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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Compiled & Annotated by Barry R. Ashpole

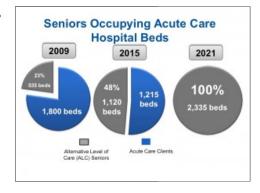
Errors in end-of-life care: Scroll down to <u>Specialist Publications</u> and 'Checklist to meet ethical and legal obligations to critically ill patients at the end of life' (p.10), published in *Healthcare Quarterly*.

Canada

Series of articles on end of life care

Are Canadians ready to talk about the cost of dying?

GLOBE & MAIL | Online article – 25 November 2011 – Health ministers are now meeting in Halifax to begin discussing how to fund the system into the future. I have a disturbing but, ultimately, liberating question for them: Why are so many of our health care resources consumed by the dying? A couple of weeks ago I led a discussion on the future of health care. The group was made up of ordinary citizens, not experts, and their task was to discuss the sustainability — or un-sustainability — of the health-care system. We started with some cold



hard facts about costs, which, they all agreed, show that if something doesn't happen soon the health care system will hit a financial wall. Most provinces now spend between 40% and 50% of their annual budgets on health care and this figure is rising quickly. Yet, as bad as these numbers are, the real shocker for our participants lay elsewhere. The pie charts ... [above] ... show how in one province the number of seniors occupying acute care beds is also rising precipitously. Indeed, so much so that, if nothing is done to alter the trend, 10 years from now seniors will occupy 100% of the acute care beds in that province. Other provinces are in a similar situation. http://www.ipolitics.ca/2011/11/25/op-ed-are-canadians-ready-to-talk-about-the-cost-of-dying/

N.B. Links to the complete series: http://www.theglobeandmail.com/life/health/end-of-life/; to an interview with the author Lisa Priest on TV Ontario: http://www.theglobeandmail.com/life/health/end-of-life/; to an interview with the author Lisa Priest on TV Ontario: http://www.theglobeandmail.com/life/health/end-of-life/; to an interview with the author Lisa Priest on TV Ontario: http://www.tvo.org/video/168722/lisa-priest-end-life

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | Vancouver Sun (OpEd) 24 November 2011 'Politicians need to walk the talk on laws.' We frequently hear people, especially politicians, emphasize that judges should not legislate from the bench. Rather, laws ought to emanate from Parliament and provincial legislatures, particularly on issues of great social importance. Given this view, we frequently hear people, especially politicians, express outrage when courts do make decisions on contentious social concerns. Recall the reaction just a few years ago when the courts issued decisions on same-sex marriage, and before that, weighed in on abortion. But the courts really had no choice. When presented with a case, courts, unlike politicians, can't decide not to decide. And there's the rub: Not only can politicians refuse to tackle contentious subjects, but such practice has become routine. http://www.vancouversun.com/news/Politicians+need+walk+talk+laws/5760269/story.html
- QUEBEC | Montreal Gazette (OpEd) -24 November 2011 - 'We need a national debate on life-and-death issues.' There is a glaring lack of political will on the part of the major parties in Parliament to come to grips with the issue of assisted suicide and voluntary euthanasia. It is indeed a thorny topic, and its grim nature is such that there is scant potential for political capital to be reaped from championing one side or the other of the argument. The safest course for politicians is to simply look the other way. And yet, circumstances are making this increasingly difficult because it is being pushed to the fore by a number of factors. There should first be a national conversation on the subject in the form of a royal commission that would

examine the implications and repercussions, closely study the rules applied and results obtained in other places where the law has been changed, and determine just where the Canadian public stands on the issue. http://www.montrealgazette.com/news/need+national+debate+life+death+issues/5758661/story.html

Specialist Publications

Of particular interest:

'Line between acts and omissions blurred, euthanasia critics argue' (p.13), published in the Canadian Medical Association Journal.

From Media Watch dated 31 May 2010:

■ THE LAWYERS WEEKLY (Canada) | Online OpEd – 28 May 2010 – 'Slow down on assisted suicide.'
Bill C-384 ... was defeated ... 228-59. While no doubt disappointing to some, the defeat is hardly surprising. Some form of legislative intervention is no doubt required to bring legal clarity to the regulation of assisted death in Canada. However, Bill C-384 ... failed to do that because, quite simply, it overshot the mark. http://www.lawyersweekly.ca/index.php?section=article&volume=30&number=4&article=1

Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://www.ipcrc.net/barry-r-ashpole.php

U.S.A.

