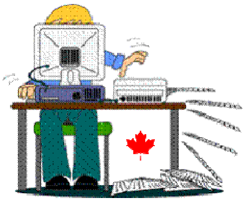
Media Watch...

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 and research.

13 August 2012 Edition | Issue #266



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

Compiled & Annotated by Barry R. Ashpole

Paediatric palliative care: Scroll down to Specialist Publications and 'We didn't do anything wrong, we tried our best, but they just died … we tried, we really tried': Child deaths in the Paediatric Intensive Care Unit, Red Cross Children's Hospital, Cape Town, South Africa' (p.5), published in *African Studies.*

Canada

Compassionate Care Benefit

Employment Insurance benefits extended to families of seriously ill children

CBC NEWS | Online report – 7 August 2012 – The federal government will follow through with a 2011 ... promise to extend employment insurance benefits to parents who need time off to care for seriously ill children. The benefits would be available to families for up to 35 weeks. Up to 6,000 families are expected to take advantage of the assistance each year. http://www.cbc.ca/news/politics/story/2012/08/07/pol-stephen-harper-british-columbia.html

Specialist Publications

Of particular interest:

'Palliative care subspecialty in the offing' (p.6), published in the *Canadian Medical Association Journal.*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *Vancouver Sun* – 11 August 2012 – **'Judge upholds Gloria Taylor's right to die.'** Gloria Taylor's right to avoid a "frightening and repugnant" death ... shouldn't be sacrificed because the courts have yet to decide the fate of Canada's doctor-assisted suicide ban, a judge ruled as she upheld the British Columbia woman's personal exemption from the law. The West Kelowna woman ... was among the plaintiffs in a landmark case that saw the B.C. Supreme Court strike down Canada's ban on doctor-assisted suicide as unconstitutional. While the court suspended its decision, Taylor was granted an exemption, making her the only person in Canada who can legally die with a doctor's help. The federal government launched an appeal ... and also asked the Appeal Court to revoke Taylor's exemption until the case is heard. case of doctor-assisted suicide. http://www.vancouversun.com/health/Judge+upholds+Gloria+Taylor+right/7076196/story.html

Cont.

Noted in Media Watch, 18 June 2012:

- BRITISH COLUMBIA (B.C.) | *Globe & Mail* – 15 June 2012 – **'B.C. Supreme Court strikes down ban on physician-assisted suicide.'** http://www.theglobeandmail.com/news/british-columbia/bc-supreme-court-strikes-down-ban-on-physician-assisted-suicide/article4267631/

U.S.A.

At the end of life, talk helps bridge a racial divide

NEW YORK TIMES | Online essay – 6 August 2012 – The family seated opposite me is tense. Having met at the bedside of a critically ill patient only moments earlier, we have gathered in a quiet alcove next to the intensive care unit to discuss what can only be bad news. The patient – someone's spouse, parent, child – is dying. As a palliative care specialist, I am to explain this with clarity and empathy and elicit an informed decision about what to do next. This encounter has come after days, weeks or even months of terrible emotional and physical anguish, avalanches of bewildering, conflicting information and opinion, hopes raised and lost, and long vigils in the family waiting area. Now, it is the opinion of the ICU [Intensive Care Unit] staff that survival is no longer an option, and I share this opinion. Living or dying is not at issue. The question this family confronts is how the patient will die: a little sooner, with adequate morphine, surrounded by loved ones in the hospice unit, or a little later, in a never dark or quiet patch of the ICU, ribs broken by failed, if well-intentioned, CPR. Add to this the following: The patient and family are black. And while race should not be relevant at this moment, research tells us otherwise.[1] Blacks are much more likely than whites to elect aggressive care and to decline do-not-resuscitate [DNR] orders. DNR election of even 30% is rare in any black community, and hospice enrollment is likewise low. hospice enrollment is likewise low. http://www.nytimes.com/2012/08/07/health/views/at-the-end-of-life-talk-helps-bridge-a-racial-divide.html?_r=1

1. 'Differences in level of care at the end of life according to race,' *American Journal of Critical Care*, 2010;19(4):335-343. http://ajcc.aacnjournals.org/content/19/4/335.abstract

Noted in Media Watch, 4 June 2012:

