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

Compiled & Annotated by Barry R. Ashpole

Practical implications for practicing compassion: Scroll down to <u>Specialist Publications</u> and 'Conceptualizing compassion as recognizing, relating and (re)acting: A qualitative study of compassionate communication at hospice' (p.10), published in *Communication Monographs*.

Canada

Teaching doctors a new approach to the end-of-life process

ONTARIO | Globe & Mail – 15 July 2012 – Designed by James Downar, a critical care and palliative care physician at Toronto General Hospital ... [a] ... unique program is part of a growing push among members of the medical community to revamp the way doctors, patients and families approach the end-of-life process. Many patients die uncomfortable, sometimes painful, deaths in the intensive care unit when they could have benefited from the support of palliative care. The reluctance to confront the inevitability of death and continuing to pursue aggressive treatment can do unnecessary harm to patients and relatives during what is already an extremely difficult period, according to Dr. Downar. The core issue is that family members often don't recognize when further intervention is futile, that a family member is not going to improve or enjoy real quality of life ever again. http://www.theglobeandmail.com/life/health-and-fitness/health/teaching-doctors-anew-approach-to-the-end-of-life-process/article4416607/?cmpid=rss1

Montreal falls short of provincial standards for palliative-care beds, data show

QUÉBÉC | Montreal Gazette – 11 July 2012 – Government resources for tending to the terminally ill are "abysmal" in Montreal and the dying are suffering in silence, charges the chief of palliative care at the Jewish General Hospital. Dr. Bernard Lapointe ... accused the Québéc government ... of failing to adequately fund palliative care in Montreal hospitals, hospices and Centre Local de Services Communautaires clinics. Lapointe told *The Gazette* ... "Montreal is well-known for having an abysmal level of care for those dying at home." Lapointe made those comments after a pensioners' association made public internal government data showing that Montreal lags far behind the rest of Québéc in palliative-care beds relative to its population. Although Montreal does have the greatest total number of beds for so-called end-of-life care of any region, it actually falls far short of the provincial norm, according to the Association québécoise des retraité(e)s des secteurs public et parapublic. Ideally, each region should assign one palliative bed per 10,000 inhabitants. http://www.montrealgazette.com/health/Montreal+falls+short+provincial+standards+palliative+care+beds+data+show/6917397/story.html

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE CATHOLIC REGISTER | Online report 13 July 2012 'Federal government appeals B.C. decision striking down euthanasia laws.' The federal government ... will appeal the 15 June British Columbia Supreme Court Carter decision that struck down Canada's laws against euthanasia and assisted suicide. "After careful consideration of the legal merits," the Government of Canada will appeal the Carter decision to the British Columbia Court of Appeal and seek "a stay of all aspects of the lower court decision," said Justice Minister and Attorney General Rob Nicholson... "The Government is of the view that the Criminal Code provisions that prohibit medical professionals, or anyone else, from counselling or providing assistance in a suicide, are constitutionally valid," said Nicholson. "The Government also objects to the lower court's decision to grant a 'constitutional exemption' resembling a regulatory framework for assisted suicide." In the Carter decision, B.C. Supreme Court Justice Lynn Smith said the laws against assisted suicide and euthanasia violated the equality rights of those who could not commit suicide without help, since suicide is legal. She also argued the Criminal Code provisions violated disabled peoples' Section 7 rights of life, liberty and security of the person. http://www.catholicregister.org/news/canada/item/14880-federal-government-appeals-bc-decision-striking-down-euthanasia-laws
 - 'Response of the Attorney General of Canada to the British Columbia Supreme Court decision on assisted suicide,' Department of Justice Canada, 13 July 2012. http://canada.justice.gc.ca/eng/news-nouv/nr-cp/2012/doc_32769.html
- THE UNITED CHURCH OBSERVER | Online report Accessed 10 July 2012 'Rights and wrongs at the edges of life [Survey].' Readers [were asked] to complete a survey designed to gauge opinion on ethical issues related to the beginning and the end of life. The same survey was administered online to English-speaking non-readers. Overall, the [national] survey shows that readers, who are mostly churchgoers, are more liberal in their views on issues such as abortion, euthanasia and assisted suicide than non-readers, who are less likely to be involved in organized religion.http://www.ucobserver.org/features/2012/07/rights_wrongs/

Specialist Publications

Of particular interest:

'Organization position statements and the stance of "studied neutrality" on euthanasia in palliative care' (p.13) published in the Journal of Pain & Symptom Management.

U.S.A.

