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.

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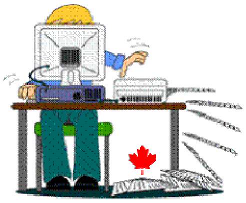


Compiled & Annotated by Barry R. Ashpole

Patient preferences in end-of-life care: Scroll down to Specialist Publications and 'Choice is a small word with a huge meaning': Autonomy and decision making at the end of life' (p.7), published in *Policy & Politics.*

Canada

In the reality of death

Alberta reaches deal with funeral directors

ALBERTA | CBC News (Edmonton) – 2 May 2012 – The province's poor and those who die in government care will continue getting state-funded funerals. The province has reached a deal with the industry after funeral directors threatened to pull their services, complaining their contract didn't cover a lot of their costs. Negotiated in the 1990s, the contract forced children who died while in provincial care to be buried in adult coffins rather than more expensive child caskets. The same contract also called for bodies to be embalmed, an affront to the religious beliefs of Jews, Sikhs and Hindus. http://www.cbc.ca/news/canada/edmonton/story/2012/05/02/edmonton-funerals-government-care.html

Hassan Rasouli case

Consider medical fallibility

MANITOBA | *Winnipeg Free Press* (OpEd) – 28 April 2012 – Science and technology have improved our understanding of the body, illness and injury, but art – a physician's experience that helps interpret symptoms of disease and disability – still plays a huge role in medicine. The diagnosis and prognosis of a patient who appears to be in a persistent vegetative state is a good illustration of the limitations of medical art and science. Neuroscientist Adrian Owen ... at the University of Western Ontario co-wrote a study[1] ... of 16 patients deemed to be in a persistent vegetative state – a condition in which people on life-support exhibit no sign of being aware of themselves or their environment. The study used a new method of tracking brain activity through electroencephalography; three patients repeatedly responded appropriately to commands. Almost 20% ... classified as essentially brain-dead appeared to be cognizant... The finding could have broad implications. http://www.winnipegfreepress.com/opinion/editorials/consider-medical-fallibility-149344575.html

Cont.

1. 'Bedside detection of awareness in the vegetative state...' *The Lancet*, 10 November 2011 (noted in Media Watch, 14 November 2011). http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61224-5/fulltext

From Media Watch, 30 April 2012:

- ONTARIO | *Globe & Mail* (Toronto) – 25 April 2012 – **'Vegetative patient now able to give 'thumbs up'...** http://www.theglobeandmail.com/news/national/vegetative-patient-now-able-to-give-thumbs-up-fuelling-debate-over-life-support/article2413296/?from=sec431

U.S.A.

Discovering the true cost of at-home caregiving

MINNESOTA PUBLIC RADIO | Online report – 1 May 2012 – Walk through any nursing home, and your first thought might be: "I need to take care of Mom myself." Few people want to turn over a loved one to institutional care. No matter how good the nursing home, it may seem cold and impersonal – and very expensive. But making the choice to provide care yourself is fraught with financial risks and personal sacrifices. Those who become full-time caregivers often look back and wish they had taken the time to better understand the financial position they would be getting themselves into. "I used to hear about people saying, 'Oh you know, we've got to put our parents in a home; we can't deal with it anymore,' " said Yolanda Hunter, 43, a Maryland resident who is struggling with her decision to drop out of the human resources field to become a full-time caregiver for her grandmother. "And I used to think: 'Oh, how cruel are you?' "You know, but now? I understand," she said. Hunter belongs to one of three families being profiled in [an] eight-week series, 'Family Matters: The Money Squeeze.' Each family is struggling with how to afford care for an older generation. http://minnesota.publicradio.org/features/npr.php?id=151472617

Terminal breast cancer leads woman to pick palliative care, not aggressive therapy