- *JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED,* 2012;23(1):28-58. **'What influences African American end-of-life preferences?'** Many African Americans choose aggressive life-sustaining treatment at the end of life, even if that treatment seems likely to confer great burden with little chance of benefit. The reasons for this are multi-faceted and include knowledge of/access to services, historical mistrust of the health care system, and spiritual beliefs. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/journal_of_health_care_for_the_poor_and_underserved/v023/23.1.wicher.html

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

Living to the end - palliative care for an ageing population

World hospice & palliative care day

October 13 2012

http://www.worldday.org/

International

Care in the community

Poor care at homes leads to thousand of elderly being admitted to hospital

U.K. (ENGLAND) | *Daily Telegraph* – 9 August 2012 – Hundreds of thousands of elderly people are admitted to hospital as emergencies because of poor care in the community, a study has found.[1] The failure of GPs, community health services and social care services to work together means large numbers of over 65s are admitted to hospitals, the King's Fund think tank has found. Researchers found that 2.3m overnight stays in hospital could be prevented if all areas of the country performed as well as the top 25%. This is the equivalent of 7,000 hospital beds, or several medium sized hospitals full of elderly emergency cases every night of the year. Savings of £462m could be made which could be reinvested in community services to keep the elderly well at home.http://www.telegraph.co.uk/health/healthnews/9461163/Poor-care-at-homes-leads-to-thousand-of-elderly-being-admitted-to-hospital.html

1. 'Explaining variation in use of emergency hospital beds by patients over 65,' King's Fund, August 2012. http://www.kingsfund.org.uk/publications/emergency_beds.html

End of Life Care Authority ...
profiles instant atlas map

U.K. (ENGLAND) | Bolton's Health Matters – 11 August 2012 – The End of Life Care Local Authority Profiles 2012 present over 50 indicators for each local authority in England. They include social care indicators for the first time. This is presented within an interactive map. There are indicators that can be used to predict need. http://www.boltonshealthmatters.org/knowledgehub/end-life-care-authority-upper-tier-profiles-instant-atlas-map

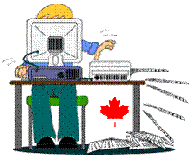
Specialist Publications

Of particular interest:

'Organizational interventions concerning palliation in community palliative care services: A literature study' (p.6), published in *ISRN Nursing*.

Of related interest:

- U.K. (ENGLAND) | *Weston, Worle & Somerset Mercury* (Weston-Super-Mare) – 6 August 2012 – **'New project helps terminal hospital patients.'** http://www.thewestonmercury.co.uk/news/new_project_helps_terminal_hospital_patients_1_1473108
- U.K. (WALES) | *South Wales Argus* (Maesglas, Newport) – 6 August 2012 – **'Gwent making strides in care of the dying.'** http://www.southwalesargus.co.uk/news/gwentnews/9857687.Gwent_making_strides_being_made_in_care_of_the_dying/



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

Palliative care is a human right to be protected

U.K. (SCOTLAND) | *The Scotsman* (OpEd) – 9 August 2012 – Earlier this week *The Scotsman*'s website reported Andrew de Beaux's suggestion that NHS [National Health Service] funding for palliative care should be redirected towards funding surgery for obese people,[1] questioning whether it is worth paying for the terminally ill to be given "expensive treatments which have little benefit," aside from "prolonging life by a few weeks." The debate appears to be based on a misunderstanding of palliative care. By definition, it intends neither to hasten nor postpone death. Instead, it helps people live well before they die by meeting the physical, emotional, practical and spiritual needs of each individual. Its power to transform someone's quality of life, and the effect this has on their friends and family, should never be underestimated. It is dangerous to consider palliative care as an expendable luxury. A dying person is still a living person, and we would all want our loved ones to live comfortably and with dignity, with their physical and emotional pain under control, if they were to have a terminal illness. Hospices make a huge contribution to supporting people at the end of life and their families, caring for 360,000 people a year. Most hospices are independent local charities, only receiving a minority of their funding from the NHS. Together, hospices must raise £1.5 million every day, making them collectively the biggest fundraising cause in the U.K. http://www.scotsman.com/news/jonathan-ellis-palliative-care-is-a-human-right-to-be-protected-1-2456653

1. 'NHS funds 'better spent on obesity,' *The Scotsman*, 4 August 2012. http://www.scotsman.com/news/nhs-funds-better-spent-on-obesity-1-2451782

Armenian cabinet meeting to discuss concept of palliative care

ARMENIA | Panorama»am – 7 August 2012 – An Armenian cabinet meeting is due to discuss the concept of palliative care. Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering. http://www.panorama.am/en/comments/2012/08/07/government/

