Media Watch...

is intended as an advocacy tool and change document. The weekly report is international in scope and distribution – to 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 inform discussion and encourage further inquiry.*

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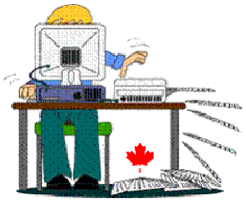


Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

Literature review: 'When frailty should mean palliative care' (p.8), in *Journal of Nursing Education & Practice.*

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CTV News – 14 January 2013 – **'Give the people the right to die with medical assistance: Quebec panel.'** The Quebec government says it believes it has found a way of not running afoul of Ottawa after a legal panel recommended that a terminally ill patient has the right to die. Provincial junior health minister Veronique Hivon said the panel determined that provinces have the legal jurisdiction to legislate in matters of health and that the future Quebec legislation would clarify how acts to end a life wouldn't be considered suicide. Euthanasia and assisted suicide are illegal in Canada under the Criminal Code. Julie Di Mambro, a spokeswoman for federal Justice Minister Rob Nicholson, said the government's position remains the same. "This is a painful and divisive issue that has been thoroughly debated in Parliament," she said. "We respect Parliament's decision." Hivon said the Quebec government can now pass a law with strict guidelines that will respect the wishes of the dying to shorten their suffering and provide doctors with a clear legal framework. http://www.ctvnews.ca/canada/give-people-the-right-to-die-with-medical-assistance-quebec-panel-1.1115524

  Of related interest:

  - QUEBEC | *Montreal Gazette* (OpEd) – 21 January 2013 – **'Legalizing assisted suicide is wrong and dangeous.'** http://www.montrealgazette.com/opinion/Opinion+Legalizing+assisted+suicide+wrong+dangerous/7834749/story.html
  - QUEBEC | *The Globe & Mail* – 16 January 2013 – **'Quebec leading the way in end-of-life issues.'** http://www.theglobeandmail.com/life/health-and-fitness/health/andr-picard-quebec-leading-the-way-on-end-of-life-issues/article7447929/

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

U.S.A.

Preparing America to care: Training our nation's homecare workers

AGING TODAY | Online – Accessed 23 January 2013 – One of the greatest challenges we face in the immediate future is building a skilled, stable caregiving workforce to help meet the daily needs of America's rapidly aging population. Homecare is the nation's fastest growing job category, underscoring the reality that insufficient numbers of family members – primarily spouses and adult children – are available to provide needed care. Millions of Americans struggle to balance paid employment with caregiving. But while the homecare and personal assistance industry is adding jobs faster than any other U.S. industry, the problematic quality of homecare jobs – poor wages, inadequate training and lack of supervisory support – undermines our efforts to recruit and retain workers. http://www.asaging.org/blog/preparing-america-care-training-our-nations-homecare-workers

"You should not have to be dying to get this care"

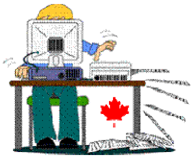
Learning the right lessons from hospice

FORBES | Online – 18 January 2013 – Health policymakers love the idea of hospice. Yet Medicare seems to be learning exactly the wrong lessons from the success of the program, which provides well-integrated patient-centered comfort care to people with terminal illness. Instead of trying to understand why hospice is growing in popularity, Medicare is instead making it harder to enroll. As often happens in its regulation of health care, Medicare is focusing on abuses. And make no mistake, those concerns are real when it comes to the $14 billion hospice business. Providers have figured out clever ways to game Medicare, which pays for 84% of all hospice care. By focusing on fraud, Medicare is missing the bigger point. Hospices are doing something right and they are doing it in a way patients and their families really like. Instead of trying to make coordinated, comfort-based care fit into the limits of the hospice box, policymakers should be figuring out how to take what hospice does well and expand it through the rest of the health system. http://www.forbes.com/sites/howardgleckman/2013/01/18/learning-the-right-lessons-from-hospice/

