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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The physical, psychological and economic stresses of caregiving: Scroll down to <u>Specialist</u> <u>Publications</u> and 'Interventions for supporting informal caregivers of patients in the terminal phase of a disease' (p.8), published in *Cochrane Database of Systematic Reviews*.

<u>Canada</u>

Funding palliative care

Million-dollar fund-raising campaign helps shine a light on Canada's hidden healthcare crisis

ONTARIO | Healing Cycle Foundation press release - 16 June 2011 - Six years ago, a small but dedicated group of volunteers decided to take on what appeared to be an impossible challenge: create a volunteerbased foundation to raise \$1 million for palliative care, a healthcare service that most people don't even know exists – until they need it. Today, those same volunteers are the driving force behind a respected registered charity, The Healing Cycle Foundation, which is on the verge of reaching – and exceeding – the \$1 million goal. Better still, awareness of the growing need for palliative care is rising and the Foundation has become so successful that it is now helping fund other hospices and hospitals that deliver palliative care in

communities throughout Ontario. http://www.newswire.ca/en/releases/archive/ June2011/16/c6722.html

Specialist Publications

Of particular interest:

'Ontario introduces "hospital secrecy clause" (p.8), for an article on freedom-of-information requests related to quality of care, published in the *Canadian Medical Association Journal.*

'Access to palliative care services in hospital: A matter of being in the right hospital' (p.11), for the findings of a hospital charts study in a Canadian city, published in *Palliative Medicine*.

Quotable Quotes

The reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient. Francis Peabody (1881-1927)

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

Patient Protection & Affordable Care Act

Helping seniors live at home longer

CALIFORNIA | *Los Angeles Times* – 19 June 2011 – Home-based care is increasingly seen as a legitimate and less costly alternative to nursing home care. The Patient Protection & Affordable Care Act ... includes provisions to assist people who want to stay in their homes longer. About 1.5 million people live in nursing homes in the U.S., according to the Centers for Disease Control & Prevention. And more than 10 million Americans – mostly people 65 or older – need long-term services and support to help them with daily activities, according to the Kaiser Family Foundation. The cost of staying at a nursing home ranges from about \$40,000 to \$85,000 a year, according to a recent report by John Hancock Financial Services Inc., an insurance and financial services company. The average cost of a home health aide, on the other hand, is about \$37,000 a year. http://www.latimes.com/health/la-he-long-term-care-20110612,0,5299087.story

Population trends

U.S. lags behind top nations on life spans

NATIONAL PUBLIC RADIO | Online report -15 June 2011 – The expected lifespans for Americans born recently are impressive: 75.6 years for males and 80.8 years for females who entered the world in 2007. We're living longer than ever. Well, some of us are. But many Americans aren't faring so well. A fresh analysis of recent changes in longevity finds there are wide variations in how long people in the U.S. can expect to live, depending on their county of residence. So for American men, the life expectancy ranged from 65.9 to 81.1 years. For women, the outlook ranged from 73.5 to 86.0. And when the outlook for Americans' lifespans is compared to those for people in other countries with the best life expectancies, we're falling behind. The analysis¹ was performed by researchers from the Institute for Health Metrics & Evaluation at the University of Washington, with help from colleagues at Imperial College London. http://www.npr.org/blogs/health/2011/06/15/ 137199606/u-s-lags-behind-top-nations-onlifespans

 'Falling behind: Life expectancy in U.S. counties from 2000 to 2007 in an international context,' *Population Health Metrics*, published online 15 June 2011. <u>http://www.pophealthmetrics.com/conten</u> <u>t/pdf/1478-7954-9-16.pdf</u>

Cancer death rate gap widens based on education

ASSOCIATED PRESS | Online report – 17 June 2011 – The gap in cancer death rates between college graduates and those who only went to high school is widening, the American Cancer Society reports. Among men, the least educated died of cancer at rates more than 2½ times that of men with college degrees. In the early 1990s, they died at two times the rate of most-educated men. <u>http://www.ajc.com/health/cancer-deathrate-gap-979436.html</u>

From Media Watch dated 27 July 2009:

SOCIETY, 2009;46(3):232-234. 'The past as prologue in life extension.' Increased longevity
over the past century has already raised urgent, unresolved issues of equity, social cohesion, and
human dignity. These developments, and our past experiences in dealing with them, provide a
basis for revisiting the basic questions raised by all attempts to extend human life: what does life
mean, and why is it worth extending? <u>http://www.springerlink.com/content/m48123u20l583142/</u>