Specialist Publications

Of particular interest:

'Palliative care developments in Ukraine' (p.9), published in *Progress in Palliative Care.*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLUMBIA | *Columbia Reports* (Medellin) – 9 August 2012 – **'Colombian Senate approves regulation of euthanasia.'** A Colombian Senate commission approved the regulation of euthanasia 15 years after its decriminalization. Euthanasia was decriminalized in Colombia in 1997 but proper regulation has not been introduced until now. http://colombiareports.com/colombia-news/news/25483-colombian-senate-approves-regulation-of-euthanasia.html
- GERMANY | *The Local* (Berlin) – 6 August 2012 – **'Half of Germans approve of euthanasia businesses.'** Nearly half of Germans are in favour of legalising euthanasia businesses, a recent survey revealed. The German parliament is still divided over proposed changes to assisted suicide laws. The survey ... found that 49% of Germans would be in favour of lifting the ban on privately-run euthanasia services. Just 41% said they would be against... Last week, Justice Minister Sabine Leutheusser-Schnarrenberger said that she was going to present a redrafted version of the country's assisted suicide laws in parliament. The new laws would see doctors, carers and close family being able to help someone end their life without facing punishment. Oddly, Emnid found that only 47% of the 501 people they asked, approved of this, as opposed to the 49% who approved lifting the ban on commercial euthanasia. http://www.thelocal.de/national/20120806-44189.html

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

Paediatric palliative care

'We didn't do anything wrong, we tried our best, but they just died … we tried, we really tried': Child deaths in the Paediatric Intensive Care Unit, Red Cross Children's Hospital, Cape Town, South Africa

AFRICAN STUDIES, 2012;71(2):287-303. This article argues that child deaths in the Paediatric Intensive Care Unit generate profound moral struggle amongst caregivers. The author deconstructs how caregivers manage the messy and at times problematic circumstances that clinical necessity requires from them in order to save children's lives. One result of this is that on many occasions they care for them at their time of death. When deaths are well managed compassion is engendered into the child's dying and the death becomes restorative for the family and unit. In this, consultants – who are intensive-care specialists – play a critical role as they take responsibility for the clinical management of child deaths. In doing so, they inform a team-based deliberation process to consider the child's clinical assessment in the context of other ethical and moral issues. In addition, consultants must take part in the social negotiation of these events with family and caregivers. Nurses in contrast are more intimately involved in child deaths and are shown to be more affected by the emotional, psychological and social consequences of deaths. http://www.tandfonline.com/doi/abs/10.1080/00020184.2012.702970

> **N.B.** This issue of the *African Studies* includes several articles on the study of loss and death in Africa. Contents page: http://www.ingentaconnect.com/content/hart/klj/2012/00000023/00000002

End-of-life and palliative care education in U.S. pharmacy schools

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 9 August 2012 – Results [of this study] revealed that the lecture format of teaching on end-of-life issues continues to be used today with an increase in offerings and greater participation by students than [indicated in an earlier study] in 1986. Recently established guidelines and standards regarding end-of-life issues for pharmacy schools are being addressed, thus today's pharmacists should be better prepared to relate to patients with terminal illnesses and their families than [noted] in [the] 1986 [study]. http://ajh.sagepub.com/content/early/2012/08/06/1049909112457011.abstract

Noted in Media Watch, 24 January 2011:

- *JOURNAL OF PALLIATIVE MEDICINE*, 2011;14(1):7-11. **'Where is the community pharmacist?'** http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0369

Palliative care and hematologic oncology: The promise of collaboration

BLOOD REVIEWS | Online article – 7 August 2012 – While recent medical advances have led to cure, remission or long-term disease control for patients with hematologic malignancy, many still portend poor prognoses and all are associated with significant symptom and quality of life burden for patients and families. The gravity of a diagnosis of a hematologic malignancy also weighs heavily on the medical team, who typically develop close and long-term relationships with their patients. Palliative care teams provide an additional layer of support to patients, family caregivers, and the primary medical team through close attention to symptoms and emotional, practical, and spiritual needs. Barriers to routine palliative care co-management in hematologic malignancies include persistent health professional confusion about the role of palliative care and its distinction from hospice; inadequate availability of palliative care provider capacity; and widespread lack of physician training in communicating about achievable goals of care with patients, family caregivers, and colleagues. The authors review the evidence of need for palliative care services in hematologic malignancy patients in the context of a growing body of evidence demonstrating the beneficial outcomes of such care when provided simultaneously with curative or life-prolonging treatment. http://www.bloodreviews.com/article/S0268-960X(12)00049-5/abstract