WASHINGTON POST | Online commentary – 30 April 2012 – I asked why he wanted to remove my breast when the cancer had already spread to my spine. "You don't want to see the cancer. Do you?" he answered, looking annoyed. The specialist never asked me what I wanted. He didn't mention my needs or treatment goals. He didn't know – or seem to care – that my hope was to extend my quality time on this planet rather than merely linger. He didn't care about the toll of the treatments on my body and my remaining days. Were I to choose his one-size-fits-all approach, I'd strip myself of the very type of life I'm pleased to have now, probably without gaining any benefit. If I had detected even a whiff of caring about me as a person or as a patient, I would have explained, "No, that's totally wrong for me. I want to work, enjoy family and friends, do things that are important to me – while feeling good – for as long as possible. Once I can't, I'm not interested in aggressively extending the length of my life." http://www.washingtonpost.com/national/health-science/terminal-breast-cancer-leads-woman-to-pick-palliative-care-not-aggressive-therapy/2012/04/30/gIQAY6rBsT_story.html

N.B. This article is an excerpt of 'Living life in my own way – and dying that way as well,' published in *Health Affairs*, 2012;31(4):871-874. http://content.healthaffairs.org/content/31/4/871.full?nm

Of related interest:

- GEORGIA | Fox (Atlanta) – 1 May 2012 – **'Terminally ill offer life lessons.'** We all know we're going to die someday, but for most of us, it's an abstraction – something we'll acknowledge when the time comes. For people with terminal illness, that time is now. Their insights as they face death can teach us a lot about how to live. http://www.myfoxatlanta.com/dpp/news/local_news/Terminally-Ill-Offer-Life-Lessons

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON | North West Public Radio – 3 May 2012 – **'One story behind Washington 2011 Death with Dignity Act statistics.'** The latest statistics on Washington's Death with Dignity Act show a steady increase in the people who have legally ended their lives under the law.[1] Seventy terminally people hastened their deaths in 2011 with the help of a doctor's prescription. Since 2009, a total of 255 terminally ill adults have ended their lives in this way. http://www.nwpr.org/post/one-story-behind-washington-2011-death-dignity-act-statistics

    1. Washington State Department of Health 2011 Death with Dignity Act Report (Executive Summary), May 2012. http://www.doh.wa.gov/dwda/forms/DWDA2011.pdf

International

Senate inquiry

Strain on Hunter palliative services

AUSTRALIA (NEW SOUTH WALES) | ABC News – 3 May 2012 – Health officials from the Hunter Valley have told a Senate inquiry that local palliative care services are feeling the strain, particularly in the region's rural areas. The inquiry is examining the factors influencing access to and choice of appropriate palliative care services. The Hunter New England Local Health District has told the inquiry that pressure on specialist palliative care services in rural and regional areas limits the number of patients that can be serviced. It says the provision of afterhours care is not possible due to sole practitioners and small teams covering large areas. It is also worried about a lack of culturally appropriate services for indigenous people. In addition it says low care services in the Hunter are not adequately staffed, with at least two carers needed to offer around the clock support when patients are in their terminal phase, after choosing to die at home. The health service notes that there is not even a telephone hotline for palliative care patients, adding it would not be safe to establish one due to fragmented clinical information. http://www.abc.net.au/news/2012-05-03/strain-on-hunter-palliative-services/3986478

- AUSTRALIA (SOUTH AUSTRALIA) | Adelaide Now – 3 May 2012 – **'Dying patients without cancer miss out on palliative care...'** Terminally ill South Australians with diagnoses other than cancer are regularly missing out on palliative care services, an expert says. Flinders University Professor of Palliative and Support Services David Currow says people with end-stage organ failure and neuro-degenerative diseases are being overlooked across the country, despite their needs being very similar to those with cancer. http://www.adelaidenow.com.au/news/south-australia/dying-patients-miss-out-on-palliative-care/story-e6frea83-1226346282415

From Media Watch, 5 December 2011:

- *AUSTRALIAN AGEING AGENDA* | Online report – 1 December 2011 – **'Senate announces palliative care inquiry.'** Australia's palliative care system will be the subject of a new, full-scale Senate inquiry, which boasts broad terms of reference spanning all facets of service provision, from the factors influencing access and choice to funding and the system's interface with the aged care sector. http://www.australianageingagenda.com.au/2011/12/01/article/Senate-announces-palliative-care-inquiry/RKITDATLYH

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 wills' need to be completely clear, rules judge

