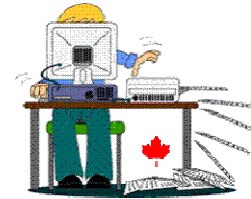


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Not only at the end of life: Scroll down to [Specialist Publications](#) and 'The unlikely patient and the most likely patient: A personal reflection on two patients and the lessons learned regarding physician communication in the field of palliative medicine' (p.8), published in the *American Journal of Hospice & Palliative Medicine*.

Canada

Family caregivers in distress without home-care help, Health Council finds

ONTARIO | *Toronto Star* – 16 April 2012 – A Health Council of Canada report¹ on the state of home-care services for senior citizens nationwide describes how many people caring for their loved ones with complex and multiple health needs at home are in distress because they are not receiving enough support from the public system. "The report from the independent agency funded by Health Canada commissioned analyses of data gleaned from assessments by home care professionals in five regions – including 2010 data from Ontario – on ongoing longer-term home care clients aged 65 and up. The analyses showed in Ontario family caregivers devote an average of 18 hours per week to caring for their loved one, compared to seven hours per week from home care services. Family caregivers increase their weekly hours along with the needs of their loved ones – with family caregivers in Ontario devoting an average of nearly 30 hours/week caring for those with physical disability, cognitive impairment, challenging behaviour, wandering and falls. The analyses show the hours of home care services increase very little, if they do at all.

<http://www.thestar.com/news/canada/politics/article/1162117--family-caregivers-in-distress-without-home-care-help-health-council-finds>

Extract from Health Council of Canada report

Although this report does not focus specifically on palliative (end-of-life) home care, it is an important part of any discussion about home care and seniors. The RAI-HC [Resident Assessment Instrument – Home Care] analyses show that home care costs and resources for seniors who have less than six months to live are roughly double what are required for all other home care recipients.

1. 'Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada?' Health Council of Canada, April 2012. http://healthcouncilcanada.ca/tree/HCC_HomeCare_FA.pdf

Cont.

Of related interest:

- BRITISH COLUMBIA | *Saanich News* – 15 April 2012 – '**University of Victoria palliative care expert weighs in on end-of-life ruminations.**' Those who care for people dying in towns across the province are now able to pick up the phone and call for support around the clock. On 10 April, the Ministry of Health revealed plans to expand the After-Hours Palliative Nursing Service. By calling HealthLinkBC, those eligible to receive palliative nursing services are connected to a registered nurse. <http://www.vicnews.com/news/147535945.html>
- QUÉBEC | *Montreal Gazette* – 13 April 2012 – '**Québec seniors bear brunt of home-care cuts.**' In 2003, the Québec government instituted a policy favouring home care for the elderly and disabled over long-term care institutions, but complaints are growing that the government is not delivering on its commitment. Provincial ombudsman Raymonde Saint-Germain has found that while Québec's home-care policy does not allow the government to deprive anyone of home-care services, some people needing help to remain in their homes are excluded, others have their service reduced, waiting lists are getting longer and caregiver burnout is growing among family members. <http://www.montrealgazette.com/health/Quebec+seniors+bear+brunt+home+care+cuts/6450836/story.html>

N.B. At the time of distributing this week's edition of Media Watch, only the French language version of the Ombudsman's report ('Chez soi: toujours le premier choix? L'accessibilité aux services de soutien à domicile pour les personnes présentant une incapacité significative et persistante') was available: http://www.protecteurducitoyen.qc.ca/fileadmin/medias/pdf/rapports_speciaux/2012-03-30_Accessibilite_Soutien_domicile.pdf

N.B. Scroll down to [International](#) and '800,000 vulnerable elderly fighting to stay in their homes' (p.6), published in the U.K.'s *Daily Telegraph*.

In the patient's best interest

Important new guidelines for doctors and patients on treatment for advanced cancer

CTV NEWS | Online report – 11 April 2012 – As an oncologist, I can say without hesitation that nothing in my daily practice compares to the unhappy duty of breaking bad news. Telling a patient with progressing cancer that further chemotherapy treatments are unlikely to be effective signals the end of the hopeful phase of their journey and an inevitable transition to palliative care. Such discussions are especially difficult when they involve younger patients. "You mean you're giving up on me?" is the (usually) unasked question reflected in their facial expression. Yet, no matter how delicately and sympathetically the subject of "no further treatment" is broached, some patients shoot the messenger, blaming the doctor for failing them, and demanding a referral to another oncologist. Sometimes, recommending that treatment be stopped can be made even more difficult by the knowledge that some colleagues continue to recommend treatment beyond the "norm," even when there is no hope for a meaningful outcome. Most often, this refusal to "throw in the towel" reflects a genuine concern that no stone be left unturned. But when is such an approach unreasonable and counter-productive? Thankfully, new guidelines issued by the American Society of Clinical Oncology (ASCO)¹ ... go a long way in identifying who should, and should not, be considered for further chemotherapy treatment when metastasized cancer progresses on therapy. <http://healthblog.ctv.ca/post/Knowing-when-to-stop-treatment-in-advanced-cancer-Important-new-guidelines-for-doctors-and-patients.aspx>

1. 'American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, published online (noted in Media Watch, 13 February 2012). <http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract>

N.B. Scroll down to [U.S.A.](#) and 'Overtreatment in cancer: Common sense medicine' (p.4), a commentary on the ASCO guidelines published in the *Huffington Post*.

