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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Literature review: Scroll down to <u>Specialist Publications</u> and 'A social capital framework for palliative care: Supporting health and well-being for people with life-limiting illness and their carers through social relations and networks' (p.9), published in the *Journal of Pain & Symptom Management*.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | Montreal Gazette (Editorial) 16 July 2012 'It's time for a national debate on assisted suicide.' Last week, federal Justice Minister Rob Nicholson announced that the federal government will appeal all aspects of the decision, including the exemption granted the plaintiff. 1,2,3 This is as it should be, because the issue of assisted suicide should be decided not on the judicial, but on the political level. But rather than merely appealing the ruling in hopes that it will be reversed by a higher court, the government should commit itself to engaging a formal national conversation on assisted dying, possibly by way of a royal commission, and thereafter a free vote in Parliament on whether to maintain the law as it is or to change it. It is a profoundly difficult choice in that both advocates and opponents have compelling arguments. On the one side are those who maintain that terminally ill people in the grip of unending excruciating pain should have the right to "die with dignity" should they so choose and have recourse to medical assistance in the process. On the other are those who warn of embarking on a "slippery slope" that would see people who could live longer with proper palliative care opt to die because they feel they are a burden on their families and caregivers, or they feel pressured by family members who consider them to be that.

 http://www.montrealgazette.com/news/time+national+debate+assisted+suicide/6942302/story.html
 - 'Federal government appeals B.C. decision striking down euthanasia laws,' *The Catholic Register*, 13 July 2012 (noted in Media Watch, 16 July 2012). http://www.catholicregister.org/news/canada/item/14880-federal-government-appeals-bc-decision-striking-down-euthanasia-laws
 - 'Conservatives not eager for suicide debate,' Chronicle-Herald (Halifax, Nova Scotia), 20 June 2012 (noted in Media Watch, 25 June 2012). http://thechronicleherald.ca/opinion/109051-conservatives-not-eager-for-suicide-debate
 - 3. 'B.C. Supreme Court strikes down ban on physician-assisted suicide,' *Globe & Mail*, 15 June 2012 (noted in Media Watch, 18 June 2012). http://www.theglobeandmail.com/news/british-columbia/bc-supreme-court-strikes-down-ban-on-physician-assisted-suicide/article4267631/

U.S.A.

Governor signs amended health care law to protect patients according to Halacha

NEW YORK | *Vos Iz Neias* (What's New) – 19 July 2012 – Governor Andrew Cuomo signed ... the Palliative Care Act into law ... which ensures that patients in the end stages of life will be informed of all their options, including their right to ongoing medical treatments as well as palliative care. Under the earlier version of the law, health care providers were only required to inform terminally ill patients of their right to palliative care – not of the option of ongoing, aggressive medical treatment of their condition. The amended version of the law now requires all of the options to be discussed with the patient. The option of aggressive treatment to sustain life for as long as possible must be presented to each patient. With the passage of this law, the patient can consult with his rabbi and opt for the halachically [Jewish religious law] mandated course of action. http://www.vosizneias.com/110251/2012/07/19/albany-ny-gov-signs-amended-health-care-law-to-protect-patients-according-to-halacha/

Palliative care physician shortage

Bill works to make palliative and hospice care available to all Americans

WASHINGTON D.C. | Senator for Oregon posting - 19 July 2012 - The Palliative Care and Hospice Education and Training Act focuses on training for new and existing doctors, those who teach palliative care, and other providers who are part of the palliative care team. It also provides academic and career awards to incentivize practice and study of palliative and hospice care. "Gaps in the workforce continue to limit access to hospice and palliative care for many Americans," [Senator for Oregon Ron] Wyden said. "Right now, there are simply not enough welltrained doctors to handle the overwhelming need for specialized treatment coordinated with patients, their families and across all their healthcare providers. By improving the training in these areas and incentivizing the study and practice of palliative and hospice care, more patients suffering from serious illnesses will be able to have access to care that will improve their quality of life." The legislation focuses on three key areas to grow the palliative care and hospice workforce: education centers to expand interdisciplinary training in palliative and hospice care; training of physicians who plan to teach palliative medicine and fellowships to encourage re-training of mid career physicians; and, academic career awards and career incentive awards to support physicians and other health care providers who provide palliative and hospice care training. http://www.wyden.senate.gov/news/press-releases/wyden-bill-works-to-make-palliative-andhospice-care-available-to-all-americans