Palliative care subspecialty in the offing

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online report – 8 August 2012 – An aging population, a tide of chronic disease and spotty access to quality end-of-life care makes the establishment of palliative medicine as a subspecialty, and certification of family physicians with added competence in palliative medicine, logical steps in the provision of care to Canadians, experts contend. Now in the offing, the changes will ultimately result in bolstered capacity to serve societal needs, says Dr. Cori Schroder, co-chair of the Royal College of Physicians & Surgeons of Canada and the College of Family Physicians of Canada Conjoint Advisory Committee on Palliative Medicine. "I think the bottom line is that this is going to promote more accessible and more complete care for a broadening patient population." A two-year subspecialty program in palliative medicine is currently under consideration for approval by the Royal College of Physicians & Surgeons of Canada, while the College of Family Physicians of Canada is drafting the criteria under which a certificate of added competence in palliative medicine should be awarded. http://www.cmaj.ca/site/earlyreleases/8aug12_palliative-care-subspecialty-in-the-offing.html

Noted in Media Watch, 30 July 2012:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 25 July 2012. **'Palliative care training substandard.'** http://www.cmaj.ca/site/earlyreleases/25july12_palliative-care-training-substandard.xhtml

N.B. Canada was rated 9th (of the 40 countries surveyed) in The Quality of Death: Ranking End of-life-Care Across the World, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Palliative and end-of-life care in Newfoundland's deaf community

JOURNAL OF PALLIATIVE CARE, 2012;28(2):105-112. Qualitative research was used to explore the experiences of family caregivers who provided end-of-life care for a deaf person. Key findings indicate that the deaf community has limited understanding of their options for palliative and end-of-life care. Communication and health literacy are key barriers to accessing appropriate end-of-life care. Pain and symptom management, consideration of physical environments, and limited access to bereavement care are common issues faced by deaf people when caring for loved ones at the end of life. http://www.ncbi.nlm.nih.gov/pubmed/22860383

Organizational interventions concerning palliation in community palliative care services: A literature study

ISRN NURSING (International Scholarly Research Network) | Online article – Accessed 7 August 2012 – The study of the literature identified 19 studies described in 20 articles that relate to development efforts and interventions regarding the organisation of palliative care in communities. Nearly all of the studies were based on health care professionals' assessments of users (the relatives). However, it is unknown whether or how patients and relatives experience a positive effect of the interventions. The literature study shows that it is a great methodological challenge to complete and evaluate studies concerning organisation and cooperation using methods that make the results useful for others. http://www.isrn.com/journals/nursing/2012/769262/

Elders' preferences for life-prolonging treatment and their proxies' substituted judgment: Influence of the elders' current health

JOURNAL OF AGING & HEALTH | Online article – 6 August 2012 – Stronger preferences for life-prolonging treatments in worse-health prospects were expressed by both elders and proxies [i.e., study participants] when the elders' current health was relatively poor. The interaction effect was at least as pronounced for proxies' substituted judgment as for elders' own preferences. http://jah.sagepub.com/content/early/2012/07/20/0898264312454572.abstract

Cont.

Noted in Media Watch, 13 June 2011:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 6 June 2011 – **'Approaching patients and family members who hope for a miracle.'** http://www.jpsmjournal.com/article/S0885-3924(11)00243-0/abstract

Noted in Media Watch, 7 March 2011:

- *ANNALS OF INTERNAL MEDICINE* | Online article – 28 February 2011 – **'The effect on surrogates of making treatment decisions for others.'** http://www.annals.org/content/154/5/336.abstract?sid=f6073a72-011f-4649-a4bb-1a4fa9e1f04e

Noted in Media Watch, 10 January 2011:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2011;13(1):16-28. **'Patients' and surrogates' decision-making characteristics: Withdrawing, withholding, and continuing life-sustaining...'** http://journals.lww.com/jhpn/Abstract/2011/01000/Patients__and_Surrogates__Decision_Making.6.aspx

Nurses' knowledge about end-of-life care: Where are we?