Assisted (or facilitated) death

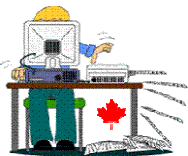
Representative sample of recent news media coverage:

- ALBERTA | *Calgary Herald* – 9 April 2012 – **'When doctors and nurses become death's servants.'** According to the newly released report, 'Dying with Dignity,'¹ co-signed by nine Quebec politicians, people are now ready to regard death through a new lens. We can free ourselves from a traditional "paternalistic" relationship with our physicians in order to embrace a more informed attitude in facing suffering and end-of-life issues. Our values, the report says, have greatly evolved in the past 20 years; therefore, it is only normal that in our farewell to life, we should take a close look at a new option offered by the state. The writers caution that although in the past Quebecers' values were mainly rooted in religion, people who still hold to those principles should not impose them on others. We live in a secular society. The sacred view of life no longer applies as a civic value. <http://www.calgaryherald.com/David+When+doctors+nurses+become+death+servants/6429331/story.html>
- 1. 'La Commission spéciale sur la question de mourir dans la dignité dépose son rapport' (noted in Media Watch, 26 March 2012; at this time only the French language version of the report is available). http://www.gouv.qc.ca/portail/quebec/pgs/commun/actualites/actualite/asurveiller_120323_soins-palliatifs/?lang=en

U.S.A.

Hospice profits raise questions about Medicare volunteer rule

FLORIDA | *Palm Beach Post* – 14 April 2012 – For-profit companies have been a driving force behind the quadrupling of annual hospice costs to \$13 billion since 2000, making it the fastest-growing part of Medicare, government reports show. Volunteers sometimes help for-profit hospitals and other businesses, but hospice is unique. It is the only service that requires volunteers to provide at least 5% of the hours spent caring for patients in order to qualify for Medicare payments. The Medicare Payment Advisory Commission report released in March raises renewed concerns about blending for-profit business models with government rules written when most hospice providers were non-profit. Medicare began paying for hospice care in 1983. "When the requirement was established, virtually all hospice providers were 'voluntary' or charitable organizations," the report said. "Today, more than half are for-profit providers." The situation "raises questions about the role the volunteer requirement plays in hospice care," the report said. There are no plans to drop the volunteer requirement, a spokeswoman for the Center for Medicare and Medicaid Services said. <http://www.palmbeachpost.com/health/hospice-profits-raise-questions-about-medicare-volunteer-rule-2305341.html>



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>

Overtreatment in cancer: Common sense medicine

HUFFINGTON POST | Online commentary – 9 April 2012 – Treatment for cancer has gotten out of hand. For almost every type of cancer, there are now dozens of potential treatments, in what are often hundreds of combinations. And, what is infinitely worse, these treatments can be lined up one after the other in a seamless row so that when one treatment fails, a doctor and patient simply step up to the next one. It's gotten so that it's almost impossible to stop treating cancer, because doing so means saying "no" to the next treatment that is ready and waiting. If you don't believe that this is a very real problem, you need look no further than the recommendations ... by the American Society for Clinical Oncology (ASCO).¹ The country's leading professional organization for cancer care, ASCO thought that this endless chain of treatment was concerning enough to draft a recommendation that, they hoped, would constrain the unfettered use of chemotherapy for advanced cancer. The short summary is that we tend to continue treatment for advanced cancer long past the point at which such treatment offers benefit. Their core message? Learn to say "no." The real message in ASCO's recommendation, though, isn't what this organization said. Instead, to get a real sense of the depth and breadth of the problem of overtreatment in advanced cancer, just take one simple sentence. Oncologists, they suggest, should not use chemotherapy for patients very near the end of life, particularly when treatment has not been proven to be effective.

http://www.huffingtonpost.com/david-casarett-md/cancer-treatment_b_1411993.html

1. 'American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, published online (noted in Media Watch, 13 February 2012). <http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract>

