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.

11 April 2011 Edition | Issue #196



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

Compiled & Annotated by Barry R. Ashpole

Media Watch online: The weekly report is now posted on the website for the International Palliative Care Resource Center, an initiative of The Institute for Palliative Medicine at San Diego Hospice. Scroll down to Media Watch Online (p.7) for a list of the websites that post the weekly report.

Canada

Home care in bad shape: Report

ONTARIO | Chronicle Journal (Thunder Bay) - 5 April 2011 - Huge waiting lists, unequal access to care and high administrative costs continue to plague Ontario's home care system, the Ontario Health Coalition [OHC] claims. Those are some of the findings in ... Still Waiting: An assessment of Ontario's Home Care System After Two Decades of Restructuring. Though home care has been repeatedly reformed since the mid-1990s, the coalition states that changes made by policy-makers have not addressed the problems that are central to the very purpose of the home care system. The [provincial] auditor general's findings in 2010²... reveal a failure by successive governments to make accessible public home care their priority, the report said. Problems cited ... in the IOHC1 report include no assessment of community need for care. nor standards for access to care; underfunded programs and poor access to care; high administrative costs mean the system suffers; poor oversight and lack of assessment of quality of care; staffing shortages and poor working conditions across the system; too much for-profit privatization of service: no democratic governance and a lack of public

accountability; and a failure by governments to address long-standing problems. http://www.chroniclejournal.com/content/news/local/2011/04/05/home-care-bad-shape-report

- Still Waiting: An assessment of Ontario's Home Care System After Two Decades of Restructuring, OHC, 4 April 2011. http://www.web.net/~ohc/homecare2011 finalreport.pdf
- Ontario Auditor General 2010 Annual Report, December 2010 (Chapter 3; Section 3.04, pp.113-131). http://www.auditor.on.ca/en/reports_en/en10/2010ar_en.pdf

Extract from Ontario Health Coalition report

Palliative care, outpatient rehabilitation ... [and] ... chronic care have been dramatically cut in hospitals all across Ontario. But home care in the community has been insufficiently funded and organized to meet the needs of downloaded hospital patients, as well as the elderly and persons with disabilities who require these services.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

BRITISH COLUMBIA | Vancouver Sun -8 April 2011 - 'B.C. group trying to legalize assisted suicide files constitutional challenge.' A B.C. group fighting to legalize assisted suicide has filed a constitutional challenge in B.C. Supreme Court. The directors of the Farewell Foundation for the Right to Die are challenging a section of the Criminal Code which makes aiding and abetting suicide an offence punishable by up to 14 years in prison. The group argues the Charter infringes on people's freedom to choose how they want to die by punishing those who help them end their lives.http://www.vancouversun.com/new s/group+trying+legalize+assisted+suicid e+files+constitutional+challenge/458433 4/story.html

Specialist Publications

Of particular interest:

'Court rules that withdrawal of life support is a plan of treatment requiring consent' (p.7), published in the Canadian Medical Association Journal.

'Navigating assisted death and end-of-life care' (p.8), published in the Canadian Medical Association Journal.

'Legalizing euthanasia or assisted suicide: The illusion of safeguards and controls' (p.8), published in *Current Oncology*.

U.S.A.

What You Can Do When a Friend (Like Me) Faces the End of Life

For dying people, a chance to shape their legacy

MISSOURI | National Public Radio (St. Louis) – 9 April 2011 – Imagine that you've just been told you have only a short time to live. What would you want your family and community to remember most about you? In St. Louis, a hospice program called Lumina helps patients leave statements that go beyond a simple goodbye. Suzanne Doyle, the founder of Lumina at BJC Hospice, sits quietly thumbing through a stack of books and photo albums she helped create. Her eyes begin to moisten as she recalls a recent patient, Courtney Strain, who died of brain cancer last summer at the age of 25. In the months before Strain died, she met weekly with Doyle. In those meetings, Strain revealed one constant frustration: feeling like an outcast. People didn't know what to say to her, she told Doyle, so they said nothing at all. "I said, 'You know, I'm thinking, Courtney, that you can be a teacher,' "Doyle says. " 'You know what people, not just your age, but all dying people, need. ... And I wonder if we can't come up with some kind of teaching tool.' "The teaching tool they completed together is a simple guide they called *What You Can Do When a Friend (Like Me) Faces the End of Life*. Strain's mother, Becky Brooks, says Lumina gave her daughter a voice at the end of her young life. http://www.npr.org/2011/04/09/134463410/for-dying-people-a-chance-to-shape-their-legacy