Noted in Media Watch, 16 July 2012:

HEALTH LEADERS | Online report – 13 July 2012 – 'Palliative care challenged by [U.S.] physician shortage.' While there is about one cardiologist for every 71 people experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative care physician for every 1,200 people living with a serious or life-threatening illness, according to the Center to Advance Palliative Care. http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage

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

Health care reform: Palliative care perspective

Rational healthcare, not rationing

CALIFORNIA | Los Angeles Times (Commentary) – 18 July 2012 – The [Patient Protection &] Affordable Care Act remains in Republican cross hairs and very much in the news. In recent days, several patients have asked me what the law will mean for them. Many of the people I care for are incurably ill and need expensive medical care to stay alive. They've heard politicians say "Obamacare" will take away their choices, rob them of hope for living longer and cast their fate to "death panels" of faceless bureaucrats. Fortunately, none of this is true. As a palliative care physician, I was relieved by the Supreme Court's ruling and hope Congress allows the law to stand. This is not a partisan reaction. Diseases know no politics. I'm relieved because this law may well unravel patterns of payment and practice that promote irrational care and make dying much harder than it has to be. Today, most doctors are salaried employees and healthcare is a complex industry. Yet we still pay physicians for the quantity of procedures they perform rather than the quality of care and results they provide. Our system is specialist-centered rather than patientcentered. And anyone who has watched a loved one die badly will tell you that sometimes specialists do too much. http://www.latimes.com/news/opinion/commentary/la-oebyock-palliative-care-aca-20120718,0,467862.story

Extract from Los Angeles Times article

The state of end-of-life care in America is marked by too many treatments and too little attention to alleviating pain, clear communication between doctors and patients (or their families), and coordination among multiple specialists or treatment centers. In the quest to save lives, our healthcare system has become exclusively a disease-treatment system.

<u>International</u>

Palliative care in India

Supreme Court directs governments to respond on palliative care policy

INDIA | Press Trust of India (New Delhi) - 20 July 2012 - Taking strong exception to the Union and state governments' failure to respond to a plea for framing a palliative care policy, the Supreme Court warned that their health secretaries would be summoned if they fail to file their replies within four weeks. A bench of justices ... granted last chance to the government to file their replies on the petition by Indian Association of Palliative Care, filed in 2007. "This petition is pending for so many years. Enough is enough. Let health secretaries be present if they fail to file their responses." the bench observed while granting the governments four weeks more for the purpose. The association pleaded that a palliative care policy be framed by governments and it should be included in medical and nursing curricula. It also sought easier access to pain medicine morphine, without the dilution of checks against misuse. http://www.businessstandard.com/generalnews/news/sc-directsgovts-to-respondpalliative-care-policy/34709/

BBC Series

The New Elizabethans: Dame Cicely Saunders

Dame Cicely founded the modern hospice movement and revolutionised end-of-life care, helping people to die with dignity, free from fear and

pain. She was inspired to build St. Christopher's Hospice by two Polish patients with whom she developed close friendships and raised the money through charitable donations. The U.K. hospice opened in 1967. By the time of her death at St. Christopher's, in 2005, there was a network of hospices across the world: 50,000 health professionals from 120 countries had been trained in end of life care at St. Christopher's. Dame Cicely's thesis: "You matter because you are you, and you matter until the last moment of your life. We will do all we can to help you, not only to die peacefully, but to live until you die."

http://www.bbc.co.uk/iplayer/episode/b01ks534/The_New Elizabethans Cicely Saunders/

N.B. The subjects of the BBC's series have been chosen by a panel of leading historians who were asked to choose: "Men and women whose actions during the reign of Elizabeth II have had a significant impact on lives in these islands and/or given the age its character, for better or worse."