A facade of autonomy in end-of-life care?

TEXAS | Galveston Daily News – 23 November 2011 – "Autonomy" in ethics lingo means your right to make your own choices. It's been a mainstay of bioethics during the past four decades that patients' autonomy should be respected in decisions for care at the end of life. Respecting autonomy has been taken to mean that when patients are alert and able to converse, physicians should ask them what they want and discuss the various options. When patients are in a coma or otherwise unable to speak for themselves, physicians should respect previous declarations of their wishes, such as a living will or a durable power of attorney for health care (advance directives). Those who study what actually happens at the end of life have been raising concerns about

respect for autonomy. They describe circumstances I believe might be termed "a facade of autonomy." It seems like we're being respectful of a patient's or a family's right to choose, yet really we are undermining meaningful choice. http://galvestondailynews.com/story/274330

Specialist Publications

Of particular interest:

'Checklist to meet ethical and legal obligations to critically ill patients at the end of life' (p.10), published in *Healthcare Quarterly*.

In prison hospice, at a loss for the right words

CALIFORNIA | Los Angeles Times (2nd of two articles) – 21 November 2011 – As his 'little brother' Freddy Garcia weakens in his battle against cancer, hospice worker John Paul Madrona struggles to craft an apology to the family of the chemist he'd killed in 1993. 'Sometimes, honestly, it feels hopeless.' http://www.latimes.com/news/local/la-me-1121-prison-hospice-html,0,280840.htmlstory

From Media Watch dated 21 November 2011:

CALIFORNIA | Los Angeles Times (1st of two articles) – 20 November 2011 – 'Amid ill and dying inmates, a search for redemption.' In the hospice, the oldest inside a California prison and one of the nation's first, some of the dying men looked robust, as if defying their illnesses. Some were hunched and gaunt. http://www.latimes.com/news/local/la-me-1120-prison-hospice-html.0,6904576.htmlstory

A look at end-of-life care issues for Native Americans

INDIAN COUNTRY TODAY | Online article – 21 November 2011 – More than 4 million people in the U.S. identify themselves as either American Indian or Alaska Native (Al/AN), a diverse group of people who come from more than 500 tribes. Access to quality health care by Al/AN is often compromised by poverty, lack of health insurance, and the fact that many live in isolated regions. Although as a group, Al/AN have a lower incidence of most types of cancer than non-Hispanic white Americans, they are more likely to be diagnosed with late-stage disease, and their cancer survival is generally poorer than that of other groups. Yet despite this burden, their access to palliative care, hospice, and end-of-life services lags behind the rest of the nation. The Al/AN populations need these services not only for cancer patients, but also for patients with other diseases that are more common in the Al/AN population than the white population – diseases such as diabetes, tuberculosis, pneumonia and influenza, and gastrointestinal and heart conditions. http://indiancountrytodaymedianetwork.com/2011/11/21/a-look-at-end-of-life-care-issues-for-native-americans-63942

From Media Watch dated 4 October 2010:

SOCIAL SCIENCE & MEDICINE, 2011;72(3):355-364. 'Aboriginal peoples, health and healing approaches: The effects of age and place on health.' Older Aboriginal people face unique challenges – e.g., loss of traditional approaches to healing, geographic isolation, identity politics, constitutional and legal divisions within the Aboriginal community – with respect to their health and access to health services. http://www.sciencedirect.com/science/article/pii/S0277953610006714

From Media Watch dated 20 April 2009:

CANADIAN FAMILY PHYSICIAN, 2009;55(4):394-395. 'Palliative care of First Nations people.'
The authors sought to understand cross-cultural hospital-based end-of-life care from the
perspective of bereaved First Nations [i.e., Aboriginal] ... family members (who) described palliative
care as a community and extended family experience. http://www.cfp.ca/cgi/reprint/55/4/394

International

Swaziland second African state with palliative care policy

SWAZILAND | Swazi Observer (Mbabane) – 28 November 2011 – Swaziland has been hailed by the African Palliative Care Association as the second country in Africa to have a palliative care policy after Uganda. Palliative care is central to care and support for people living with HIV and other life-limiting illnesses. It is underpinned by a holistic approach to service delivery which encompasses clinical, psychological, social and spiritual care provided from time of diagnosis and throughout the continuum of care. Swaziland has the highest HIV prevalence in the world. http://www.observer.org.sz/index.php?news=32786