U.K. | *Daily Telegraph* – 2 May 2012 – 'Living wills' that stipulate exactly how a person wants to die should be drawn up with absolute clarity, a judge ruled after concluding a 67-year-old man with motor neurone disease had made a "valid decision" to refuse treatment. The man, referred to in court only as XB, communicated his desires with relatives and lawyers through eye movements on a number of occasions. Last November, documentation of the "advance decision" ... was drawn up in front of witnesses... However, another carer questioned whether XB had actually "communicated his agreement" and thereby given consent, the Court of Protection heard. Consequently the carer's employer, an NHS [National Health Service] trust, applied to the court to ask for clarification on the matter. It is the first such case to come before the court, part of the High Court.http://www.telegraph.co.uk/health/healthnews/9239559/Living-wills-need-to-be-completely-clear-rules-judge.html

Specialist Publications

Of particular interest:

'"I don't want to die like that …": The impact of significant others' death quality on advance care planning' (p.8), published in *The Gerontologist.*

Assisted (or facilitated) death

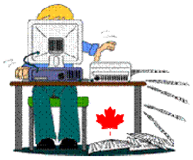
Representative sample of recent news media coverage:

- NEW ZEALAND | IOL News (South Africa) – 1 May 2012 – **'New Zealand looks at voluntary euthanasia.'** Politician Maryan Street is pushing legislation that will allow a person to help someone end their life without facing criminal charges. Parliament last debated the issue in 2003 after a woman was jailed for 15 months on a charge of attempted murder after her terminally ill mother died. Despite an outpouring of public sympathy ... parliament rejected a Death with Dignity Bill by a 60-57 vote. http://www.iol.co.za/news/world/new-zealand-looks-at-voluntary-euthanasia-1.1286506

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

On sinking and swimming: The dialectic of hope, hopelessness, and acceptance in terminal cancer

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 2 May 2012 – The aim of this study was to examine the relationship between hope and hopelessness in advanced cancer and to identify factors that maintain hope and increase vulnerability to hopelessness. Hope and hopelessness were identified [in study participants] as distinct, often co-occurring, and dialectically interacting constructs. The relationship between hope and hopelessness often balanced on acceptance, perceived as diametrically opposed to hopelessness, and conducive to redirecting hope toward new goals. Positive interpersonal relationships enhanced hope, and uncontrolled physical pain increased vulnerability to hopelessness. http://ajh.sagepub.com/content/early/2012/04/29/1049909112445371.abstract



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

Perceptions and attitudes about hospice and palliative care among community-dwelling older adults

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 2 May 2012 – The authors surveyed 187 community dwelling older adults about several aspects related to end-of-life (EOL) care. Participants were much more familiar with the term hospice than palliative care. In general, they had positive attitudes towards hospice and palliative care. Although experience caring for a dying relative was common, it wasn't associated with better attitudes towards hospice and palliative care or better familiarity with these terms. Familiarity with the term palliative care was associated with better attitudes towards EOL care. Their findings highlight the need for enhanced end-of-life care education among older adults, and reinforce the need for further research in this area. http://ajh.sagepub.com/content/early/2012/04/29/1049909112445305.abstract

With the "graying" of America

Is geriatric medicine terminally ill?

ANNALS OF INTERNAL MEDICINE, 2012;156(9):654-656. Geriatric medicine was established as a discipline to care for the complex needs of elderly patients. After much pioneering work, the American Board of Internal Medicine and American Board of Family Medicine granted geriatric medicine a Certificate of Added Qualifications in 1988. Board eligibility required completion of an accredited 2-year fellowship or qualification under the "practice pathway" based on practice experience. Even with this recognition, geriatric medicine in the U.S. has struggled to clearly identify its clinical niche and to attract interest among physicians. With the "graying" of America, geriatric medicine should, in theory, be a thriving subspecialty. Instead ... why the lack of interest in geriatric medicine? Can the subspecialty survive? http://www.annals.org/content/156/9/654.extract

- *ANNALS OF INTERNAL MEDICINE*, 2012;156(9):657-659. **'Treating our societal scotoma: The case for investing in geriatrics, our nation's future, and our patients.'** In the U.S., our society has a scotoma, which prevents us from seeing the necessity of changing our health system in the face of an aging population. It also prevents us from investing in the expertise of geriatric medicine, training an adequate number of geriatricians, and ensuring that all physicians have basic competency in caring for older patients. http://www.annals.org/content/156/9/657.extract