An ethical quandary, no matter the species

NEW YORK TIMES | Online OpEd – 9 April 2012 – Expensive treatments now available in veterinary medicine pose profound dilemmas for pet lovers. In every case we need to consider the meaning and significance of people's bonds with their pets, as well as the most humane decision for the animal. Abundant studies document the health and mental health benefits to humans of their bonds with companion animals. They offer joy, affection, a sense of security and faithful companionship. Most pet owners have strong attachments with their pets. Many, particularly if living alone, consider them their most significant relationship. In family life, pets are treated as valued members of the family. They play an important role in everyday family functioning, and they support the resilience of children through times of adversity. It's not uncommon or abnormal for individuals to grieve as profoundly with the death of their pet as with the loss of a human loved one. So it's understandable that many pet owners are reluctant to forgo treatments, especially for a beloved animal that is suffering or may die. Until recently, euthanasia ("putting down" an animal) was the most common decision in such situations. Devoted pet lovers increasingly go to great lengths for veterinary care, even forgoing expenses on themselves. Yet, the costs of treatments, the inadequacy and unaffordability of insurance coverage, or caregiving burdens must also be weighed, as well as medical considerations like the age, prognosis and well being of the animal. Profound ethical questions are raised when, as with medical advances for human treatments, we must grapple with the many considerations. People should not be judged if they cannot, or decide not to, provide all available treatments for their pet, just as they may not be able to, or may decide not to, for themselves or a loved one. <http://www.nytimes.com/roomfordebate/2012/04/09/the-ethics-of-spending-25000-on-pet-health-care/an-ethical-quandary-no-matter-the-species>

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>

60% of cancer patients die in a hospital, Dartmouth study finds

MASSACHUSETTS | *Boston Globe* – 9 April 2012 – Although most Americans say they want to die at home, not hooked up to a hospital ventilator, many doctors still feel compelled to treat even terminal cancer with the most aggressive care. Sixty percent of cancer patients die in a hospital, one-quarter of them in intensive care. And it makes no difference whether patients are treated by doctors at community hospitals, teaching hospitals or specialized cancer care centers, according to a study of Medicare patients.¹ Dr. Nancy E. Morden, an assistant professor at Dartmouth Medical School and the study's principal investigator, said that she's appalled so many patients are denied the kind of death they say they want. "It is not just futile" to treat terminal cancer patients, Morden said, "but it is torture." Morden said she and her fellow researchers expected to find that cancer care centers were more sensitive to patients' desires, but they found al-

most no difference in care among different types of hospitals. The only distinction: Community hospitals were more likely to deliver chemotherapy to patients within two weeks of their death – even though such late treatment rarely does any good. <http://www.boston.com/Boston/dailydose/2012/04/percent-cancer-patients-die-hospital-dartmouth-study-finds/nfAOhRV7JBZCLhqbQumKN/index.html>

Specialist Publications

Of particular interest:

'How cancer patients value hope and the implications for cost-effectiveness assessments of high-cost cancer therapies' (p.11), published in *Health Affairs*.

1. 'End-of-life care for Medicare beneficiaries with cancer is highly intensive overall and varies widely,' *HEALTH AFFAIRS*, 2012;31(4):786-796. <http://content.healthaffairs.org/content/31/4/786>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- LOUISIANA | *Times-Picayune* (New Orleans) – 11 April 2012 – **'Bill would strengthen ban on euthanasia and assisted suicide.'** A proposal to strengthen [the] ban on euthanasia and assisted suicide will be debated by the full House. The measure would spell out that someone authorized to approve medical procedures for another person may not approve any procedure that would be considered assisted suicide or euthanasia. The bill was supported by the House Health & Welfare Committee. http://www.nola.com/politics/index.ssf/2012/04/louisiana_house_bill_would_str.html
- *NEW YORK TIMES* | Online article – 11 April 2012 – **'Comfort and familiarity.'** Permitting doctors to help dying patients who are suffering unbearably to die sooner and more peacefully is indeed more controversial in the U. S. than in some other countries. But where it is legal, as in Oregon and Washington, it is far less controversial. The law in Oregon has been in effect for 14 years, and the evidence is clear that it is used sparingly and exactly as intended. A similar law has been in effect in Washington for three years, and is also popular. Evidently, where the public is familiar with the practice, Americans approve of it, just as the Dutch, Belgians and Swiss approve of their euthanasia laws. <http://www.nytimes.com/roomfordebate/2012/04/10/why-do-americans-balk-at-euthanasia-laws/comfort-familiarity-and-assisted-suicide-laws>
- VERMONT | *Burlington Free Press* (Montpelier) – 11 April 2012 – **'Physician-assisted death amendment surprises opponents.'** The Senate Health & Welfare Committee was finishing up a bill barring youths from using tanning beds ... when the panel took a surprise detour. With barely a word said about it, the panel voted 3-2 to attach a physician-assisted death bill to the tanning bed bill, a maneuver that sets up a possible Senate floor vote on the controversial end-of-life issue that had failed to make it out of another committee. [The bill was subsequently defeated on the Senate floor.] <http://www.burlingtonfreepress.com/article/20120410/NEWS03/120410016/1095/Physician-assisted-death-amendment-surprises-opponents>