Heart patients prefer longevity over quality of life

SWITZERLAND | Reuters Health – 25 November 2011 – When an elderly person's chronic disease is impossible to cure, many doctors might assume that patient would chose to improve the quality of his or her remaining life rather than to extend it as is. Those doctors would be mistaken most of the time, according to a new study. Researchers who surveyed more than 500 elderly heart failure patients found three quarters wouldn't trade a longer life with symptoms for a shorter life without them, and the severity of symptoms was not a good predictor of who would pick a measure of relief over more time. http://www.reuters.com/article/2011/11/25/us-heart-patients-longevity-idUSTRE7AO1UR20111125

1. 'End-of-life preferences of elderly patients with chronic heart failure,' *European Heart Journal*, published online 8 November 2011 (noted in Media Watch dated 14 November 2011).

Hospices helping to banish images of suffering in Romania

ROMANIA | *Edinburgh Evening News* (Scotland) – 24 November 2011 – Since the Casa Sperantei hospice in Brasov first opened its doors, 11,000 terminally ill adults and children have received medical, psychological and emotional care, as have their families. And what started as a small team – one Romanian doctor, a British nurse and a local nurse – has become the leading palliative care charity in south Eastern Europe, with a number of home care teams, the Princess Diana training centre – which has trained 9000 healthcare professionals – and a hospice in Belgrade in Serbia. Now the charity is planning to open two more hospices, one for adults in Bucharest, the other for children. http://www.scotsman.com/edinburgh-evening-news/edinburgh/hospices helping to banish images of suffering in romania 1 1983437

N.B. Romania is profiled in *The Quality of Death: Ranking End of-life-Care Across the World* (p.22), commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf

Facilitating access to palliative care

Patient choice is set to improve in Gwent

U.K. (WALES) | South Wales Argus – 24 November 2011 – Specialist palliative care staff are being appointed in Gwent, to work with GPs and a cancer charity to improve patients' choice of, and access to, end-of-life care. Aneurin Bevan Health Board has set up two GP facilitator posts as part of a three-year project with MacMillan Cancer Support. Their role is to support GPs in improving palliative care by identifying appropriate patients, encouraging advance care planning, and improving continuity of care between GPs and out-of-hours services. Much work has been done in Gwent to develop palliative care services, and the new project is intended to make care seamless for patients and their families...

http://www.southwalesargus.co.uk/news/9382927.Patient choice is set to improve in Gwent/

Basic home care help 'breaching human rights'

U.K. (ENGLAND) | BBC News – 23 November 2011 – Basic care for the elderly in their own homes in England is so bad it breaches human rights at times, an inquiry says. The home care review by the Equality & Human Rights Commission highlighted cases of physical abuse, theft, neglect and disregard for privacy and dignity. It said on many occasions support for tasks such as washing and dressing was "dehumanising" and left people "stripped of self-worth." The findings have added weight to calls for a complete overhaul of the system. Campaigners described the situation as "shameful," while councils, which are in charge of providing such services, said without urgent reform services would just get worse. There are currently nearly 500,000 people who are getting council-funded support in their own homes. http://www.bbc.co.uk/news/health-15836500

 Close to home: An inquiry into older people and human rights in home care, Equality & Human Rights Commission, November 2011. http://www.equalityhumanrights.com/uploaded files/homecareFI/home care report.pdf

Of related interest:

U.K. (ENGLAND) | Public Finance – 22 November 2011 – 'Care Quality Commission launches spot checks on home care providers.' The ... Commission will carry out spot inspections of 250 home care providers next year to root out 'bad practice' in the sector. The 'themed' inspections will focus on the respect, care and welfare of people who receive care services in their own homes, as well as the support given to staff. http://www.publicfinance.co.uk/news/2011/11/cqc-launches-spot-checks-on-home-care-providers/

Good Life, Good Death, Good Grief

'I feel good when I talk about her' – family supporting campaign for greater openness about death

U.K. (SCOTLAND) | *The Courier* (Dundee) – 23 November 2011 – Leah Johnstone from Leuchars died earlier this year following an agonising battle with long-term illness. Her parents Kim and David are now backing a new campaign outlining the need to be "more open" about death. They spoke out as an alliance of 40 organisations came together to launch the Good Life, Good Death, Good Grief campaign. The decision to establish the ... campaign comes after research found that most people haven't talked to their family and friends about the kind of care their loved ones would want at the end of their life, including where they would like to die. This is despite the same survey finding that 61% of people were scared of dying in hospital and 60% saying that if people felt more comfortable talking about death and dying they would be less likely to die alone. http://www.thecourier.co.uk/News/National/article/19132/i-feel-good-when-i-talk-about-her-family-supporting-campaign-for-greater-openness-about-death.html

