequisites underpinning end-of-life care for persons with intellectual disability and advanced dementia

*JOURNAL OF POLICY & PRACTICE IN INTELLECTUAL DISABILITIES*, 2010;7(2):143-152. To better address palliative care and end-of-life issues for persons with intellectual disability (ID) and dementia, work was undertaken to understand the perspectives of agency staff in both the ID services and specialist palliative care fields. Challenges were raised [by the participants in the study] for service systems in the areas of aging in place, person-centered care, and inter-service collaboration. <http://www3.interscience.wiley.com/journal/123522698/abstract?CRETRY=1&SRETRY=0>

From Media Watch dated 21 June 2010:

- *DEMENTIA*, 2010;9(2):259-284. **'Challenges to improving end of life care of people with advanced dementia in the U.K.'** Currently, inappropriate admissions to hospital are common in the U.K. and patients are less likely to be referred to palliative care services, receive less pain control, but undergo more invasive interventions compared to their cognitively intact counterparts. <http://dem.sagepub.com/cgi/content/abstract/9/2/259>
- *PALLIATIVE MEDICINE* | Online article – 17 June 2010 – **'An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disability.'** Both palliative care and intellectual disability services staff lacked confidence in their ability to provide palliative care. <http://pmj.sagepub.com/cgi/content/abstract/0269216310371413v1>



### 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.

## **Should feeding tubes always be continued in terminal illness? Not necessarily, according to new guidance from the [U.S.] Catholic Church**

*NEUROLOGY TODAY*, 2010;10(2):30. Bioethicists highlight those aspects of a revised directive on artificial nutrition and nutrition from the Catholic Church that would apply to neurologists working in Catholic hospitals. Although a recent revision to the U.S. Conference of Catholic Bishops' instructions to Catholic hospitals underscores the church's insistence on the use of medically assisted nutrition and hydration (ANH), neurologists should not assume ANH is required in all cases. The revision to Directive 58 of the Ethical & Religious Directives for Catholic Health Care Services says there is a general moral obligation to provide patients with nutrition and hydration if it would prolong their lives, but there are exceptions to that obligation.

[http://journals.lww.com/neurotodayonline/Fulltext/2010/06170/Should\\_Feeding\\_Tubes\\_Always\\_Continue\\_in.14.aspx](http://journals.lww.com/neurotodayonline/Fulltext/2010/06170/Should_Feeding_Tubes_Always_Continue_in.14.aspx)

From Media Watch dated 4 January 2010:

- U.S. | *San Francisco Chronicle* (California) – 3 January 2010 – '**New Catholic mandate on comatose patients.**' The nation's Catholic hospitals ... face a new religious mandate in the new year: to provide life-sustaining food, water and medicine to comatose patients who have no hope of recovery. <http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2010/01/03/BA321BC2R1.DTL>

## **Reconciling informed consent and 'do no harm': Ethical challenges in palliative-care research and practice in chronic obstructive pulmonary disease**

*PALLIATIVE MEDICINE*, 2010;24(5):469-472. The challenges associated with patient-based research in palliative care are well documented. This paper focuses on the ethical challenges and discusses them in the context of a pilot study to explore the palliative-care needs of patients with moderate and severe chronic obstructive pulmonary disease. The main ethical challenge encountered related to problems surrounding the use of terminology, specifically the terms 'palliative care' and 'chronic obstructive pulmonary disease.' The approving ethics committee specified that these terms be removed from all patient materials in order to protect patients from undue distress. The impact of this ethical advice on patients' ability to give fully informed consent is discussed. <http://pmj.sagepub.com/cgi/content/abstract/24/5/469>

### **Home-based family caregiving at the end of life (Part 1)**

*PALLIATIVE MEDICINE* | Online article – 18 June 2010 – The changing context of palliative care over the last decade highlights the importance of recent research on home-based family caregiving at the end of life. This article reports on a comprehensive review of quantitative research (1998–2008) in this area, utilizing a systematic approach targeting studies on family caregivers, home settings, and an identified palliative phase of care. Findings suggest the need for knowledge regarding: family caregiving for patients with non-malignant terminal conditions; whether needs and outcomes differ between family caregivers at the end of life and comparison groups; and caregiver outcomes in bereavement. Clear definitions of 'family caregiving,' 'end of life,' and 'needs' are required as well as greater application and testing of theoretical and conceptual explanations. <http://pmj.sagepub.com/cgi/content/abstract/0269216310371412v1>

- *PALLIATIVE MEDICINE* | Online article – 24 June 2010 – '**Home-based family caregiving at the end of life (Part 2).**' Findings are presented in the following areas: the caregiving experience and contextual features; supporting family caregivers at end of life; caregiving roles and decision-making; and rewards, meaning and coping. The authors noted a lack of definitional clarity; a reliance on interview methods and descriptive, thematic analyses, and a relative lack of diversity of patient conditions. <http://pmj.sagepub.com/cgi/content/abstract/0269216310371411v1>

"I like to be an informed person, but..."