- *FORBES* | Online – 19 January 2013 – **'Time for a shakeup in hospice care.'** http://www.forbes.com/sites/carolynmcclanahan/2013/01/19/time-for-a-shakeup-in-hospice-care/

Noted in Media Watch, 7 January 2013:

- *THE NEW YORK TIMES* | Online OpEd – 4 January 2013 – **'Better, if not cheaper, care.'** http://opinionator.blogs.nytimes.com/2013/01/03/better-if-not-cheaper-care/?emc=eta1



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

Slowly dying patients, an audit and a hospice's undoing

CALIFORNIA | *Kaiser Health News* – 16 January 2013 – Death sometimes came slowly at one of the nation's largest and most respected hospices. That's not unusual. But here's a twist: For some patients, it came not at all. While hospices normally treat patients with fewer than six months to live, San Diego Hospice often served people who had much more time left. Not anymore. In the wake of an ongoing federal audit and an internal investigation, the non-profit hospice's patient load has dropped by hundreds as it targets its services more tightly to only those within the six-month window. The resulting cash crunch forced it to cut 260 workers and close a 24-bed hospital this month. Across the country, hospices with generous admissions policies may find themselves on life support too. Medicare, which heavily funds hospice programs, is cracking down on the industry's growing habit of embracing those whose deaths aren't imminent. It's not clear how many hospice programs are being investigated. But there's definitely an increased level of scrutiny, said J. Donald Schumacher, president of the National Hospice & Palliative Care Organization. http://www.kaiserhealthnews.org/Stories/2013/January/16/san-diego-hospice.aspx

Why this spotlight on hospice?

Because it's a booming business, a $14 billion industry that served an estimated 1.65 million people in the U.S. in 2011. That's about 45% of all those who died that year, the hospice association estimates. Medicare paid for the hospice benefits of 84% of those patients. When used properly to provide dying patients with palliative care instead of continuing futile medical treatments, hospice care can save the government money, research has shown. ***KHN***

Noted in Media Watch, 7 January 2013:

- CALIFORNIA | KPBS News (San Diego) – 31 December 2012 – **'San Diego Hospice sees more layoffs, hospital closure.'** http://www.kpbs.org/news/2012/dec/31/sd-hospice-more-layoffs-hospital-closure/

Of related interest:

- LOUISIANA | WWLTV News (New Orleans) – 16 January 2013 – **'End of month will be end of hospice care for some Louisiana patients.'** Starting 1 February Louisiana will stop offering hospice care services to most patients on Medicaid. The Louisiana Department of Health & Hospitals is eliminating the service to families in the state due to state budget cuts. Critics are up in arms. http://www.wwltv.com/news/February-1st-Means-End-of-Hospice-Care-For-Some-Louisiana-Patients-187228501.html

Battle over father's medical care spotlights difficulties involved in making decisions

INDIANA | *The Indianapolis Star* – 12 January 2013 – ...the responses and requests uttered by the gravely ill [Paul G.] Smith from his bed at St. Vincent Hospital carry little weight. That's because hospital officials are following directives in a living will Smith signed nearly a decade ago. It restricts actions medical providers can take to keep him alive and hands decisions about artificially supplied nutrients and fluids to ... [his] daughter, Judith Sly. Last week, doctors removed Smith from the ventilator that helped ease his labored breathing, apparently acting in accordance with the living will and Sly. Hospital staff occasionally moisten Smith's lips with a damp sponge, but a feeding tube that once provided nourishment also was disconnected. Those moves infuriate [Smith's daughter Susan] Rissman, exacerbating a long-standing family divide that has only deepened since Smith, whose condition deteriorated rapidly, was hospitalized in December with dehydration. Even though Smith's attorney tried unsuccessfully in November to name Rissman her father's legal guardian, Sly has authority over his care and legal affairs. Rissman has been her father's primary caregiver for the past several years and is against stopping an active treatment regimen for him. She thinks any decision should be left up to Smith because he is able to talk and answer questions. http://www.indystar.com/article/20130112/LIFE/301120336/End-life-case-splits-family?nclick_check=1