Watchdog may intervene over 'do not resuscitate' order

U.K. | *The Guardian* – 23 November 2011 – Britain's equality and human rights watchdog may intervene in a landmark case over the use of 'do not resuscitate' orders for patients in hospitals, care homes, and their own homes. The Equality & Human Rights Commission (EHRC) will decide next month whether to seek high court permission to act as an independent witness in the case being brought by the husband of Janet Tracey against the management of Addenbrooke's hospital, Cambridge, where she died, and Andrew Lansley, the health secretary. David Tracey alleges medical staff at the hospital unlawfully issued such orders without his wife's consent – cancelling the first after she objected and days later adding another to her medical notes without her consent or any discussion with her. http://www.guardian.co.uk/society/2011/nov/23/watchdog-do-not-resuscitate-order?newsfeed=true

End of the care conveyor belt: Death in intensive care units

AUSTRALIA | The Conversation (Commentary) - 22 November 2011 -Intensive Care Units (ICU) were only just being established when I first became a specialist in 1981. They were small and intended for patients with life-threatening illnesses who could be supported for a few days to make a full recovery. Admitted patients included sufferers of serious trauma or infections and those who had complex surgery, such as open-heart operations. Thirty years later, the speciality has its own unique and legitimate place in medicine. Every large hospital has an ICU. I started with six beds in the early 1980s and have recently moved into a 60-bed unit. The operating cost for each bed is over \$1 million annually. Their role has also changed. It's

now difficult to die peacefully in a hospital and an increasing number of our community will spend their last few days in an ICU. http://theconversation.edu.au/end-of-the-care-conveyor-belt-death-in-intensive-care-units-249

Specialist Publications

Of particular interest:

'The impact of a palliative care unit on mortality rate and length of stay for medical intensive care unit patients' (p.11), published in *Palliative & Supportive Care*

Of related interest:

AUSTRALIA (QUEENSLAND) | Health Canal – 24 November 2011 – 'Queensland University of Technology [QUT] to study appropriate level of medical treatment for dying patients.' The research ... will reveal why treatment which is considered unnecessary from a strictly medical point of view is sometimes provided. Limited research had been conducted in the U.S. and Canada and anecdotal evidence collected in Australia, this would be the first comprehensive study to determine the size of the issue and the best ways of dealing with it. http://www.healthcanal.com/public-health-safety/23810-QUT-study-appropriate-level-medical-treatment-for-dying-patients.html

At-home deaths treated like crime scenes

AUSTRALIA (NEW SOUTH WALES) | Sydney Morning Herald – 22 November 2011 – Families who care for a dying loved one are being treated like criminals because of bureaucratic rules which force even predictable deaths to be reported to police if there is no GP available to certify them, Palliative Care NSW says. Its president, Peter Cleasby, said families were often given the unpalatable choice of either admitting the person to hospital when they were close to death or waiting hours with the body of a loved one after death, until their GP was open for business. Family members unfamiliar with the laws would often immediately call an ambulance after death. This sets in place a chain reaction of a police investigation and inquest, which could have been avoided if a GP who had been involved with the person's care was available to vouch for the death in person or by phone. http://www.smh.com.au/national/health/athome-deaths-treated-like-crime-scenes-20111121-1nr05.html

Women with advanced breast cancer 'feel neglected' by the healthcare system and left suffering extreme pain

U.K. | Daily Mail – 21 November 2011 – Millions of women with advanced breast cancer experience debilitating pain which is ignored by GPs, experts warned today. More than a third of those surveyed said they experience extreme pain and over 50% – who have been living with the disease for more than two years – revealed they feel neglected by the healthcare system. The national charity Breast Cancer Campaign, which funded the investigation is now calling for health workers to be trained in 'core competencies' – including symptom control. http://www.dailymail.co.uk/health/article-2064317/Women-advanced-breast-cancer-feel-neglected-healthcare-left-suffering-extreme-pain.html

Extract from Daily Mail article

But the latest findings reveal that many patients aren't given the necessary treatment and there is 'little evidence of involvement of general practitioners and palliative care services.'