Australia's Good Death Project

Dying a good death

AUSTRALIAN AGEING AGENDA | Online report – 19 July 2012 – A national end-of-life care pathways program should be implemented to enable aged care residents to die well in their location of choice... A La Trobe University study¹ on The Good Death Project has found that by improving end-of-life care practices in residential aged care, staff can negate the need to unnecessarily rush the dying to hospital for treatment in their last moments and thereby improve the quality of an individual's last days. The study ... tested the acceptance and feasibility of a best-practice approach to end-of-life care pathways. The pathways, which aimed to optimise the use of medicines to manage symptoms at the end-of-life, were introduced throughout 14 participating aged care facilities across Victoria and South Australia. The study found that unnecessary transfers to hospital – where residents were returned immediately from hospital to the aged-care facility after an urgent referral – fell from 14% to two per cent when care was consistent with best practice. The paper also stated that end-of-life care pathways would be encouraged and more widely accepted if a national program was established to support the use of end-of-life care pathways. http://www.australianageingagenda.com.au/2012/07/19/article/Dying-a-good-death/QKLJODRFRM.html

 'Acceptability and feasibility of end-of-life care pathways in Australian residential aged care facilities,' The Medical Journal of Australia, 2012;197(2):106-109. https://www.mja.com.au/journal/2012/197/2/acceptability-and-feasibility-end-life-care-pathways-australian-residential-aged

Proposals for cemetery beside children's hospice spark fury

U.K. (NORTHERN IRELAND) | *Belfast Telegraph* – 16 July 2012 – Newtownabbey Borough Council is under fire after hundreds of people signed a petition to block a planned cemetery beside the Northern Ireland Children's Hospice. Signatories have branded the proposed 18-acre cemetery, which will be located within Valley Park, beside the hospice, as heartless. Newtownabbey Borough Council, which is bringing forward the plans, said space at the existing Carnmoney Cemetery is so tight that it will not be able to accommodate burials within 18 months, leaving space at only two, more rural, cemeteries in the borough. A spokeswoman for the council stressed that less than one-third of land at Valley Park would be used for a cemetery. However, Derek McCabrey ... said any such development would be "brutally insensitive" to patients and families attending the Children's Hospice. http://www.belfasttelegraph.co.uk/news/local-national/northern-ireland/proposals-for-cemetery-beside-childrens-hospice-spark-fury-16185369.html

Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ GERMANY | Deutsche Welle (Bonn) – 19 July 2012 – 'Strasbourg hits euthanasia ball back into German courts.' The European Court of Human Rights has ruled that it's up to individual countries to decide on euthanasia. It also decided, however, that the German courts should not have thrown out a widower's appeals. Europe's top court ... decided not to issue a ruling on the right to assisted suicide, saying this duty fell to individual countries. The judges chose not to rule on whether ... Bettina Koch should have been permitted to seek medically-assisted suicide. She ultimately went to Switzerland in 2005, where such a practice is allowed, and sought help from the company Dignitas. Her widower Ulrich Koch had pursued the case after her death in Germany, and then in Strasbourg. The European Court of Human Rights did rule, however, that the German courts were negligent in refusing to hear the woman's case and the subsequent, posthumous appeals filed by her husband. http://www.dw.de/dw/article/0,,16109861,00.html

Cont.

- GERMANY | Deutsche Welle 19 July 2012 'European court rules on euthanasia debate.' Germany's laws ... draw a fine line between what's permitted, what's not. http://www.dw.de/dw/article/0,,16105808,00.html
- FRANCE | The Connexion (Monaco) 18 July 2012 'President launches euthanasia debate.' President [François] Hollande has reignited debate on euthanasia, saying he wants to "go further" than the existing "Léonetti Law" on the end of life, which rules it out. Visiting a hospice in the Hauts-de-Seine, the president said he wants to put in place a reform of care for the terminally ill in the "coming months," possibly allowing for a form of assisted dying. The current law says that where someone is terminally ill doctors are not obliged to persist with "relentless" attempts to prolong their life without regard to the quality of it. It falls short, however of allowing doctors to take any active role in shortening life. http://www.connexionfrance.com/Hollande-debate-euthanasia-terminally-ill-Leonetti-13937-view-article.html

N.B. The 2005 Léonetti Law Act established the right to "let die." The law opposes the "unreasonable obstinacy" of undertaking or continuing "unnecessary or disproportionate" treatment, "with no other effect than maintaining life artificially."

