Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in hospice, palliative care and end-of-life issues – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Is it recorded in the notes?: Scroll down to <u>Specialist Publications</u> and 'Documentation of end-of-life care and preferred place to die discussions in the final weeks of life' (p.6), published online at *BMC Palliative Care*.

<u>Canada</u>

Better service, lower cost

ONTARIO | *Ottawa Citizen* – 5 November 2011 – One of the curious contradictions of Ontario health care is that government can afford the highest cost services but it doesn't have the money for services that are better suited to the public's needs and more cost effective. There probably isn't a better example than hospice palliative care. Hospices provide a homelike atmosphere for people in their last weeks of life. That's good for people, but it's good for the health care budget, too. An acute care hospital bed costs about \$1,000 a day. A hospice bed costs \$400. This is a situation that begs for a sensible solution and Ottawa is on the verge of taking a small step in the right direction, with the Champlain LHIN [Local Health Integrated Network] expected to approve the creation of 10 new hospice beds by the end of the year. It is part of a larger 30-bed program that in itself only goes part way to meeting Ottawa's demand for hospice beds, which is estimated at 66 to 80 beds. Right now, the May Court hospice is the only stand-alone residential hospice in Ottawa, with nine beds. A little less than half of the cost of the May Court hospice is provided by the provincial government, and that's after an injection of new funding during the recent election campaign. http://www.ottawacitizen.com/health/Better+service+lower+cost/5661616/story.html

Aging prison population facing new challenges

CTV NEWS | Online report – 1 November 2011 – The federal prison ombudsman warns that Canada's inmates are growing old in institutions ill-equipped to meet their changing needs.¹ Nearly one in five inmates is 50 or older, a reflection of an aging society and the fact more prisoners are entering custody later in their adult life than ever before. The population of greying offenders has increased by 50% over the past decade, says correctional investigator Howard Sapers. Penitentiaries were not designed to assist prisoners with physical disabilities or those in need of palliative care. <u>http://www.ctv.ca/CTVNews/Politics/20111101/aging-prisoners-canada-population-111101/</u>

1. 38th Annual Report (2010-2011) of the Office of the Correctional Investigator, June 2011. http://www.oci-bec.gc.ca/rpt/annrpt/20102011-eng.aspx

<u>U.S.A.</u>

Daughter's complaint puts focus on Medicare payment to for-profit hospice

FLORIDA | *Miami Herald* – 2 November 2011 – The irony is that for years, healthcare policy experts have viewed hospice as the cheaper, more humane alternative to patients spending their last weeks in intensive care units. That has also represented a business opportunity. In the past five years, hospice services have been the fastest-growing Medicare service – climbing an average of 10% per year, a Medicare spokeswoman says. Hospice costs in nursing homes have been soaring even faster during that time – up nearly 70% – often for care that wasn't provided or wasn't necessary, federal investigators say. Elliott Fisher, a Dartmouth professor of medicine who studies healthcare costs and quality, says soaring hospice costs exemplify much of what's wrong with American healthcare – starting with costs in Miami that are twice as much as per senior as they are in Minneapolis. http://www.miamiherald.com/2011/10/09/2446620/daughters-complaint-puts-focus.html

From Media Watch dated 1 August 2011:

 U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES | Office of Inspector General – 18 July 2011 – 'Medicare hospices that focus on nursing facility residents.' Medicare spending on hospice care for nursing facility residents has grown nearly 70% since 2005. Hundreds of hospices had a high percentage of their beneficiaries residing in nursing facilities, and most of these hospices were for-profit. <u>http://oig.hhs.gov/oei/reports/oei-02-10-00070.asp</u>

From Media Watch dated 18 April 2011:

- NEW YORK TIMES | Online article 11 April 2011 'Hospital care at life's end: A disparity.' At the end of life, people with chronic diseases like cancer get more aggressive medical care in the New York area than anyplace else in the country, continuing a trend going back decades, according to a report released ... by researchers at Dartmouth College.¹ The study ... found that 46% of chronically ill patients in the Manhattan hospital region, which also covers most of Brooklyn and Staten Island, were being treated at hospitals when they died, as opposed to dying at home or in hospices or nursing homes. http://www.nytimes.com/2011/04/12/nyregion/12hospitals.html
 - 1. Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness, A report of the Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, April 2011. http://www.dartmouthatlas.org/downloads/reports/EOL Trend Report 0411.pdf

Does choosing hospice mean giving up?