International

800,000 vulnerable elderly fighting to stay in their homes

U.K. | *Daily Telegraph* – 16 April 2012 – Some 800,000 vulnerable elderly people are struggling to live in their own homes without any state-provided home help, say campaigners who argue the most vulnerable in society are being "catastrophically let down" by social services. Councils have slashed spending on social care in the last few years, as Westminster has cut local authority funding. Now more than four in five councils (82%) will only fund home help for people with substantial or critical care needs, up from about half in 2005, according to official figures.

<http://www.telegraph.co.uk/health/healthnews/9205546/800000-vulnerable-elderly-fighting-to-stay-in-their-homes.html>

How can a profession whose *raison d'être* is caring attract so much criticism for its perceived callousness? Does nursing need to be managed differently? Or is the answer to develop a new culture of compassion?

U.K. | *Independent* (OpEd) – 12 April 2012 – British culture has changed. We value care much less than we used to. Many of us, as the MP Margot James pointed out in the debate she tabled in October on care of the elderly, seem to be more interested in our rights than our responsibilities. Nursing takes a bigger proportion of young people out of schools than any other profession, and these people, however well-intentioned, are going to reflect the attitudes of society at large. "It is," said one lecturer in nursing who didn't want to be named, "not uncommon for a student nurse to have to be told that she should not text her friends while standing at a patient's bedside. Most of my colleagues," she said, "who teach pre-registration nursing find this is a huge problem." You can't, points out Liz Fradd, who was awarded a DBE three years ago for her services to nursing, "expect people to have a particular attitude, which we think is the right attitude, when they have no experience of, for example, elderly people being treated with dignity." Even those who go into nursing because they want to provide compassionate care often find themselves becoming "socialised", as another lecturer in nursing put it, into systems and cultures that make this difficult.

<http://www.independent.co.uk/life-style/health-and-families/health-news/how-can-a-profession-whose-raison-dtre-is-caring-attract-so-much-criticism-for-its-perceived-callousness-does-nursing-need-to-be-managed-differently-or-is-the-answer-to-develop-a-new-culture-of-compassion-7637490.html>

From Media Watch, 9 April 2012:

- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online article – 6 April 2012 – '**Liars, medicine, and compassion.**' <http://j.mp.oxfordjournals.org/content/early/2012/04/06/jmp.jhs007.abstract>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 4 April 2012 – "'**Tu Souffres, Cela Suffit**": **The compassionate hospital.**' <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0378>

N.B. Scroll down to [Worth Repeating](#) and 'Human rights and healthcare: Changing the culture' (p.14), published in *Age & Ageing*.

Quotable Quotes

Wonders are many on earth, and the greatest of these is man ... For every ill he hath found its remedy. Save only death. Sophocles (c.497-406 BC)

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

End-of-life care: Pain control carries risk of being called a killer

AMERICAN MEDICAL NEWS | Online report – 16 April 2012 – Three decades after hospice emerged as the standard of care for terminally ill patients, the end-of-life treatments that palliative medicine physicians provide are frequently referred to as murder, euthanasia and killing. More than half of hospice and palliative medicine physicians say patients, family members and even other health professionals have used those terms to describe care they recommended or implemented within the last five years, according to a nationwide survey of 663 palliative care doctors.¹ <http://www.ama-assn.org/amednews/2012/04/16/pr120416.htm>

1. 'Prevalence of formal accusations of murder and euthanasia against physicians,' *Journal of Palliative Medicine*, published online 8 March 2012 (noted in Media Watch, 12 March 2012). <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0234>

Comfort measures only: Agreeing on a common definition through a survey

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 10 April 2012 – Despite how frequently we say "comfort measures only" (CMO) in the hospital setting, review of the medical literature yields poor representation and definition of the term. The authors aimed at understanding what doctors understand as CMO [176 physicians responded to the survey]. They asked them about the moment in the patient care timeline when to use it and what degree of respiratory support, laboratory draws, antibiotic therapy, level of care, and code status should be a part of it. Disparities in responses were the norm, and common defining characteristics were the exception. <http://ajh.sagepub.com/content/early/2012/03/05/1049909112440740.abstract>