JOURNAL OF CONTINUING EDUCATION IN NURSING, 2012;43(8):379-384. This study examined nurses' knowledge of end-of-life care and also the relationship between the nurses' knowledge and their characteristics. The mean score on the Palliative Care Quiz for Nursing was 8.95 of a possible 20. Participants who had the end-of-life care education tended to score higher than those without this education, and the difference was statistically significant. Comprehensive continuing education programs on end-of-life care should be provided to fill the gap in knowledge and skill of staff nurses. http://www.healio.com/nursing/journals/JCEN/%7B5B9CB609-D1E3-45AE-86B1-E0DA9107CD9C%7D/Nurses-Knowledge-About-End-of-Life-Care-Where-Are-We#

Of related interest:

- *JOURNAL OF CONTINUING EDUCATION IN NURSING*, 2012;43(8):342-343. **'NICU perspectives on palliative care.'** Few health care professionals have received palliative care training to comfort dying infants and their families. A palliative care program in the neonatal intensive care unit setting is discussed. http://www.healio.com/nursing/journals/JCEN/%7B489CD9C1-7025-44FE-A259-D2E4B9917C49%7D/NICU-Perspectives-on-Palliative-Care

Diabetes and palliative care

Symptom burden of adults with type 2 diabetes across the disease course: Diabetes and aging study

JOURNAL OF GENERAL INTERNAL MEDICINE | Online article – 3 August 2012 – In a diverse cohort of adults with type 2 diabetes, pain and non-pain symptoms were common among all patients, not only among those near the end of life. However, symptoms were more prevalent among patients with shorter survival. Older adults reported more physical symptoms, whereas younger adults reported more psychosocial symptoms. Diabetes care management should include not only good cardio-metabolic control, but also symptom palliation across the disease course. http://www.springerlink.com/content/rl36734554122075/

Noted in Media Watch, 4 June 2012:

- *SCANDINAVIAN JOURNAL OF CARING SCIENCES*, 23 May 2012. **'Diabetes and end of life: Ethical and methodological issues in gathering evidence to guide care.'** http://onlinelibrary.wiley.com/doi/10.1111/j.1471-6712.2012.01016.x/abstract

Cont.

Noted in Media Watch, 21 May 2012:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2012;14(4):293-302. **'The experiences and care preferences of people with diabetes at the end of life: A qualitative study.'** http://journals.lww.com/jhpn/Abstract/2012/06000/The_Experiences_and_Care_Preferences_of_People.10.aspx

Ethical facets of new diagnostic methods

Disorders of consciousness: Responding to requests for novel diagnostic and therapeutic interventions

THE LANCET NEUROLOGY, 2012;11(8):732-738. Severe brain injury can leave patients with chronic disorders of consciousness. Because of impaired responsiveness, many of these patients have traditionally been regarded as unaware. However, findings from recent clinical studies herald a potential paradigm shift: functional imaging and neurophysiological studies have identified ways to assess awareness and have revealed astounding cases of awareness despite clinical unresponsiveness. Hence, diagnostic classifications have been rewritten, prognostic knowledge is improving, and therapeutic studies have regained momentum, showing for the first time some therapeutic effects on responsiveness. Clinicians must increasingly respond to requests by patients' families and surrogate decision makers to use novel techniques for diagnosis, prognosis, and treatment, and in doing so several ethical and social issues need to be considered. Such requests provide an opportunity for clinicians to learn about patients' values and preferences and to maintain clinical acumen for changes in patient status with the patients' best interests in mind. http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(12)70154-0/abstract

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.

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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Music during after-death care: A focus group study

NURSING IN CRITICAL CARE | Online article – 5 August 2012 – Including ambient music in an after-death care programme can help nurses show respect for the deceased as the body is being prepared. Played during the viewing may be a way of helping relatives in their time of grieving. It may ease the situation by making that event special and memorable. However, standardizing this intervention does not seem appropriate. http://onlinelibrary.wiley.com/doi/10.1111/j.1478-5153.2012.00525.x/abstract;jsessionid=7742566165C823FCB9219837A4369F8D.d04t01?deniedAccessCustomisedMessage=&userIsAuthenticated=false

Palliative care for advanced Parkinson disease: An interdisciplinary clinic and new scale, the ESAS-PD