International

End-of-life care in India

Governments palliative care scheme proves a hit in Mavoor

INDIA | *The Times of India* – 17 January 2013 – A study to find the health status of patients receiving palliative care through the government home-based scheme revealed that the service has succeeded in addressing the medical, psycho-social and supportive needs of the patients.[1] The service has helped mitigate patients' pain and symptoms, it said. The study was conducted in Mavoor panchayat [council] to evaluate the effectiveness of palliative homecare services provided by the local self-government bodies in Kerala. The study was conducted among 104 palliative patients from October 2011 to June 2012, under the door-to-door pain and palliative care service of the Mavoor panchayat. http://timesofindia.indiatimes.com/city/kozhikode/Govts-palliative-care-scheme-proves-a-hit-in-Mavoor/articleshow/18055193.cms

1. 'Assessment of status of patients receiving palliative home care and services provided in a rural area – Kerala, India,' *Indian Journal of Palliative Care*, 2012;18(3):213-218. http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2012;volume=18;issue=3;spage=213;epage=218;aulast=Thayyil;type=0

Noted in Media Watch, 14 January 2013:

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2012;18(3):149-154. **'Palliative care in India: Current progress and future needs.'** http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2012;volume=18;issue=3;spage=149;epage=154;aulast=Khosla;type=0

Evaluation: Programme to Support Palliative and Hospice Care in the Republic of Ireland: Final Report

IRELAND | The Atlantic Philanthropies – 17 January 2013 – There has been significant expansion in palliative care services in Ireland over the last 25 years, although gaps in provision remain. This report presents the findings of a five-phased evaluation of the programme, which assessed the progress and impact of the programme to date, and the strategic learning for the field. http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation_Programme_Support_Palliative_and_Hospice_Care_%20Republic_of_Ireland.pdf

N.B. Ireland was rated 4th (of 40 countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

End-of-life care in England & Wales

Liverpool Care Pathway needs name change, says Norman Lamb

U.K. | *The Daily Telegraph* – 15 January 2013 – Norman Lamb, the Care Services Minister, said doctors should not use the term because it "means nothing" to patients. He also said he was "uncomfortable" using the word "pathway" in relation to death. He has asked a panel of experts, who will be undertaking a wide-ranging review of the guidelines, to come up with an alternative. Relatives of those put on the pathway have raised considerable concerns over its use in recent months. Many have said they were not told loved-ones were put on it, while others have claimed patients were left in clear distress after hydration was withheld. A small number of doctors has even argued the pathway has been used to hasten death – a claim strongly rejected by most medics. http://www.telegraph.co.uk/health/healthnews/9801033/Liverpool-Care-Pathway-needs-name-change-says-Norman-Lamb.html

End-of-life care in Scotland

Funds-threat hospice given highest rating by inspectors

U.K. (SCOTLAND) | *The Evening Times* (Glasgow) – 15 January 2013 – St. Margaret of Scotland Hospice in Clydebank has been awarded five "excellent" ratings by Healthcare Improvement Scotland.[1] It is the first time the inspectors have given an independent hospice such a high rating with no recommendations for improvement. The 58-bed hospice, Scotland's oldest and largest, was given the top rating in quality of care, environment, staff, management and information for patients and relatives. [The report] comes after a difficult few years for the hospice which faced losing £1.2million of annual NHS [National Health Service] funding for 30 continuing care beds. NHS Greater Glasgow & Clyde was forced to make a U-turn following a long-running campaign by patients and relatives. Jean Anne Mitchell, who has direct experience with the hospice, has raised a petition calling for increased funding. She said: "I believe that a comparison of funding shows that St. Margaret of Scotland Hospice receives substantially less funding than the sector average." http://www.eveningtimes.co.uk/news/funds-threat-hospice-given-highest-rating-by-inspectors-112540n.19918221

1. 'St Margaret of Scotland Hospice: Independent Healthcare unannounced inspection,' Healthcare Improvement Scotland, 14 January 2013. (Dated of inspection: 14 November 2012.) http://www.healthcareimprovementscotland.org/programmes/inspecting_and_regulating_care/ihc_reports/st_margaret_of_scotland_jan_13.aspx

   N.B. Scroll down to 'Downloads' for a copy of the report.