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/

Terminally ill and homeless: Saving a death

CALIFORNIA | San Francisco Chronicle (OpEd) – 6 April 2011 – We all live in fear of that moment. You know the one - when your nice, but kind of formal, doctor rolls over on his stool to tell you the results of your biopsy. Before the words even leave his lips. you know. You know it's bad, and your brain flees, backing away into a deep, silent corner. Only the words incurable and cancer slither into the darkness where your thoughts are hiding. The night after such an experience, you feel stalked by fears. You cannot sit still; your thoughts dart and flee, trying to avoid being taken down into sheer and utter panic. Hissing recriminations, pounding regrets, a smothering pang of longing for the world to be different – these

are the monsters that come out that night. So what happens that night if you're homeless? http://www.sfgate.com/cgibin/blogs/gurley/detail?entry id=86430

Specialist Publications

Of particular interest:

'Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of health and social services professionals' (p.11), published in *Palliative Medicine*

From Media Watch dated 15 November 2010:

CANADIAN HEALTHCARE NETWORK | Online article – 9 November 2010 – 'End-of-life care for homeless.' It's a tough subject, even for people with stable housing and plenty of support: Where and how do they wish to be cared for as life draws to a close? But for homeless and marginalized people on the streets of Halifax, Nova Scotia, there's a good chance that, when their time comes, they may not have the opportunity to choose the kind of end-of-life that care that they would prefer. http://www.canadianhealthcarenetwork.ca/nurses/news/movers-shakers/monica-flinn-end-of-life-care-for-homeless-6956

From Media Watch dated 26 July 2010:

ANNALS OF INTERNAL MEDICINE, 2010;153(2):76-84. 'Effect of an end-of-life planning intervention on the completion of advance directives in homeless persons.' Homeless persons can respond to an intervention to plan for end-of-life care and can express specific preferences for care or a surrogate decision maker, but additional studies are needed to assess the effect of these directives on subsequent care. http://www.annals.org/content/153/2/76.abstract

From Media Watch dated 6 April 2009:

MISSOURI | Kansas City Star – 1 April 2009 – 'A last kindness to the homeless.' She's known ... as the case manager of death. It's a title Jan Brown, the intensive case manager for the Kansas City Rescue Mission, is proud to hold. http://www.kansascity.com/news/local/story/1119812.html

Study: Blacks in DC less likely to use hospice

WASHINGTON DC | Associated Press – 6 April 2011 – A study by Capital Hospice found that in the District of Columbia, African-Americans over 65 who are eligible for hospice care are 34% less likely than white people to use it. http://www.necn.com/04/06/11/Study-Blacks-in-DC-less-likely-to-use-ho/landing_health.html?&blockID=3&apID=ceddc8a2721e4344ad28158966e29db0

From Media Watch dated 10 January 2011:

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2011;13(1):41-46. "Will patients want hospice or palliative care if they do not know what it is?" Knowledge of hospice care was lower among African Americans than whites and among those with limited education.
http://journals.lww.com/jhpn/Abstract/2011/01000/Will_Patients_Want_Hospice_or_Palliative_Care_if.9.aspx

Dying? Plan ahead: Priests scarce for last rites

CLEVELAND | *USA Today* – 5 April 2011 – In days long gone, Roman Catholic priests regularly made deathbed house calls, even in the middle of the night with little notice, to pray over the dying and anoint them with holy oils. The candlelight ritual, popularly known as last rites, continues in hospitals, nursing homes, hospice houses and private homes. But it happens less frequently because priests – the only ones who can perform the service – are in short supply. http://www.usatoday.com/news/religion/2011-04-06-dying Catholic priest 05 ST N.htm