Parental perceptions of care of children at end of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 10 April 2012 – Little is known regarding the perceptions of parents about end-of-life care for their children. This study describes parental perceptions of the care of hospitalized, terminally ill children in the areas of 1) clinical management; 2) interdisciplinary support; and, 3) pain and symptom management. Parental satisfaction [of study participants] with their child's care during end of life indicates need for improvement in pain management, communication, and parental involvement in decision making. While education cannot guarantee desired changes in attitudes or behaviors, it may provide the essential foundation of knowledge, skills, and ethical understanding needed by professional providers. <http://ajh.sagepub.com/content/early/2012/03/05/1049909112440836.abstract>

From Media Watch, 26 September 2011:

- *JOURNAL OF PEDIATRIC NURSING* | Online article – 12 September 2011 – '**Parent perspectives on care of their child at the end of life.**' Recurring themes include poor communication/lack of information, strained relationships/inadequate emotional support, parental need to maintain parent/child relationships in life and death, quality of care continues after the death of the child, influence of services/planning on parent/child impacts quality of life, and the difficult decision to terminate life support. <http://www.sciencedirect.com/science/article/pii/S0882596311005343>

Middle East experience in palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 10 April 2012 – Palliative Care (PC) is still a relatively new concept in the Middle East (ME). It was first introduced in Saudi Arabia in 1992 and only recently in countries such as Qatar, Bahrain, and the United Arab Emirates. Although the majority of Middle-Eastern countries, including Palestine, Iraq, Oman and Lebanon are in the capacity building phase, others such as Saudi and Jordan already have localized provision. In the absence of any of the ME countries approaching integration with the mainstream service providers, Saudi Arabia and Jordan are currently setting examples of achievement in the field. There are countries with little or no known palliative care activity (Yemen and Syria). Political issues, scarcity of resources, and lack of education and awareness seem to be the common factors restricting the progress of this field in most countries. In order to improve the sub-optimal PC services in the ME, emphasis should be directed toward providing formal education to professionals and raising awareness of the public. It is also necessary to put all differences aside and develop cross-border collaborations, whether through third party organizations such as the Middle East Cancer Consortium... This review compiles the available literature on the history and progress of the field of PC in most ME countries, while pointing out the major obstacles encountered by the active parties of each country.

<http://ajh.sagepub.com/content/early/2012/03/05/1049909112439619.abstract>

The unlikely patient and the most likely patient: A personal reflection on two patients and the lessons learned regarding physician communication in the field of palliative medicine

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 10 April 2012 – Palliative care is somewhat of a new field in medicine. A field which requires within it an intricate understanding of disease and its prognostic indicators. A field which considers the patient as a whole with the goal of patient-directed care. And a field which necessitates as much medicine as it does art. However, palliative care is often consulted by intensivists and primary teams during the last moments of life. And although we can be helpful during this time, we can be of more assistance when incorporated earlier by providing not only end-of-life care, but enhanced pain and symptomatic management, elucidating goals of care, as well as affording patients and their families with emotional, spiritual, and psychosocial sup

From Media Watch,
11 April 2011:

Palliative care in Middle-Eastern countries

A supplement to the current issue of the *Journal of Pediatric Hematology/Oncology* focuses on palliative care in Middle-Eastern countries with articles on end of life care in Cyprus, Egypt, Israel, Pakistan, the Palestinian Authority and Turkey. Other articles focus on opioid use in pain management. Contents page: <http://journals.lww.com/jpho-online/toc/2011/04001>

American Medical Association publishes physician guide to home care

AMERICAN MEDICAL NEWS | Online report – 16 April 2012 – The American Medical Association, in conjunction with the American Academy of Home Care Physicians, released on March 26 a guidebook for physicians regarding the medical management of patients receiving a range of health care services in their own residence. *Medical Management of the Home Care Patient: Guidelines for Physicians, 4th Edition* outlines the physician's role in home care, the relationship with patients and caregivers and the implementation of a care plan. The monograph also tackles hospice and palliative care at home and the detection of abuse and neglect. <http://www.ama-assn.org/amednews/2012/04/16/bibf0416.htm>

port. Our expertise can be useful in all patients, not just the dying.

<http://ajh.sagepub.com/content/early/2012/03/05/1049909112439618.abstract>

Cont.