Better preparation could improve the quality of death – and life – for terminal patients

SCIENTIFIC AMERICAN | Online article – 9 July 2012 – Terminally ill patients in the U.S. these days face expensive care and prolonged declines. And many hospitals lack a designated palliative care team, which focuses on patient comfort at any point in the life cycle but becomes more critical at the end. In terms of care, the solution to our medical system's woes might be as simple as a conversation about how we die. "Many clinicians are afraid to talk about prognosis—how long a patient may have to live," says Alexander Smith, a palliative care physician at the University of California, San Francisco. "Talking about death in America is forbidden, a taboo topic." Voices clamor to be heard in the discussion about end-of-life care. Patients prefer to die at home and in comfort. Physicians struggle to speak to patients they have been trying to save but worry about legal issues. Politicians debate the best way to curb rising health care costs and shun "death panels." Amid this fervor, researchers in Sweden found last year that conversations about imminent death are associated with improved care and less pain and suffering. Now, a team at Harvard Medical School reveals more detail about the social and psychological factors that affect quality of death. http://www.scientificamerican.com/article.cfm?id=better-preparation-quality-life-death

- U.S.A. NEWS & WORLD REPORT | Online report 9 July 2012 'What makes the end-of-life experience peaceful?' Dying patients face their final days better if they are not in the hospital, not on a feeding tube or chemotherapy and feel that they have a trusting relationship with their doctor, a new survey of terminally ill cancer patients reveals. Other factors that helped them find peace in the end ... were prayer, meditation, a pastor's visit and freedom from excessive worry or anxiety. http://health.usnews.com/health-news/news/articles/2012/07/09/what-makes-the-end-of-life-experience-peaceful
- 'Factors important to patients' quality of life at the end of life,' Archives of Internal Medicine, 9 July 2012. Scroll down to <u>Specialist</u> <u>Publications</u> (p.9), for an abstract of/link to this journal article and an accompanying, invited commentary.

Specialist Publications

Of particular interest:

'Palliative care challenged by physician shortage' (p.10), published in *Health Leaders*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHEUSETTS | Boston Globe 12 July 2012 'Assisted dying, without the doctor? Ethicist says physicians can help without prescribing lethal dose.' Dr. Lisa Soleymani Lehmann, director of the Center for Bioethics at Brigham and Women's Hospital, and research assistant Julian Prokopetz propose a policy they say could distance doctors from the process¹ perhaps resolving one of the main objections to the ballot question Massachusetts voters will consider in November on whether to allow terminally ill patients to end their lives. "Writing a prescription that allows a patient to acquire a lethal dose of a medication with the explicit intention of ending their own life really goes beyond the accepted norms of what physicians do," Lehmann said in an interview. http://articles.boston.com/2012-07-12/health-wellness/32643233 1 physician-assisted-suicide-patients-life-ending-drugs
 - 'Redefining physicians' role in assisted dying.' New England Journal of Medicine, 2012;367(2):97-99. http://www.nejm.org/doi/full/10.1056/NEJMp1205283
- NEW MEXICO | Solutions (OpEd) 11 July 2012 'Doctors, patient challenge New Mexico assisted suicide ban.' The question before the court in New Mexico is absurdly simple and yet impossibly complex. What is the meaning of "assisting suicide"? If a terminally-ill patient refuses a ventilator or a feeding tube and the physician yields to that decision, is that assisting suicide? If the patient is in excruciating pain and requests total sedation and no nutrition or fluids, can the doctor be held accountable for his death? What if the patient seeks a prescription from her physician so that when the pain of dying is overwhelming she can seek the ultimate relief on her own? Two oncologists from the University of New Mexico Health Science Center and a patient with advanced cancer are the plaintiffs in a lawsuit filed in New Mexico District Court designed to clarify the legal definition of assisting suicide. That decision, likely to come in the next year, could send reverberations through the medical establishment in the Rocky Mountain West and across the country. http://www.healthpolicysolutions.org/2012/07/11/doctors-patient-challenge-new-mexico-assisted-suicide-ban/

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

International

Ministry of Health to strengthen efforts to provide palliative care to more patients

SINGAPORE | *Today* – 14 July 2012 – The Ministry of Health (MOH) will be strengthening efforts to provide home care for patients going through the last stages of their lives. With the prevalence of chronic diseases, the ministry is looking into extending palliative care beyond traditional cancer care to benefit more non-cancer patients. Currently, MOH is funding a S\$12 million programme for over 3,000 end-organ failure patients to receive structured home palliative care over a five-year period. A three-year pilot project for integrated home palliative care is also already underway. Started in February last year, the project involving Dover Park Hospice and Tan Tock Seng Hospital sees patients being directly admitted to the hospital if they require higher-intensity care. http://www.todayonline.com/Singapore/EDC120714-0000075/MOH-to-strengthen-efforts-to-provide-palliative-care-to-more-patients

New plans being introduced for 'end of life care'

U.K. (ISLE OF MAN) | Energy FM (Douglas) – 13 July 2012 – The Department of Health is moving forward with its plans to introduce a new care strategy for people who are dying. The Island's first ever End of Life Care Framework has been launched following months of detailed research and analysis. The framework tackles the often taboo topic of death and looks at how people are cared for, as well as the profound effect it can have on their family and friends. A major part of the research involved asking for the public's views. Over 1,200 people responded and their opinions have been taken into account. The survey identified inconsistencies in the current provision, depending on what diseases are suffered. http://www.energyfm.net/cms/news_story_223176.html