U.K. (WALES) | BBC News – 5 April 2011 – 'Church in Wales call over lack of burial space.'
Church leaders have warned it will become increasingly difficult for people to be buried in their own communities as space runs out. http://www.bbc.co.uk/news/uk-wales-12969729

When ailments pile up, asking patients to rethink free dialysis

NEW YORK TIMES | Online article – 1 April 2011 – Of all the terrible chronic diseases, only one – end-stage kidney disease – gets special treatment by the federal government. A law passed by Congress 39 years ago provides nearly free care to almost all patients whose kidneys have failed, regardless of their age or ability to pay. But the law has had unintended consequences, kidney experts say. It was meant to keep young and middle-aged people alive and productive. Instead, many of the patients who take advantage of the law are old and have other medical problems, often suffering through dialysis as a replacement for their failed kidneys but not living long because the other chronic diseases kill them. Kidney specialists are pushing doctors to be more forthright with elderly people who have other serious medical conditions, to tell the patients that even though they are entitled to dialysis, they may want to decline such treatment and enter a hospice instead. http://www.nytimes.com/2011/04/01/health/01dialysis.html? r=1

International

Generation of doctors untrained in care of dying

RADIO NEW ZEALAND | Online report – 10 April 2011 – Two senior physicians in palliative care say a whole generation of doctors has not been trained in the care of the dying. Palliative care started in New Zealand in the 1980s and has been taught at medical schools only in the last five to 10 years, meaning many senior doctors are untrained in it. Dr. Simon Allan and Dr. Frank Brennan say doctors in many Western countries did not get the training, partly because palliative care was a new discipline and partly because people did not want to talk about it. http://www.radionz.co.nz/news/national/72562/generation-of-drs-untrained-in-care-of-dying

From Media Watch dated 12 April 2010:

SOCIETY & ANIMALS, 2010;18(2):152-162. 'End-of-life issues in U.S. veterinary medicine schools.' The average number of hours students devote to end-of-life issues [in the 28 veterinary medicine schools in the U.S.] is 14.64, about the same as for U.S. medical and ... nursing schools. http://www.ingentaconnect.com/content/brill/saa/2010/00000018/00000002/art00004

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.

"It lifts our spirit and helps us to cope with the grief"

Laughter therapy is no joke

SOUTH AFRICA | *Mail & Guardian* (Cape Town) – 8 April 2011 – The nurses and caregivers at the Matlosana Hospice and Khaya Tshepo Paediatric Palliative ... cannot start the day without a big belly laugh. Every morning before their day starts, the staff gather in a circle and one facilitates the session and leads the group. It starts with a well-known technique – a clap and saying, "Very good, very good, yay," and the giggles just start, according to Estelle du Toit, a nursing director at the hospice. This has become part of their daily routine. Laughter is easily stimulated in a group and often the activities involve a great deal of eye contact, childlike playfulness and laughter exercises. http://mg.co.za/article/2011-04-08-laughter-therapy-is-no-joke/

Smaller organisation ... less bureaucracy

Erdington Hospice John Taylor facing £600,000 cash crisis

U.K. | *Birmingham Mail* – 6 April 2011 – Erdington's John Taylor hospice, which celebrated its 100th anniversary last year, left direct NHS [National Health Service] control after staff won the right to run the hospice as an independent social enterprise..The site's clinical lead Helen Karakas, who leads a team of 52 in-patient nurses and a bank staff of 35 more, said: "We will be a smaller organisation and there will be less bureaucracy. We will be able to respond quickly and decisions will be taken at a local level." But the change will also present a financial challenge with the hospice's League of Friends ... warning they would need ... an additional £600,000 per year. http://www.birminghammail.net/news/birmingham-news/2011/04/06/erdington-hospice-john-taylor-facing-600-000-cash-crisis-97319-28466468/