Specialist Publications

Of particular interest:

'Palliative sedation: not just normal medical practice. Ethical reflections on the Royal Dutch Medical Association's guideline on palliative sedation' (p.9), published in the JOURNAL OF MEDICAL ETHICS

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

Providing quality palliative care in end-stage Alzheimer disease

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 18 July 2012 – Providing quality palliative care is a daunting task profoundly impacted by diminished patient capacity at the end of life. Alzheimer disease (AD) is a disorder that erases our memories and is projected to increase dramatically for decades to come. By the time the patients with AD reach the end stage of the disease, the ability of patients to provide pertinent subjective complaints of pain and discomfort would have vanished. Historical perspectives of palliative care, exploration of the AD process, ethical issues, and crucial clinical considerations are provided to improve the understanding of disease progression and quality of care for patients with end-stage AD. http://ajh.sagepub.com/content/early/2012/07/16/1049909112453644.abstract

Noted in Media Watch, 2 April 2012:

 AGING WELL, 2012;5(2):18. 'Integrating palliative medicine with dementia care.' http://www.agingwellmag.com/archive/031912p18.shtml

Noted in Media Watch, 6 February 2012:

AMERICAN JOURNAL OF ALZHEIMER'S DISEASE & OTHER DEMENTIAS | Online article – 31
January 2012 – 'Palliative care for advanced dementia: A pilot project in two nursing homes.'
http://aja.sagepub.com/content/early/2012/01/04/1533317511432732.abstract

Expressions of loss and separation

Palliative health care: Ancient wisdom

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 18 July 2012 – An ancient story from [the Hindu text] Bhagavata Purana may be relevant to the psychology and spirituality of palliative care in modern medicine. This article brings an ancient Indian story that people still use during the grieving process. Symbolism of the old story is explained in a modern perspective. http://ajh.sagepub.com/content/early/2012/07/16/1049909112453081.abstract

Of related interest:

■ AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 18 July 2012 – 'Waking.' An indubitable aspect of laboring in the realm of hospice care is the "everydayness" of human loss or the stark encounter of death in the human experience. This can pose as opportunity to adopt each day in a particular manner. The focus of [the author's] reflection is on transposing certain dynamics of a (funeral) wake to broader professional and personal socio-existential processes. http://ajh.sagepub.com/content/early/2012/07/16/1049909112454214.abstract

Volunteer Retention Questionnaire

Holding on to what you have got: Keeping hospice palliative care volunteers volunteering

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 18 July 2012 The Volunteer Retention Questionnaire asks volunteers to rate the importance of each item to their decision to continue volunteering. The items that received the highest mean importance ratings [in this study] included enjoying the work they do, feeling adequately prepared/trained to perform their role, and learning from their patients' experiences/listening to their patients' life stories. Being recognized (e.g., pins for years of service or being profiled in the hospice newsletter), receiving phone calls/cards from their volunteer coordinator on special occasions, and being reimbursed for out-of-pocket expenses were among the items that received the lowest mean importance ratings. http://ajh.sagepub.com/content/early/2012/07/16/1049909112453643.abstract

Noted in Media Watch, 16 January 2012:

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 12 January 2012 – 'Should I stay or should I go: A study of hospice palliative care volunteer satisfaction and retention.' http://ajh.sagepub.com/content/early/2012/01/04/1049909111432622.abstract