MONTANA | Independent Record (Helena) – 2 November 2011 – There is a story going around that when a person chooses hospice care at the end of life, this choice represents giving up. In a society that values eternal youthfulness, it is hardly surprising that there is anxiousness about how to approach end-of-life concerns. For many, anything short of waging a heroic, all-out battle against death represents giving up and signifies a failure on the part of the patient and his or her family and caregivers. While this is quite understandable, given our society's focus on masking the process of aging and hiding completely the process of dying, it is also quite misguided and unhelpful. http://helenair.com/news/opinion/does-choosing-hospice-mean-giving-up/article_9107977a-0518-11e1-8069-001cc4c002e0.html

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. <u>http://www.pcn-e.com/community/pg/file/owner/MediaWatch</u>

End-of-life care: An Oregon innovation helps people avoid unwanted interventions

OREGON | *Oregonian* (Portland) – 2 November 2011 – An end-of-life care innovation developed in Oregon is proving a reliable way for people to avoid unwanted medical interventions. Undesired treatments such as breathing machines, CPR and dialysis were withheld as requested 94% of the time, in a study of 870 nursing home residents in Oregon, West Virginia and Wisconsin. People spelled out their wishes with a document called Physician Orders for Life-Sustaining Treatment, or POLST. <u>http://www.oregonlive.com/health/index.ssf/2011/11/end-of-life_care_an_oregon_inn.html</u>

1. 'The consistency between treatments provided to nursing facility residents and orders on the Physician Orders for Life-Sustaining Treatment Form,' *Journal of the American Geriatric Society*, published online 22 November 2011 (noted in Media Watch dated 31 October 2011).

Duke [University] researchers find doctors can learn empathy

NORTH CAROLINA | *Herald-Sun* (Durham) - 1 November 2011 - Doctors care. Most care deeply about their patients. "But patients don't always know that," said James Tulsky, director of the Duke University Center for Palliative Care. "That's because when patients express distress or concern to their doctors, the physicians are unlikely to respond appropriately to that concern." The doctors do have empathy, Tulsky said, but they generally don't have the means to express it. But they can learn those means, according to researchers at Duke. In a study appearing in the Annals of Internal Medicine, Tulsky and several colleagues describe a new interactive computer training tool that helps oncologists give more empathic responses to patients.¹ According to the study, that results in patients reporting areater trust in their doctors, which is a key component of care that enhances quality of life. The tutorial includes an hour-long lecture on basic communication skills, including how to recognize and respond to opportunities in conversations when patients share a negative emotion, and how to share

information about a patient's prognosis. When a patient is worried, for instance, about an upcoming test, "many physicians might just say, 'well, don't worry," Tulsky said. "Frankly, that's not very helpful." The program teaches the doctors to say, instead, "it's normal to be a little scared," Tulsky said. "We're going to go through this together,' which is a lot more supportive." <u>http://www.heraldsun.com/view/full_story/16</u> <u>236464/article-Duke-researchers-finddoctors-can-learn-empathy--</u>?instance=homefifthleft

Quotable Quotes

One of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore ... most of us would rather forget our own vulnerability ... Listening is hard but it is also a fundamental moral act. Arthur Frank, The Wounded Story Teller: Body, Illness and Ethics (University of Chicago Press, 1995)

 'Enhancing communication between oncologists and patients with a computer-based training program,' Annals of Internal Medicine, 2011;155(9):593-601. http://www.annals.org/content/155/9/593.abstract

Assisted (or facilitated) death

Representative sample of recent news media coverage:

 GEORGIA | Atlanta Journal Constitution – 2 November 2011 – 'Georgia Supreme Court to review ban on assisted suicide.' The state Supreme Court just sent word that it will review a challenge to the state's ban on assisted suicide, arising from the indictment of officials connected with Final Exit Network of New Jersey. <u>http://blogs.ajc.com/political-insider-jim-galloway/2011/11/02/georgiasupreme-court-to-review-state-ban-on-assisted-suicide/</u>