Media Watch Online

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/ (Scroll down to 'Palliative Care Network: Media Watch'')

Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: http://www1.petermac.org/apli/links.htm (Scroll down to 'Links,' then to 'Media Watch')

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

Europe

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c

International

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://www.ipcrc.net/archive-global-palliative-care-news.php

PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | *Irish Times* – 17 January 2013 – **'Assisted suicide appeal date set.'** The Supreme Court has provisionally fixed 19 February 19 to hear the appeal by a terminally ill woman against the High Court's rejection of her landmark challenge to the absolute ban on assisted suicide. Chief Justice Susan Denham said the court would make itself available to hear Marie Fleming's appeal which ... was likely to take two to three days. It is expected a seven judge Supreme Court will hear the appeal. http://www.irishtimes.com/newspaper/breaking/2013/0117/breaking22.html

- IRELAND | *Irish Times* (OpEd) – 15 January 2013 – **'DPP needs clear protocols after assisted suicide ruling.'** Without being entitled to issue guidelines, the DPP [Director of Public Prosecutions] can only look to the U.K.[1] This is surreptitious and insufficient. Last week's lengthy High Court judgment that rejected Marie's bid to legally end her own life with the assistance of her partner may not signal the end of the debate on the issue of assisted suicide.[2] Indeed, it would be best if it did not. Irrespective of any appeal to the Supreme Court, the mixed messages sent by the High Court illustrate the unsatisfactory nature of the legal position that the court upheld. http://www.irishtimes.com/newspaper/opinion/2013/0115/1224328850639.html

    1. 'Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide.' The Crown Prosecutors Service (England & Wales). [Noted in Media Watch, 1 March 2010] http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html
    2. 'Assisted suicide ban cannot be diluted even in 'harrowing' case of MS sufferer,' *The Irish Times*, 11 January 2013. [Noted in Media Watch, 14 January 2014] http://www.irishtimes.com/newspaper/ireland/2013/0111/1224328672530.html

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

Palliative sedation: From the family perspective

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 15 January 2013 – The authors explore the experience of family members during a PS [palliative sedation] procedure. All the relatives [i.e., study participants] noticed a significant improvement in the refractory symptom with a mean reduction in the estimated suffering of 6.25 points on a visual analog scale. http://ajh.sagepub.com/content/early/2013/01/13/1049909112472930.abstract

Noted in Media Watch, 7 January 2013:

- *BIOETHICS*, 2013;27(1):1-11. **'Narratives of 'terminal sedation' and the importance of the intention-foresight distinction in palliative care practice.'** http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2011.01895.x/abstract

A 'good death' at home: Community nurses helping to make it possible

BRITISH JOURNAL OF COMMUNITY NURSING, 2013;18(1):40-42. The number of people dying at home rather than in a hospital is increasing, albeit slowly. This coincides with a growing emphasis across the U.K. to increase choice and enable individuals to both live and die well, and in the preferred setting of their choice. While most health professionals would support this approach, it is clear that providing end of life care in the community to all, irrespective of where they live, is complex. Communities face different challenges to hospital based care settings, one of these being geographical distances. This article discusses current end of life policies and how the community nurse is central to their implementation. It draws on some recent research which has identified the important steps that enable a community nurse to facilitate a good death and a particular research study which illustrated the unique role of the community nurse in providing end of life care in a rural setting, but also the challenges. http://www.bjcn.co.uk/cgi-bin/go.pl/library/article.html?uid=96212;article=BJCN_18_1_40_42

Does quality of life assessment in palliative care look like a complex screening program?