National policy on palliative care for children

1st consultant in child palliative care

IRELAND | Irish Health - 5 April 2011 -Ireland's first consultant in children's palliative medicine has been appointed ... the Irish Hospice Foundation has announced. Dr. Mary Devins ... will have "a national role in supporting all clinicians who provide palliative care to children." She will also provide leadership and support to outreach nurses working with children with life-limiting conditions. An estimated 1,400 children are living with life-limiting conditions in Ireland at any one time, while around 350 children die here every year, the majority in the first year of life. Dr. Devins' appointment is one of a number of measures outlined [last year] ... by the Department of Health & Children. http://www.irishhealth.com/article.h tml?id=18943

 Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy, March 2010. http://www.dohc.ie/publications/pdf/palliative-care-en.pdf?direct=1

Of related interest

U.K. | ACT (Association for Children's Palliative Care) online reports – 7 April 2011 – 'ACT's new resources to support the withdrawal of lifesustaining treatment within a children's palliative care framework.' ACT has launched A Care Pathway to Support Extubation within a Children's Palliative Care Framework and A parent's guide: Making critical care choices for your child. http://www.act.org.uk/news.asp?section=94§ionTitle=News&itemid=983

Specialist Publications

Of particular interest:

'Pediatric nurses' individual and group assessments of palliative, end-of-life, and bereavement care' (p.10), published in the *Journal of Palliative Medicine*

National guidance on "last offices"

Nurses to lead on care after death

U.K. | *Nursing Times* – 5 April 2011 – Registered nurses have been charged with responsibility for overseeing the care of patients after death, under the first national guidance on "last offices." The guidelines, shared exclusively with *Nursing Times*, outlines how bodies should be treated, how to communicate with bereaved families, and legal requirements following a patient's death. They have been developed by specialist nurses working with the National Health Service National End of Life Care Programme in response to a lack of training and guidance for the profession on the emotionally challenging work of caring for patients after death. An investigation by *Nursing Times* last year suggested procedures ... were not carried out properly for more than half of deceased hospital patients. http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/nurses-to-lead-on-care-after-death/5028024.article

From Media watch dated 14 June 2010:

U.K. | Nursing Times (OpEd) – 11 June 2010 – 'Nurses need national guidance to standardise last offices care.' The care of deceased patients presents nurses with a unique challenge. They are the only profession to care for people both in the period leading up to death and immediately afterwards.http://www.nursingtimes.net/nursing-practice-clinical-research/acute-care/nurses-need-national-guidance-to-standardise-last-offices-care-/5015832.article

From Media Watch dated 17 May 2010:

U.K. | Nursing Times – 11 May 2010 – 'Last offices neglected in over half of hospital deaths.' A dearth of training and guidance means nurses are failing to follow "last offices," the simple procedures for treating dead patients with dignity and respect [see sidebar], a Nursing Times investigation has found. http://www.nursingtimes.net/whats-new-in-nursing/acute-care/last-offices-neglected-in-over-half-of-hospital-deaths/5014365.article

What should last offices involve?

- If the patient is not catheterised, apply gentle pressure over the bladder to allow it to drain
- Remove and record jewellery and any personal items, unless requested or advised otherwise
- Attend to hygiene needs, particularly hair, nail and mouth care
- Replace dentures
- Attempt to close the eyes, using a small piece of clinical tape if required
- · Attach identification labels
- Dress the patient in a gown/shroud or own clothes, as required
- Place an incontinence pad under the buttocks to contain any soiling

Ombudsman for Wales wants power to investigate hospices

U.K. (WALES) | BBC News – 5 April 2011 – The Ombudsman for Wales has called for his office to be given more power to independently investigate hospices. It follows complaints from the family of a teenage girl who died of leukaemia about the way their concerns over her care were handled. Peter Tyndall said the response to their complaints by Healthcare Inspectorate Wales was muddled. The inspectorate has apologised unreservedly and said it was changing the way it handles complaints. The report details how the teenage girl was transferred from hospital to the hospice with a rare form of leukaemia in February 2008. She was discharged in April and died at home in August. During her 10 weeks at the hospice the girl's family were keen to play an active part in her care but disagreements arose with staff over her treatment. Hospice staff became concerned about their access to the patient and contacted Healthcare Inspectorate Wales for advice. http://www.bbc.co.uk/news/uk-wales-12966369