Funerals matter

Worldwide, funeral costs and burial customs have generated a great deal of media attention in recent months, for example:

- U.K. (SCOTLAND) | Scotsman (Edinburgh) 26 November 2011 'Cost of dying doubles as councils try to offset cuts.' Town halls have been accused of imposing "death taxes" on bereaved families by raising cemetery costs to help pay for front-line services. Some ... councils have doubled their charges for burials and cremations in recent years, while many others have increased them by more than 50%, according to figures obtained through Freedom of Information laws. http://www.scotsman.com/news/politics/cost of dying doubles as councils try to offset cut s 1 1986715
- U.S. | Denver Post (Colorado) 24 November 2011 'Requests for help in burial cost soar.' The number of indigent burials paid for by the state has increased by nearly 40% since 2006, a number that has crept steadily upward each year, according to figures provided by the Colorado Department of Human Services. http://www.denverpost.com/business/ci 19407640
- CANADA | The National 21 November 2011 'No one grieves, anymore.' Funeral practices in Canada have changed. Obituaries now commonly read: "At the request of the deceased, there will be no funeral; cremation and interment have already taken place." Admittedly, it is expensive to die; one friend paid \$7,000 just for cremation last year. Religious rituals are less common. As part of "dying well," people plan their own funerals. If they conclude that they "don't want a lot of fuss and expense," relatives must comply. http://fullcomment.nationalpost.com/2011/11/21/reverend-graham-bland-on-saying-goodbye-no-one-grieves-anymore/
- IRELAND | Independent (Dublin) 14 November 2011 'Families opt for no-frills funerals to cut costs.' A growing number of bereaved families are sparing themselves added financial grief by trimming down on funeral costs. Undertakers say the average cost of a funeral has dropped by almost 40% in the past five years. They say cash-strapped families have had little choice but to compromise on funeral ceremonies by foregoing extras that they once took for granted, like flowers, music and limousines. http://www.independent.ie/business/personal-finance/latest-news/families-opt-for-nofrills-funerals-to-cut-costs-2933665.html
- U.K. (ENGLAND) | The Argus (Brighton) 14 November 2011 'Hove mum's sponsored walk to pay son's funeral bill.' A mother has been forced to do a sponsored walk to pay for her son's funeral. Michael Linley, who succumbed to bowel cancer two weeks ago, is still in the mortuary because his mother cannot afford funeral costs. Lynne Harris, who is currently claiming Job Seekers Allowance, said she has been told she is not entitled to any state support towards the cost. http://www.theargus.co.uk/news/9362434.Hove mum s sponsored walk to pay son s funeral bill/

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SRI LANKA | Sunday Times (Colombo) 27 November 2011 'Should euthanasia be legalized in Sri Lanka in exceptional situations?' After studying the legal changes and case law in other countries, an Act of Parliament is necessary to practise euthanasia in Sri Lanka. In a country where even a simple amendment to the abortion laws enacted in 1883 is not possible even after 128 years, it will not be an easy task to facilitate euthanasia legally. The question is not whether euthanasia should be legalized in exceptional circumstances but will it ever be legalized in Sri Lanka. http://www.sundaytimes.lk/111127/Plus/plus 17.html
- INDIA TODAY | Online report 24 November 2011 'Girl suffering from rare disease seeks euthanasia as family can't afford treatment.' Unable to afford treatment for a critical disease, a 21-year-old girl from Fatehpur in Uttar Pradesh has sought permission for mercy killing. The patient Alka Tiwari has been suffering from a rare blood disease and the cost of treatment has been estimated at Rs.25 lakh. Her family has already sold their house and other property for her treatment. Alka has been battling for her life at Vellore's Christian Medical College (CMC). She needs a bone marrow transplant for complete cure but her family cannot afford it. http://indiatoday.intoday.in/story/girl-suffering-from-rare-disease-seeks-euthanasia/1/161413.html

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

Public Involvement in Research

Talking about living and dying with the oldest old: Public involvement in a study on end of life care in care homes

BMC PALLIATIVE CARE | Online article – 23 November 2011 – There were three areas where involvement of the Public Involvement in Research group (PIRg) positively influenced the study process: recruitment, governance and safeguarding, and in collaboration with the residents in the care homes, the discussion and interpretation of emergent findings. PIR group members were of similar age to the residents and their involvement provided different and often more reflective insights of the significance of the findings for the participants. There were examples where decision making about the range of PIRg participation was not always negotiable, and this raised issues about power relationships within the team. PIRg members expressed personal benefit and satisfaction through participating in the research and a commitment to continue to support research with this older age group. http://www.biomedcentral.com/content/pdf/1472-684x-10-20.pdf

Of related interest:

JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article − 21 November 2011 −

'Designing research with hospice and palliative care populations.' This review seeks to inform and assist researchers ... to design studies targeting hospice and palliative care patients by presenting a thorough review of the published literature. This review covers English-language articles published from 1990 through 2009 listed in the PsycInfo, Medline, or CINAHL research databases under relevant keywords. Issues discussed include study design, informed consent, and recruitment for participants. Synthesized recommendations for researchers in these populations are presented. http://ajh.sagepub.com/content/early/2011/11/17/1049909111427139.abstract

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

Breaking bad news sensitively: What is important to patients in their last year of life?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – 25 November 2011 – Patients [i.e., study participants] were most likely to recall the pace and clarity with which bad news was conveyed. A direct approach was most common, without much prior warning for the patients. Direct information was usually received well when the patient knew the health professional and when it had been suggested that the patient should be accompanied to the appointment. Some professionals did work to set the scene for the eventual news, with a gradual build-up of information, and narrowing down of options. This approach was perceived as appropriate and sensitive. http://spcare.bmj.com/content/early/2011/11/25/bmjspcare-2011-000084.abstract

From Media Watch dated 21 November 2011:

GESELLSCHAFT FÜR MEDIZINISCHE AUSBILDUNG | Online article – 15 November 2011 –
 'Breaking bad news – an interdisciplinary curricular teaching-concept.' The authors describe the conceptual process, didactic background, and first experiences with the new interdisciplinary course "Delivering bad news" as a compulsory part of the palliative medicine curriculum. http://www.egms.de/static/en/journals/zma/2011-28/zma000764.shtml

From Media Watch dated 2 May 2011:

U.K. | The Economist: Intelligent Life – 26 April 2011 – 'Breaking bad news.' Breaking bad news might seem straightforward. "It's not rocket science," said one surgeon I spoke to, "you've just got to be a half-decent person and give them the facts." But common sense tells us that those facts are an emotional bomb waiting to go off. http://moreintelligentlife.com/content/ideas/breaking-bad-news

From Media Watch dated 23 August 2010:

INDIAN JOURNAL OF PALLIATIVE CARE, 2010;16(2):61-65. "BREAKS' protocol for breaking bad news.' Six-step SPIKES protocol is widely used for breaking bad news. The authors put forward another six-step protocol, the BREAKS protocol as a systematic and easy communication strategy for breaking bad news. http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2010;yolume=16;issue=2;spage=61;epage=65;aulast=Narayanan

Palliative medicine: Barriers and developments in Mainland China

CURRENT ONCOLOGY REPORTS, 2011;13(4):290-294. The development of palliative care in China is vital to the care of its aging population and associated increase in cancer incidence. There are physician-related and population-related barriers which impede palliative care development. The first institute for hospice care was established in Tianjin. Community hospices ... have been established by the Li Ka Shing Foundation. Academic centers such as the one in Chengdu associated with Sichuan University have partnered with the World Health Organization to establish centers of excellence to both develop and teach palliative care to physicians in training and practice. The National Hospice Service Program has developed five principles to the practice of palliative care in China. http://www.springerlink.com/content/cx88v1m582w532mj/

From Media Watch dated 7 February 2011:

■ BBC WORLD SERVICE | Online report – 2 February 2011 – **'Extreme world: Dying.'** Imagine a country in which the population is rapidly ageing and yet people do not want to talk about how to care for the elderly because they think it could bring bad luck. And where most of the people do not even write a will, believing that it could actually bring death one step closer. That country is China. And on the issue of ageing and dying, much of the country has a collective response: "We don't want to talk about it." http://www.bbc.co.uk/news/world-asia-pacific-12334284

N.B. China rated 37th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Checklist to meet ethical and legal obligations to critically ill patients at the end of life

HEALTHCARE QUARTERLY, 2011;14(4):60-66. Despite improvements in communication, errors in end-of-life care continue to be made. For example, healthcare professionals may take direction from the wrong substitute decision-maker, or from family members when the patient is capable; permit families to propose treatment plans; conflate values and beliefs with prior expressed wishes or fail to inquire about prior expressed wishes. Sometimes healthcare professionals know what prior expressed wishes are but do not respect them; others do not believe they have enough time to have an end-of-life discussion or lack the confidence, willingness and skills to manage one. http://www.longwoods.com/content/22652

Of related interest:

- JOURNAL OF EMERGENCY MEDICINE | Online article - 21 November 2011 – 'Nationwide assessment of living wills and do not resuscitate orders.' Concern exists that living wills are misinterpreted and may result in compromised patient safety. The survey posed a fictitious living will with and without additional clarification in the form of code status. An emergent patient care scenario was then presented that included medical history and signs/symptoms. Respondents were asked to assign a code status and choose appropriate intervention. At baseline, 22% denoted "full code" as the code status for a typical living will, and 36% equated "full care" with a code status DNR. Adding clinical context improved correct responses by 21%. Specifying code status further improved correct interpretation by 28% to 34%. Treatment decisions were either improved 12-17% by adding code status ('Full Code,' 'Hospice Care') or worsened 22% ('DNR'). http://www.jemjournal.com/article/S0736-4679(11)00853-5/abstract
- JOURNAL OF CLINICAL ONCOLOGY I Online article - 21 November 2011 -'Use of a decision aid to help caregivers discuss terminal disease status with a family member with cancer: A randomized controlled trial.' The authors randomly assigned caregivers ... to a group that received a video and a companion workbook that showed either how they can discuss the prognosis with their patient (experimental arm) or how cancer pain can be controlled (control arm). Decision aids can help ... with the aid of trained professionals, to communicate with patients about their terminal illness. http://jco.ascopubs.org/content/early/201 1/11/16/JCO.2011.35.3870.abstract

"Her husband doesn't speak much English"

Conducting a family meeting with an interpreter

JOURNAL OF PALLIATIVE MEDICINE | Online article - 22 November 2011 - A growing percentage of critically ill patients and their families in the U.S. speak limited English. The authors present the case of a palliative care consult conducted across language barriers to frame a discussion about the use of interpreters for family meetings, including the evidence for using a professional interpreter, the burden experienced by interpreters involved in end-of-life discussions, potential challenges encountered when conducting a family meeting with an interpreter, and recommended best practices for interpreter use in these settings. http://www.liebertonline.com/doi/abs/10.1089/ipm .2011.0169

From Media Watch dated 6 December 2010:

SUPPORTIVE CARE IN CANCER | Online article – 26 November 2010 – 'A bridge between cultures: Interpreters' perspectives of consultations with migrant oncology patients.' Three broad dilemmas faced by interpreters emerged: accuracy versus understanding; translating only versus cultural advocacy and sensitivity; and professionalism versus providing support. http://www.springerlink.com/content/a16531825 q256254/fulltext.pdf

From Media Watch dated 25 January 2010:

QUALITATIVE HEALTH RESEARCH, 2010;20(2):170-181. 'Dimensions of trust: The tensions and challenges in provider-interpreter trust.' The authors identify four dimensions of trust, theoretical constructs that can strengthen or compromise provider-interpreter trust: interpreter competence, shared goals, professional boundaries, and established patterns of collaboration. http://qhr.sagepub.com/cgi/content/abstract/20/2/170

[U.S.] Hospice eligibility in patients who died in a tertiary care center

JOURNAL OF HOSPITAL MEDICINE | Online article – 15 November 2011 – The majority of terminally ill inpatients [i.e., in this retrospective chart review] did not have a documented discussion of hospice with their care provider. Educating physicians to recognize the stepwise decline of most illnesses and hospice admission criteria will facilitate a more informed decision-making process for patients and their families. A consistent commitment to offer hospice earlier than the terminal admission would increase access to community or home-based care, potentially increasing quality of life. http://onlinelibrary.wiley.com/doi/10.1002/jhm.975/abstract

Of related interest:

■ NURSE.COM (U.S.) | Online article – 21 November 2011 – 'Patients, families benefit when hospice, palliative care referrals are made sooner.' Patients often are referred to hospice programs shortly before their deaths. Nurses who work in palliative care and hospice programs are trying to change that timeline so patients and families can benefit from their services earlier in the process. However, getting that message across can mean battling a physician who sees hospice as "giving up" or stereotypes that keep families from hearing anything about hospice. The problem is prevalent... http://news.nurse.com/article/20111121/NATIONAL01/311210004/-1/frontpage

The lack of standard definitions in the supportive and palliative oncology literature