Government white paper

Care for the elderly: Mr. Lansley's commitment phobia

U.K. | *The Guardian* (OpEd) – 11 July 2012 – Let us start with two seemingly contradictory statements. First, Britain is in a crisis about providing care for its elderly and disabled. Second, there is no lack of well-researched, convincingly costed ideas on what should be done about the issue. And yet the crisis escalates. It will barely be eased by the policy proposal announced by [Secretary of State for Health] Andrew Lansley. Far from being his declared "watershed moment," this was a series of half-measures and sticking plasters, marked by a lack of intellectual honesty about the real solutions at stake and a failure of political courage. The health secretary, who was happy enough to charge into a hasty and drastic reorganisation of the National Health Service – ignoring the protests of doctors, nurses and healthcare professionals – shows no such bravery in dealing with the much more pressing issue of long-term care – despite professionals pleading with him to do so. http://www.guardian.co.uk/commentisfree/2012/jul/11/care-for-the-elderly-andrew-lansley

- 'Andrew Lansley: Elderly will be able to opt in to social care insurance scheme,' The Guardian, 11
 July 2012. http://www.guardian.co.uk/society/2012/jul/11/andrew-lansley-social-care-insurance?CMP=twt_fd
- 'Care and Support White Paper,' Department of Health, July 2012. http://www.dh.gov.uk/health/2012/07/careandsupportwhitepaper/

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

Southwest leading on end of life choice

U.K. | Scilly Today (St. Mary's) – 10 July 2012 – More people in the Isles of Scilly and Cornwall are able to choose the place where they die – usually their own home – than in most areas in England. That's according to figures from the 2012 National End of Life Care Profiles, which show our area, one with a significantly higher than average numbers of over-65s, is leading the way on patient choice. http://www.scillytoday.com/2012/07/10/southwest-leading-on-end-of-life-choice/

 'New End-of-Life Care Primary Care Trust Profiles,' National End of Life Care Intelligence Network, 28 May 2012 (noted in Media Watch, 4 June 2012). http://www.endoflifecare-intelligence.org.uk/end of life care profiles/primary care trust profiles.aspx

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- 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.¹ The findings [of their study] ... show that about three percent of all deaths in 2010 were the result of euthanasia or assisted suicide. This compares to pre-legalisation levels of 2.8%. When euthanasia was legalised in 2002, opponents warned that there would be an increase in the involuntary euthanasia of terminally ill or elderly patients. However, Professor Bregje Onwuteaka-Philipsen of Amsterdam's VU University says there has actually been a drop in such deaths. Based on interviews with 6,000 doctors and research into 7,000 deaths, the team found just 300 cases of euthanasia where the patient had not given explicit consent in 2010, compared with around 1,000 in the years prior to legalisation. http://www.rnw.nl/english/article/dutch-euthanasia-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

Of related interest:

- BMJ PALLIATIVE & SUPPORTIVE CARE | Online article 11 July 2012 'Continuous palliative sedation until death: Practice after introduction of the Dutch national guideline.' Continuous palliative sedation practice in The Netherlands largely reflects the recommendations from the national guideline. Issues needing further attention are the pressure felt by physicians to start continuous sedation and the potential life-shortening effect as mentioned by the physicians. http://spcare.bmj.com/content/early/2012/07/09/bmjspcare-2011-000063.abstract
- SWITZERLAND | Swiss.info 9 July 2012 'Finding a place for assisted suicide in society.'
 With the number of people availing of assisted suicide in Switzerland up 60% over the past five years, policymakers want to improve access to palliative care to alleviate the widespread fear of dying badly. The two main Swiss assisted suicide organisations ... made it possible for 560 people to end their lives in 2011. While the right to die is consistently backed by a majority of the electorate, there are details within the practice of assisted suicide that split opinion, such as the vote in canton Vaud last month over exercising the right to die in a residential care home. Voters in the French-speaking canton accepted the local government's proposal to oblige nursing homes and hospitals to accept the practice only when the person in question is suffering from an incurable illness or injury.http://www.swissinfo.ch/eng/swiss news/Finding a place for assisted suicide in society.htm l?cid=32986262

Living to the end - palliative care for an ageing population

World hospice & palliative care day

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

Hospital administrators' views on barriers and opportunities to delivering palliative care in the emergency department

