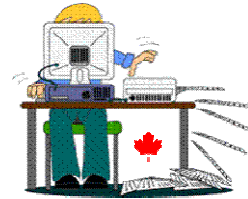


Media Watch...

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.

28 May 2012 Edition 2012 | Issue #255



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

Compiled & Annotated by Barry R. Ashpole

Institutionalization of end-of-life care: Scroll down to [Specialist Publications](#) and 'Routinization and medicalization of palliative care: Losses, gains and challenges' (p.9), published in *Palliative & Supportive Care*.

Canada

Daily life as important as care

SASKATCHEWAN | *Star Phoenix* (Saskatoon) – 24 May 2012 – When health-care costs are reviewed, the disproportionate expenses consumed in the last few months and weeks of life are never mentioned. That is unfortunate. A report from the Manitoba Centre for Health Policy found that 21.3% of all health-care costs in Manitoba were consumed in the final six months of life. Putting these numbers into a Saskatchewan context, approximately \$1 billion a year supports the last six months of life. A report published in the *Archives of Internal Medicine* found that a third of those costs come in the final month alone. Perhaps surprisingly, end-of-life costs differ by age, even after controlling for cause of death. A report published in the *Journal of the American Medical Association* found that those aged 65 through 74 consume \$35,300 in their final year of life in comparison to \$21,600 for those aged 85 and over. That's because, once one adjusts for cause of death, more elderly patients are less likely to receive aggressive care that will not benefit them. <http://www.thestarphoenix.com/health/Daily+life+important+care/6669902/story.html>

N.B. Active links to the report of the Manitoba Centre for Health Policy and the two journal articles cited were not available at the time of distribution of this issue of Media Watch.

Ageism in health care needs to end, doctor says

ONTARIO | CBC News – 21 May 2012 – Some doctors are warning of a culture of ageism in the medical world, saying health workers commonly treat old people as though they don't deserve the same care as younger Canadians. Nathan Stall has just graduated from medical school and unlike the other 146 students in his class at Western University in London, he plans to specialize in geriatrics. Stall laments how old people with multiple chronic illnesses are often viewed as second-rate patients. "They're often not afforded the same investigations, the same histories that another patient would be afforded under the same circumstances," Stall said. Stall called for sweeping changes at medical schools.¹ <http://www.cbc.ca/news/health/story/2012/05/18/medical-agism.html>

Cont.

1. 'Time to end ageism in medical education,' *Canadian Medical Association Journal* (accessed 22 May 2012). <http://www.cmaj.ca/content/184/6/728.full?sid=20e18c28-7964-4724-8e0c-cc2e3931e014>

From Media Watch, 7 May 2012:

- *ANNALS OF INTERNAL MEDICINE*, 2012;156(9):654-656. 'Is geriatric medicine terminally ill?' <http://www.annals.org/content/156/9/654.extract>
- *ANNALS OF INTERNAL MEDICINE*, 2012;156(9):657-659. 'The case for investing in geriatrics, our nation's future, and our patients.' <http://www.annals.org/content/156/9/657.extract>

[U.S.A.](#)

Massachusetts Senate skirts end-of-life counseling controversy

MASSACHUSETTS | WBUR News (Boston) – 23 May 2012 — With no debate, and a quick call of the ayes and nays, the Massachusetts Senate approved a requirement last week that all doctors and nurses talk to dying patients about their end-of-life options. In passing the amendment, legislators avoided a minefield that exploded repeatedly during the national health care debate. <http://www.wbur.org/2012/05/23/mass-end-of-life>

- UTAH | *City Weekly* (Salt Lake City) – Accessed 24 May 2012 – '**10 (untrue) reasons Utahns fear the ACA.**' Sarah Palin ... death-panel remark spread like a summer wildfire across the conservative media grid, and national surveys two weeks later showed that 30% of Americans believed the ACA [Patient Protection & Affordable Care Act] would let the government pull the plug on Grandma. <http://www.cityweekly.net/utah/article-443-15955-what-is-this-a-liberal-site-obama-care-is-a-s.html>