Position statement on ethical marketing practices released by National Hospice & Palliative Care Organization

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Press release – 13 June 2011 – *Hospice & Palliative Care: Ethical Marketing Practices* ... reinforces the need for hospice and palliative care providers to utilize ethical marketing practices, which in turn, will ensure trust and support among those being served. "Hospice and palliative care providers are caring for individuals and families who may be particularly vulnerable as they cope with serious and life-limiting illness. The highest ethical practices and standards are necessary from every single provider in the industry – with no exceptions," said J. Donald Schumacher, NHPCO president and CEO. "This position statement will help providers to establish accountability for sound ethical practices as they engage in marketing efforts and business development," he added. <u>http://www.prnewswire.com/news-releases/position-statement-on-ethical-marketingpractices-released-by-national-hospice-and-palliative-care-organization-123741174.html</u>

From Media Watch dated 23 May 2011:

- UNITED PRESS INTERNATIONAL | Online report 19 May 2011 'For-profit hospice industry raises worries.' End-of-life hospice care is being dominated by investor-owned chains that cherry-pick patients and cut labor costs to maximize profits, researchers [at Indiana University] say.¹ The for-profit hospice industry grew by 128% from 2001 to 2008, while the non-profit sector grew by only 1%. <u>http://www.upi.com/Health_News/2011/05/19/For-profit-hospice-industry-raises-worries/UPI-78121305782622/</u>
 - 1. 'In the business of dying: Questioning the commercialization of hospice,' *Journal of Law, Medicine & Ethics*, 2011;39(2):224-234. <u>http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2011.00591.x/abstract</u>
- U.S. NEWS & WORLD REPORT | Online report 16 May 2011 'Hospice care more common in wealthier areas, study finds.' The availability of hospice care in the U.S. is strongly associated with a local area's average household income, a new study says.¹ <u>http://health.usnews.com/healthnews/managing-your-healthcare/economics/articles/2011/05/16/hospice-care-more-common--inwealthier-areas-study-finds</u>
 - 1. 'Community supply of hospice: Does wealth play a role?' *Journal of Pain & Symptom Management*, online article posted 24 March 2011. <u>http://www.jpsmjournal.com/article/S0885-3924(11)00019-4/abstract</u>

From Media Watch dated 7 February 2011:

- CALIFORNIA | Los Angeles Times 1 February 2011 'For-profit hospices may choose cheaper-to-treat patients, study finds.' Research findings report that for-profit hospice services may be selecting patients who are less expensive to treat – leaving the pricier patients to non-profit agencies.¹ <u>http://www.latimes.com/health/boostershots/la-heb-for-profit-hospice-</u> 20110201,0,5630476.story
 - 'Association of hospice agency profit status with patient diagnosis, location of care, and length of stay,' Journal of the American Medical Association, 2011;305(5):472-479. <u>http://jama.ama-assn.org/content/305/5/472.abstract</u>



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

Assembly panel advances bills to assist with end-of-life care decisions

NEW JERSEY TODAY | Online report – 13 June 2011 – An Assembly [i.e., State Legislature] panel approved a package of bills intended to make end-of-life care decisions easier for New Jersey families. The first measure (A-3475) would require the state to create a form called the Physician Orders for Life-Sustaining Treatment (POLST) to enable ... patients to indicate their preferences for health care. The second bill (A-3839) would establish the New Jersey Advisory Council on End-of-Life Care in the Department of Health and Senior Services. The third bill (A-4098) would create a system through which patients who lack decision-making capacity and have no one available to decide for them could receive care in the most appropriate setting, with minimal delay, and without unnecessary cost. http://njtoday.net/2011/06/13/assembly-panel-advances-bills-to-assist-with-end-of-life-care-decisions/

From Media Watch dated 21 March 2011:

WALL STREET JOURNAL | Online report – 15 March 2011 – 'New efforts to simplify end-of-life care wishes.' POLST (Physician Orders for Life-Sustaining Treatment) programs are currently in use in 14 states and regions in the U.S., and another 16 states and six regions are developing programs. http://online.wsj.com/article/SB10001424052748703327404576194942197661606.html