ANNALS OF EMERGENCY MEDICINE | Online article - 9 July 2012 - Barriers to integrating palliative care and emergency medicine from the administrative perspective [identified in this study] include the ED [emergency department] culture of aggressive care, limited knowledge, palliative care staffing, and medico-legal concerns. Incentives to the delivery of palliative care in the ED from these key informants' perspective include improved patient and family satisfaction, opportunities to provide meaningful care to patients, decreased costs of care for admitted patients, and avoidance of unnecessary admissions to more intensive hospital settings, such as the ICU, for patients who have little likelihood of benefit. Though hospital administration at three urban hospitals on the East coast has great interest in integrating palliative care and emergency medicine to improve quality of care, patient and family satisfaction, and decrease length of stay for admitted patients, palliative care staffing, medico-legal concerns, and logistic issues need to be addressed. [See sidebar, right]http://www.annemergmed.com/article/S 0196-0644(12)00609-9/abstract

How family physicians address diagnosis and management of depression in palliative care patients

ANNALS OF FAMILY MEDICINE, 2012; 10(4):330-336. Family physicians in The Netherlands perceive the diagnosis and management of depression in palliative care patients as challenging but generally feel competent to address the issue. Physicians do not strictly apply criteria of depressive disorder when evaluating patients but rather rely on their clinical judgment and strongly considered patients' context and background factors. Participants acknowledged difficulty in discerning depression from normal sadness and identified a lack of knowledge, time, and additional support sources as challenges.http://www.annfammed.org/content/1 0/4/330/suppl/DC1

Palliative care ED: Noted in past issues of Media Watch:

'Viewpoint: Palliative care belongs in the ED,'

Emergency Medicine News, 2012;34(6):3-19.

http://journals.lww.com/em-news/Citation/2012/06000/Viewpoint Palliative Care

Belongs in the ED.14.aspx

'Half of older Americans seen in emergency department in last month of life: Most admitted to hospital, and many die there,' *Health Affairs*, 2012;31(6):1277-1285.

http://content.healthaffairs.org/content/31/6/1277.abstract

'Why do palliative care patients present to the emergency department? Avoidable or unavoidable?' *American Journal of Hospice & Palliative Care*, 23 May 2012.

http://ajh.sagepub.com/content/early/2012/05/18/10499 09112447285.abstract

'Practically speaking: Emergency medicine and the palliative care movement,' *Emergency Medicine Australasia*, 2012;24(1):4-6. http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01531.x/full

'Palliative care in the emergency department: An oxymoron or just good medicine?' *Emergency Medicine Australasia*, 2012;24(1):102-104. http://onlinelibrary.wiley.com/doi/10.1111/j.1742-6723.2011.01505.x/abstract

'Does palliative care have a future in the emergency department?' *Journal of Pain & Symptom Management*, 2012;43(1):1-9. http://www.jpsmjournal.com/article/S0885-

3924(11)00272-7/abstract

'IPAL-EM launches to improve palliative care in emergency medicine,' Center to Advance Palliative Care, 10 October 2011.

http://www.eurekalert.org/pub_releases/2011-11/tmsh-ilt110411.php

'The palliative care model for emergency department patients with advanced illness,' *Journal of Palliative Medicine*, 18 July 2011. http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.

0011

Association between elder self-neglect and hospice utilization in a community population

ARCHIVES OF GERONTOLOGY & GERIATRICS | Online article – 5 July 2012 – Elder self-neglect is associated with substantial 1-year mortality. However, hospice utilization among those with self-neglect remain unclear. [In this population-based study] elder self-neglect was associated with increased risk of hospice use in this community population. Elder self-neglect is associated with shorter length of stay in hospice care and shorter time from hospice admission to death. http://www.sciencedirect.com/science/article/pii/S016749431200132X

Communicating with physicians about medical decisions: A reluctance to disagree

ARCHIVES OF INTERNAL MEDICINE | Online article – 9 July 2012 – A reluctance, indeed a fear, to disagree appears to be a significant barrier to shared decision making that is present across all socio-demographic strata. To the authors' knowledge, a patient-held fear to voice disagreement has not been found or examined in previous research, and yet it is a major challenge to making progress toward shared decision making. Reluctance to express disagreement in the office may correlate with poor adherence outside the office. Limitations of this study include the use of a large convenience sample and a hypothetical scenario. The findings [of this study] point to the need to test interventions that explicitly allow patients to voice disagreement with their physicians. http://archinte.jamanetwork.com/article.aspx?articleid=1212630

Cont. next page

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?PHPSESID=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