International

Study highlights need for 'living will' legislation

IRELAND | Irish Times (Dublin) – 1

November 2011 – The need for legislation ... to recognise and enforce advance-care directives, or "living wills," has been highlighted by a new study. Dr. Alice Coffey, lecturer in the School of Nursing & Midwifery at University College Cork [UCC], said while advance-care directives were legal in the U.S. and other jurisdictions, there was no legislation providing for their enforcement in Ireland, where the issue was under discussion. Prof. William Molloy, who joined UCC as chairman of gerontology and rehabilitation in 2010, has a long history of research experience in the area of advance-

11 hospitals to care for the terminally ill

healthcare directives in the U.S. and Canada.<u>http://www.irishtimes.com/newspap</u> er/health/2011/1101/1224306841017.html

Specialist Publications

Of particular interest:

'Responding to surrogate requests that seem inconsistent with a patient's living will' (p.9), published in the *Journal of Pain & Symptom Management.*

KENYA | *Daily National* (Nairobi) – 1 November 2011 – Eleven public hospitals will start offering special care for terminally ill Kenyans with cancer, stroke and diabetes. The three conditions have joined AIDS as the major killers in the country. Called palliative care, and aimed at relieving a patient from pain, make them feel better and supported, the programme will be rolled out in provincial and district hospitals in areas with high cases of cancer, diabetes and heart-related conditions. <u>http://www.nation.co.ke/News/11+hospitals+to+care+for+the+terminally+ill+/-</u>/1056/1265140/-/moav22/-/

Media Wa	atch (Dnli	ne

The weekly report can be accessed at several websites, among them:

Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx

Ontario | HPC Consultation Services: http://www.hpcconnection.ca/newsletter/inthenews.html

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

U.S.A.

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

International

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

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

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/news.htm

Assisted (or facilitated) death

Representative sample of recent news media coverage:

U.K. | BBC News – 4 November 2011 – 'Philip Nitschke lectures criticised by Debbie Purdy.' A woman who has campaigned for the law on assisted dying to be made clearer has said an Australian right-to-die campaigner's lectures are "dangerous." Debbie Purdy from Bradford, who has multiple sclerosis, says Dr. Philip Nitschke merely explains how people can kill themselves. Dr. Nitschke, dubbed "Dr. Death", argues that people need to have the facts. Ms. Purdy said it was important people were aware of the alternatives to suicide. <u>http://www.bbc.co.uk/news/uk-england-york-north-yorkshire-15588231</u>

From Media Watch dated 3 August 2009:

 U.K. | Guardian – 31 July 2009 – 'Right-to-die law to be clarified.' The Director of Public Prosecutions (for England & Wales) is to issue urgent guidance to clarify the law on assisted suicide after Debbie Purdy, who has multiple sclerosis, won a historic judgement from the House of Lords. http://www.guardian.co.uk/uk/2009/jul/31/assisted-suicide-law-debbie-purdy

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

Should the "slow code" be resuscitated?

AMERICAN JOURNAL OF BIOETHICS, 2011;11(11):8-12. Most bioethicists and professional medical societies condemn the practice of "slow codes." The American College of Physicians ethics manual states, "Because it is deceptive, physicians or nurses should not perform half-hearted resuscitation efforts ('slow codes')." A leading textbook calls slow codes "dishonest, crass dissimulation, and unethical." A medical sociologist describes them as "deplorable, dishonest and inconsistent with established ethical principles." Nevertheless, the authors believe that slow codes may be appropriate and ethically defensible in situations in which cardiopulmonary resuscitation (CPR) is likely to be ineffective, the family decision makers understand and accept that death is inevitable, and those family members cannot bring themselves to consent or even assent to a do-not-resuscitate (DNR) order. In such cases, they argue, physicians may best serve both the patient and the family by having a carefully ambiguous discussion about end-of-life options and then providing resuscitation efforts that are less vigorous or prolonged than usual. http://www.tandfonline.com/doi/abs/10.1080/15265161.2011.603793