## Negotiating responsibility for treatment decisions in cancer care

*SOCIAL SCIENCE & MEDICINE* | Online article – 23 June 2010 – Social expectations surrounding sickness have undergone a transformation in Western welfare states. Emerging discourses about patients' roles and responsibilities do not however always map neatly onto patients' actions, experiences or desires. The authors highlight research participants' complex responses to their responsibility for treatment decisions: their accepting, deflecting and reframing and their active negotiation of responsibility with professionals. The literature on treatment decision making typically characterizes people who resist taking an active role as overwhelmed, misinformed about the nature of treatment decisions, or more generally lacking capacity to participate. The authors suggest that patients' expressions of ambivalence about making treatment choices can be understood otherwise: as efforts to recast the identities and positions they and their physicians are assigned in the organization of cancer care. The authors also begin to map key features of this organization, particularly discourses of patient empowerment, and evidence-based medicine. [http://www.sciencedirect.com/science?\\_ob=ArticleURL&\\_udi=B6VBF-50CDSS8-2&user=10&coverDate=06%2F23%2F2010&rdoc=5&fmt=high&orig=browse&srch=doc-info\(%23toc%235925%239999%2399999999%23999999%23FLA%23display%23Articles\)&cdi=5925&sort=d&docanchor=&ct=104&acct=C000050221&version=1&urlVersion=0&userid=10&md5=6b82c5d3459aa74e95823d131b7b61c](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-50CDSS8-2&user=10&coverDate=06%2F23%2F2010&rdoc=5&fmt=high&orig=browse&srch=doc-info(%23toc%235925%239999%2399999999%23999999%23FLA%23display%23Articles)&cdi=5925&sort=d&docanchor=&ct=104&acct=C000050221&version=1&urlVersion=0&userid=10&md5=6b82c5d3459aa74e95823d131b7b61c)

Of related interest:

- *CANCER* | Online article – 22 June 2010 – **'Influence of patients' preferences and treatment site on cancer patients' end-of-life care.'** Research suggests that patients' end-of-life (EOL) care is determined primarily by the medical resources available, and not by patient preferences. The treatment preferences of patients with advanced cancer may

play a more important role in determining the intensity of medical care received at the EOL than previously recognized. <http://www3.interscience.wiley.com/journal/123553171/abstract?CRETRY=1&SRETRY=0>

- *NATURE REVIEWS: UROLOGY* | Online article – 22 June 2010 – **'End-of-life care: Preparing patients and families.'** The priority for care at the end of life is to ensure that all patients experience high-quality care, irrespective of their diagnosis or preferred place of care. This phase of an individual's disease journey is fraught with complex decision-making that can obscure and impair the provision of high-quality care in the absence of advance care planning. <http://www.nature.com/nrurol/journal/vaop/ncurrent/abs/nrurol.2010.82.html>

### The evolution [in the U.S.] of health care advance planning law and policy

*MILLBANK QUARTERLY*, 2010;88(2):211-239. This article is a longitudinal statutory and literature review of health care advance planning from its origins to the present. While considerable variability across the states still remains, changes in law and policy over time suggest a gradual paradigm shift from what is described as a "legal transactional approach" to a "communications approach," the most recent extension of which is the emergence of Physician Orders for Life-Sustaining Treatment (POLST).<sup>1</sup> The communications approach helps translate patients' goals into visible and portable medical orders. States are likely to continue gradually moving away from a legal transactional mode of advance planning toward a communications model, albeit with challenges to authentic and reliable communication that accurately translates patients' wishes into the care they receive. In the meantime, the states and their health care institutions will continue to serve as the primary laboratory for advance care planning policy and practice. <http://www3.interscience.wiley.com/journal/123528917/abstract>

1. Physician Orders for Life-Sustaining Treatment (POLST): <http://www.ohsu.edu/polst/>

## Learning what dying is like

### **Jade and the journalists: Media coverage of a young British celebrity dying of cancer**

*SOCIAL SCIENCE & MEDICINE* | Online article – 23 June 2010 – In contemporary western societies, dying usually occurs in old age, out of sight in hospitals and institutions; how then do lay people learn what dying is like? Since the 1970s, one source of information in Anglophone societies has come from individuals who have chosen to publicise their dying of cancer. This article examines the most high profile case of this to date in the U.K. In 2009, celebrity Jade Goody publicised in tabloid newspapers and celebrity magazines the final weeks of her dying of cervical cancer. What did she and her media say and write about dying? This article examines ... coverage of her final weeks, and four different voices are identified: those of Goody, of journalists, of her publicist, and of photographers, each representing her dying somewhat differently. Two major themes are discussed: Jade's struggles to retain autonomy (challenged by her disease and by other people), and the framing of her final weeks not primarily as a typical media cancer story of heroism, but as one of redemption in which she attained social respectability through dying. [http://www.sciencedirect.com/science?\\_ob=ArticleURL&\\_udi=B6VBF-50C71Y5-1&\\_user=10&\\_coverDate=06%2F22%2F2010&\\_rdoc=8&\\_fmt=high&\\_orig=browse&\\_srch=doc-info\(%23toc%235925%239999%2399999999%2399999%23FLA%23display%23Articles\)&\\_cdi=5925&\\_sort=d&\\_docanchor=&\\_ct=104&\\_acct=C000050221&\\_version=1&\\_urlVersion=0&\\_userid=10&md5=ddea468e54280a9131a0e9ffae63413c](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-50C71Y5-1&_user=10&_coverDate=06%2F22%2F2010&_rdoc=8&_fmt=high&_orig=browse&_srch=doc-info(%23toc%235925%239999%2399999999%2399999%23FLA%23display%23Articles)&_cdi=5925&_sort=d&_docanchor=&_ct=104&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=ddea468e54280a9131a0e9ffae63413c)