N.B. In April 2011, the American Association for Retired Persons Public Policy Institute published *Improving* Advanced Illness Care: The Evolution of State POLST Programs. The authors explore the experience of 12 states with POLST programs to identify factors that helped or hindered adoption and meaningful implementation of the protocol. <u>http://assets.aarp.org/rgcenter/ppi/cons-prot/POLST-Report-04-11.pdf</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CATHOLIC SENTINEL | Online report 16 June 2011 'Bishops approve first major statement on physician-assisted suicide.' Taking on the issue of physician-assisted suicide in the state [i.e., Washington] where voters most recently approved it, the U.S. Catholic bishops hope to counter the recent "strong resurgence" in activity by the assisted suicide movement. The bishops approved a policy statement¹ ... at its Spring General Assembly. 'To Live Each Day with Dignity,' passed with a vote of 191-1. It marks the first time the full body of bishops has issued a statement devoted to this issue. http://www.catholicsentinel.org/Main.asp?SectionID=2&SubSectionID=34&ArticleID=15409
 - 1. 'To Live Each Day with Dignity,' U.S. Conference of Catholic Bishops, 16 June 2011. http://www.usccb.org/toliveeachday/bishops-statement-physician-assisted-suicide.pdf
- OREGON | Reuters 16 June 2011 'Oregon lawmakers vote to outlaw suicide kit sales.' The Oregon Legislature gave final approval to a bill that would outlaw sales of suicide kits such as the apparatus used by a man from Eugene to kill himself late last year. The measure, which cleared the Oregon Senate on a 30-0 vote after the state House of Representatives approved it, now goes to the desk of Governor John Kitzhaber, a Democrat who has yet to take a position on it. Even if Kiztzhaber, a former emergency room physician, declines to the sign the measure, it will become law automatically in five days unless he vetoes it first. http://www.fox59.com/news/nationworld/sns-rt-us-suicide-oregontre75f7cz-20110616,0,400105.story

International

Older people cared for at home 'lacking basic rights'

U.K. | BBC News – 20 June 2011 – Care of older people in their homes is so poor their human rights are being overlooked, an inquiry by the Equality & Human Rights Commission has found. http://www.bbc.co.uk/news/health-13813460

National End of Life Care Intelligence [Network] one year on

U.K. | National End of Life Care Intelligence Network (NEoLCIN) online report – 16 June 2011 – Accessible and reliable data is more important than ever in an era of patient choice and funding challenges. The NEoLCIN aims to improve the collection and analysis of data about end of life care services. It provides valuable information to government, service providers, commissioners and researchers on adults approaching the end of life and on the quality, volume and costs of care provided to them. Such intelligence will help drive improvements in the quality and productivity of services. http://www.endoflifecare-intelligence.org.uk/news/default.aspx

Dealing with death puts life in perspective

THE AUSTRALIAN (Melbourne, Victoria) | Online article – 15 June 2011 – When you regularly deal with death there isn't much that will faze you, even if you are a first-time vice-chancellor just weeks into your new job. Linda Kristjanson, Swinburne University of Technology's new boss, has a warm serenity about her that no doubt goes with the territory. A palliative care nurse and internationally recognised researcher in the field, she has spent her professional life at death's coalface and it has given her a clearsighted view of what's important and what's not. "When you meet people at the end of their life it really reminds you of what matters," Kristjanson says. "It helps to put priorities in order, and when you think you are having a crisis you probably aren't. If

you aren't really aware that we are all going to die and that we are rehearsing for this all the time, you can start to get fussy about things and be negative and complaining." <u>http://www.theaustralian.com.au/higher-</u> <u>education/dealing-with-death-puts-life-in-</u> <u>perspective/story-e6frgcix-1226075171333</u>

Specialist Publications

Of particular interest:

'New doctors see death as a medical failure' (p.9), published in *Irish Medical News.*

Of related interest:

 U.K. | The Guardian – 19 June 2011 – 'Living with death.' Four people share their experiences of living with a terminal illness – from a 25-year-old who has learned to love life, to a biker who's angry as hell. <u>http://www.guardian.co.uk/lifeandstyle/2011/jun/19/living-death-terminal-illness-cancer</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | Daily Mail (U.K.) 14 June 2011 'Organs of people killed by euthanasia being 'harvested for transplant surgery in Belgium." The organs of people killed by euthanasia in Belgium are being harvested for transplant surgery, a report revealed yesterday.¹ A quarter of all lung transplants in Belgium are from people killed by lethal injection. The study, led by Dirk van Raemdonck a surgeon from Leuven, found doctors preferred lungs taken from those who die through euthanasia as they are in a far superior condition to those from people killed in accidents. The paper showed about 23.5% of lung transplant donors and 2.8% of heart transplant donors are killed by euthanasia. Mr Van Raemdonck insisted doctors were acting within Belgian guidelines on euthanasia, which was legalised in 2002. <u>http://www.dailymail.co.uk/news/article-2003280/Organspeople-killed-euthanasia-harvested-transplant-surgery-Belgium.html?ITO=1490</u>
 - 1. 'Initial experience with transplantation of lungs recovered from donors after euthanasia.' *Applied Cardiopulmonary Pathophysiology*, 2011;15(1):38-48. <u>http://www.applied-cardiopulmonary-pathophysiology.com/fileadmin/downloads/acp-2011-1_20110329/05_vanraemdonck.pdf</u>

Cont.