HEALTH & QUALITY OF LIFE OUTCOMES | Online – 14 January 2013 – It is not clear how QoL [quality of life] should be measured in PC [palliative care] practice. The aim of this study is to define a framework to help researchers to develop and evaluate clinical interventions focused on QoL assessment in PC. The authors reviewed each of the WHO Population Screening Principles and adapted them to QoL assessment, taking into account the defined criteria. As a result, a new framework, the QoL Assessment Principles in Palliative Care, was developed. It consisted of 4 sections, for a total of 11 principles. http://www.hqlo.com/content/pdf/1477-7525-11-7.pdf

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 15 January 2013 – **'Best practice' in developing and evaluating palliative and end-of-life care services: A meta-synthesis of research methods for the MORECare project.'** Improved and cost-effective palliative and end-of-life care is an international policy imperative. Developments are impeded by a weak, often inconsistent evidence base. http://pmj.sagepub.com/content/early/2013/01/14/0269216312467489.abstract

  N.B. MORECare is a collaboration between King's College London, University of Manchester, University of Aberdeen and University of Edinburgh, to identify, appraise and synthesise 'best practice' methods for evaluation of palliative and end-of-life care. http://www.csi.kcl.ac.uk/our-research.html

Detached, distraught or discerning? Fathers of adolescents with chronic illness

INTERNATIONAL JOURNAL OF ADOLESCENT MEDICINE & HEALTH | Online – Accessed 15 January 2013 – The authors address the challenges to the father's role as breadwinner, leader and strength-giver in the family. Three time-periods describe the obstacles fathers tackle when parenting children with chronic disease: a) diagnosis and short-term, characterized by distress, isolation and uncertainty; b) the mastery period, characterized by the struggle to establish routine and by support and spirituality; and, c) the long-term, characterized by relationship and personality change, worries and bereavement. http://www.degruyter.com/abstract/j/ijamh.ahead-of-print/ijamh-2013-0018/ijamh-2013-0018.xml?rskey=HXDplo&result=1&q=fathers

A different approach to patients and loved ones who request futile treatments

JOURNAL OF CLINICAL ETHICS, 2012;23(4):291-298. The author describes an alternative approach that care providers may want to consider when caring for patients who request interventions that care providers see as futile. This approach is based, in part, on findings of recent neuro-imaging research. The author also provides several examples of seemingly justifiable "paternalistic omissions" ... The author suggests that while care providers should always give patients and their loved ones all potentially relevant information regarding "futile" decisions, care providers may wish to consider, paradoxically, not giving advice in these situations, when the advice is based mostly or wholly on their own moral views, based on this same, ethical rationale. http://www.clinicalethics.com/single_article/tr0abia7r7A.html

Of related interest:

- *JOURNAL OF KOREAN MEDICAL SCIENCES*, 2013;28(1):1-3. **'Life-sustaining medical treatment for terminal patients in Korea.'** Life-sustaining medical treatment like mechanical ventilation has contributed much for acute illnesses. However, it might be harmful for the terminal patients with chronic illnesses like metastatic cancer, because it just prolongs dying process without reversing the underlying medical condition. Active euthanasia or physician-assisted suicide is not an issue in Korea, but futility near the end-of-life is a big problem. http://synapse.koreamed.org/search.php?where=aview&id=10.3346/jkms.2013.28.1.1&code=0063JKMS&vmode=FULL

  N.B. The *Journal of the Korean Medical Association*, noted in Media Watch, 7 January 2013 (p.12), includes several articles on life-sustaining treatment. Contents page: http://jkma.org/.