From Media Watch, 20 February 2012:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online article – 13 February 2012 – **'Report of the Geriatrics-Hospice & Palliative Medicine Work Group: American Geriatrics Society and American Academy of Hospice & Palliative Medicine Leadership Collaboration.'** http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03864.x/abstract

End-of-life care and Canada's indigenous peoples

Cultural understanding in the provision of supportive and palliative care: Perspectives in relation to an indigenous population

BMJ PALLIATIVE & SUPPORTIVE CARE | Online article – 3 May 2012 – The provision of supportive and palliative care for an indigenous people in Nova Scotia, Canada, was examined to further our understanding and thereby improve cultural competency. Most of Nova Scotia's indigenous people are Mi'kmaq. The Mi'kmaq Nation lives in Atlantic Canada as well as New England in the eastern U.S. Themes were identified in the literature and through discussion with seven experts who have Mi'kmaq health and cultural research expertise. This paper has been reviewed and approved by two Mi'kmaq consultants who frequently speak on behalf of the Mi'kmaq people in relation to health and cultural understanding. Recommendations for non-indigenous care providers are presented. The themes identified focused on jurisdictional issues and cultural understanding. They are interconnected and grounded in the historic Mi'kmaq context of colonialism. Jurisdictional issues experienced by the Mi'kmaq affect access, continuity and appropriateness of care. Cultural concepts were associated with worldview, spirituality, the role of family and community relationships and communication norms, and thereby with the alignment of values and language in the provision of care. Recommendations relate to the health system, relationships with individual persons and direction for research. http://spcare.bmj.com/content/early/2012/05/03/bmjspcare-2011-000122.full.pdf+html

Extract from *BMJ Palliative & Supportive Care* article

Terms related to providing Mi'kmaq supportive and palliative care

Apiksiktatultimk: A Mi'kmaq term used to describe when a person is thought to be dying, family and friends go to the bedside to partake in this act of mutually being present with each other which may include forgiveness or reconciliation. This has the intent of ensuring that the dying person will go to the spirit world without any burden while also preparing all involved for the inevitable.

Nemu'ltus: A commonly used Mi'kmaq saying which translates to 'I'll see you.' It is mostly used as a form of goodbye, but is also used when someone is dying. The implication here is that death is not final. Life and death are events. Death is understood to be a verb since if it were a noun, it would be final. Life is also a verb as it is a process of living and of being alive.

Salite: Mi'kmaq feast after a person leaves this world. Feasts are common for First Nations peoples for closure after events. Usually the Elders are the first to begin the meal. This is a community event with everyone bringing goods for an auction. In the past, the Salite auctioned the belongings of the person who has gone to the spirit world. Today, community members bring goods to auction to help raise funds to pay for the wake and other expenses and debts the person may have had. Salite is an important aspect of care. It acknowledges the interconnectedness of the person who has moved on to the spirit world and the community.

From Media Watch, 4 October 2010:

- *SOCIAL SCIENCE & MEDICINE* | Online article – 29 September 2010 [subsequently published in 72(3):355-364] – **'Aboriginal peoples, health and healing approaches: The effects of age and place on health.'** http://www.sciencedirect.com/science/article/pii/S0277953610006714

From Media Watch, 20 April 2009:

- *CANADIAN FAMILY PHYSICIAN*, 2009;55(4):394-395. **'Palliative care of First Nations people.'** http://www.cfp.ca/cgi/reprint/55/4/394
- *CANADIAN FAMILY PHYSICIAN*, 2009;55(4):443-444. **'When family doctors and aboriginal patients meet.'** http://www.cfp.ca/cgi/reprint/55/4/443

Are U.K. primary care teams formally identifying patients for palliative care before they die?