Of related interest:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article 16 July 2012 'Factors considered in end-of-life care decision-making by healthcare professionals.' The respondents [to this cross-sectional survey] rated patients' wishes (96.6%), their clinical symptoms (93.9%), and patients' beliefs (91.1%) very high. In all, 94.6% of the HCPs [health care professionals] would respect a competent patient's wishes over the family's wishes when goals conflict. However, 59.9% of HCPs would abide by the family's wishes when the patient loses capacity even if the patient's previously expressed wishes are known. End-of-life care decision making by HCPs appears largely patient centered, although familial determination still wields significant influence... http://ajh.sagepub.com/content/early/2012/07/12/1049909112453193.abstract
- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article 12 July 2012 'Physician knowledge, attitude, and experience with advance care planning [ACP], palliative care, and hospice...' Often, discussions about ACP or referrals to palliative care or hospice do not occur until the patient is near the end of life. Our results indicate that primary care physician's personal and professional experience with ACP may be contributing to some of the barriers to these discussions. http://aih.saqepub.com/content/early/2012/07/11/1049909112452467.abstract
- CHEST, 2012;142(1):128-133. 'The effect of end-of-life discussions on perceived quality of care and health status among patients with COPD.' This study demonstrated that having end-of-life discussions is associated with higher ratings of patient satisfaction with and quality of medical care. The paucity of these conversations at even the most advanced stages of disease, however, suggests that significant additional effort will be needed to facilitate these discussions. More importantly, these results suggest that patients perceive high-quality care as care that includes discussions about the end of life and that physicians should not be reticent to have discussions about end-of-life care. http://journal.publications.chestnet.org/article.aspx?articleid=1206615
- GENERAL SURGERY NEWS, 2012;39(7). "Failure to pursue rescue" ups deaths from complications.' Elderly patients who sign a pre-operative "do not resuscitate" order are more likely to die from complications following surgery than matched controls because they turn down aggressive management of their complications... Investigators call this phenomenon a "failure to pursue rescue," and say surgeons, caregivers and policymakers need to be aware of the trend. "Failure to pursue rescue is a more accurate description of what happens here," said lead author John E. Scarborough, MD, assistant professor of trauma and surgical critical care, Duke University Medical Center. "It's not that patients die after massive attempts to prevent their deaths; it's that these patients or their families refuse to accept aggressive management of their complications." http://www.generalsurgerynews.com/ViewArticle.aspx?d=In %2Bthe%2BNews&d_id=69&i=July+2012&i_id=865&a_id=2
- JOURNAL OF CLINICAL ONCOLOGY | Online article 9
 July 2012 'Advance care planning in patients with
 cancer referred to a Phase I clinical trials program: The
 MD Anderson Cancer Center Experience.' Although most
 patients [i.e., study participants] ... remained optimistic,
 many had discussed a living will, medical power of attorney,
 and/or DNR order with their physician, family, and/or attorney. A significant minority had not addressed this issue with
 anyone, and many refused to take a survey on the topic.
 http://jco.ascopubs.org/content/early/2012/07/09/JCO.2011.
 38.0758.abstract

Interpretation for discussions about end-oflife issues: Results from a national survey of health care interpreters

JOURNAL OF PALLIA-TIVE MEDICINE | Online article - 12 July 2012 -The majority of interpreters have experience with end-of-life discussions but, independent of interpreter training and experience, only half report that these discussions usually go well. Interpreters want and may benefit from targeted educational interventions that could improve the quality of care for vulnerable patients and families in these difficult situations. http://online.liebertpub.co m/doi/abs/10.1089/jpm.2 012.0032

Therapeutic alliance

Factors important to patients' quality of life at the end of life

ARCHIVES OF INTERNAL MEDICINE | Online article – 9 July 2012 – Few data exist on what predicts better QOL [quality of life] at the end of life (EOL) for advanced cancer patients. The aim of this study was to derive parsimonious models of the set of factors that have the greatest influence on QOL at the EOL. On the basis of the authors' conceptual model of determinants of EOL outcomes, they posited that in addition to the negative effects of intensive life-prolonging care, modifiable psychosocial factors would be of paramount importance. Specifically. the authors hypothesized that the therapeutic alliance between patients and their physicians, patients' and caregivers' mental health, and support of patients' spiritual needs would be the most significant modifiable contributors to higher QOL and EOL. http://archinte.jamanetwork.com/article.aspx ?articleid=1212631

Shifting hospital-hospice boundaries: Historical perspective on the institutional care of the dying

AMERICAN JOURNAL OF HOSPICE & PALLIA-TIVE MEDICINE | Online article - 9 July 2012 -Social forces have continually framed how hospitals perceive their role in care of the dying. Hospitals were originally conceived as places of hospitality and spiritual care, but by the 18th century illness was an opponent, conquered through science. Medicalization transformed hospitals to places of physical cure and scientific prowess. Death was an institutional liability. Equipped with new technologies, increased public demand, and the establishment of Medicare in 1965, modern hospitals became the most likely place for Americans to die - increasing after the 1940s and spiking in the 1990s. Medicare's 1983 hospice benefit began to reverse this trend. Palliative care has more recently proliferated, suggesting an institutional shift of alignment with traditional functions of care toward those facing death.

http://ajh.sagepub.com/content/early/2012/06/27/1049909112452336.abstract

Invited commentary:

ARCHIVES OF INTERNAL MEDICINE | Online article – 9 July 2012 – Selecting predictors from a large set of measures is fraught with difficulties, not the least of which is whether results capitalize on chance and the low likelihood for replications in independent samples. Future work should be broadly inclusive of the diversity of this country as well as those whose first language is not English. http://archinte.jamanetwork.com/article.aspx?articleid=1212635