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 21 November 2011 – Among the 1213 articles found, 678 (56%) were from 2009. "Palliative care" and "end-of-life" were the most frequently used terms. "Palliative care," "end-of-life," and "terminally ill" appeared more frequently in palliative care journals, whereas "supportive care" and "best supportive care" were used more often in oncology journals. Among 35 of 601 (6%) articles with a definition for "palliative care," there were 16 different variations (21 of 35 articles used the World Health Organization definition). "Hospice care" had 13 definitions among 13 of 151 (9%) articles. "Supportive care" and other terms were rarely defined (less than 5% of articles that used the term). The authors' findings highlight the lack of definitional clarity for many important terms in the supportive and palliative oncology literature. Standard definitions are needed to improve administrative, clinical, and research operations. http://www.jpsmjournal.com/article/S0885-3924(11)00428-3/abstract

N.B. World Health Organization definition of palliative care: http://www.who.int/cancer/palliative/definition/en/

The impact of a palliative care unit on mortality rate and length of stay for medical intensive care unit patients

PALLIATIVE & SUPPORTIVE CARE, 2011;9(4):387-392. The creation of an inpatient Palliative Care Unit resulted in a statistically significant reduction in both Medical Intensive Care Unit mortality rate and MICU length of stay, as terminally ill patients were transitioned out of the MICU to the PCU for end-of-life care. A dedicated inpatient PCU, capable of providing care to patients requiring mechanical ventilation or vasoactive agents, can protect terminally ill patients from an ICU death, while providing more appropriate care to dying patients and their loved ones. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8437671&fulltextType=RA&fileId=S147895151100040X

From Media Watch dated 21 November 2011:

CRITICAL CARE MEDICINE | Online article – 10 November 2011 – 'Integrating palliative care in
the surgical and trauma intensive care unit: A report from the Improving Palliative Care in
the Intensive Care Unit Project Advisory Board and the Center to Advance Palliative Care.'
http://journals.lww.com/ccmjournal/Abstract/publishahead/Integrating palliative care in the surgical and.98189.aspx

Associations between filial responsibility and caregiver well-being: Are there differences by cultural group?

RESEARCH ON AGING | Online article – 18 November 2011 – The purpose of this study was to examine associations between filial responsibility attitudes and both self-rated health and well-being within three cultural groups: Caucasian Canadian, Chinese Canadian, and Hong Kong Chinese. Multivariate analyses for the entire sample indicated associations between filial responsibility attitudes and both self-rated health status and overall well-being. Analyses performed within each cultural subgroup indicated that filial responsibility is associated with worse self-rated health in the Caucasian Canadian group. The results suggest caution in assuming that filial responsibility attitudes will be beneficial for caregiver outcomes; there may also be cultural variation. http://roa.sagepub.com/content/early/2011/11/18/0164027511422450.abstract

Palliative care quality indicators in Italy. What do we evaluate?

SUPPORTIVE CARE IN CANCER | Online article – 22 November 2011 – The number of palliative service providers has increased significantly. Policymakers, managers of palliative care programs, and others committed to the improvement of end-of-life care need methods and criteria to measure and evaluate the care delivered. As quality measurement is expensive and difficult to undertake, it is fundamental that quality measures evaluate the right things. Quality evaluation in Italy is supported by health authorities who have developed some indicators of palliative care. Most of the quality indicators analyzed deal with the structure and process of palliative care, however they miss outcomes and do not cover domains mainly concerned with spiritual, ethical, cultural, or existential aspects of care. http://www.ncbi.nlm.nih.gov/pubmed/22105162

Of related interest:

 INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2011;17(11):570. 'Politics and palliative care: Italy.' No abstract available. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=88020;article=IJPN 17 11 570

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/pg/file/owner/MediaWatch

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

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- CANADIAN MEDICAL ASSOCIATION JOURNAL | Online report 23 November 2011 'Line between acts and omissions blurred, euthanasia critics argue.' Decriminalization of assisted suicide and voluntary euthanasia is an unethical alternative to redressing current deficiencies in palliative care in Canada, physicians, ethicists and patient advocates argue. Decriminalization would offer a false choice so long as Canadians lack access to palliative care, the critics contended while panning the recommendation of the Royal Society of Canada panel report¹ ... which called for sweeping reforms to the Criminal Code on the grounds that there is no ethical distinction between assisted suicide or voluntary euthanasia, and withholding or withdrawing life-sustaining treatment from competent adults. http://www.cmaj.ca/site/earlyreleases/23nov11_line-between-acts-and-omissions-blurred-euthanasia-critics-argue.xhtml
 - Royal Society of Canada Expert Panel: End of Life Decision Making, November 2011 (noted in Media Watch dated 21 November 2011). http://www.rscsrc.ca/documents/RSCEndofLifeReport2011 EN Formatted FINAL.pdf

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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.

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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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