 U.K. | Daily Mail – 14 June 2011 – 'Anti-euthanasia backlash hits BBC after 900 viewers complain about Terry Pratchett documentary showing death at Dignitas.' Hundreds of viewers have complained about the BBC broadcasting the final moments of a man's 'assisted death' on screen – warning it would lead to copycat suicides. Many viewers took to social networks and online message boards after watching Peter Smedley, 71, beg for water and take his last gasp before slipping out of consciousness on the programme, 'Terry Pratchett: Choosing to Die.' http://www.dailymail.co.uk/news/article-2003256/Anti-euthanasia-backlash-hits-BBC-Terry-Pratchett-shows-death-Dignitas.html?ito=feeds-newsxml

N.B. In an official statement, the BBC denied the Pratchett film was biased, saying it was "about one person's experience" and would help viewers make up "their own minds." The broadcaster added: "The aim of the programme was to create discussion and this is clearly a subject that resonates." The BBC denied that the screening could lead to copycat suicides. The film and debate that followed on BBC's 'Newsnight' are available online. Documentary: <u>http://www.bbc.co.uk/iplayer/episode/b0120dxp/Terry_Pratchett_Choosing_to_Die/</u>. Debate: <u>http://www.bbc.co.uk/iplayer/episode/b012119k/Newsnight_Choosing_to_Die_Newsnight_Debate/</u>

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

Research priorities for palliative and end-of-life care in the emergency setting

ACADEMIC EMERGENCY MEDICINE, 2011;18(6):e70-e76. In a workgroup session at the 2009 Agency for Healthcare Research & Quality/American College of Emergency Physicians conference ... four key research questions arose: 1) which patients are in greatest need of palliative care services in the ED [emergency department], 2) what is the optimal role of emergency clinicians in caring for patients along a chronic trajectory of illness, 3) how does the integration and initiation of palliative care training and services in the ED setting affect health care utilization, and 4) what are the educational priorities for emergency clinical providers in the domain of palliative care? These four key questions may be answered by strengthening the evidence using six categories of inquiry: descriptive, attitudinal, screening, outcomes, resource allocation, and education of clinicians. <u>http://onlinelibrary.wiley.com/doi/10.1111/j.1553-</u> 2712.2011.01088.x/abstract

Of related interest:

 INTENSIVE CARE MEDICINE | Online article – 10 June 2011 – 'End-of-life attitudes of intensive care physicians in Poland: Results of a national survey.' The practice of withholding and withdrawing therapy in ICU patients is common in Poland. Actively shortening life is considered unacceptable. <u>http://www.springerlink.com/content/u143588522772j70/</u>

N.B. Singapore was rated 15th in *The Quality of Death: Ranking End of-life-Care Across the World*, July 2010. <u>http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf</u>

From Media Watch dated 4 April 2011:

 JOURNAL OF INTENSIVE CARE MEDICINE | Online article – 24 March 2011 – 'End of life care in ICU: A practical guide.' The purpose of this manuscript is to provide a practical guide to end of management for all bedside practitioners. The manuscript outlines not all but some fundamentally important ethical concepts and provides helpful rules and steps on end-of-life management... http://jic.sagepub.com/content/early/2011/02/13/0885066610392697.abstract

N.B. Additional articles on the palliative care in the intensive care unit are noted in this issue of Media Watch.

Media Watch posted on Palliative Care Network-e Website

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

Ethical issues in palliative care

Care as process and the quest for autonomy

ASIAN BIOETHICS REVIEW, 2011;3(2):150-154. Ethical issues are prominent in palliative care. How is patient autonomy to be secured under conditions of dependency? What should be the role of family in decisions about care? What is a good death? Care is much more to be seen as a complex process that unfolds itself during time and place than that it is a simple product to be delivered, as if on a market with consumers. This observation does not only apply to the character of palliative care itself, but also when it comes to the question of how we can respect autonomy in care situations. Respecting the autonomy of a patient means much more than simply respecting free choices that are made by the individual. Instead, autonomy should be seen more as something to be attained than as something that is already there. From a so-called ethics of care perspective, the character of care as an embedded practice and process is emphasised. http://muse.jhu.edu/login?uri=/journals/asian_bioethics_review/v003/3.2.verkerk.html