Of related interest:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article 12 July 2012 'Dying is a transition.' The authors' data ... suggest that patients undergo transition into another state of consciousness beyond anxiety, ego, and pain. Transition appears to have three stages. Anxiety, struggle, denial/acceptance, family processes, and maturation (i.e., finding meaning and dignity, coping with trauma) may depend on the transitional process and also hinder or facilitate this transitional process. http://ajh.sagepub.com/content/early/2012/07/11/1049909112451868.abstract
- BMJ SUPPORTIVE & PALLIATIVE CARE | Online article 11 July 2012 'Spiritual care: How to do it.' [Study] Participants identified spiritual care as both a specialised care domain and as a philosophy of care that informs and is embedded within physical and psychosocial care. Hearing, sight, speech, touch and presence were identified as the means by which healthcare professionals impacted patients' spiritual well-being regardless of clinician's awareness or intent. An empirical framework is presented providing clinicians with a pragmatic way of incorporating spiritual care into clinical practice. http://spcare.bmj.com/content/early/2012/07/09/bmjspcare-2011-000191.abstract

Chemotherapy at the end of life: Up until when?

CLINICAL & TRANSLATIONAL ONCOLOGY | Online article – 7 July 2012 – Even when it is known that the majority of cancer patients become resistant to CT [chemotherapy] at the end of their lives, it is often given to patients of all ages. The request for palliative care is rare and often late. http://www.springerlink.com/content/k50165138242r7m1/

Noted in Media Watch. 11 June 2012:

ANNALS OF ONCOLOGY, 2012;23(Suppl3):29-32. 'Palliative communications: Addressing chemotherapy in patients with advanced cancer.' Patients with advanced cancers often endure chemotherapy late in their disease course leading to unnecessary adverse effects, loss of quality of life, and delay in hospice referral. http://annonc.oxfordjournals.org/content/23/suppl 3/29.abstract

Conceptualizing compassion as recognizing, relating and (re)acting: A qualitative study of compassionate communication at hospice

COMMUNICATION MONOGRAPHS, 2012;79(3):292-315. This study explores the communication of compassion at work, providing an in-depth understanding of one of the most quickly growing healthcare contexts and offering a new conceptualization of compassion. The analysis is framed with emotional labor, burnout, and compassion literature, and shows how communicating compassion emerged as a central theme. The heart of the paper provides a rich description of hospice workers as they engaged in the compassionate communication activities of recognizing, relating, and (re)acting. The study extends past research on compassion, highlighting its holistic nature and providing a model that demonstrates its core communicative action. In doing so, it opens the door for future research and suggests practical implications for practicing compassion at work. http://www.tandfonline.com/doi/abs/10.1080/03637751.2012.697630

Palliative care challenged by [U.S.] physician shortage

HEALTH LEADERS | Online report – 13 July 2012 – In the past decade, medical schools have significantly increased their emphasis on palliative care education, but there is a shortage of palliative care physicians. 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. According to the December 2010 study¹ ... the current shortage of palliative ...and, "We need more trained people in palliative care, particularly at the physician end of the spectrum," says Timothy E. Quill, MD, director of the center of ethics, humanities, and palliative care at the Rochester (N.Y.) Medical Center. "We don't have enough people to go to places where there is a need. We have been working hard nationally to find funding to train people. It's an uphill battle. http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage

 'Estimate of current hospice and palliative medicine physician workforce shortage,' *Journal of Pain & Symptom Management*, 2012;40(6):899-911 (noted in Media Watch, 13 December 2010). http://www.jpsmjournal.com/article/S0885-3924(10)00602-0/abstract

Do models of care designed for terminally ill 'home alone' people improve their end-of-life experience? A patient perspective

HEALTH SOCIAL CARE IN THE COMMUNITY | Online article – 14 July 2012 – This article describes the experiences of terminally ill 'home alone' people using one of two models of care aimed at maintaining participants' need for independent living, focusing on the effect of these two models of care on their physical, social and emotional needs. The care-aide model of care resulted in benefits such as easing the burden of everyday living; supporting well-being; enhancing quality of life and preserving a sense of dignity; and reducing loneliness and isolation. The personal alarm model of care imparted a sense of security; provided peace of mind; and helped to deal with feelings of isolation. Participants in both groups felt that they could remain at home longer. By providing a safer, more secure environment through the use of a personal alarm or additional care-aide hours, patients were able to continue their activities of daily living, could build a sense of 'normality' into their lives, and they could live independently through support and dignity. https://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2012.01074.x/abstract

Of related interest:

JOURNAL OF TELEMEDICINE & TELECARE | Online article – 12 July 2012 – 'Use of home telehealth in palliative cancer care.' Overall the patients, family caregivers and tele-nurses [i.e., study participants] felt that home tele-health enabled family caregiving, citing increased access to care, and patient and family caregiver reassurance. Pain management was the most common reason for initiating contact with the nurse, followed by emotional support. Concerns included lack of integration of services, inappropriate timing of the intervention and technical problems. http://jtt.rsmjournals.com/content/early/2012/07/10/jtt.2012.111201.abstract

Posttraumatic stress disorder after bereavement: Early psychological sequelae of losing a close relative due to terminal cancer

JOURNAL OF LOSS & TRAUMA: INTERNATIONAL PERSPECTIVES ON STRESS & COPING, 2012;17(6):508-521. Very few studies have investigated posttraumatic stress disorder (PTSD) as a consequence of bereavement from terminal illness. Therefore, knowledge on the traumatizing effects of bereavement and risk factors for traumatization from bereavement is rather sparse. This study investigated prevalence and predictors of PTSD in a group of people who had recently lost a close relative due to incurable cancer. One month after the loss, 29.5% of the subjects had clinical PTSD and an additional 26.2% reached a sub-clinical PTSD level. Negative affectivity, social support, and locus of control in relation to the loss predicted 57% of the variance in PTSD severity. http://www.tandfonline.com/doi/abs/10.1080/15325024.2012.665304

Professional issues

Reporting of funding sources and conflict of interest in the supportive and palliative oncology literature

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 9 July 2012 – [In this study] three hundred forty-four of 848 (41%) and 504 (59%) articles were from 2004 and 2009, respectively. Five hundred two of 848 (59%) studies reported no funding sources, whereas 216 (26%), 70 (8%), 34 (4%), and 26 (3%) reported one, two, three, and four or more sources, respectively. Key funding sources included governmental agencies, philanthropic foundations, university departments, and industry. Conflict of interest was not reported in 436 of 848 (51%) studies, and only 94 of 848 (11%) explicitly stated no conflict of interest. Other than extramural funding, conflict of interest reporting of any kind was extremely rare (mostly less than 1%). Conflict of interest reporting increased between 2004 and 2009. Both funding and conflict of interest reporting were associated with prospective studies, larger sample sizes, non-therapeutic studies, North American authors, and publication in palliative care/oncology journals. A majority of supportive/palliative oncology studies did not report funding sources and conflict of interest, raising the need for standardization. http://www.jpsmjournal.com/article/S0885-3924(12)00158-3/abstract

Palliative care in Croatia on the threshold of entering the European Union: Medical-legal and medical-ethical review

MEDICINA FLUMINENSIS, 2012;48(2):131-141. This paper analyzes the current situation in the Croatian health care system with special emphasis on the organization of palliative care. Recommendations from the European Association for Palliative Care proves the flaw in the Croatian system of palliative care, with special emphasis on the need to prompt establishment of a national health policy of palliative care. The first step on this path should be the establishment of institutions for palliative care. Palliative care is an integral part of the health system and an inseparable element of citizens' rights to health care and is therefore, the responsibility of the government of each member state to guarantee palliative care and make it accessible to those in need of it. http://hrcak.srce.hr/index.php?show=clanak&id_clanak_jezik=125308

The conceptual framework of palliative care applied to advanced Parkinson's disease

PARKINSONISM & RELATED DISORDERS | Online article – 9 July 2012 – Recently our understanding of advanced Parkinson's disease has led to the question of whether Palliative care approaches would be complementary to the care of these patients. The experience of Parkinson's patients mirrors that of advanced cancer patients in many important ways. The predominant symptoms of these patients are often non-neurological. Pain has become recognized as a common symptom that can be difficult to treat. Given the success of early Palliative care involvement in cancer populations, it should not be surprising that our specialized Palliative Parkinson's Clinic at the Toronto Western Hospital has become indispensable for our patients. http://www.prd-journal.com/article/S1353-8020(12)00250-7/abstract

Noted in Media Watch, 13 February 2012:

 NATIONAL COUNCIL FOR PALLIA-TIVE CARE (U.K.) | Online posting – 6 February 2012 – 'New guide to manage last days of life in Parkinson's disease.'

http://www.ncpc.org.uk/news/83

Noted in Media Watch, 11 April 2011:

JOURNAL OF MULTIDISCIPLINARY
HEALTHCARE, 2011;2011(4):33-38.
 'Parkinson's disease permanent care
unit: Managing the chronic-palliative
interface.' A specially designed and
staffed care unit for Parkinsonism patients seems to fill a need for patients
and caregivers, as well as for social and
health care authorities.
http://www.dovepress.com/parkinsonrsq
uos-disease-permanent-care-unitmanaging-the-chronic-palli-peerreviewed-article-JMDH