Assisted (or facilitated) death

Representative sample of recent news media coverage:

SWITZERLAND | Swiss.info – 5 April 2011 – 'Assisted suicides increase in 2010.' Assisted suicide organisation Exit helped 257 people to die in 2010, an increase of 15% over the 2009 total of 217 assisted deaths. The organisation ... saw its overall membership rise by 4,000 to 70,000 people.http://www.swissinfo.ch/eng/swiss_news/Assisted_suicides_increase_in_2010.html?cid=29 929052

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

Court rules that withdrawal of life support is a plan of treatment requiring consent

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 8 April 2011 – Ontario doctors cannot withdraw life-sustaining treatment from patients without their consent or that of their substitute decision-makers, the province's Superior Court of Justice has ruled. Physicians at the Sunnybrook Health Sciences in Toronto, Ontario, had sought to withdraw mechanical ventilation from a 59-year-old man in a persistent, vegetative state without the consent of his substitute decision-maker. The patient, Hassan Rasouli ... had undergone surgery at the hospital in October 2010 to remove a benign tumour in his head. Following surgery, he had developed bacterial meningitis and ventriculitis, and had slipped into a coma, from which various experts said he would never emerge. He is being kept alive by a mechanical ventilator and feeding tube. Dr. Brian Cuthbertson and Dr. Gordon Rubenfeld had sought to withdraw the life-sustaining equipment, place Rasouli on palliative therapy and transfer him to another facility. But Rasouli's spouse, Parichehr Salasel, a physician in Iran until the family emigrated to Canada in April 2010, objected. primarily on the grounds that withdrawal of life-sustaining treatment violated a tenet of the Shia Muslim faith that health care treatment should be provided until there are no signs of life. http://www.cmai.ca/earlyreleases/8april11 court-rules-that-withdrawal-of-life-support-is-a-plan-oftreatment-requiring-consent.dtl

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.hpcconnection.ca/newsletter/inthenews.html

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

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/search/?tag=Media+Watch

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

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

ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU

CHEST, 2011;139(4):795-801. Psychologic symptoms of posttraumatic stress disorder (PTSD) and depression are relatively common among family members of patients who die in the ICU. The patient-level risk factors for these family symptoms are not well understood but may help to target future interventions. Family members of younger patients and those for whom mechanical ventilation is not withdrawn are at increased risk of psychologic symptoms and may represent an important group for intervention. Increased PTSD symptoms among family members present at the time of death may reflect a closer relationship with the patient or more involvement with the patient's ICU care but also suggests that family should be offered the option of not being present. http://chestjournal.chestpubs.org/content/139/4/795.abstract

Assisted (or facilitated) death

Legalizing euthanasia or assisted suicide: The illusion of safeguards and controls

CURRENT ONCOLOGY, 2011;18(2):e38e45. Euthanasia or assisted suicide – and sometimes both – have been legalized in a small number of countries and states. In all jurisdictions, laws and safeguards were put in place to prevent abuse and misuse of these practices. Prevention measures have included, among others, explicit consent by the person requesting euthanasia, mandatory reporting of all cases, administration only by physicians (with the exception of Switzerland), and consultation by a second physician. The present paper provides evidence that these laws and safeguards are regularly ignored and transgressed in all the jurisdictions and that transgressions are not prosecuted. For example, about 900 people annually are administered lethal substances without having given explicit consent, and in one jurisdiction, almost 50% of cases of euthanasia are not reported. Increased tolerance of transgressions in societies with such laws represents a social "slippery slope." as do changes to the laws and criteria that followed legalization. Although the initial intent was to limit euthanasia and assisted suicide to a last-resort option for a very small number of terminally ill people, some jurisdictions now extend the practice to newborns, children, and people with