Hospice program specifically for veterans

ILLINOIS | *Northwest Herald* (Crystal Lake) – 22 May 2012 – Hospice of Illinois has created a new program to meet the needs of veterans. More than 875,000 veterans live in Illinois. The veterans-specific program^{1,2} ... provide[s] specialized care. The program consists of three specialized components: a comprehensive assessment of each patient, including identifying veteran-specific clinical issues, such as post-traumatic stress disorder (nurses are also experts in pain and symptom management; specially trained staff assist patients and family members with military benefits, record recovery and burial arrangements; veteran volunteers who are often able to form unique connections with hospice patients because they can empathize and understand common experiences. <http://www.nwherald.com/2012/05/21/hospice-program-specifically-for-veterans/ajudfg/>

1. 'Understanding veterans' challenges at the end of life,' NewsWorks, 8 February 2012 (noted in Media Watch, 13 February 2012). <http://www.newsworks.org/index.php/local//item/33755-understanding-veterans-challenges-at-the-end-of-life/>
2. 'Helping the brave fight their final battle,' *Los Angeles Times*, 28 December 2010 (noted in Media Watch, 3 January 2011). <http://www.latimes.com/health/sc-fam-1228-senior-health-veteran-20101228,0,7667701.story>



Hospice being marketed as a cost-cutter for hospitals

USA TODAY | Online report – 22 May 2012 – Hospice marketers, exploring possibilities for new revenue to help continue the industry's remarkable growth, are looking to exploit a provision in the 2010 health care law by persuading hospitals to send Medicare patients into end-of-life hospice care instead of readmitting them to the hospital. Such a move, the hospice marketers say, will enable hospitals to avoid paying the Medicare penalties required by the new law when hospitals discharge patients and then have to readmit them within 30 days: Instead of readmitting the patients, hospitals should send them to hospice care, which also is covered by Medicare, according to a USA TODAY analysis of marketing materials. Patients with severe heart problems and pneumonia tend to decline quickly and often move in and out of hospitals, said hospice marketing specialist Rich Chesney, who proposed the idea. It might be better, Chesney said, if a hospital CEO hired people to talk to family members about hospice, instead of a doctor, who is more focused on not losing a patient. <http://www.usatoday.com/money/industries/health/story/2012-06-11/hospice-marketing-Medicare/55120284/1>

Of related interest:

- CONNECTICUT | *Stamford Advocate* – 22 May 2012 – **'New regulations may expand hospice care.'** Closure of the Richard L. Rosenthal Hospice last year is an illustration of how the state's longstanding rules for hospice kept nursing and health-care outfits from providing needed in-patient care for terminally ill patients. Reformed regulations ... open the possibility that an interested health-care agency, nursing home operator and foundations could unite to open standalone facilities to care for the terminally ill. <http://www.stamfordadvocate.com/news/article/New-regulations-may-expand-hospice-care-3576277.php>

To resuscitate or not to resuscitate: Is that the right question?

MASSACHUSETTS | *Boston Globe* – 21 May 2012 – There's debate about the right time and setting for the end-of-life discussion: Most favor having it with a primary care doctor or another long-term provider that a patient knows and trusts. Some argue that a patient isn't ready to have the conversation until a hospital stay throws his mortality into sharp relief. The reality is that it's our job as doctors to know the answer to this question every time a patient arrives on the hospital floor, and the task often falls to an intern working in the middle of the night. Unfortunately, trainees and even full-fledged doctors don't do a great job of having this discussion: We ask out of the blue, instead of placing the questions in the context of a patient's broader goals for her life and death. The way we ask about, and document, the end-of-life decision ("full code" versus "do not resuscitate (DNR)") creates a false dichotomy between doing something and doing nothing and fails to capture either the shades of gray in end-of-life care or the value of doing "nothing." We don't present a realistic view of the violence of chest compressions, nor the probability of surviving past CPR (in the elderly and chronically ill, less than five percent. It doesn't help that in the movies and television, a common source of information on CPR, characters who go into cardiac arrest are usually brought back from the dead with a few thumps to the chest. We present a daunting list of end-of-life options (CPR? Breathing tube? Defibrillator?) with little guidance on navigating it – the medical version, maybe, of the menu at The Cheesecake Factory. In our quest for patient-centered care, we forget it's still our job to frame choices and render them manageable. http://www.boston.com/lifestyle/health/blog/shortwhitecoat/2012/05/to_resuscitate_or_not_to_resus.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. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Making the call: When a child goes on life support, parents must follow their hearts