N.B. This issue of the *American Journal of Bioethics* includes several articles on the issue of "slow codes." Contents page: <u>http://www.tandfonline.com/toc/uajb20/current</u>

Paediatric palliative medicine in the U.K.: Past, present, future

ARCHIVES OF DISEASE IN CHILDHOOD | Online report – 28 October 2011 – Like any new specialty, paediatric palliative medicine is facing challenges as it establishes itself. While many of the required core skills have their roots in adult palliative medicine, its practitioners come from a range of paediatric backgrounds that include oncology, community paediatrics, neurodisability and acute pain. Such heterogeneity has been invaluable in bringing together the diverse set of skills and competencies needed by children and families facing life-limiting illness. At the same time, it brings its own challenges in establishing consistent standards of clinical expertise, education and research – essential if children are to have access to the same degree of medical expertise in palliative care already available to most adults. This article traces the origins of palliative care in children, examines its current strengths and challenges, and considers how those might shape its future. http://adc.bmj.com/content/early/2011/10/28/archdischild-2011-300432.abstract

From Media Watch dated 21 March 2011:

 PEDIATRIC BLOOD & CANCER | Online article – 17 March 2011 – 'Pediatric palliative care provision around the world: A systematic review.' The systematic review identified 117 peerreviewed and non-peer reviewed resources. Based on this information, each country was assigned a level of provision; 65.6% of countries had no known activities, 18.8% had capacity building activities, 9.9% had localized provision, and 5.7% had provision that was reaching mainstream providers. <u>http://onlinelibrary.wiley.com/doi/10.1002/pbc.23100/abstract</u>

Early identification of and proactive palliative care for patients in general practice, incentive and methods of a randomized controlled trial

BMC FAMILY PRACTICE | Online article – 3 November 2011 – According to the World Health Organization, patients who can benefit from palliative care should be identified earlier to enable proactive palliative care. Up to now, this is not common practice and has hardly been addressed in scientific literature. Still, palliative care is limited to the terminal phase and restricted to patients with cancer. Therefore, the authors trained general practitioners in identifying palliative patients in an earlier phase of their disease trajectory and in delivering structured proactive palliative care. The aim of their study [i.e., a two-armed randomized controlled trial] is to determine if this training, in combination with consulting an expert in palliative care regarding each palliative patient's tailored care plan, can improve different aspects of the quality of the remaining life of patients with severe chronic diseases such as chronic obstructive pulmonary disease. congestive heart failure and cancer. http://www.biomedcentral.com/content/pdf/1 471-2296-12-123.pdf

Personal reflection

Come home sweetheart: A fight for my father's last wish

JOURNAL OF PALLIATIVE MEDICINE, 2011; 14(11):1266-1267. This trying experience for my father and my family taught us many things about confronting a dear one's death: 1) Communication must occur and be continuous between the family members and the providers (you can never trust that the conversation is over); 2) Death is always difficult, but it is much more tolerable when your provider is listening to you or your loved one and trying to provide as much pain relief and comfort as possible: and. 3) As much as we try to control how we want to die, it's almost never exactly like we imagine. All we can hope for is that our family and medical providers are with us and respect our last wish. http://www.liebertonline.com/doi/full/10.1089/jpm. 2011.0152

Is it recorded in the notes?

Documentation of end-of-life care and preferred place to die discussions in the final weeks of life

BMC PALLIATIVE CARE | Online article – 4 November 2011 – While there was evidence that discussions relating to end of life care and preferred place to die had taken place in around half of the audited case notes, there appeared to be a lack of a systematic approach to the recording of discussions with patients or carers about these kind of issues. Health care staff subsequently highlighted that initiating discussions about end of life care and preferences in relation to place of death was challenging and that the recording and tracking of such preferences was problematic. Further work is required to establish how information may be adequately recorded, revised and transferred across services to ensure that patients' preferences in relation to end of life care and place of death are, as far as possible, achieved. <u>http://www.biomedcentral.com/content/pdf/1472-684x-10-18.pdf</u>

Cont.