dementia. A terminal illness is no longer a prerequisite. In The Netherlands, euthanasia for anyone over the age of 70 who is "tired of living" is now being considered. Legalizing euthanasia and assisted suicide therefore places many people at risk, affects the values of society over time, and does not provide controls and safeguards. http://current-

oncology.com/index.php/oncology/article/vie w/883/645

An appraisal of life's terminal phases and euthanasia and the right to die

CURRENT ONCOLOGY, 2011;18(2):65-66. Given that, by the 21st century, medicine had more than doubled life expectancy over that in the 19th century, there is now a demographic bulge of seniors challenging palliative geriatric and terminal medical practices. Terminal management should be part of medical training. Without advance directives, societal consciences dominate, but the right to die and passive euthanasia should not be in conflict. Active euthanasia as an elective policy remains spurious, just as committing suicide is murder. http://journals.sfu.ca/multimed/oncology/index.php/oncology/article/view/864/626

Of related interest:

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2011;183(6):643-644. 'Navigating assisted death and end-of-life care.' Abstract unavailable. http://www.cmaj.ca/cgi/reprint/183/6/643

Extending the team component of the Latimer ethical decision-making model for palliative care

JOURNAL OF HEALTHCARE LEADERSHIP, 2011;2011(3):41-52. The study findings substantiated many of the team practice concepts outlined in [Elizabeth] Latimer's model. Palliative care teams engage in a number of processes that address patient symptoms, suffering, hopes, and plans. However, several new findings also emerged from the data that were not explicit in Latimer's original model. Teams employed five additional emergent team processes when addressing patient symptoms and suffering while attempting to fulfill patient hopes and plans. Those five team processes included explicating practice norms, leadership, provider assumptions, interdisciplinary teaching, and patient safety. http://www.dovepress.com/extending-the-team-component-of-the-latimer-ethical-decision-making-mo-peer-reviewed-article-JHL

 'Caring for seriously ill and dying patients: The philosophy and ethics,' Canadian Medical Association Journal, 1991;144(7):859-864. Palliative care must be based on a philosophy that acknowledges the inherent worth and dignity of each person. In addition, it must take place within the framework of four ethical principles: autonomy, beneficience, nonmaleficience and justice. http://www.cmaj.ca/cgi/content/abstract/144/7/859

Parkinson's disease permanent care unit: Managing the chronic-palliative interface

JOURNAL OF MULTIDISCIPLINARY HEALTHCARE, 2011;2011(4):33-38. 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. This model is sensitive to the changing needs and capacities of patients, ensuring that appropriate services are available in a timely manner. There was a rather short duration of patient stay and remaining life span after admission to the unit. http://www.dovepress.com/parkinsonrsquos-disease-permanent-care-unit-managing-the-chronic-palli-peer-reviewed-article-JMDH

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.

Pediatric nurses' individual and group assessments of palliative, end-of-life, and bereavement care

JOURNAL OF PALLIATIVE MEDICINE | Online article – 10 April 2011 – Nurses [i.e., participants in this cross-sectional survey] rated the most important goals as managing pain, maintaining the child's quality of life, and improving communication. Commonly cited problems were lack of opportunity to debrief after a patient's death, uncertainty about the goals of care, and the health care team's reluctance to discuss hospice with family. Based on individual views about goals and problems, nurses clustered into 5 groups that differed in terms of the adamancy of their views and the scope of the goals and problems they considered important or significant. The hospital unit was the most important factor in predicting nurses' degree of collaboration with the palliative care team even after accounting for individual characteristics.

http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0409

Editorial

The global palliative care lottery: Can we overcome it?