UTAH | *Salt Lake Tribune* – 21 May 2012 – [Gerr] Osman found herself in the impossible situation scores of families face each year: choosing between removing a loved one from life support after a sudden accident, or letting them linger as they hope for a miracle recovery that doctors say likely will never happen. Parents fall on both sides, some visiting their unresponsive children in a care facility for years while others decide that quality of life isn't what their children would want. Doctors can tell a family what the expected outcome is, but there is no medical certainty about how fully a child will recover from a brain injury. "There's no right answer and no wrong answer," said Toni Sherwood, a pediatric nurse practitioner who works for Rainbow Kids Pediatric Palliative Care. "It's what's in your heart." <http://www.sltrib.com/sltrib/news/53808462-78/son-osman-doctors-brain.html.csp>

Stuck between old and new: Black caregivers deal with stress

NEW YORK STATE | *Amsterdam News* – 17 May 2012 – Black caregivers (41%) are more likely than their white (28%) and Asian-American counterparts (23%) to help others engage in daily activities, like helping someone get out of bed, get dressed, get to and from the toilet and feeding and managing incontinence. Over half of Black caregivers said they found themselves "sandwiched" between caring for an older person, a younger person under the age of 18 and caring for more than one older person. http://www.amsterdamnews.com/news/local/stuck-between-old-and-new-black-caregivers-deal-with-stress/article_f384bc5e-a043-11e1-8cf1-0019bb2963f4.html

International

Terminally-stage patients 'need stronger pain relief'

U.K. | Choices (National Health Service) – 23 May 2012 – Many patients with "advanced cancer and other debilitating conditions" aren't being given strong enough pain relief. This is thought to be due to doctors being reluctant to prescribe strong opioids, such as morphine, partly as a result of patients' concerns over addiction. Patients may also wrongly assume that they are nearer the end of their life, as there is a misconception that opioids are only given during the final stages of terminal disease. The news is based on new medical guidelines¹ on the safe and effective prescribing of strong pain-relieving drugs for people living with and dying from a terminal condition (palliative care). <http://www.nhs.uk/news/2012/05may/Pages/opioid-painkillers-palliative-care-guidelines.aspx>

1. 'Opioids in palliative care: Safe and effective prescribing of strong opioids for pain in palliative care of adults,' National Institute for Health & Clinical Excellence (NICE), May 2012. <http://publications.nice.org.uk/opioids-in-palliative-care-safe-and-effective-prescribing-of-strong-opioids-for-pain-in-palliative-cg140>

Hospice's level of care that shames the National Health Service

U.K. | *Daily Telegraph* – 22 May 2012 – When a policy is inconvenient or doesn't quite fit with the patient's wishes, rather than the blank, recalcitrant stares that patients are all too often met with by some of the staff on hospital wards, staff at the hospice listen, furrow their brow, have a think and then see if there's a way around it. If visiting hours aren't convenient, or patients want to talk while a nurse is writing up some notes, or they're hungry or need help in the lavatory, everything is dropped – because, according to the ethos of the hospice, these are far more important things than the banal machinations of form-filling. Knowing someone is going to die sharpens the sense of what is really important. <http://www.telegraph.co.uk/news/features/9278140/Hospices-level-of-care-that-shames-the-NHS.html>

Cont.