BRITISH JOURNAL OF GENERAL PRACTICE, 2012; 62(598):e344-e352. Most patients with advanced progressive illnesses, especially those with non-malignant disease, are not being formally identified for a palliative care approach before they die. Those identified are more likely to benefit from coordinated care and may be more likely to die at home. In total, 29% of patients who died were recorded as being on the practice palliative care register before death. Two-thirds of patients with cancer were recorded on the register, but for those with non-malignant conditions only around 20% had any palliative care documented. This was a result of GPs not finding the current guidelines useful and being reluctant to discuss palliative care overtly with patients early in their illness. Palliative care services and documentation were geared towards patients with cancer. More district nurses than GPs saw the benefits of inclusion on the palliative care register. http://www.ingentaconnect.com/content/rcgp/bjgp/2012/00000062/00000598/art00032

Of related interest:

- *BRITISH JOURNAL OF GENERAL PRACTICE*, 2012; 62(598):e353-e362. **'Factors supporting good partnership working between generalist and specialist palliative care services: A systematic review.'** Multiple examples exist of good partnership working between specialist and generalist providers; however, there is little consistency regarding how models of collaborative working are developed, and which models are most effective ... [or] ... the direct impact of collaborative working on patient outcomes. http://www.ingentaconnect.com/content/rcgp/bjgp/2012/00000062/00000598/art00033

- *JOURNAL OF THE ROYAL SOCIETY OF MEDICINE* | Online article – 25 April 2012 – **'Funding health and social services for older people – a qualitative study of care recipients in the last year of life.'** There is a gap between the health and social care system that older adults expect and what may be provided by a reformed welfare state at a time of financial stringencies. The values that underpinned the views expressed – mutuality, care for the most needy, and the importance of working to contribute to society – are an important contribution to the debate on welfare funding. http://jrsm.rsmjournals.com/content/early/2012/04/25/jrsm.2012.110189.abstract

'Choice is a small word with a huge meaning': Autonomy and decision making at the end of life

POLICY & POLITICS, 2012; 40(2):211-226 The U.K. End-of-Life Care Strategy ... recommends the identification, documentation and review of people's preferences for care and highlights the importance of choice at an individual level. Drawing on data from a qualitative research study, this article reflects on the complex range of interconnected factors impacting on older people's preferences and decision-making processes at the end of life. As older people consider not only themselves but also the impact on loved ones when making decisions, the pertinence of a relational conceptualisation of autonomy is considered. Impact of structural issues on the realisation of preferences is also explored.http://www.ingentaconnect.com/content/tpp/pap/2012/00000040/00000002/art00004

Clinical implications for supporting caregivers at the end-of-life: Findings from a qualitative study

CONTEMPORARY FAMILY THERAPY | Online article – 27 April 2012 – Despite families providing considerable care at end of life, there are substantial gaps in the provision of supportive care. A qualitative interview study was conducted with 17 caregivers of people supported by an adult hospice to explore the support needs of families. Family members readily identified the ways in which the diagnosis of a life-limiting illness impacted on them and the family as a whole, not just the patient. Implications for practice demonstrate the need to intervene at a family and relational level prior to bereavement, in order to mitigate complicated grief for the surviving family members. Such an approach offers a fruitful prospective alternative to supporting caregivers post-bereavement. http://www.springerlink.com/content/037nj8v56220xq93/

Of related interest:

- *JOURNAL OF NURSING EDUCATION*, 2012; 51(4):1-7. **'Life of a caregiver simulation: Teaching students about frail older adults and their family caregivers.'** This article describes the design, implementation, and preliminary outcomes of a unique learning experience, the Life of a Caregiver Simulation, which uses narrative pedagogy to increase students' awareness and understanding of the needs of older adults, their family caregivers, and the community services they use. http://www.healio.com/journals/JNE/%7BDB03261E-1478-4F55-9DA6-CD759C90AE5D%7D/Life-of-a-Caregiver-Simulation-Teaching-Students-About-Frail-Older-Adults-and-Their-Family-Caregivers

"I don't want to die like that …": The impact of significant others' death quality on advance care planning

THE GERONTOLOGIST | Online article – 30 April 2012 – The author examines whether 5 aspects of a significant other's death quality (pain, decision-making capacity, location, problems with end-of life care, and preparation) affect whether one does advance care planning (ACP). She also identifies specific aspects of others' deaths that respondents say triggered their own planning. Multivariate analyses revealed "positive" role model effects; persons who witnessed significant others' deaths that occurred at home, were free of problems associated with end-of-life care; and, where advance directives were used are more likely to make end-of-life preparations. Open-ended data showed that 19% cited others' deaths as the main trigger for their own planning, with most citing negative factors (pain, connection to machines, coma) that they hoped to avoid. Practitioners should encourage patients to use conversations about others' deaths as springboards for discussions about one's own end-of-life care, and to engage in ACP together with family. http://gerontologist.oxfordjournals.org/content/early/2012/04/29/geront.gns051.abstract