Literature review

When frailty should mean palliative care

JOURNAL OF NURSING EDUCATION & PRACTICE, 2013;3(7):75-91. There is difficulty for practitioners in recognising frailty and in establishing palliative care. This clinical entity is the sum of several illnesses or syndromes that are curable if taken separately. Practitioners have difficulty integrating the inevitably fatal nature of the situation. The aim of this work is to assist physicians in providing proper care for the frail elderly. It consists in a systematic review of the literature available, intended answer the following questions: 1) Is frailty an appropriate indication for the instatement of palliative care? 2) When is the right moment to instate palliative care for the frail elderly subject? 3) What tools are available to assist care teams? 4) Are there efficient organisational models that integrate the frail elderly into palliative care? There are answers to these questions. But the level of evidence is low. It can be concluded that frailty is an indication for the instatement of palliative care. http://www.sciedu.ca/journal/index.php/jnep/article/view/1689

Of related interest:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 15 January 2013 – **'Every patient is an individual: Clinicians balance individual factors when discussing prognosis with diverse frail elderly adults.'** http://onlinelibrary.wiley.com/doi/10.1111/jgs.12098/abstract

Noted in Media Watch, 26 March 2012:

- CANADA | *Globe & Mail* (Halifax, Nova Scotia) – 18 March 2012 – **'Sometimes, for the frail elderly, the less medical intervention, the better.'** Instead of herding the frail elderly through hospital... http://www.theglobeandmail.com/news/opinions/editorials/sometimes-for-the-frail-elderly-the-less-medical-intervention-the-better/article2373292/

Elisabeth Kübler-Ross, *On death and dying*: A reappraisal

MORTALITY | Online – 16 January 2013 – Elisabeth Kűbler-Ross's influential book ... is a collection of very moving case studies of people approaching death, which, in 1969, helped to bring public attention to the topic and drew attention to the need for improving care. Sadly, her self-promotion, and her failure to acknowledge or to work with other pioneers in the developing field of Hospice and Palliative Care, left her isolated from the mainstream and vulnerable to exploitation by her devotees. http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.758629

"Funerals aren't nice, but it couldn't have been nicer" – The makings of a good funeral

MORTALITY | Online – 15 January 2013 – There is growing comment in both academic and popular writing about the shape and content of funerals today, with general agreement that we are seeing marked changes with a growing trend towards secularisation and personalisation. Despite this, there is as yet relatively little systematic research on the topic. This article reports on a study ... into spirituality in contemporary funerals. The way ... [study] ... participants engaged with the funeral and its constituent elements in an active process of meaning-seeking, meaning-creating and meaning-taking was closely aligned with contemporary understandings of humanistic spirituality. There was, however, little evidence of adherence to formal religious belief systems or wider philosophical frameworks amongst the bereaved families but considerable evidence of drawing on religious tradition and specific beliefs to locate personal meaning-making. The authors conclude that the funeral remains a significant ceremonial event which is psycho-social-spiritual in character and purpose. http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.755505

Access to opioid analgesics and pain relief for patients with cancer

NATURE REVIEWS CLINICAL ONCOLOGY | Online – 15 January 2013 – Access to pain relief is a crucial concern for patients with cancer, and remains so at all stages of the illness trajectory. This review covers the scope of the problem and considers the optimal palliative strategy, mainly through the use of opioids. It also discusses various barriers to effective pain management around the world, including regulatory and attitudinal barriers towards opioids, and the unwillingness of national governments to integrate palliative care effectively in cancer control efforts. http://www.nature.com/nrclinonc/journal/vaop/ncurrent/abs/nrclinonc.2012.237.html

Noted in Media Watch, 29 October 2012:

- *PALLIATIVE MEDICINE* | Online – 26 October 2012 – **'Multivariate analysis of countries' government and health-care system influences on opioid availability for cancer pain relief and palliative care: More than a function of human development.'** http://pmj.sagepub.com/content/early/2012/10/25/0269216312461973.abstract