From Media Watch, 14 May 2012:

- U.K. | National End of Life Care Intelligence Network – 8 May 2012 – **'New report captures the latest information on end of life care in England – the good and the bad.'** The report highlights areas where improvements have been made as well as where further action is needed to improve care for people who are dying. The publication is divided into 16 categories ranging from place of care and death to latest trends in different settings, different disease types, costs, quality of care, workforce and public attitudes. <http://www.endoflifecare-intelligence.org.uk/news/default.aspx>

N.B. *'What do we know now that we didn't know a year ago? New intelligence on end of life care...'* http://www.housinglin.org.uk/library/Resources/Housing/Support_materials/Other_reports_and_guidance/What_we_know_about_end_of_life_care_report.pdf

Palliative care in Australia

Coast no place to die

AUSTRALIA (QUEENSLAND) | *Sunshine Coast Daily* (Maroochydore) – 20 May 2012 – The Sunshine Coast is facing a desperate shortage of palliative care services for people who are in pain and need expert care to reduce their end-of-life suffering. Palliative Care Queensland said the demand for palliative care on the Coast had grown from about 250 referrals a year about five years ago to 100 referrals a month today, but there was only enough funding to cater for 16. "I think dying people don't have a loud voice. When people are dying, their families don't jump up and down, they just grieve," said John-Paul Kristensen of Palliative Care Queensland [PCQ]. "People who are missing out on cancer treatment or heart treatment, they jump up and down; people who are dying don't, so the palliative care indus-

try doesn't have a very loud voice and the government doesn't hear us." The situation on the Sunshine Coast gets even worse. An area like this, with a population of almost 300,000, should have at least 20 care beds dedicated to the terminally ill. The area has 12. <http://www.sunshinecoastdaily.com.au/story/2012/05/20/sunshine-coast-no-place-for-the-dying-palliative>

Extract from *Sunshine Coast Daily* report

To add a legal kicker to the controversial issue, those who fail to provide adequate pain relief to the terminally ill soon could find themselves facing court for human rights abuses.

Of related interest:

- AUSTRALIA (QUEENSLAND) | ABC News (Brisbane) – 23 May 2012 – **'Have you told your family how you want to die?'** A new survey [see news item below] has found that despite nearly two-thirds of Australians saying they would turn to their family first to make decisions about their end of life care, almost half of the people surveyed think their families don't know what they want at the end of their life. And over a third think that those final wishes may be ignored by their relatives anyway. <http://blogs.abc.net.au/queensland/2012/05/have-you-told-your-family-how-you-want-to-die.html>
- AUSTRALIA (VICTORIA) | 9 News (Melbourne) – 21 May 2012 – **'People need an 'end of life' plan.'** More than one-third of Australians believe their relatives may ignore their wishes near the end of their life. A survey of 1,000 Australians commissioned by Palliative Care Australia (PCA) also found that 53% of respondents thought their final wishes might be ignored by their health care professional. According to PCA, many people are not telling their relatives or health professionals what they want at the end of life, such as where they would like to die. The survey found that almost 90% of respondents lacked an advance care plan, and 78% did not know what an advance care plan was. <http://news.ninemsn.com.au/article.aspx?id=8470558>

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

Grief & bereavement

Nature and impact of grief over patient loss on oncologists' personal and professional lives

ARCHIVES OF INTERNAL MEDICINE | Online article – Accessed 22 May 2012 – To the authors' knowledge, this study is the first qualitative exploration of the nature and impact of grief in oncologists. They found that for oncologists, patient loss was a unique affective experience that had a smoke-like quality. Like smoke, this grief was intangible and invisible. Nonetheless, it was pervasive, sticking to the physicians' clothes when they went home after work and slipping under the doors between patient rooms. Of greatest significance to our health care system is that some of the oncologists' reactions to grief reported in our study (e.g., altered treatment decisions, mental distraction, emotional and physical withdrawal from patients) suggest that the failure of oncologists to deal appropriately with grief from patient loss may negatively affect not only oncologists personally but also patients and their families. One way to begin to ameliorate these negative effects would be to provide education to oncologists on how to manage difficult emotions such as grief starting at the residency stage and as continuing education throughout their careers, with the recognition that grief is a sensitive topic that can produce shame and embarrassment for the mourner.⁷ <http://archinte.jamanetwork.com/article.aspx?articleid=1160665>