Of related interest:

- *DIMENSIONS OF CRITICAL CARE NURSING*, 2012;31(3):170-182. **'Prognostic communication of critical care nurses and physicians at end of life.'** Many critical care nurses express reluctance to communicate prognostic information to patients and family members, especially prior to physician communication of this information. The findings from this study indicate that critical care nurses play a crucial, complementary role to physicians in prognostic communication. http://journals.lww.com/dccjournal/Abstract/2012/05000/Prognostic_Communication_of_Critical_Care_Nurses.7.aspx
- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2012;14(3):191-198. **'Patients' understanding of medical technology in palliative home care: A qualitative analysis.'** Healthcare reforms and reductions in the number of hospital beds are leading to an increasing amount of medical technology moving from hospitals into home care, affecting the daily lives of patients. The aim of this study was ... to describe the ways patients understand medical technology in palliative home care. http://journals.lww.com/jhpn/Abstract/2012/05000/Patients_Understanding_of_Medical_Technology_in.8.aspx
- *MEDICAL DECISION MAKING* | Online article – 13 April 2012 – **'Decision coaching to prepare patients for making health decisions: A systematic review of decision coaching in trials of patient decision aids.'** Compared with usual care, decision coaching improved knowledge. However, the improvement in knowledge was similar when coaching was compared with patient decision aids alone. Outcomes for other comparisons are more variable, some trials showing positive effects and other trials reporting no difference. Given the small number of trials and variability in results, further research is required to determine the effectiveness of decision coaching. <http://mdm.sagepub.com/content/early/2012/04/13/0272989X12443311.abstract>

What does respect for the patient's autonomy require?

BIOETHICS | Online article – 10 April 2012 – Personal autonomy presupposes the notion of rationality. What is not so clear is whether, and how, a compromise of rationality to various degrees will diminish a person's autonomy. In bioethical literature, three major types of threat to the rationality of a patient's medical decision are identified: insufficient information, irrational beliefs/ desires, and influence of different framing effects. To overcome the first problem, it is suggested that patients be provided with information about their diseases and treatment choices according to the objective standard. [The author] explain[s] how this should be finessed. Regarding the negative impact of irrational beliefs/desires, some philosophers have argued that holding irrational beliefs can still be an expression of autonomy. He rejects this argument because the degree of autonomy of a decision depends on the degree of rationality of the beliefs or desires on which the decision is based. Hence, to promote patient autonomy, we need to eliminate irrational beliefs by the provision of evidence and good arguments. Finally, [the author] argue[s] that the way to smooth out the framing effects is to present the same information in different perspectives: it is too often assumed that medical information can always be given in a complete and unadorned manner. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2012.01973.x/abstract>

Of related interest:

- *BIOETHICS* | Online article – 10 April 2012 – **'Respecting autonomy without disclosing information.'** There is widespread agreement that it would be both morally and legally wrong to treat a competent patient, or to carry out research with a competent participant, without the voluntary consent of that patient or research participant. Furthermore, in medical ethics it is generally taken that that consent must be informed. The most widely given reason for this has been that informed consent is needed to respect the patient's or research participant's autonomy. In this article I set out to challenge this claim by considering in detail each of the three most prominent ways in which 'autonomy' has been conceptualized in the medical ethics literature. I will argue that whilst these accounts support the claim that consent is needed if the treatment of competent patients, or research on competent individuals, is to respect their autonomy, they do not support the claim that informed consent is needed for this purpose. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2012.01971.x/abstract>

Cont.

- *MEDICAL JOURNAL OF AUSTRALIA*, 2012;196(6):404-405. **'Autonomy versus futility: Barriers to good clinical practice in end-of-life care: A Queensland case.'** Findings from a Queensland coronial inquest [into the death of June Woo] highlight the complex clinical, ethical and legal issues that arise in end-of-life care when clinicians and family members disagree about a diagnosis of clinical futility. The tension between the law and best medical practice is highlighted in this case, as doctors are compelled to seek family consent to not commence a futile intervention. Good communication between doctors and families, as well as community and professional education, is essential to resolve tensions that can arise when there is disagreement about treatment at the end of life. <https://www.mja.com.au/journal/2012/196/6/autonomy-versus-futility-barriers-good-clinical-practice-end-life-care-queensland>

Awareness of do-not-resuscitate orders: What do patients know and want?

CANADIAN FAMILY PHYSICIAN, 2012;58(4):e229-e233. Most [survey] respondents were well informed about the meaning of DNR [do not resuscitate], thought DNR discussions should take place when patients were still healthy, preferred to discuss DNR decisions with family physicians, and did not consider the topic stressful. Yet few respondents reported having had a conversation about DNR decisions with any health care provider. Disparity between patient preferences and experiences suggests that family physicians can and should initiate DNR discussions with younger and healthier patients. <http://www.cfp.ca/content/58/4/e229.abstract>

Moral distress

"Stop the noise!" From voice to silence

CANADIAN JOURNAL OF NURSING LEADERSHIP, 2012;25(1):90-104. Nurses are frequently portrayed in the literature as being silent about ethical concerns that arise in their practice. This silence is often represented as a lack of voice. However, in this study, the authors found that nurses who responded to questions about moral distress were not so much silent as silenced. These nurses were enacting their moral agency by engaging in diverse, multiple and time-consuming actions in response to situations identified as morally distressing with families, colleagues, physicians, educators or managers. In many situations, they took action by contacting other healthcare team members, making referrals and coordinating care with other departments such as home care and hospice, as well as initiating contact with groups such as professional regulatory bodies or unions. Examining the relationship between ethical climate, moral distress and voice offers insights into both the meaning and impact of being silenced in the workplace. <http://www.longwoods.com/content/22828>