Integrating palliative and cancer care

Palliative care always

ONCOLOGY | Online – 15 January 2013 – Palliative cancer care is the integration into oncologic care of therapies that address the issues that cause physical and psychosocial suffering for the patient and family. Effective provision of palliative cancer care requires an interdisciplinary team that can provide care in all settings (home, inpatient, and outpatient). There is clear evidence for improved outcomes in multiple domains – symptoms, quality of end-of-life care, provider satisfaction, cost of care – with the integration of palliative care into cancer care. As a result, there are now guideline-based recommendations for incorporating palliative care into cancer care. Unfortunately there continue to be barriers to effective integration; these include gaps in education and research, and a cultural stigma that equates palliative care with end-of-life care. These barriers will need to be addressed in order to achieve seamless palliative care integration across the continuum of cancer care for all patients and their families. http://www.cancernetwork.com/palliative-and-supportive-care/content/article/10165/2121558

Representative sample of articles on integrating palliative and cancer care noted in past issues of Media Watch:

JOURNAL OF CLINICAL ONCOLOGY | Online – 29 October 2012- **'Referral practices of oncologists to specialized palliative care.'** http://jco.ascopubs.org/content/early/2012/10/29/JCO.2012.44.0248.abstract

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2012;10(10):1192-1198. **'Integrating palliative care into comprehensive cancer care.'** http://www.jnccn.org/content/10/10/1192.abstract

SUPPORTIVE CARE IN CANCER | Online – 31 August 2012 – **'Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature...'** http://www.ncbi.nlm.nih.gov/pubmed/22936493

JOURNAL OF CLINICAL ONCOLOGY | Online – 6 February 2012 – **'American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care.'** http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract

Of related interest:

- *ONCOLOGY* | Online – 15 January 2013 – **'Integrating palliative care into oncology care: Confronting the barriers.'** http://www.cancernetwork.com/palliative-and-supportive-care/content/article/10165/2121568

- *ONCOLOGY* | Online – 15 January 2013 – **'Early palliative care: Moving from 'why' to 'how."** http://www.cancernetwork.com/palliative-and-supportive-care/content/article/10165/2121563

Pediatric palliative care

Parental explicit heuristics in decision-making for children with life-threatening illnesses

PEDIATRICS | Online – 14 January 2013 – All parents in this study employed explicit heuristics [decision-making aids or shortcuts expressed verbally as terse rules of thumb, aphorisms, maxims, or mantras and intended to convey a compelling truth or guiding principle] in interviews about decision-making for their children, with the number of identified explicit heuristics used by an individual parent ranging from tens to hundreds. They served 1) to depict or facilitate understanding of a complex situation; 2) to clarify, organize, and focus pertinent information and values; 3) to serve as a decision-making compass; 4) to communicate with others about a complex topic; and, 5) to justify a choice. Recognizing explicit heuristics in parent interactions and understanding their content and functions can aid clinicians in their efforts to partner with parents in the decision-making process. http://pediatrics.aappublications.org/content/early/2013/01/08/peds.2012-1957.abstract

Pediatric concurrent care report emphasizes need for collaboration

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Online report – 16 January 2013 – The 'Pediatric Concurrent Care Briefing' shares examples from states that have implemented options to provide pediatric palliative and hospice care services and outlines eight implementation strategies that can help ensure that providers are serving the children and families in the community that may be in need of the unique services hospice and palliative care brings. The goal of the briefing is to foster the necessary collaboration among providers and advocates within each state to ensure that the most medically fragile children and their families have the quality care they deserve and desperately need. Children aged 0-19 years accounted for 1.9% of all deaths in 2009. Slightly more than half of childhood deaths occur in infancy. http://www.nhpco.org/files/public/ChiPPS/Continuum_Briefing.pdf