- *DEATH STUDIES*, 2012;36(6):541-564. **'Helpful aspects of bereavement support for adults following an expected death: Volunteers' and bereaved people's perspectives.'** Most commonly reported themes were the provision of hope and reassurance, and the opportunity for continued sharing and support. Significantly more clients than volunteers reported provision of information, and talking to someone outside their social network as helpful, and both groups scored higher on helpfulness ratings than comparative groups of psychotherapists and clients. Clients' grieving styles and the quality of the helping relationship were also related to what was seen as helpful. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2011.553334>
- *THE PREVENTION RESEARCHER*, 2012;18(3):3-9 **'Adolescent development and bereavement: An introduction.'** In order to provide the best support possible to grieving youth it is important to understand how bereavement impacts adolescent development and how adolescent development impacts bereavement. This article ... explores these two key components focusing on cognitive, behavioral, and affective responses during three stages of adolescence (early, middle, and later). http://www.tpronline.org/article.cfm/Adolescent_Development_and_Bereavement

A direct advance of advance directives

BIOETHICS, 2012;26(5):267-274. Advance directives (ADs), which are also sometimes referred to as 'living wills', are statements made by a person that indicate what treatment she should not be given in the event that she is not competent to consent or refuse at the future moment in question. As such, ADs provide a way for patients to make decisions in advance about what treatments they do not want to receive, without doctors having to find proxy decision-makers or having recourse to the doctrine of necessity. While patients can request particular treatments in an AD, only refusals are binding. This paper will examine whether ADs safeguard the autonomy and best interests of the incompetent patient, and whether legislating for the use of ADs is justified, using the specific context of the legal situation in the U.S. to illustrate the debate. The issue of whether the law should permit ADs is itself dependent on the issue of whether ADs are ethically justified; thus we must answer a normative question in order to answer the legislative one. It emerges that ADs suffer from two major problems, one related to autonomy and one to consent. First, ADs' emphasis on precedent autonomy effectively sentences some people who want to live to death. Second, many ADs might not meet the standard criteria for informed refusal of treatment, because they fail on the crucial criterion of sufficient information. Ultimately, it transpires that ADs are typically only appropriate for patients who temporarily lose physical or mental capacity. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2010.01853.x/abstract>

End-of-life care across Southern Europe: A critical review of cultural similarities and differences between Italy, Spain and Portugal

CRITICAL REVIEWS IN ONCOLOGY/HEMATOLOGY, 2012;82(3):387-401. In order to understand how cultural factors are used to explain similarities and differences in EoL [end of life] care between Spain, Italy and Portugal, database and hand searches were performed and cross-cutting core themes identified. Similarities included higher proportions of people who wished to die at home than actually died at home, a persistent trend for partial disclosure in Italy and Spain, low use of advance directives, and low incidence of all medical EoL decisions (with the exception of terminal sedation) compared to northern European countries. The role of religion and the importance of family ties were the two main cultural factors used to explain the similarities. <http://www.sciencedirect.com/science/article/pii/S1040842811001600>

N.B. Italy was rated 24th, Spain 26th and Portugal 31st (of the forty countries surveyed) in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Addressing spirituality within the care of patients at the end of life: Perspectives of patients with advanced cancer, oncologists, and oncology nurses

JOURNAL OF CLINICAL ONCOLOGY | Online article – 21 May 2012 – The majority of patients (77.9%), physicians (71.6%), and nurses (85.1%) believed that routine spiritual care would have a positive impact on patients. Only 25% of patients had previously received spiritual care. Among patients, prior spiritual care, increasing education and religious coping were associated with favorable perceptions of spiritual care. Physicians held more negative perceptions ... than patients. Qualitative analysis identified benefits of spiritual care, including supporting patients' emotional well-being and strengthening patient-provider relationships. Objections to spiritual care frequently related to professional role conflicts. Participants described ideal spiritual care to be individualized, voluntary, inclusive of chaplains/clergy, and based on assessing and supporting patient spirituality. <http://jco.ascopubs.org/content/early/2012/05/18/JCO.2011.40.3766.abstract>