PARKINSONISM & RELATED DISORDERS | Online article – 6 August 2012 – The Edmonton Symptom Assessment System Scale for Parkinson's disease [ESAS-PD] is a quick, effective scale for assessment of late stage PD symptoms. Scores are sensitive to intervention, and therefore have potential clinical utility for physicians and other healthcare providers. Advanced PD patients have a similar degree of symptoms as metastatic cancer patients, respond to treatment in a similar way, and therefore should have access to palliative care services. http://www.prd-journal.com/article/S1353-8020(12)00251-9/abstract

Noted in Media Watch, 16 July 2012:

- *PARKINSONISM & RELATED DISORDERS* | Online article – 9 July 2012 – **'The conceptual framework of palliative care applied to advanced Parkinson's disease.'** http://www.prd-journal.com/article/S1353-8020(12)00250-7/abstract

Noted in Media Watch, 13 February 2012:

- NATIONAL COUNCIL FOR PALLIATIVE CARE (U.K.) | Online posting – 6 February 2012 – **'New guide to manage last days of life in Parkinson's disease.'** http://www.ncpc.org.uk/news/83

Noted in Media Watch, 11 April 2011:

- *JOURNAL OF MULTIDISCIPLINARY HEALTHCARE*, 2011;2011(4):33-38. **'Parkinson's disease permanent care unit: Managing the chronic-palliative interface.'** A specially designed and staffed care unit for Parkinsonism patients seems to fill a need for patients and caregivers, as well as for social and health care authorities. http://www.dovepress.com/parkinsonrsquos-disease-permanent-care-unit-managing-the-chronic-palli-peer-reviewed-article-JMDH

Palliative care developments in Ukraine

PROGRESS IN PALLIATIVE CARE | Online article – 9 August 2012 – Desk review and personal communications with palliative care providers, policy makers, patients, and volunteers suggest that Ukraine is undergoing the initial stages of palliative care development; limited numbers of hospices and palliative care units are available. Most health providers working in these facilities have only limited specialized training in palliative care or pain management. In the majority of cases, training was obtained through international donor support and only occasionally through the governmental medical post-graduate education system. Access to medications, even in specialized palliative care units, is limited by a lack of funding and extremely strict regulations for controlled medications, such as morphine. An absence of clinical guidelines and protocols on palliative care and pain management results in a non-unified approach to patient care that offers few treatment options. The overall situation can be explained by the absence of a national strategy or program to promote and support palliative care and integrate it into the general health care system. Although the first steps are being taken to promote evidence-based standards of practice in palliative care, there are considerable barriers that should be addressed by the government and the professional community. http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000029

Cont.

Noted in Media Watch, 16 May 2011:

- UKRAINE | Associated Press – 12 May 2011 – **'Ukrainian cancer patients denied pain relief.'**[1] http://www.seattlepi.com/news/article/Ukrainian-cancer-patients-denied-pain-relief-1376503.php

  1. *Uncontrolled Pain: Ukraine's Obligation to Ensure Evidence-Based Palliative Care*, Human Rights Watch, 12 May 2011. http://www.hrw.org/en/reports/2011/05/12/uncontrolled-pain-0

Negotiating sensitivities and grappling with intangibles: Experiences from a study of spirituality and funerals

QUALITATIVE RESEARCH | Online article – 2 August 2012 – The project used qualitative methods to explore the ways in which mourners sought, ascribed and expressed meaning through the funeral and analysed these processes in relation to evidence of religion and a broader spirituality. The article considers ethical and practical factors in conducting research around a sensitive event where participants may be vulnerable. It describes the analysis process of data obtained concerning religious and other beliefs and comments on the value and difficulties of a multidisciplinary approach. http://qrj.sagepub.com/content/early/2012/08/02/1468794112439008.abstract

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2012;44(2):307-312. **'Life is uncertain. Death is certain. Buddhism and palliative care.'** http://www.jpsmjournal.com/article/S0885-3924(12)00262-X/abstract

Media Watch Online

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

U.S.A.