Of related interest:

- *AMERICAN MEDICAL NEWS* | Online report – 30 April 2012 – **'Wisconsin doctors get support to help patients complete advance directives.'** The Wisconsin Medical Society is leading a statewide initiative to improve the rate at which patients complete advance care planning by training non-physician health professionals to facilitate discussions with patients and encouraging community discussions [of the] subject. http://www.ama-assn.org/amednews/2012/04/30/prsc0430.htm

- *JOURNAL OF CANCER EDUCATION* | Online article - 27 April 2012 – **'Feasibility of training oncology residents in shared decision making: A pilot study.'** Although shared decision making (SDM) is the crux of patient-centered care, physicians are not formally trained in SDM http://www.springerlink.com/content/j41v817484151283/

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2012;366(18):1655-1657. **'Freedom from the tyranny of choice – teaching the end-of-life conversation.'** Thirty years ago, an intern had a conversation with a patient that he regrets to this day. The patient, a young man with widely metastatic lymphoma, unresponsive to chemotherapy, now had progressive dyspnea. The intern knew that even with intubation, his patient would soon die. http://www.nejm.org/doi/full/10.1056/NEJMp1201202

African Americans and decisions about hospice care: Implications for health message design

HOWARD JOURNAL OF COMMUNICATION | Online article – 27 April 2012 – Despite the widespread use and acceptance of hospice care in the U.S., African Americans underuse these services when faced with life-limiting illnesses. Many scholars have identified the barriers that may limit hospice enrollment and have called for the development of outreach campaigns to educate African Americans about hospice services. The design and implementation of such campaigns requires that campaign planners understand the issues that are most relevant to African American patients and families in making decisions about hospice care. Three broad third-order themes were identified as relevant to African Americans' decisions regarding hospice care: necessary knowledge of hospice services, the role of family members, and religious/spiritual considerations. http://www.tandfonline.com/doi/abs/10.1080/10646175.2012.667724

From Media Watch, 10 October 2011:

- REUTERS | Online report – 5 October 2011 – **'Downsides of cancer care rarely seen in black media.'** Historically, African Americans with advanced cancer have been more likely than whites to opt for aggressive treatment, and less likely to want hospice care.[1] There's also evidence that hospice care ... does not speed death – and in some cases, may help people live longer than aggressive cancer treatment would. But doctors often don't bring up options for end-of-life care... http://www.reuters.com/article/2011/10/05/us-downsides-cancer-care-idUSTRE79455V20111005

  1. 'Is public communication about end-of-life care helping to inform all? Cancer news coverage in African American versus mainstream media,' *Cancer*, published online 22 September 2011 (noted in Media Watch, 3 October 2011). http://onlinelibrary.wiley.com/doi/10.1002/cncr.26499/full

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/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/news.htm

(Scroll down to 'International End of Life Roundup')

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

A survey of chaplains' roles in pediatric palliative care: Integral members of the team

JOURNAL OF HEALTH CARE CHAPLAINCY, 2012;18(1-2):74-93. To date, the field of health care chaplaincy has had little information about how pediatric palliative care (PPC) programs meet the spiritual needs of patients and families. The authors describe the PPC chaplain activities, evidence regarding chaplain integration with the PPC team, and physician and chaplain perspectives on the chaplains' contributions. Chaplains [i.e., study participants] described their work in terms of processes such as presence, while physicians emphasized outcomes of chaplains' care such as improved communication. Learning to translate what they do into the language of outcomes will help chaplains improve health care colleagues' understanding of chaplains' contributions to care for PPC patients and their families. In addition, future research should describe the spiritual needs and resources of PPC patients and families and examine the contribution chaplains make to improved outcomes for families and children facing life-limiting illnesses. http://www.tandfonline.com/doi/abs/10.1080/08854726.2012.667332

> **N.B.** See 'Together for Short Lives Charter' (p.11), published by the U.K. advocacy group, which sets out "the standards of support which should be available" to all children and young people with life-limiting or life-threatening conditions, and their families'