From Media Watch, 21 May 2012:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 11 May 2012 – **'What can we learn about the spiritual needs of palliative care patients from the research literature?'** [http://www.jpmsjournal.com/article/S0885-3924\(11\)00870-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(11)00870-0/abstract)
- *COCHRANE DATABASE OF SYSTEMATIC REVIEWS* | Online article – Accessed 15 May 2012 – **'Spiritual and religious interventions for well-being of adults in the terminal phase of disease.'** <http://discovery.ucl.ac.uk/1347180/>

Withdrawing and withholding artificial nutrition and hydration from patients in a minimally conscious state: *Re: M* and its repercussions

JOURNAL OF MEDICAL ETHICS | Online article – 17 May 2012 – In 2011 the English Court of Protection ruled that it would be unlawful to withdraw artificial nutrition and hydration from a woman, M, who had been in a minimally conscious state for 8 years. It was reported as the first English legal case concerning withdrawal of artificial nutrition and hydration from a patient in a minimally conscious state who was otherwise stable. In the absence of a valid and applicable advance decision refusing treatment, of other life-limiting pathology or excessively burdensome suffering, the judgement makes it clear that the obligation on health professionals falls strongly in favour of preserving life. Although the Court sought to limit the judgement as closely as possible to the facts of the case, it is likely to have a significant impact on life-sustaining treatment decisions for people in states of low awareness. This paper outlines the main legal features of the judgement. <http://jme.bmj.com/content/early/2012/05/16/medethics-2012-100662.abstract>

Cont.

- *JOURNAL OF MEDICAL ETHICS* | Online article – 17 May 2012 – **'Should we respect precedent autonomy in life-sustaining treatment decisions?'** The recent judgement in the case of *Re:M* in ... raises a number of ethical issues of wide application. Central to these is the extent to which precedent autonomous decisions should be respected in the absence of a legally binding advance decision. Well-being interests can survive the loss of many of the psychological faculties that support personhood. <http://jme.bmj.com/content/early/2012/05/16/medethics-2012-100663.abstract>

Of related interest:

- *PLOS ONE* | Online article accessed – 14 May 2012 – **'What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients.'** <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0037117>

Palliative care interventions may boost overall survival of cancer patients

NEWS MEDICAL | Online report – 19 May 2012 – Recent studies have shown that palliative care interventions aimed at addressing patients' emotional, spiritual and social needs have a significant impact on cancer patients' quality of life and may even improve cancer patients' overall survival. Despite this, most cancer patients being cared for in their communities do not have access to these services. Most cancer patients also do not have advance directives addressed and are not aware of the benefits of hospice services. In order to address this issue, researchers at Mayo Clinic in Florida decided to test whether a nurse practitioner-driven consultation that used quality-of-life assessment tools and advance directives tools resulted in improvement in the cancer patients' quality of life. The researchers ... say their study¹ suggests that a consultative visit between a nurse practitioner and a metastatic cancer patient goes a long way to improving that patient's emotional and mental well-being. <http://www.news-medical.net/news/20120519/Palliative-care-interventions-may-boost-overall-survival-of-cancer-patients.aspx>

1. 'A nurse practitioner directed intervention improves the quality of life of patients with metastatic cancer: Results of a randomized pilot study,' *Journal of Palliative Medicine*, posted 4 May 2012. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0014>

From Media Watch, 23 January 2012:

- *THE ONCOLOGIST* | Online article – 17 January 2012 – **'Palliative care in advanced cancer patients: How and when?'** Early palliative care access can improve symptom control and quality of life and reduce the cost of care [and] show that early palliative care access can also extend survival. <http://theoncologist.alphamedpress.org/content/early/2012/01/12/theoncologist.2011-0219.abstract>

From Media Watch, 1 January 2012:

- *JOURNAL OF CLINICAL ONCOLOGY* | Online article – 27 December 2011 – **'Effect of early palliative care on chemotherapy use and end-of-life care in patients with metastatic non-small-cell lung cancer.'** Prior research shows that introducing palliative care soon after diagnosis for patients with metastatic non-small-cell lung cancer is associated with improvements in quality of life, mood, and survival. <http://jco.ascopubs.org/content/early/2011/12/20/JCO.2011.35.7996.abstract>



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>

Routinization and medicalization of palliative care: Losses, gains and challenges

PALLIATIVE & SUPPORTIVE CARE | Online article – 15 May 2012 – This article investigates some of the criticisms that have been directed at the hospice movement in the process of interaction with the traditional Western healthcare system, such as those relative to its routinization and medicalization. It also aims to review some of the consequences of this process of institutionalisation for the field of end-of-life care: surveillance and control over the process of dying, at the expense of decisions preferably based on the patient and that patient's ability to decide how to die, with the loss of wider objectives originally established by the movement, such as unconditional reception for the patient. Based on these criticisms, some considerations are made regarding the moral implications and risks related to this specific mode of action, the hospice way of care.

<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8584120&fulltextType=RA&fileId=S1478951511001039>

From Media Watch ([Worth Repeating](#)), 18 July 2011:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2009;11(1):19-24. **'Hospice and palliative care: What unites us, what divides us?'** The modern development of the hospice palliative care movement in Canada is reviewed in the context of a social movement. Is this a social movement that has reached its conclusion with the mainstreaming and medicalization of palliative care? http://journals.lww.com/jhpn/Abstract/2009/01000/Hospice_and_Palliative_Care_What_Unites_Us_What.9.aspx

From Media Watch, 22 March 2010:

- CALIFORNIA | *Los Angeles Times* (OpEd) – 15 March 2010 – **'The medicalization of life.'** http://www.latimes.com/news/opinion/la-oe-welch15-2010mar15_0.6629446.story

"They don't just disappear": Acknowledging death in the long-term care setting

PALLIATIVE & SUPPORTIVE CARE | Online article – 15 May 2012 – Attendees felt that the room blessing provided an opportunity to formally acknowledge the death of the resident and their grief; the majority felt that this was a positive experience and that it provided an element of closure. Staff members and residents expressed their appreciation for the opportunity to connect with family members of the deceased to express their condolences during the ritual. Participants also identified the inclusivity of the ritual (i.e., an open invitation to all staff, residents, and family members) as a positive aspect that served as a reminder that others shared in their grief.

<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8584114&fulltextType=RA&fileId=S1478951511000964>

Of related interest:

- *DEATH STUDIES*, 2012;36(6):487-518. **'Five residents speak: The meaning of living with dying in a long-term care home.'** The lived experience of residents emerged as a compilation of 5 dynamically occurring themes, including a) mapping relations, b) pacing oneself, c) maintaining belongingness, d) reconciling death as part of life, and e) engaging in preparatory review. The overarching essence of the lived experience was defined as reflection toward resolution of dying as a "resident" in a sea of life gains and losses. Residents' expressions revealed that living with peers' dying in a nursing home is closely entwined with how life is experienced during one's final days. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2011.591608>

From Media Watch, 18 April 2011:

- *AGEING & SOCIETY*, 2011;31(4):529-544. **'A discourse of silence: Professional carers reasoning about death and dying in nursing homes.'** The [study's] findings show that the discourse had three characteristics: a) dying was silent and silenced; b) emotions were pushed into the background; and, c) attentiveness to death arose after the moment of the elderly person's death. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8235355&fulltextType=RA&fileId=S0144686X10000905>

Challenges in end-of-life care management for low-income frail elders: A case study of the Wisconsin Family Care Program