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 16 January 2013 – **'Chronic pain management as a barrier to pediatric palliative care.'** http://ajh.sagepub.com/content/early/2013/01/15/1049909112473632.abstract
- *HOME HEALTHCARE NURSE* | Online – 9 January 2013 – **'Concurrent care for children: How this new legislation has opened hospice care to children with high technology home care needs.'** The author discusses the U.S. Patient Protection & Affordable Care Act. http://journals.lww.com/homehealthcarenurseonline/Citation/publishahead/Concurrent_Care_for_Children__How_This_New.99980.aspx
- *NURSING CHILDREN & YOUNG PEOPLE*, 2012;24(9). **'Reflections on the provision of community palliative care for terminally ill children in Ireland.'** The author reflects on caring for a child with a life-limiting condition using the McNeilly (2006) reflection model. http://nursingchildrenandyoungpeople.rcnpublishing.co.uk/archive/article-reflections-on-the-provision-of-community-palliative-care-for-terminally-ill-children-in-ireland

Advance care planning and end-of-life management of adult patients with congenital heart disease

WORLD JOURNAL FOR PEDIATRIC & CONGENITAL HEART SURGERY, 2013;4(1):62-69. As a result of advances in the diagnosis and treatment of congenital heart disease (CHD), it is now adult care providers, rather than pediatric providers, who are faced with the majority of patient deaths. Guidelines recommend early completion of advance directives and addressing EOL [end of life] issues in routine care. This article reviews the pattern of shifting CHD mortality, current knowledge regarding advanced care planning and EOL discussions ... and guidelines to facilitate and optimize these important discussions. http://pch.sagepub.com/content/4/1/62.abstract

Cont.

Of related interest:

- *JOURNAL OF NEURAL TRANSMISSION* | Online – 18 January 2013 – **'Palliative care and end-of-life planning in Parkinson's disease.'** Over recent years lower proportions of people have been dying at home, and this is especially true for Parkinson's disease, but home may well be where they would have preferred to die. However, there is little evidence to guide health professionals about how, when, and by whom, advance care planning should be approached. http://link.springer.com/article/10.1007%2Fs00702-013-0967-3

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *THE HASTINGS REPORT* | Online – 11 January 2013 – **'Alzheimer's disease and personhood.'** As in the U.S., the Dutch conversation about assisted suicide emerged primarily in the context of cancer. At least in that context, before acceding to a request for assistance in dying, caregivers must be sure that the person has made a voluntary and carefully considered request, and that her suffering is unbearable and without prospect of improvement. The Dutch have recently been trying to use those criteria in the context of Alzheimer's disease. Given the wave of Alzheimer's cases poised to crash onto wealthy countries ... we should be grateful to the Dutch for that attempt. http://onlinelibrary.wiley.com/doi/10.1002/hast.116/abstract

  Noted in Media Watch, 8 October 2012:

  - *JOURNAL OF AGING STUDIES*, 2012;26(4):377-385. **'Alzheimer's disease and euthanasia.'** http://www.sciencedirect.com/science/article/pii/S089040651200028X

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.

Worth Repeating

With poem, broaching the topic of death

ARIZONA | *The New York Times* – 24 January 2011 – Mitzie Begay, an elegant 76-year-old Navajo, can interpret the nuances of her language and traditions with contemporary verve and understated wit – qualities that make her a good fit for a job that could hardly have been imagined in the Navajo Nation a generation ago. Ms. Begay, whose title is cross-cultural coordinator for the home-based care program at the Fort Defiance Indian Hospital here in northeastern Arizona, helps Navajos deal with the complex and confusing process of decision-making at the end of life. In Navajo culture, talking about death is thought to bring it about, so it is not discussed. A dead person's name is never spoken. Only designated tribal members are permitted to touch and bury the dead. So it is up to Ms. Begay and her colleagues to find ways to teach people (many with little or no English) about things like living wills, durable powers of attorney, do-not-resuscitate orders, electroencephalograms, feeding tubes and ventilators. In spite of the taboos, they are trying to find a comfortable way to begin a conversation with patients and their families about death and dying. http://www.nytimes.com/2011/01/25/health/25navajo.html?pagewanted=all

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