N.B. This issue of *Asian Bioethics Review* includes several articles on end of life care. Contents page (scroll down to 'Case Corner'): <u>http://muse.jhu.edu/journals/asian_bioethics_review/toc/asb.3.2.html</u>

Of related interest:

 JOURNAL OF LAW & MEDICINE, 2011;18(4):773-797. 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria, Australia).' This is the third article in a series of three that examines the legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment from adults who lack capacity. <u>http://eprints.gut.edu.au/41908/1/41908a.pdf</u>

N.B. Part 1 (New South Wales) and Part 2 (Queensland) of the *Journal of Law & Medicine* series are noted in Media Watch dated 30 May 2011 (p.8).

Albanian medical system and health legislation

Inapplicability of advance directives in a paternalistic setting: The case of a post-communist health system

BMC MEDICAL ETHICS | Online report – 15 June 2011 – The Albanian medical system and Albanian health legislation have adopted a paternalistic position with regard to individual decision making. This reflects the practices of a not-so-remote past when state-run facilities and a totalitarian philosophy of medical care were politically imposed. Because of this history, advance directives concerning treatment refusal and do-not-resuscitate decisions are still extremely uncommon in Albania. Medical teams cannot abstain from intervening even when the patient explicitly and repeatedly solicits therapeutic abstinence. The Albanian law on health care has no provisions regarding limits or withdrawal of treatment. This restricts the individual's healthcare choices. http://www.biomedcentral.com/content/pdf/1472-6939-12-12.pdf

Intervention for depression among palliative care patients and their families: A study protocol for evaluation of a training program for professional care staff

BMC PALLIATIVE CARE | Online article – 13 June 2011 – Clinical depression is highly prevalent yet under-detected and under-treated in palliative care settings and is associated with a number of adverse medical and psychological outcomes for patients and their family members. This article presents a study protocol to evaluate a training intervention for non-physician palliative care staff to improve the recognition of depression and provide support for depressed patients and their family members. <u>http://www.biomedcentral.com/content/pdf/1472-684x-10-11.pdf</u>

From Media Watch dated 30 May 2011:

 BMC PALLIATIVE CARE | Online article – 27 May 2011 – 'Expert opinion on detecting and treating depression in palliative care: A Delphi study.' This study applied the Delphi method to evaluate expert opinion on choice of screening tool, choice of antidepressant and choice of psychological therapy. The aim was to inform the development of best practice recommendations for the European Palliative Care Research Collaborative clinical practice guideline on managing depression in palliative care. <u>http://www.biomedcentral.com/content/pdf/1472-684x-10-10.pdf</u>

Freedom-of-information requests related to quality of care

Ontario introduces "hospital secrecy clause"

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 14 June 2011 – The Ontario government plans to exempt hospitals from being obliged to respond to freedom-of-information requests related to quality of care on the grounds that doing so will encourage more frank discussion of medical errors. But critics say the "hospital secrecy clause," as they call it, is entirely unjustified. "This clause excludes any quality information produced for or by a committee in a hospital from public access," says Natalie Mehra, director of the Ontario Health Coalition, a patient advocacy group. The Ontario Nurses' Association (ONA) ... also expressed dismay at the government's decision. Ontario residents can still request information on quality of care, and if a hospital refuses to release it under the exemption, they can appeal to the province's Information & Privacy Commissioner. http://www.cmaj.ca/cgi/content/short/183/9/E552

Interventions for supporting informal caregivers of patients in the terminal phase of a disease

COCHRANE DATABASE OF SYSTEMATIC REVIEWS, 2011, Issue No. 6. It is often family and friends who play a central role in providing support, despite health professional input and regardless of whether the patient is at home or elsewhere. Such informal caring may involve considerable physical, psychological, and economic stresses. A range of supportive programmes for caregivers is being developed including psychological support and practical assistance. There is evidence that supportive interventions may help reduce caregivers' psychological distress. Findings suggest practitioners should enquire about the concerns of caregivers and should consider they may benefit from additional support. There is need for further research to explore the benefits identified, and to assess the interventions' effects on physical health, and potential harms.