Quality of care and quality of dying in nursing homes: Two measurement models

JOURNAL OF PALLIATIVE MEDICINE | Online article – 2 May 2012 – There is consistent evidence of significant variation in the quality of end-of-life care among nursing homes, with many facilities ill-prepared to provide optimal physical and psychological care that is culturally sensitive and respectful of the needs and preferences of residents and their family members. There is continued evidence that what is impeding efforts to improve care is that most measurement tools are hampered by a lack of distinction between quality of care and quality of dying as well as a lack of complete psychometric evaluation. Further, health services researchers cite the need to include "system-level" factors, variables that reflect leadership, culture, or informal practices, all of which influence end-of-life care and can be used to differentiate one setting from another. The authors report advancement in conceptualizing quality end-of-life care in nursing homes and offer a refined approach to measurement. http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0497

From Media Watch, 21 March 2011:

- COCHRANE COLLECTION | Online article – Accessed 18 March 2011 – **'Interventions for improving palliative care for older people living in nursing care homes.'** The aim of this review was to see how effective palliative care interventions in care homes are and to describe the outcome measures used in the studies. The authors found only three suitable studies ... all from the U.S. There was little evidence that interventions to improve palliative care for older people in care homes improved outcomes for residents. There is a need for more high quality research. http://onlinelibrary.wiley.com/o/cochrane/clsysrev/articles/CD007132/frame.html

Monolithic moral frameworks: How are the ethics of palliative sedation discussed in the clinical literature?

JOURNAL OF PALLIATIVE MEDICINE | Online article – 30 April 2012 – A variety of moral frameworks can assist clinicians in making ethical decisions. In examining articles on palliative sedation and terminal extubation, the authors were struck that bioethical discussions uniformly appealed to principlism and especially to the rule of double effect. Other moral frameworks were rarely invoked, an observation consistent with [American philosopher] Daniel Callahan's assertion that principlism has a "blocking effect" on broader ethical deliberation. They review here the principle of double effect as it applies to clinical acts that may hasten death, and present one radically different ethical formulation developed by [American bioethicist] Dan Brock. The authors then offer brief examples of how clinicians might use other moral frameworks to assess the ethics of preemptive sedation for terminal extubation. They argue for greater moral pluralism in approaching end-of-life decisions. http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0157

Paediatric palliative care

Together for Short Lives Charter sets out the standards of support which should be available to all children and young people with life-limiting or life-threatening conditions, and their families

U.K. | Online posting – Accessed 1 May 2012 – The charter has been developed to represent all children who have a life-threatening or life-limiting condition.

1. Every child/young person shall be treated with dignity and respect whatever their physical or intellectual ability.

2. Parents shall be acknowledged as the primary carers and involved as partners in all care and decisions involving their child.

3. Every child/young person shall be given the opportunity to participate in decisions affecting his or her care, according to age and understanding.

4. An honest and open approach shall be the basis of all communication.

5. Information shall be provided for the parent, the child/young person, the siblings and other relatives, appropriate to age and understanding.

6. The family home shall remain the centre of caring whenever possible. Care away from home shall be provided in a child-centred environment by staff trained in the care of children.

7. Every family shall have access to a 24-hour multi-disciplinary children's palliative care team for flexible support in the home, and be in the care of a local paediatrician.

8. Every child and family shall receive emotional, psychological and spiritual support to meet their needs. This shall begin at diagnosis and continue throughout the child's lifetime, death and in bereavement.

9. Every family shall be entitled to a named key worker who will enable the family to build up and maintain access to an appropriate network of support.

10. Every family shall be given the opportunity of regular consultations with a paediatric specialist who has particular knowledge of the child's condition.

11. Every family shall have access to suitable flexible short term breaks both in their own home and away from home, with appropriate children's nursing and medical support.

12. Every child shall have access to education, extended school opportunities and other appropriate childhood activities.

13. The needs of adolescents and young people shall be addressed and planned for well in advance using a person-centred approach.

14. Every family shall have timely access to practical support, including clinical equipment, financial grants, suitable housing and domestic help.