Prison Terminal: http://www.prisonterminal.com/news%20media%20watch.html

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

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/ (Scroll down to 'What's New: Reading List Update')

International

Australasian Palliative International Link: http://www1.petermac.org/apli/links.htm (Scroll down to 'Media Watch')

Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

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

Economics at the end of life: Hospital and ICU perspectives

SEMINARS IN RESPIRATORY & CRITICAL CARE MEDICINE, 2012;33(4):362-369. Not all feasible care is desirable care. At the end of life, aggressive interventions may not only be futile but also inappropriate because they may impair the quality of the remaining life for both the patient and the caregiver. Although it is challenging to identify patients with a poor prognosis, certain terminal conditions among the elderly, such as end-stage dementia, heart failure, and metastatic cancer, demand a more measured use of aggressive care. Frank discussions with patients and family about their desires in the context of the prognosis, as well as symptom support, can yield both economic savings and better quality of life. https://www.thieme-connect.de/ejournals/html/10.1055/s-0032-1322399

Moral instruction in dying well

Making death 'good': Instructional tales for dying in newspaper accounts of Jade Goody's death

SOCIOLOGY OF HEALTH & ILLNESS | Online article – 8 August 2012 – Facilitating a 'good' death is a central goal for hospices and palliative care organisations. The key features of such a death include an acceptance of death, an open awareness of and communication about death, the settling of practical and interpersonal business, the reduction of suffering and pain, and the enhancement of autonomy, choice and control. Yet deaths are inherently neither good nor bad; they require cultural labour to be 'made over' as good. Drawing on media accounts of the controversial death of U.K. reality television star Jade Goody, and building on existing analyses of her death, the authors examine how cultural discourses actively work to construct deaths as good or bad and to position the dying and those witnessing their death as morally accountable. By constructing Goody as bravely breaking social taboos by openly acknowledging death, by contextualising her dying as occurring at the end of a life well lived and by emphasising biographical continuity and agency, newspaper accounts serve to position themselves as educative rather than exploitative, and readers as information-seekers rather than ghoulishly voyeuristic. The authors argue that popular culture offers moral instruction in dying well which resonates with the messages from palliative care. http://onlinelibrary.wiley.com/doi/10.1111/j.1467-9566.2012.01492.x/abstract

Noted in Media Watch, 28 June 2010:

- *SOCIAL SCIENCE & MEDICINE* | Online article – 23 June 2010 – **'Jade and the journalists...'** http://www.sciencedirect.com/science/article/pii/S0277953610004697

Noted in Media Watch, 25 May 2009:

- U.K. | *Daily Telegraph* – 18 May 2009 – **'Jade Goody tragedy helped people think about dying.'** http://www.telegraph.co.uk/news/newstopics/celebritynews/jadegoody/5342038/Jade-Goody-tragedy-helped-people-think-about-dying.html

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2012;184(11):1227. **'Choosing when and how to die: Are we ready to perform therapeutic homicide?'** The Dying with Dignity commission of the Quebec National Assembly has issued its report after two years of public hearings, consultations with experts and visits to countries where there is now some experience with a range of options on ways of dying. The commission and the Charest government deserve equal praise for their thoughtful report and their courage in addressing this controversial topic. The principal theme of the report holds that palliative care has come of age and is adequate to meet the needs of most dying people; however, it is underprovided, particularly in remote and rural areas.

Cont.

A second important theme concerns "l'aide médicale à mourir" – medical assistance to die. On this subject, the report calls for a change in thinking, arguing that there will still be cases where suffering is great, irreversible and unrelievable, such that the only option is actively helping a person to die. The recommendation is based on two legal considerations. First, the civil code recognizes the right of adult patients to make medical decisions concerning their care, even if refusing or stopping treatment may result in their death. Second, both the Quebec and Canadian charters of rights and freedoms enshrine the rights to personal dignity and integrity. These rights imply a respect for self-determination and a person's physical and psychological well-being. These are powerful arguments and suggest that an individual should be able to make life's important decisions in a free and unconditional way, including deciding when the struggle to stay alive should end. However, this line of reasoning only supports an individual's right to end his or her own life.
http://www.cmaj.ca/content/184/11/1227.full

Worth Repeating

Creating compassionate care within the hospital intensive care unit: Beyond positivism and toward wisdom and responsibility

QUALITATIVE RESEARCH, 2003;3(1):119-138. Of deaths in the U.S., an increasing proportion occur within hospital intensive care units amidst miraculous medical technology. A positivist ethos dominates, despite the severe philosophic criticisms levelled at its axiomatic foundations. As patients are transformed into "cases," they lose social identity, and their dying becomes a medical defeat, rather than a natural and social process. Families encounter sedated intubated specimens rather than social persons from whom they wish ceremonially to depart. There are ongoing efforts at transformation and remediation. Viewing biomedicine in relationship to phronesis, this article explores the dilemmas. http://qrj.sagepub.com/content/3/1/119.abstract

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