N.B. Contents page (scroll down to 'Highlighted new and updated *Cochrane Reviews*'): <u>http://onlinelibrary.wiley.com/o/cochrane/clsysrev/articles/CD007617/frame.html;jsessionid=CD88EA1F</u> EBAB8218588C22C7545966A7.d03t02

Of related interest:

IRISH HEALTH | Online report – 13 June 2011 – 'Call to support carers of the dying.' Members
of the public are being urged to show compassion and support to any friends and neighbours who
are caring at home for someone who is dying. According to Marie Lynch ... [of] ... the Irish Hospice
Foundation, caring for a seriously ill loved one who has only weeks or days to live is an 'allconsuming and intensely emotional experience.' http://www.irishhealth.com/article.html?id=19323

N.B. Ireland's Quarterly National Household Survey identified 274,000 people who provide unpaid help or assistance to someone. This equates to 10% of women in Ireland and 6% of men. Full time family carers provide an average of 110 hours of care per week.

JOURNAL OF CLINICAL NURSING | Online article – 15 June 2011 – 'Sudden informal caregivers: The lived experience of informal caregivers after an unexpected event.' The extent to which caregivers feel connected with others, redefine their personal use of time and feel comfortable with their new responsibilities indicates how they are managing this transition and how well they are achieving balance in their new role, i.e., from feeling 'exclusively' a caregiver to being 'also' a caregiver. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2010.03644.x/abstract

Patients 'being coded as palliative to cut death rates,' inquiry told

HEALTH SERVICE JOURNAL (U.K.) | Online report – 14 June 2011 – Patients with diabetes and rheumatoid arthritis are being coded under palliative care to reduce death rates, a leading expert has told the Mid Staffordshire Foundation Trust public inquiry. Professor Sir Brian Jarman, one of the founders of the Dr. Foster Unit at Imperial College London, told the inquiry Mid Staffs was one of three trusts in the West Midlands region where the number of patients recorded as palliative care shot up between quarters one and three of 2008. By the end of the period Mid Staffs was coding about 30% of patients as palliative, George Eliot Hospital NHS [National Health Service] Trust almost 40%, and Walsall Hospitals NHS Trust 78%. "The only way you could get dramatic changes like that would be if the three trusts suddenly became terminal care hospitals overnight," he said. http://www.hsj.co.uk/home/patients-being-coded-as-palliative-to-cut-death-rates-inquiry-told/5031106.article

From Media Watch dated 8 November 2010:

 JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 1 November 2010 – 'Hospital mortality rates: How is palliative care taken into account?' Using mortality rates to measure hospital quality presumes that hospital deaths are medical failures. Palliative care and hospice leaders need to educate themselves and hospital administrators about the extent to which these mortality rates take end-of-life care into account. <u>http://www.jpsmjournal.com/article/S0885-3924(10)00654-8/abstract</u>

New doctors see death as a medical failure

IRISH MEDICAL NEWS | Online report - 14 June 2011 – Newly-gualified Irish doctors see death as a medical failure, as opposed to recognising it as part of the normal process, research presented at a major international conference on palliative care has established. All newly-gualified doctors surveyed felt ill-prepared on gualification to manage dving patients, the researcher ... found, "Newly-qualified doctors feel wholly unprepared to manage death and dying, due to a lack of training at both undergraduate and postgraduate level. Both patients and doctors suffer from this lack of training, reinforcing for the newly-gualified doctor that death is seen as a medical failure, as opposed to recognising it as part of the normal process," said Dr. Pauline Kane, who is currently on a specialist medical training scheme in the U.K. It was imperative, she said, that adequate training be instigated for undergraduates and newly-gualified doctors to better equip them to manage this vulnerable patient group.

http://www.imt.ie/news/latestnews/2011/06/new-doctors-see-death-as-amedical-failure.html

Media Watch Online

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

Canada

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

Ontario | HPC Consultation Services: http://www.hpcconnection.ca/newsletter/inthenews.html

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

U.S.A.

Prison Terminal:

http://www.prisonterminal.com/news%20media%20watc h.html

International

Global | Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/world/world/

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

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

Visions of dead relatives at deathbed 'normal'

IRISH MEDICAL NEWS | Online report – 14 June 2011 – Deathbed experiences (DBE), an umbrella term for phenomena such as visions in which the dying person reports seeing dead relatives or religious figures, would appear to be a normal part of the dying process and could be comforting for many patients and relatives, new Irish research concludes. The most common DBEs involved patients having visions of deceased relatives, followed by sightings of people, animals or birds "out of the corner of the eye". While noting that visions were frequently associated with drug- or fever-induced hallucinations, one of the researchers, palliative medicine consultant Dr. Regina McQuillan concluded distinct qualities associated with DBE were identified. http://www.imt.ie/news/latest-news/2011/06/visions-of-dead-relatives-at-deathbed-normal.html