Of related interest:

 AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 3 November 2011 – 'Symptom prevalence in the last days of life in Germany: The role of place of death.' The authors sought to assess the symptom prevalence of chronically ill people in Germany and how this prevalence differs depending on the place of death. http://ajh.sagepub.com/content/early/2011/11/03/1049909111425228.abstract

Palliative care in amyotrophic lateral sclerosis: A review of current international guidelines and initiatives

BMJ SUPPORTIVE & PALLIATIVE CARE, 2011;1(3):343-348. Despite an international consensus that ALS [amyotrophic lateral sclerosis] management should adopt a multidisciplinary approach, integration of palliative care into ALS management varies considerably across health care systems. Late referral to palliative services in ALS is not uncommon and may impact negatively on the quality of life of ALS patients and their caregivers. However, common themes and principles of engagement can be identified across different jurisdictions, and measurement systems have been established that can assess the impact of palliative care intervention. http://spcare.bmj.com/content/1/3/343.abstract

From Media Watch dated 10 October 2011:

MUSCLE & NERVE | Online article – Accessed 9 October 2011 – 'Amyotrophic lateral sclerosis [ALS] and palliative care: Where we are, and the road ahead.' Expert multidisciplinary care may improve both quality and length of life of patients with ALS. However, while advances have been made in the treatment of some symptoms, others, including pain management, remain poorly studied. Involvement of palliative care specialists as part of the ALS multidisciplinary team is recommended, as we continue to work toward improving the quality of life for patients and their families. <u>http://onlinelibrary.wiley.com/doi/10.1002/mus.22305/abstract</u>

Improving end-of-life care for people with dementia

BRITISH JOURNAL OF PSYCHIATRY, 2011;199(5):357-359. One in three adults over the age of 60 years will die with dementia. Most will have complex physical and psychological needs. Despite this, many people with dementia receive poor-quality end-of-life care. Recent government strategies have highlighted the importance of improved coordination and provision of services. http://bjp.rcpsych.org/content/199/5/357.short

 BRITISH JOURNAL OF PSYCHIATRY, 2011;199(5):417-422. 'Dying well with dementia: Qualitative examination of end-of-life care.' The data highlighted the challenge and imperative of 'dementia-proofing' end-of-life care for people with dementia. This requires using dementia expertise to meet physical care needs, going beyond task-focused care and prioritising planning and communication with families. <u>http://bjp.rcpsych.org/content/199/5/417.abstract</u>



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

Formal supports for informal caregivers

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 3 November 2011 – Canada is overly dependent on informal caregivers to bridge the gaps in care for its aging population, yet under invests in public policies and programs to support them in that role, according to an Institute for Research on Public Policy study¹ that calls for the federal government to establish a comprehensive long-term home care system. In Canada, "it is assumed that a large amount of family care is available; family caregivers do not benefit from any direct public support. The health care system acts as a safety valve when family care is not available or not sufficient. And, at the point of entry into the health care system, policy typically is oriented toward the older adult, not the needs of caregivers or the caregiving unit," Canadian Association on Gerontology president Neena Chappell explains in the study. <u>http://www.cmaj.ca/site/earlyreleases/4theRecord.xhtml</u>

1. Population Aging and the Evolving Care Needs of Older Canadians: An Overview of the Policy Challenges, Institute for Research on Public Policy, Montreal, 19 October 2011. http://www.irpp.org/pubs/IRPPstudy/IRPP_Study_no21.pdf

From Media Watch dated 31 October 2011:

 ONTARIO | Ottawa Citizen – 25 October 2011 – 'Home care, not health care.' Providing the help that seniors need to stay in their own homes is universally acknowledged as a good idea. <u>http://www.ottawacitizen.com/life/Home+care+health+care/5600177/story.html</u>

Palliative care certification

Potential pitfalls of "specialized" primary care

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 3 November 2011 – Though Canada lacks formal accreditation and appraisal processes for general practitioners with special interests, it may be inching toward some measure of certification or national standards for determining when physicians have the competence to declare a focused practice. In fact, some jurisdictions have taken measures to ensure that patients aren't confused about their doctor's qualifications and that a family physician who performs a specialized service is just as capable in that area as a certified specialist.<u>http://www.cmaj.ca/site/earlyreleases/3nov11_poten_tial-pitfalls-of-specialized-primary-care.xhtml</u>

The evolution of palliative care nursing education

Extract from Canadian Medical Association Journal article

[The] College of Family Physicians of Canada is contemplating the creation of new standard of certification for focused practices that indicates whether a physician has additional skills in a particular area, such as geriatric or palliative care.