Download at:
http://www.act.org.uk/page.asp?section=56&sectionTitle=ACT's+charters+for+children+and+families

School for Social Care Research Methods Review: End of Life Care

LONDON SCHOOL OF ECONOMICS & POLITICAL SCIENCE (U.K.) | Online report – May 2012 – This review is an overview of the range of research methods that have been commonly used in end of life care and their relevance for social care. It provides a policy and service context for understanding end of life care research in social care and ... considers the advantages and disadvantages of different research methods and tools. The particular ethical challenges and practical issues that may arise are discussed along with strategies and sources of support to address them. http://www2.lse.ac.uk/LSEHealthAndSocialCare/pdf/SSCR-Methods-Review_12_web.pdf

Law, ethics and clinical judgment in end-of-life Decisions: How do Norwegian doctors think?

RESUSCITATION | Online article – 26 April 2012 – According to Norwegian law, an autonomous patient has the right to refuse life-prolonging treatment. If the patient is not defined as dying, however, health personnel are obliged to instigate life-saving treatment in an emergency situation even against the patient's wishes. The purpose of this study was to investigate how doctors' attitudes and knowledge agree with these legal provisions, and how the statutory provision on emergency situations influences the principle of patient autonomy for severely ill, but not dying, patients. http://www.resuscitationjournal.com/article/S0300-9572(12)00219-5/abstract

> **N.B.** Norway was rated 13th 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

Guilt and shame – a semantic concept analysis of two concepts related to palliative care

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online article – 27 April 2012 – The theoretical viewpoint of the study was based on the fundamental motive in caring science, the suffering person and his/her health and life situation, which according to the philosophy of palliative care also includes the next of kin. The latter often wish to participate in the care of their loved ones and it is thus important for them to be able to make decisions that can generate a meaningful participation. Unfulfilled obligations or wrong decisions, concerning their dying relative, can result in experiences of guilt and shame in relation to the care of the loved one. A semantic concept analysis can provide a deeper understanding of these concepts and create a deeper insight into what the concepts mean for the individual. The findings [of this study] show that guilt and shame are two separate concepts. Guilt contains meaning dimensions of being the cause of and sin. Shame contains meaning dimensions of something that gives rise to shame and ability to experience shame. http://onlinelibrary.wiley.com/doi/10.1111/j.1471-6712.2012.00992.x/abstract;jsessionid=A19303E813FB94CCA0AA72273E47F2B6.d03t02?userIsAuthenticated=false&deniedAccessCustomisedMessage=

Dignity therapy

Creating discursive order at the end-of-life: The role of genres in palliative care settings

WRITTEN COMMUNICATION | Online article – 5 April 2012 – Dignity therapy consists of a physician asking a patient a set of questions about his or her life and returning to the patient with a transcript of the interview. The authors use a rhetorical genre studies framework to explore what the dignity interview is doing, how it shapes patients' responses, and how patients improvise within the dignity interview's genre ecology. Based on a discourse analysis of the interview protocol and 12 dignity interview transcripts ... gathered in two palliative care settings ... findings suggest that these patients appear to be using the material and genre resources (especially eulogistic strategies) associated with dignity therapy to create discursive order out of their life events. This process of genre negotiation may help to explain the positive psychotherapeutic results of dignity therapy. http://wcx.sagepub.com/content/early/2012/04/04/0741088312439877.abstract

Worth Repeating

Rituals, death and the moral practice of medical futility

NURSING ETHICS, 2009;16(3):292-302. Medical futility is often defined as providing inappropriate treatments that will not improve disease prognosis, alleviate physiological symptoms, or prolong survival. This understanding of medical futility is problematic because it rests on the final outcomes of procedures that are narrow and medically defined. In this article, [Margaret] Walker's 'expressive collaborative' model of morality is used to examine how certain critical care interventions that are considered futile actually have broader social functions surrounding death and dying. By examining cardiopulmonary resuscitation and life-sustaining intensive care measures as moral practices, we show how so-called futile interventions offer ritualistic benefit to patients, families, and health care providers, helping to facilitate the process of dying. This work offers a new perspective on the ethical debate concerning medical futility and provides a means to explore how the social value of treatments may be as important in determining futility as medical scientific criteria. http://nej.sagepub.com/content/16/3/292.short

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.

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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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