From Media Watch dated 28 March 2011:

 IRELAND | Irish Times (Dublin) – 22 March 2011 – 'Going into the light.' 'Capturing the invisible: exploring Deathbed Experiences in Irish Palliative Care' ... examines the strange visions that often accompany the dying process, asking members of the Irish Association of Palliative Care to report their experiences. <u>http://www.irishtimes.com/newspaper/health/2011/0322/1224292769193.html</u>

From Media Watch dated 12 October 2009:

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 8 October 2009

 'Deathbed phenomena: Its role in peaceful death and terminal restlessness.' Collective research supports mounting evidence that deathbed visions typically yield peaceful deaths.

 http://ajh.sagepub.com/cgi/content/abstract/1049909109347328v1

Dying well: Factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland

JOURNAL OF CLINICAL NURSING, 2011;20(13-14):1824-1833. Although the literature reveals a number of factors that impact on end-of-life care, no study has examined staff perceptions concerning the provision of good end-of-life care for older people in an Irish context. The potential to 'die well' was influenced by three factors, namely philosophy, culture and organisation of care, knowing the person, and physical environment and resources. Mobilising resources to ensure that these factors are considered is crucial to ensuring that regardless of where older people die in Ireland, they will receive the highest standard of care that nurses can provide. Understanding the factors ... can help health professionals give more focused support and ensure that influencing factors are addressed so that older people at end-of-life receive quality end-of-life care. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2010.03628.x/abstract

Work-life balancing: Challenges and strategies

JOURNAL OF PALLIATIVE MEDICINE | Online article – 8 June 2011 – Balancing the personal and the professional is an ongoing struggle for most professionals, and palliative care clinicians are no exception. A sustained lack of balance can lead to feelings of frustration, inadequacy, and guilt. Palliative care physicians may find this balance particularly difficult due to the nature of their work: caring for patients and families who are often suffering and in crisis. The authors describe challenges to work-life balancing and strategies that may promote balance, including "timeshifting," goal setting, cognitive reframing, and self-care. They argue that the search for balance is a lifelong endeavor that entails self-reflection and continuing examination of one's values and goals. http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0095

Of related interest:

 NURSING ETHICS, 2011;18(3):317-326. 'Burnout in palliative care: A systematic review.' The main findings indicate burnout levels in palliative care, or in health care settings related to this field, do not seem to be higher than in other contexts. <u>http://nej.sagepub.com/content/18/3/317.abstract</u>

Family-witnessed resuscitation: Bereavement outcomes in an urban environment

JOURNAL OF PALLIATIVE MEDICINE, 2011;14(6):715-721. After 20 years of debate regarding the appropriateness of family-witnessed resuscitations, little substantive data exist to suggest a benefit or harm to the family member. A prospective comparison study was conducted at two large, urban, Midwestern teaching hospitals [in the U.S.]. Sixty-five family members were included. Bereavement related depression and post-traumatic stress disorder symptoms are commonly seen in family members of cardiac arrest victims, however, the magnitude of the effect is not impacted by witnessing or not-witnessing cardiopulmonary resuscitation in the emergency department. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0463

Of related interest:

 AMERICAN MEDICAL NEWS | Online article – 13 June 2011 – 'End-of-life care: How you can help stressed surrogates.' Surrogate decision-makers can be haunted by lingering doubts about whether they made the right choices for family members or may feel guilty about those decisions, research shows. Surrogates often feel anxious and depressed, and are at significant risk for posttraumatic stress disorder. <u>http://www.ama-assn.org/amednews/2011/06/13/prsa0613.htm</u>

Hospital charts study in a Canadian city

Access to palliative care services in hospital: A matter of being in the right hospital

PALLIATIVE MEDICINE | Online article – 16 June 2011 – Using hospital charts of all patients who died over one year (April 2008-March 2009) in two mid-sized hospitals of a large Canadian city, similar in size and function and operated by the same administrative group, this study examined which patients who could benefit from PC [palliative care] services actually received these services and which ones did not, and compared their care characteristics. A significantly lower proportion (29%) of patients dying in hospital 2 (without a PC unit and reliant on a visiting PC team) was referred to PC services as compared to in hospital 1 (with a PC unit; 68%). This lower referral likelihood was found for all patient groups, even among cancer patients, and remained after controlling for patient mix. Referral was strongly associated with having cancer and younger age. Referral to PC thus seems to depend, at least in part, on the coincidence of being admitted to the right hospital. This finding suggests that establishing PC units or a team of committed PC providers in every hospital could increase referral rates and equity of access to PC services. http://pmj.sagepub.com/content/early/2011/06/16/0269216311408992.abstract