Patient perceptions in oncology

How Tolstoy and Solzhenitsyn define life and death in cancer

AMERICAN JOURNAL OF HOSPICE & PALLIA-TIVE MEDICINE | Online article - 11 July 2012 -The authors compare two literary patients' perceptions of cancer and death (Solzhenitsyn's Cancer Ward and Tolstoy's The Death of Ivan *llyich*), with a contemporary patient perception. The patient interview revealed naive cancer perceptions: every treatment option should be tried. In Solzhenitsyn's novel, the main character finds a goal in love; Tolstoy conceptualizes death as a solution for patients' moral issues. Tolstoy's novel shows death as an honest prospect. Solzhenitsyn's novel shows the opposite: the prospect of love and life helps the protagonist patient psychologically through his disease. The patient interview revealed no discussion of death at all. http://ajh.sagepub.com/content/early/2012/07/10/ 1049909112452626.abstract

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- CHEST, 2012;142(1):218-224. 'Aid in dying: Guidance for an emerging end-of-life practice.' Aid in dying is the practice of a physician writing a prescription for medication for a mentally competent, terminally ill patient that the patient may ingest to bring about a peaceful death. The practice is increasingly accepted by physicians, and it is likely that a growing population of patients will inquire about it. Data from states that give terminally ill patients a statutory right to aid in dying demonstrate that the practice improves end-of-life care. Therefore, it is timely for clinical practice guidelines to emerge to offer guidance to physicians willing to provide aid in dying. http://journal.publications.chestnet.org/article.aspx?articleid=1206626#Abstract
- EUROPEAN JOURNAL OF HEALTH LAW, 2012;19(4):355-365. 'End-of-life healthcare decisions, ethics and law: The debate in Spain.' The debate on euthanasia ... has been ongoing from the beginning of 20th century... The debate increased significantly after the Ramon Sampedro case (1995-1998), and was fuelled with new, although very different cases, such as those of Leganés (2005-2008), Jorge Leon (2006) or Inmaculada Echevarría (2006-2007). As a consequence of these cases in 2008 the Regional Government of Andalusia^{1,2} started a legal process to pass a law regulating end-of-life decisions, excluding euthanasia and assisted-suicide ... finally enacted in 2010. Two other ... regions (Navarra and Aragón) passed similar laws. The central government also initiated a legal process to approve a national law, excluding euthanasia and assisted-suicide. http://www.ingentaconnect.com/content/mnp/ejhl/2012/00000019/00000004/art00003

- 'Family berates doctor for refusing to follow law and remove feeding tube from woman in a coma,'
 BMJ Supportive & Palliative Care, 15 September 2011 (noted in Media Watch, 18 September 2011).
 http://www.bmj.com/content/343/bmj.d5868.extract
- 'Terminally ill could get right to die faster under law approved by Spanish government,' Associated Press, 13 May 2011 (noted in Media Watch, 16 May 2011). http://www.washingtonpost.com/world/terminally-ill-could-get-right-to-die-faster-under-law-approved-by-spanish-government/2011/05/13/AF9N3g2G story.html
- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article 9 July 2012 'Organization position statements and the stance of "studied neutrality" on euthanasia in palliative care.' In recent years, palliative care and related organizations have increasingly adopted a stance of "studied neutrality" on the question of whether euthanasia should be legalized as a bona fide medical regimen in palliative care contexts. This stance, however, has attracted criticism from both opponents and proponents of euthanasia. Pro-euthanasia activists see the stance as an official position of indecision that is fundamentally disrespectful of a patient's right to "choose death" when life has become unbearable. Some palliative care constituents, in turn, are opposed to the stance, contending that it reflects an attitude of "going soft" on euthanasia and as weakening the political resistance that has hitherto been successful in preventing euthanasia from becoming more widely legalized. In this article, attention is given to examining critically the notion and possible unintended consequences of adopting a stance of studied neutrality on euthanasia in palliative care. It is argued that although palliative care and related organizations have an obvious stake in the outcome of the euthanasia debate, it is neither unreasonable nor inconsistent for such organizations to be unwilling to take a definitive stance on the issue. It is further contended that, given the long-standing tenets of palliative care, palliative care organizations have both a right and a responsibility to defend the integrity of the principles and practice of palliative care and to resist demands for euthanasia to be positioned either as an integral part or logical extension of palliative care. http://www.ipsmiournal.com/article/S0885-3924(12)00168-6/abstract

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

Older adults' preferences for independent or delegated end-of-life medical decision making

JOURNAL OF AGING & HEALTH, 2011;23(1):135-157. This study assesses the proportions of participants who prefer independent or delegated medical decision making at the end of life and examines the relationships of personal beliefs, affiliative beliefs, and end-of-life planning behaviors to decision-making preference. Four fifths of participants wanted to make decisions independently. Valuing independence, being less avoidant of thoughts of death, and valuing quality of life over length of life had strong associations with a preference for independent decision making. Those concerned about burdening a caregiver wanted to make independent decisions. Persons who both executed a living will and appointed a durable power of attorney for health care preferred independent decision making. http://jah.sagepub.com/content/23/1/135.abstract

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