From Media Watch dated 28 December 2009:

- U.S. | *Esquire* (OpEd) – 21 December 2009 – '**Aren't we enjoying all this celebrity death a little too much?**' Statistically, no more celebrities died this year than any other, but from what we're seeing across television and the Web, you'd think the whole of "Who's Who" had vanished in a single gigantic puff of glittery smoke. <http://www.esquire.com/features/thousand-words-on-culture/deadcelebrities-2009-1209>

From Media Watch dated 25 May 2009:

- U.K. | *Daily Telegraph* – 18 May 2009 – '**Jade Goody tragedy helped people think about dying.**' The death of Jade Goody, the TV reality star, has been "helpful" in making people think about the end of their own lives, according to a national poll. Nearly half of women and a third of men said the publicity surrounding Goody's death from cancer earlier this year had helped people think about death. <http://www.telegraph.co.uk/news/newstoppers/celebritynews/jadegoody/5342038/Jade-Goody-tragedy-helped-people-think-about-dying.html>

From Media Watch dated 23 March 2009:

- U.S. (NEW JERSEY) | NJ.com (Online OpEd) – 20 March 2009 – '**Celebrities may or may not tell us anything about their grief or ours.**' Our culture is one where the privatization of our emotional expressions has led to silence and a refusal to talk about the dead or death and to an exorbitant amount of useless clichés that have grown out of our discomfort with death and grief. [http://www.nj.com/helpinghands/goodgrief/index.ssf/2009/03/celebrities\\_may\\_or\\_may\\_not\\_tel.html](http://www.nj.com/helpinghands/goodgrief/index.ssf/2009/03/celebrities_may_or_may_not_tel.html)

### **Comparing face-to-face and telehealth-mediated delivery of a psychoeducational intervention: A case comparison study in hospice**

*TELEMEDICINE & E-HEALTH* | Online article – 24 June 2010 – This case study compared the delivery of a psychoeducational intervention with hospice caregivers, delivered in person and via videophone. This study demonstrates the feasibility of using telehealth tools to deliver interventions in hospice and identified ways or protocols that can be adapted for telehealth delivery. <http://www.liebertonline.com/doi/abs/10.1089/tmj.2010.0013>

## Worth Repeating

### **On being a teen [hospice] volunteer**

*INNOVATIONS IN END-OF-LIFE CARE* | Online article – July-August 2000 – One of my favorite volunteer activities is called a Life Review. A Life Review is a chance for patients to tell their life story on video for their family and friends who may or may not be able to be with them during the last phases of life. The video can become a keepsake for the survivors and can provide good memories to help the family through the grief period. Sometimes the patient describes parts of his or her life no one has ever heard about, not even the closest family members. Life Reviews have given me precious moments I will always remember. Although all my patients who do Life Reviews claim a special place in my heart, some in particular stick out in my mind. One such patient was an African American man in his early fifties, diagnosed with lung cancer. On the day I went to meet him to do his Life Review, I was going through what I thought was a tough time. I was overloaded with schoolwork, had just broken up with my girlfriend, and had to drive my mother's station wagon to school because my car was in the shop. The Life Review I did with this gentleman made me realize that these problems were self-centered, materialistic, and not all that important. The patient had been orphaned at a young age and had lived in poverty all his life. Yet, despite all his troubles, he was a radiant and happy man. He told me about his childhood. He had lived on the streets with his brother. If he had gone to a foster home, he would have been separated from his brother, whom he had promised his mother he would look after, before she died. He spoke about civil rights, his beliefs about his culture, and the importance of family. Most importantly, he told me things about life I had never really considered and problems I had never really had to face. He was so destitute all his life that, in fact, he had just

received his first and only telephone from the hospice three months prior to my interview so that he could talk to his family, ease his anxiety, and get in touch with his caregivers. He gave me hope for the future and appreciation for the things in life I had taken for granted, like my home and my family (even my little brother). Sharing that day with him, his common sense and wisdom left a permanent mark in my mind and in my heart. As a result, I grew emotionally, as we all do throughout life. This experience inspired me to do more to gain the wisdom that patients have to pass on to us as volunteers.

<http://www2.edc.org/lastacts/archives/archivesJuly00/reflections.asp>

#### Media Watch Online

The weekly report can be accessed at several websites, among them:

##### **Canada**

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network:  
<http://www.hnhbhpc.net/Resources/Usefullinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation Services:  
<http://www.hpconnection.ca/newsletter/inthenews.html>

##### **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/>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-provides-global-roundup-of-end-of-life-issues-n-96.htm>

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