Are you a successful researcher? Well, it depends on who's asking

BMJ SUPPORTIVE & PALLIATIVE CARE | Online editorial - 16 July 2012 - I have, on file, a very polite letter from a palliative care journal explaining that it would not be sending my paper out for review, since it covered a topic that was not of relevance or interest to the target audience. The editor kindly wished me every success in my future research. That letter had a profound impact on my academic career. I rationalised that rather than my rejected paper being of no interest to the palliative care readership, it was just not the right time to consider the conclusions I had drawn. We are still a young specialty; academically even more so. Challenging the established view, however well intentioned, may be interpreted as discourteous rather than a pursuit of academic rigour. My resolve was further strengthened when later that year an Australian gastroenterologist Barry Marshall along with Robin Warren was awarded the Nobel Prize for Medicine for the discovery of Helicobacter pylori and its role in gastritis and peptic ulcer disease. Initially published in the Lancet in 1982, Marshall's work attracted little interest at the time. The majority of the medical establishment rejected his work with one prominent gastroenterologist branding him 'a crazy guy saying crazy things.' It wasn't until 1994 that the causative association between H pylori and peptic ulcer disease became widely accepted, and the use of eradication therapy transformed the lives of millions of patients worldwide. The moral of this tale is not that if you wait long enough, your previously ridiculed research will earn you a date in Stockholm, courtesy of the Swedish Academy. http://spcare.bmj.com/content/early/2012/07/16/bmjspcare-2012-000301.extract

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

National End of Life Care Programme

Social work 'too often missing from end-of-life care'

COMMUNITY CARE (U.K.) | Online report – 19 July 2012 – Social workers have a vital role in end-of-life care but they often struggle to perform it because of cuts, workloads and a lack of confidence, says a report from the National End of Life Care Programme. That was the conclusion from a guide ... designed to improve the quality and impact of social work at the end of life. Social workers' skills in advocacy, listening, helping people adjust to changing circumstances and working with the whole family and their human rights value base made them a vital ingredient in good end-of-life care. Council social workers' contribution to end-of-life care was often lacking and it was seen as a luxury. http://www.communitycare.co.uk/Articles/19/07/2012/118394/Social-work-39too-often-missing-from-end-of-life.htm

 'The route to success in end of life care – achieving quality for social work,' National End of Life Care Programme, The College of Social Work & National Health Service, July 2012. http://www.endoflifecareforadults.nhs.uk/assets/downloads/EoLC_Social_Work_Route_to_Success-web.pdf

Noted in Media Watch, 9 July 2012:

BRITISH JOURNAL OF SOCIAL WORK | Online article – 2 July 2012 – 'Suggested indications for social work leadership from a study of social work practice in a palliative care setting.' http://bisw.oxfordjournals.org/content/early/2012/07/01/bjsw.bcs083.abstract

Noted in Media Watch, 2 July 2012:

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online article – 28 June 2012 – 'Integration of health and social care...' http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2012.01076.x/abstract

Noted in Media Watch, 9 January 2012:

 THE GUARDIAN (U.K.) – 5 January 2012 – '[Prime Minister] David Cameron orders merging of health and social care.' http://www.guardian.co.uk/politics/2012/jan/05/david-cameron-health-social-care

What are the priorities for developing culturally appropriate palliative and endof-life care for older people? The views of healthcare staff working in New Zealand

HEALTH & SOCIAL CARE IN THE COM-MUNITY | Online article - 20 July 2012 -The findings [of this study] demonstrated that participants viewed the involvement of family as fundamental to the provision of palliative care for Māori, Pacific Island and Chinese elders. Care staff highlighted the need to be cognisant of individual preferences both within and across cultures as a fundamental aspect of palliative care provision. Counter to the prioritisation of autonomy in Western health-care, collective decision-making was favoured by Chinese elders. Providing families with the requisite knowledge and skills to give care to older family members was important. Whilst assumptions are sometimes made about pref-

erences for end-of-life care based on cultural values alone, these data suggest that care preferences need to be ascertained by working with family members on an individual basis and in a manner that respects their involvement in palliative care provision. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2012.01083.x/abstract

Extract from Health & Social Care in the Community article

The role of family in 'hands-on' palliative care and decision-making requires care staff to relinquish their role as 'expert provider."