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2011;13(6):S8-S19. This article traces the trends, precedents, and leadership that have influenced the development of palliative care nursing education [and] emphasizes the importance of advanced practice and scholarly education to ensure high-quality and evidence-based care for individuals, families, and communities who face significant challenges and suffering related to serious, often chronic, illnesses and end-of-life issues.http://journals.lww.com/jhpn/Abstract/2011/11001/The Evolution of Palliative Care Nursing Education.3.aspx

Of related interest:

• NURSING RESEARCH & PRACTICE | Online article – Accessed 05 November 2011 – 'An examination of palliative or end-of-life care education in introductory nursing programs across Canada.' As compared to past surveys, this survey revealed more class time, practicum hours, and topics covered, with this content and experiences deliberately planned and placed in curriculums. Findings indicate nurse educators recognize the need for all nurses to be prepared to care for dying persons and their families. http://www.hindawi.com/journals/nrp/2011/907172/

Distress from voluntary refusal of food and fluids to hasten death: What is the role of continuous deep sedation?

JOURNAL OF MEDICAL ETHICS | Online article – 29 October 2011 – There is a growing trend to practise physician-assisted dying (death) (PAD) under the premise of providing quality palliative care in consensual and non-consensual life-ending situations. The WHO [World Health Organization] envisages palliative care as a comprehensive system of managing pain and distressing symptoms without intending to shorten the end-of-life (EOL) trajectory. In assisted dying, the EOL trajectory is shortened to relieve suffering. Bundling PAD with palliative care is precarious because PAD: 1) contravenes the Hippocratic principle of 'do not kill'; 2) transgresses cultural and religious values of some patients, families and healthcare professionals; and, 3) violates basic human rights. http://jme.bmj.com/content/early/2011/10/29/medethics-2011-100278

Responding to surrogate requests that seem inconsistent with a patient's living will

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2011;42(5):777-782. Clinicians may feel conflicted when a patient's legal decision maker is making decisions that seem inconsistent with a patient's living will. The authors provide evidence-based information to help clinicians consider whether a surrogate's inconsistent decisions are ethically appropriate. Surrogates are not flawless translators of their loved one's preferences; they are influenced by their own hopes and the current clinical context. Patients may be aware of this, are often concerned about burdening their loved ones, and often grant their surrogates leeway in interpreting their wishes. When appropriate, clinicians should respect surrogates' interpretations of patient values and take steps to decrease surrogate stress during the decision-making process. Finally, if clinicians are cognizant of their own values and preferences, they may recognize how these may affect their responses to certain clinical cases. http://jpsmjournal.com/article/S0885-3924(11)00427-1/abstract

Of related interest:

 JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online article – 31 October 2011 – 'Resident physician interactions with surrogate decision-makers: The resident experience.' Residents experienced significant emotional burden during interactions yet continued to value their relationships with surrogates. Despite their reservations about giving recommendations, residents adopted a variety of roles with surrogates as they gave support, information, and advice. Although residents reported little formal education about surrogate decision-making, they relied on passive role modeling and their own previous experiences to help surrogates make decisions. http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03728.x/abstract

A model for increasing palliative care in the intensive care unit: Enhancing interprofessional consultation rates and communication

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2011;42(5):676-679. Only a minority of patients who die in the medical intensive care unit (MICU) receive palliative care services. At the South Texas Veterans Health Care System Audie L. Murphy Hospital, only 5% of patients who died in the MICU from May to August 2010 received a palliative care consultation. Starting 1 October 2010 and ending 30 April 2011, the palliative care and MICU teams participated in daily "pre-rounds" to identify patients at risk for poor outcomes, who may benefit from a palliative care consultation. Palliative care consultation increased significantly from 5% to 59% for patients who died in the MICU during the intervention period. Additionally, palliative care consultation increased from 5% to 21% for all patients admitted to the MICU during the intervention period. http://jpsmjournal.com/article/S0885-3924(11)00411-8/abstract