JOURNAL OF PALLIATIVE MEDICINE. 2011;14(4):384-385. There is now acceptable evidence of the effectiveness of specialist palliative and hospice care in improving pain and symptom control and psychological well-being for patients and families. There is some evidence that specialist palliative care can reduce costs to health care providers. Accessing palliative and end-of-life care is often regarded as a central human right. Despite this there is no universal standard of access to palliative care. Access varies from country to country, by age, by social class and by disease. Even within cancer type access varies. The models of care also vary from country to country; in some instances with a greater emphasis on education of existing professionals and in other instances with a greater emphasis on direct care. While palliative care services have successfully adapted to their local circumstances and environments, including the income and health care structures within different

countries, this variation in practice and access is probably greater than many other areas of health care. And it brings with it some disadvantages – it is much easier for palliative and hospice care to become an optional add on – if it is nebulous, variable, or poorly defined, and if some groups receive it and others do not. http://www.liebertonline.com/doi/pdfplus/10.1 089/jpm.2011.9710

Palliative care in Middle-Eastern countries

A supplement to the current issue of the *Journal of Pediatric Hematology/Oncology* focuses on palliative care in Middle-Eastern countries with articles on end of life care in Cyprus, Egypt, Israel, Pakistan, the Palestinian Authority and Turkey. Other articles focus on opioid use in pain management. Contents page: http://journals.lww.com/jpho-online/toc/2011/04001

Hiding transfer to palliative care gives patients 'false hope'

NURSING TIMES | Online article – 10 April 2011 – Transfer to an end of life care pathway is rarely discussed properly with hospital patients, according to scientists. Sheffield University researchers interviewed 58 clinicians involved in palliative care. They said: "Participants identified that a structured transition to a palliative care approach... is seldom evident in acute hospital settings." In particular they reported that prognosis is not routinely discussed with inpatients. Primary care professionals confirmed patients were often discharged from hospital with 'false hope' of cure because this information had not been conveyed."

http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/hiding-transfer-to-palliative-care-gives-patients-false-hope/5028402.article

Cont.

1. 'Transitions to palliative care in acute hospitals in England: Qualitative study.' *British Medical Journal* | Online article – 29 March 2011 – Participants [in this qualitative study] identified that a structured transition to a palliative care approach of the type advocated in U.K. policy guidance is seldom evident in acute hospital settings. http://www.bmj.com/content/342/bmj.d1773

N.B. Noted in Media Watch dated 4 April 2011.

Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of health and social services professionals

PALLIATIVE MEDICINE | Online article – 4 April 2011 – Homeless persons tend to die younger than the housed population and have complex, often unmet, end-of-life care needs. High levels of illicit drug use among this population are a particular challenge for health and social services professionals involved in end-of-life care services delivery. This article explores the challenges of end-of-life care services to homeless illicit drug users based on data collected during a national study on end-of-life care services delivery to homeless persons in Canada. The authors identify a need for increased research on the role of harm reduction in end-of-life care settings to address these challenges. http://pmj.sagepub.com/content/early/2011/03/30/0269216311402713.abstract

Worth Repeating

Defective directives? Struggling with end-of-life care

AMERICAN MEDICAL NEWS | Online article - 5 January 2009 - Making health care decisions for patients who cannot is emotionally wrenching for families and poses an ethical dilemma for physicians. In a medical system that puts a premium on individual autonomy, what is to be done when patients lose the capacity to decide on care? For more than two decades, the answer has been to avoid ever getting to that point. Patients are encouraged to spell out in writing what kinds of life-sustaining care they would find acceptable. Living wills, also known as substantive or instructional advance directives, are intended to give patients prospective autonomy over decisions such as whether to be resuscitated, intubated or artificially hydrated. But according to a growing body of research, there are serious shortcomings with this type of directive.

http://www.amaassn.org/amednews/2009/01/05/prsa0105.htm

In the U.S., research indicates:

- 25% of patients receive care inconsistent with their living wills
- 29% of Americans say they have living wills
- 29% of patients change their minds about lifesustaining treatment over time.
- 30% of surrogates incorrectly interpret their loved ones' written instructions.
- 50% of terminally ill patients have advance directives in their medical records.
- 62% of patients with living wills do not give them to their physicians.
- 64% of dying patients' living wills do not cover the clinical realities they face.
- 78% of patients with life-threatening illnesses prefer to leave decisions about resuscitation to their physicians and families.

Source: American Medical News, 2009

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