Australian resident doctors want more palliative medicine education: A survey of attitudes and perceived needs

INTERNAL MEDICINE JOURNAL, 2012;42(7):828-830. Most expected deaths occur in acute hospitals, and medical staff providing end-of-life care are generally not palliative medicine specialists. This study explored resident doctors' attitudes to palliative medicine and their perceived educational needs. Fifty-two resident doctors participated, mostly acknowledging the importance of palliative medicine to their practice and emphasising that further postgraduate education is necessary. http://onlinelibrary.wiley.com/doi/10.1111/j.1445-5994.2012.02824.x/abstract

Ethical issues of incorporating spiritual care into clinical practice

JOURNAL OF CLINICAL NURSING, 2012;21(15-16):2099-2107. The aim of this article was to analyse the scholarly discourse on the ethical issues of incorporating spirituality and religion into clinical practice. The discourse analysis uncovered four themes: ethical concerns of omission; ethical concerns of commission; conditions under which health providers prefer to offer spiritual care; and strategies to integrate spiritual care. Ethical concerns of omission of spiritual care include lack of beneficence for not offering holistic care. Ethical concerns of commission are coercion and overstepping one's competence in offering spiritual care. Conditions under which providers are more likely to offer spiritual care are if the patient has a terminal illness, and if the patient requests spiritual care. Strategies for appropriate spiritual care include listening, and remaining neutral and sensitive to spiritual issues. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2012.04168.x/abstract

Of related interest:

JOURNAL OF CLINICAL NURSING, 2012;21(15-16):2126-2135. 'Spirituality and spiritual caring: Nurses' perspectives and practice in palliative and acute care environments.'
 http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2012.04180.x/abstract

Care planning

Tracking the route to sustainability: A service evaluation tool for an advance care planning model developed for community palliative care services

JOURNAL OF CLINICAL NURSING, 2012;21(15-16):2136-2148. Internationally, advance care planning programmes usually measure success by completion rate of advance directives or plans. This outcome measure provides little information to assist nurse managers to embed advance care planning into usual care and measure their performance and quality over time. An evaluation tool was developed to address this need in Australian community palliative care services. The Advance Care Planning-Service Evaluation Tool identified advance care planning progress over time across three stages of Establishment, Consolidation and Sustainability within previously established Model domains of governance, documentation, practice, education, quality improvement and community engagement. The tool was used by nurses either as a peerassessment or self-assessment tool that assisted services to track their implementation progress as well as plan further change strategies. The tool was useful to nurse managers in community palliative care. It provided a clear outline of service progress, level of achievement and provided clear direction for planning future changes. <a href="http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2012.04179.x/abstract;jsessionid=80F4EAAA684C41B2F9D81DFA00CB5EDA.d02t01?deniedAccessCustomisedMessage=&userlsAuthenticated=false

Of related interest:

THORAX | Online article – 16 July 2012 – 'Discussing an uncertain future: End-of-life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis.' http://thorax.bmj.com/content/early/2012/07/15/thoraxjnl-2012-201835

Palliative sedation: not just normal medical practice. Ethical reflections on the Royal Dutch Medical Association's guideline on palliative sedation

JOURNAL OF MEDICAL ETHICS | Online article – 18 July 2012 – The main premise of the ... guideline[s] on palliative sedation is that palliative sedation, contrary to euthanasia, is normal medical practice. Although the authors do not deny the ethical distinctions between euthanasia and palliative sedation ... [they] ... critically analyse the guideline's argumentation strategy with which euthanasia is demarcated from palliative sedation. First, they analyse the guideline's main premise, which entails that palliative sedation is normal medical treatment. After this, the authors critically discuss three crucial propositions of the guideline that are used to support this premise: 1) the patient's life expectancy should not exceed 2 weeks; 2) the aim of the physician should be to relieve suffering; and, 3) expert consultation is optional. They conclude that, if inherent problematic aspects of palliative sedation are taken seriously, palliative sedation is less normal than ... depicted in the guideline. http://jme.bmj.com/content/early/2012/07/17/medethics-2011-100353.abstract

Noted in Media Watch, 16 July 2012:

- THE NETHERLANDS | Radio Netherlands 11 July 2012 'Dutch euthanasia rates unchanged by legislation.' The legalisation of euthanasia in The Netherlands has not led to an increase in the number of cases according to a team of Dutch researchers. http://www.rnw.nl/english/article/dutcheuthanasia-rates-unchanged-legislation
 - 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: A repeated cross-sectional survey,' *The Lancet*, 11 July 2012. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)61034-4/abstract
- BMJ PALLIATIVE & SUPPORTIVE CARE | Online article 11 July 2012 'Continuous palliative sedation until death: Practice after introduction of the Dutch national guideline.'
 http://spcare.bmj.com/content/early/2012/07/09/bmjspcare-2011-000063.abstract

Literature review

A social capital framework for palliative care: Supporting health and well-being for people with life-limiting illness and their carers through social relations and networks

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article - 16 July 2012 - Social relations and networks are vital for sustaining and enhancing end-of-life care. The social capital concept supports a framework to understand the association between social relations and well-being: yet, to date, there has been very limited investigation of social capital in the palliative care literature. A framework for understanding social contexts in end-of-life care is necessary. A total of 93 articles were included in the literature review, with only two articles identifying discourse on social capital and palliative care. Four key areas integrating the social capital outcomes informed a framework for palliative care. The social capital concept provides a structure for understanding how the organization and meaning of social contexts can potentially enhance or hinder end-of-life care. Research that identifies specificity in application of social capital concepts is fundamental to issues of access to services, sustaining levels of care, quality of life, and well-being. The importance of "bridged" social capital relations and networks for improved resource acquisition and information flow was identified in the literature and outlined within the palliative care social capital framework. Differential access to social capital by disadvantaged groups provides further impetus to engage a model of social capital for palliative care. http://www.jpsmjournal.com/article/S0885-3924(12)00204-7/abstract

Noted in Media Watch, 19 September 2011:

BMJ SUPPORTIVE & PALLIATIVE CARE, 2011;1(2):129-133. 'Compassionate community networks: Supporting home dying.' How may communities be mobilised to help someone dying at home? http://spcare.bmj.com/content/1/2/129.abstract

Using sociodrama and psychodrama to teach communication in end-of-life care

JOURNAL OF PALLIATIVE MEDICINE | Online article – 16 July 2012 – End-of-life discussions can be stressful and can elicit strong emotions in the provider as well as the patient and family. In palliative care, understanding and effectively addressing emotions is a key skill that can enhance professional competency and patient/family satisfaction with care. The authors illustrate how in coursework for a Master's degree in palliative medicine we used dramatic "action methods" derived from sociodrama and psychodrama in the portrayal of two challenging cases to train providers in the emotional aspects of caring for patients with advanced cancer. They describe the specific techniques of constructing and enacting case scenarios using warm-ups, role-creation, doubling and role-reversal. In particular, the authors illustrate how these techniques and others were used to reveal and address the "hidden" emotions, attitudes, and values that were central to the communication dilemma. Finally, they present an evaluation completed by the 26 participants who attended the course. http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0030

Palliative care for children in Russia: Some steps forward

PALIATIA, 2012;5(3). The aim of this analysis is to describe palliative care for children in Russia and perspectives for its development. The authors adopted a multi-session approach, which involves the synthesis of evidence from published literature, internet resources, local expert's interviews and personal communication. Basically palliative care is provided by specialists in diverse pediatric clinical settings and by mobile teams in the community. They have found independent palliative care services for children with cancer in 8 cities within the country. Pioneering programmes have been introduced in a number of cities. These programmes involve collaboration between state and nongovernmental organizations and have grown up primarily through the inspiration of local leaders. There is evidence of wide-ranging initiatives designed to create the organization, workforce, and policy to develop capacity for hospice-palliative care services for children. http://www.paliatia.eu/modules/publisher/item.php?itemid=46

Quotable Quotes

It's still unclear who needs whom more, whether sick children need us more, or whether we need them most. They help us to compare our trivial trials with true suffering; to see what is really important, and what is ephemeral and of no value at all. Patriarch Kirill Gundyaev of Moscow and all the Russias, November 2010, on a visit to a children's hospice.