Evidence-based spiritual care: A literature review

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online article – 11 April 2012 – The majority of patient-focused studies concentrate on oncology and palliative care patients. In the review period, studies of care giver perceptions and experience came from multiple disciplines, including medicine, nursing, and chaplaincy. A discrepancy exists between the provision of spiritual care and the theoretical commitment of practitioners to offer such care. Practitioners continue to view spiritual care as part of their role to a greater extent than they provide it. This is often attributed to the absence of consensus in the field regarding the definition of spirituality, a lack of clarity of disciplinary role, and inadequate education for nurses and doctors about spiritual care. Research has further indicated that care givers' explorations of their own spirituality correlate with the provision of spiritual care. Although historically spiritual care has been most integrated into the care of palliative and oncology patients, researchers are developing and testing spiritual care assessment tools with other medical populations. http://journals.lww.com/supportiveandpalliative-care/Abstract/publishahead/Evidence_based_spiritual_care_a_literature.99825.aspx

How cancer patients value hope and the implications for cost-effectiveness assessments of high-cost cancer therapies

HEALTH AFFAIRS, 2012;31(4):676-682. Assessments of the medical and economic value of therapies in diseases such as cancer traditionally focus on average or median gains in patients' survival. This focus ignores the value patients may place on a therapy with a wider "spread" of outcomes that offer the potential of a longer period of survival. We call such treatments "hopeful gambles" and contrast them with "safe bets" that offer similar average survival but less chance of a large gain. Real-world therapy options do not have these stylized forms, but they can differ in the spread of survival gains that patients face. The authors found 77% of surveyed cancer patients with melanoma, breast cancer, or other kinds of solid tumors preferred hopeful gambles to safe bets. <http://content.healthaffairs.org/content/31/4/676.abstract?sid=f2379f01-0e33-47cb-bf6d-73f61879184f>

Of related interest:

- *HEALTH AFFAIRS*, 2012;31(4):691-699. **'Patients value metastatic cancer therapy more highly than is typically shown through traditional estimates.'** This study used data on the treatment choices of terminally ill patients to estimate the value they associate with care. The authors found that patients place high valuations on metastatic cancer therapy ... and that other traditional methods used to estimate the value of these treatments for patients significantly undervalues how patients view them. <http://content.healthaffairs.org/content/31/4/691.abstract>

Media Watch Online

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

Canada

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

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

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

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

U.S.A.

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

Europe

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

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm> (Scroll down to 'International End of Life Roundup')

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>

Diversity in death: Body disposition and memorialization

ILLNESS, CRISIS & LOSS, 2012;20(2):141-158. Among recent "trends" ... are numerous cremation options, varied casket choices, theme funerals, environmentally-correct disposition, and cemetery options. Other recent occurrences related to death include roadside memorials, automobile memorializations, and the changes brought on by the internet. Some of the questions addressed ... include: 1) What sense can we make of today's personalized death trends? 2) Is the trend occurring toward individualization? 3) What are the social and cultural changes contributing to these dying and death shifts? 4) What impact does sheer cost have on today's involvement with dying, death, and bereavement? 5) Why is final body disposition being deinstitutionalized, if indeed it is? 6) Is death today being resurrected, following a period called the dying of death? <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,4,10;journal,1,54;linkingpublicationresults,1:103734,1>

Surgery and the D-word: Approaching the topic of death and dying with surgical patients

JOURNAL OF PALLIATIVE CARE & MEDICINE | Online article – Accessed 13 April 2012 – The topic of death and dying arises frequently in surgical practice, yet represents one of the more challenging areas for many surgeons. Surgeons must feel comfortable addressing the issue of death whether it is a theoretical concern in the context of routine informed consent or an inevitable reality in the setting of end-of-life care. In the palliative setting, four essential elements must be present in order to properly address death and dying: compassion, communication, clarity, and closure. The skills set for optimally dealing with this topic in a surgical practice must not be assumed, but fortunately can and should be learned and nurtured during education and training and beyond. This will help ensure that Surgery as a profession maintains its commitment to leading the public discourse regarding death, surgery, and patient-centered policies that inform and protect. <http://omicsgroup.org/journals/2165-7386/2165-7386-2-108.pdf>