Of related interest:

- IRISH MEDICAL NEWS | Online report 14 June 2011 'Unmet needs are highlighted in study.' Results of research ... reveal that patients with non-malignant diseases, such as chronic obstructive pulmonary disease, motor neurone disease, heart failure and cystic fibrosis, are referred late to the Specialist Palliative Medicine Service at the hospital. This was notwithstanding the finding that 20% of patients with end-stage, non-malignant disease have comparable levels of symptom severity to cancer patients. <u>http://www.imt.ie/news/latest-news/2011/06/unmet-needs-arehighlighted-in-study.html</u>
- JOURNAL OF CLINICAL ONCOLOGY | Online OpEd 13 June 2011 'Palliative care and the quality of life.' New delivery and payment models that promote quality of care ... may change incentives that encourage procedures and interventions over whole-person care. Our patients will benefit, and so will we, because professional satisfaction lies in the genuine human connection that we are privileged to share with the patients we serve. <u>http://jco.ascopubs.org/content/early/2011/06/09/JCO.2011.35.9729.full.pdf</u>
- PALLIATIVE MEDICINE | Online article 15 June 2011 "That's part of everybody's job': The
 perspectives of health care staff in England and New Zealand on the meaning and remit of
 palliative care.' Data indicate ... the policy rhetoric of universal palliative care provision is not being
 straight-forwardly translated into service delivery and individual clinical practice.
 http://pmj.sagepub.com/content/early/2011/05/27/0269216311408993.abstract

Factors associated with perceived barriers to pediatric palliative care: A survey of pediatricians in Florida and California

PALLIATIVE MEDICINE | Online article – 16 June 2011 – The provision and uptake of pediatric palliative care continues to be plagued by barriers. Several studies have documented these barriers, but none have done so with a diverse sample (most are at a single institution) or specifically about pediatric palliative care. Moreover, none have investigated the factors associated with perceived barriers. The two greatest barriers reported by the pediatricians [i.e., study participants] were related to families' reluctance to accept palliative care (95%) and families viewing palliative care as giving up (94%). Only 42% of pediatricians noted that reimbursement was a barrier. http://pmj.sagepub.com/content/early/2011/06/16/0269216311409085.abstract

From Media Watch dated 7 March 2011:

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

Assisted (or facilitated) death

Representative sample of recent articles, etc:

AMERICAN JOURNAL OF BIOETHICS, 2011;11(6):32-40. 'Is continuous sedation at the end of life an ethically preferable alternative to physician-assisted suicide?' The relatively new practice of continuous sedation (CS) at the end of life is increasingly being debated in the clinical and ethical literature. This practice received much attention when a U.S. Supreme Court ruling noted that the availability of CS made legalization of physician-assisted suicide (PAS) unnecessary, as CS could alleviate even the most severe suffering. This view has been widely adopted. In this article, the authors perform an in-depth analysis of four versions of this "argument of preferable alternative." http://www.informaworld.com/smpp/content~db=all~content=a938610297~frm=abslink

N.B. This issue of the *American Journal of Bioethics* includes several articles on continuous sedation. Contents page (scroll down to 'Open Peer Commentaries'): http://www.informaworld.com/smpo/title~db=all~content=g938624806~tab=toc

 JOURNAL OF GERONTOLOGICAL NURSING | Online article – 15 June 2011 – 'Washington State Death with Dignity Act: Implications for long-term care.' The purpose of this study was to explore knowledge of Directors of Nursing (DONs) in long-term care (LTC) and assisted living facilities regarding the DWDA [Washington Death with Dignity Act]. Findings of the survey provide insight into DONs' understanding of the law and whether they have provided staff education regarding how to respond to resident requests. http://www.ncbi.nlm.nih.gov/pubmed/21667888

Worth Repeating

On the road to reform: Advocacy and activism in end-of-life care

JOURNAL OF PALLIATIVE MEDICINE, 2002;5(1):13-22. This paper argues that the general public is, and should be, an important source of activity in end-of-life care reform. Two roles for the public are described: personal advocacy and public activism. The first relates to the role of private citizens in advocating on their own or a loved one's behalf at the end of life to secure quality palliative care. The second relates to the role of leaders in mobilizing reform efforts on behalf of the larger society. These roles overlap and often function to bolster one another. City.http://www.liebertonline.com/doi/abs/10.1089/10966210252784971?prevSearch=allfield%25

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Something Missed or Overlooked?

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

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