http://www.youtube.com/watc h?v=IK7NL7k8hFY

A few psychiatrists choose path strewn with 'heartbreaking work'

PSYCHIATRIC NEWS | Online article – 20 July 2012 – A few years ago, a woman dying from a brain tumor wanted to hasten her death because she no longer found any meaning in life. She stood on a highway hoping that a car would run her down, but no driver was willing to do it. She then contacted Memorial Sloan-Kettering Cancer Center [MSKCC], and a psychiatrist working at the center visited her at home. He tried to find some way of instilling meaning in her life, but to no avail. Finally out of frustration he blurted out, "Well, you can still cry and feel." She leapt off the couch and cried out, "Yes, I feel so much! I haven't talked with my children in 20 years. I have grandchildren I have never seen. I can't die until I reconcile with my children and grandchildren and tell them that I love them." And that, the psychiatrist recalls, was "the breakthrough." The psychiatrist was William Breitbart MD, chief of psychiatry ... [at MSKCC] ... and one of only a handful of psychiatrists in North America who are devoting their professional lives to helping dying patients. The reason why there are so few of them is due to the challenges that surround this kind of work. http://psychnews.psychiatryonline.org/newsArticle.aspx?articleid=1217914

Noted in Media Watch, 26 March 2012:

 AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY, 2012;20(4). 'Palliative care has much to bring to geriatric psychiatry.' http://journals.lww.com/ajgponline/pages/currenttoc.aspx

Cont.

From Media Watch, 29 August 2011:

PEDIATRIC CLINICS OF NORTH AMERICA, 2011;58(4):1025-1039. 'Partnerships between pediatric palliative care and psychiatry.' http://www.pediatric.theclinics.com/article/S0031-3955(11)00062-9/abstract

From Media Watch, 23 May 2011:

MEDSCAPE | Online interview – 10 May 2011 – 'Palliative care psychiatry: What is it and does
it work?' http://www.medscape.com/viewarticle/741903

Of related interest:

• AMERICAN JOURNAL OF EPIDEMIOLOGY | Online article – 19 July 2012 – 'The forgotten griever: A nationwide follow-up study of mortality subsequent to the death of a sibling.' The least-studied familial relationship in the bereavement literature is that of siblings, although loss of a sibling may also involve health consequences. An elevated mortality risk associated with a sibling's death was found in all age groups studied, but the association was generally stronger at younger ages and could be observed predominantly after more than one year of follow-up. http://aje.oxfordjournals.org/content/early/2012/07/19/aje.kws163.abstract

Media Watch Online

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/inthenews.html

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

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.palliativecareconsultation.ca/?q=mediawatch

U.S.A.

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

Europe

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

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

Asia

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

International

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

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

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

Assisted (or facilitated) death

Representative sample of recent articles, etc:

VETERINARY RECORD | Online article – 11 July 2012 – 'Attitudes to animal euthanasia do not correlate with acceptance of human euthanasia or suicide.' Veterinary students and graduates [i.e., study participants] had a negative attitude towards convenience animal euthanasia, but their attitudes changed over time. Attitudes towards both human euthanasia and suicide ... remained stable over time and indicated on average a neutral stance. No correlations were found between attitudes to convenience euthanasia and either human euthanasia or suicide, suggesting a tolerance to convenience euthanasia of animals does not lead to desensitisation in valuing human life and a changed attitude to human euthanasia or suicide, or vice versa. Attitudes to human euthanasia and suicide were predictably correlated, perhaps suggesting an overarching attitude towards control over human death. https://veterinaryrecord.bmj.com/content/early/2012/07/10/vr.100451.abstract

Noted in Media Watch, 16 April 2012:

 NEW YORK TIMES | Online OpEd – 9 April 2012 – 'An ethical quandary, no matter the species.' http://www.nytimes.com/roomfordebate/2012/04/09/the-ethics-of-spending-25000-on-pet-health-care/an-ethical-guandary-no-matter-the-species

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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Links to Sources

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

Something Missed or Overlooked?

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

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