Psychiatric aspects of chronic palliative care: Waiting for death

PALLIATIVE & SUPPORTIVE CARE | Online article – 22 March 2012 – This article ... offers a view about a type of palliative care for patients reaching the pre-terminal phase of a chronic illness. Unlike cancer patients, time is not as sharply delineated and physical pain is not a major factor, but psychological distress is often a major component of the clinical condition. Starting from the perspective of a psychiatric consultant ... the author presents short clinical vignettes to introduce a discussion about psychological manifestations in patients with chronic vital organ failure. The objective is to help patients find meaning to the last stage of their life. Sensitive areas are presented for clinicians to assess end-of-life coping: pressure on character organization, the management of hope, mourning problems, and ill health as a screen for psychological distress. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8518901>

From Media Watch, 26 March 2012:

- *AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY*, 2012;20(4). **'Palliative care has much to bring to geriatric psychiatry.'** This issue highlights similarities and relationships between geriatric psychiatry and palliative care. <http://journals.lww.com/ajgponline/pages/currenttoc.aspx>

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](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>

Readability of hospice materials to prepare families for caregiving at the time of death

RESEARCH IN NURSING & HEALTH | Online article – 10 April 2012 – Many health care materials are not written at levels that can be understood by most lay people. The authors examined the readability of documents used by hospices to prepare families for caregiving at the time of death. They used two common formulae to examine the documents. The mean Flesch–Kincaid grade level was 8.95. The mean Simple Measure of Gobbledygook grade level was 11.06. When the authors used the Colors Label Ease for Adult Readers instrument, it became evident that medical terminology was the primary reason for the high-grade levels. Most documents (78%) included medical terms that were directly (46.2%) or indirectly (25.6%) explained in the text. Modification of hospice materials could improve families' comprehension of information important for optimal end-of-life care. <http://onlinelibrary.wiley.com/doi/10.1002/nur.21477/abstract>

From Media Watch, 3 May 2010:

- *BMC MEDICAL ETHICS* | Online article – 25 April 2010 – '**Readability of state-sponsored advance directive forms in the U.S.**' The readability of ... state government-sponsored advance directive forms exceeds the readability level recommended by the National Work Group on Literacy & Health and the average reading skill level of most U.S. adults. Overall, 62 advance directive forms were obtained. Such forms may inhibit advance care planning and therefore patient autonomy. <http://www.biomedcentral.com/content/pdf/1472-6939-11-6.pdf>

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.

Distribution

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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.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BIOETHICS* | Online article – 12 April 2012 – '**Attitudes towards euthanasia and assisted suicide: A comparison between psychiatrists and other physicians.**' The authors compare attitudes of 49 psychiatrists towards euthanasia and assisted suicide with a group of 54 other physicians... When controlled for religious practice, psychiatrists expressed more conservative views regarding euthanasia than did physicians from other medical specialties. Similarly female physicians and orthodox physicians indicated more conservative views. Differences may be due to factors inherent in sub-specialty education. They suggest that in light of the unique complexity and context of patient euthanasia requests, based on their training and professional expertise, psychiatrists are well suited to take a prominent role in evaluating such requests to die and making a decision as to the relative importance of competing variables. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2012.01968.x/abstract>

Worth Repeating

Human rights and healthcare: Changing the culture

AGE & AGEING, 2010;39(5):525-527. Despite the introduction [in the U.K.] of the Human Rights Act in 1998, there has been a relative failure to use the Act to improve care for older people. All older adults receiving health or social care should assume that they will be treated with dignity, respect, humanity and compassion. It should not be forgotten that Human Rights belong to everyone, and they cannot be taken away. Unfortunately, so often, admission to a hospital or a move to a care home can lead to the loss of Human Rights, particularly for those suffering from dementia. The media have highlighted their plight. The medical profession, in particular geriatricians, is in an ideal position to provide leadership to promote a better understanding of their importance and the need to protect an individual's rights both in hospital and in care homes. The Human Rights Act makes it unlawful for any public body to act in a way which is incompatible with the convention. Public authorities ... and local authorities have a duty to respect and protect basic human rights.

<http://ageing.oxfordjournals.org/content/39/5/525.full.pdf+html>

Extract from *Age & Ageing* article

A poster setting down some basic principles for dignified care has been produced. It is easy to forget the person when task orientated, and the poster provides little prompts to remind how to respect them and recognise their needs and rights. It recognises that all of the following can contribute to poor care:

- Failure to listen and explain
- Failure to identify communication problems
- Failure to involve families
- Failure to take a life history
- Failure to recognise the person's human rights and individuality
- Failure to assess the person's toileting needs
- Failure to make food and drink accessible
- Failure to promote normal mobility and function
- Failure to check for clean finger and toenails
- Failure to identify loneliness and isolation
- Failure to test for hearing and visual problems
- Failure to clean glasses
- Failure to check for oral hygiene

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