N.B. This issue of the *Journal of Pain & Symptom Management* includes several articles on palliative care in the intensive care unit. Contents page: <u>http://jpsmjournal.com/home</u>

Personal reflection

A fight to the end

JOURNAL OF PALLIATIVE MEDICINE, 2011;14(11):1268-1269. ...when I hear physicians discussing terminally ill patients who want aggressive care, the comments are often rather cynical and naïve, and typically share two themes: the lack of "dignity" with aggressive care, and the reduction of any "quality of life" with aggressive care. Dignity and quality of life are individual, based upon personal beliefs and values ... what is undignified about wanting to live or to fight relentlessly? I also hear many of these same physicians lamenting "I certainly wouldn't want aggressive treatment if I was terminally ill," but the reality is, that until we walk in the proverbial shoes of our own disease and confront the absence of a tomorrow, we truly don't know what we would want or do, irrespective of what we espouse while vibrant and healthy. Physicians do not, and cannot, understand what dying patients experience – they don't understand the torment of regrets or the vulnerability of illness, nor can they be expected to unless they have personally experienced the lessons and losses of disease. But what they can do is be present, offer support, compassion, and empathy, and allow patients to die on their own time and in their own ways. http://www.liebertonline.com/doi/full/10.1089/jpm.2011.0166

Unmet needs and distress in people with inoperable lung cancer at the commencement of treatment

SUPPORTIVE CARE IN CANCER | Online article – 28 October 2011 – People with lung cancer have high levels of unmet needs especially regarding psychological/emotional or medical communication. People with lung cancer who are classified as distressed have more unmet needs. Of the 108 patients participating [in this cross-section survey], the top unmet need was "dealing with concerns about your family's fears and worries" (62%); with the next four also coming from the psychological/emotional domain ...but, on average, most needs related to medical communication. http://www.springerlink.com/content/k3451k883135gl46/

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online report 2 November 2011 'Does the legalisation of euthanasia affect palliative care?' A new report by the European Association for Palliative Care may challenge the notion that the legalisation of euthanasia negatively affects the growth of palliative care services.¹ The study, which was originally requested by the Commission on Assisted Dying, compared palliative care indicators in countries with legalised euthanasia (Belgium, The Netherlands, Switzerland and Luxembourg) and some without (Spain, Germany and France). This was supplemented by a review of the scientific literature on the subject. The report concluded that there were well-developed palliative care services in countries with legalised euthanasia and that there was no detectable influence of euthanasia legislation upon the development of palliative care. http://blogs.bmj.com/spcare/2011/11/02/does-the-legalisation-of-euthanasia-affect-palliative-care/?g=w spcare news tab
 - 1. Palliative Care Development in Countries with a Euthanasia Law, Report for the Commission on Dying, European Association for Palliative Care, October 2011. <u>http://www.commissiononassisteddying.co.uk/wp-content/uploads/2011/10/EAPC-Briefing-Paper-Palliative-Care-in-Countries-with-a-Euthanasia-Law.pdf</u>

Worth Repeating

American Medical Association Council on Ethical & Judicial Affairs

Medical futility in end-of-life care

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 1999;281(10):937-941. Use of lifesustaining or invasive interventions in patients in a persistent vegetative state or who are terminally ill may only prolong the dying process. What constitutes futile intervention remains a point of controversy in the medical literature and in clinical practice. In clinical practice, controversy arises when the patient or proxy and the physician have discrepant values or goals of care. Since definitions of futile care are value laden, universal consensus on futile care is unlikely to be achieved. Rather, the American Medical Association Council on Ethical & Judicial Affairs recommends a process-based approach to futility determinations. The process includes at least 4 steps aimed at deliberation and resolution including all involved parties, 2 steps aimed at securing alternatives in the case of irreconcilable differences, and a final step aimed at closure when all alternatives have been exhausted. The approach is placed in the context of the circumstances in which futility claims are made, the difficulties of defining medical futility, and a discussion of how best to implement a policy on futility. <u>http://jama.ama-assn.org/content/281/10/937.abstract</u>

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Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

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Something Missed or Overlooked?

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

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