RESEARCH ON AGING | Online article – 21 May 2012 – A case study design was used to explore challenges encountered in the provision of end-of-life care management for low-income elders enrolled in an innovative partially integrated model of long-term care, in Wisconsin, the Milwaukee County Family Care program. The authors identified five major themes representing essential challenges: 1) complexity of care and high level of support needs; 2) communication constraints in advance care planning; 3) family conflicts in end-of-life decision making for elders; 4) insufficient communication and collaboration between elders, families, teams, and service providers; and, 5) limited bereavement and grief related support for families and teams after elders die. <http://roa.sagepub.com/content/early/2012/05/17/0164027512446939.abstract>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 21 May 2012 – '**Cancer family caregivers: A new direction for interventions.**' This study implicates several intervention components to be developed and tested as favorably supporting caregivers, namely, reinforcing positive aspects of caregiving, cultivating open communication, and acknowledging the prior experiences and social foundation of the caregiver's life that can be supportive or burdensome. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0046>

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.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/news.htm> (Scroll down to 'International End of Life Roundup')

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>

Managing multiple goals in family discourse about end-of-life health decisions

RESEARCH ON AGING | Online article – 16 May 2012 – Previous research on end-of-life communication in families has largely considered whether family members have talked about end-of-life healthcare (quantity of talk) but not whether certain characteristics of that discourse matter (quality of talk). In the current study, the authors adopted a multiple goals theoretical perspective to examine discursive features that individuals use to manage goal dilemmas in family conversations about end-of-life health choices. Discourse analysis of end-of-life conversations between 121 older adults and their adult children showed that participants attended to relevant task, identity, and relational goals in ways that affirmed or threatened these goals, and the ways in which certain goals were accomplished had implications for how (and whether) other goals were pursued. <http://roa.sagepub.com/content/early/2012/05/14/0164027512446942.abstract>

Of related interest:

- *BMC MEDICAL ETHICS* | Online article – 20 May 2012 – **'The four principles: Can they be measured and do they predict ethical decision making?'** People state they value these medical ethical principles but they do not actually seem to use them directly in the decision making process. <http://www.biomedcentral.com/content/pdf/1472-6939-13-10.pdf>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BIOETHICS*, 2012;26(5):231-235. **'The dangers of euthanasia and dementia: How Kantian thinking might be used to support non-voluntary euthanasia in cases of extreme dementia.'** Some writers have argued that a Kantian approach to ethics can be used to justify suicide in cases of extreme dementia, where a patient lacks the rationality required of Kantian moral agents. I worry that this line of thinking may lead to the more extreme claim that euthanasia is a proper Kantian response to severe dementia (and similar afflictions). Such morally treacherous thinking seems to be directly implied by the arguments that lead Dennis Cooley and similar writers to claim that Kant might support suicide. If rationality is the only factor in valuing a human life, then the loss of that rationality (however such loss might be defined) would allow us to use essentially utilitarian thinking in order to support non-voluntary euthanasia, since the patients themselves would no longer be moral agents that demand respect. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2011.01951.x/abstract>

N.B. Kantianism is the philosophy of Immanuel Kant, a German philosopher. The term Kantianism or Kantian is sometimes also used to describe contemporary positions in philosophy of mind, epistemology, and ethics. Source: <http://en.wikipedia.org/wiki/Kantianism>

- *SOCIAL SCIENCE & MEDICINE* | Online article – 17 May 2012 – **'Cultural differences affecting euthanasia practice in Belgium: One law but different attitudes and practices in Flanders and Wallonia.'** Acceptance of euthanasia by the general population was found to be slightly higher in Flanders than in Wallonia. Compared with their Flemish counterparts, Walloon physicians held more negative attitudes towards performing euthanasia and towards the reporting obligation, less often labeled hypothetical cases correctly as euthanasia, and less often defined a case of euthanasia having to be reported. A higher proportion of Flemish physicians had received a euthanasia request since the introduction of the law [in 2002]. In cases of a euthanasia request, Walloon physicians consulted less often with an independent physician. Requests were more often granted in Flanders than in Wallonia, and performed euthanasia cases were more often reported. The study points out some significant differences between Flanders and Wallonia in practice, knowledge and attitudes regarding euthanasia and its legal requirements which are likely to explain the discrepancy between Wallonia and Flanders in the number of euthanasia cases reported. Cultural factors seem to play an important role in the practice of (legal) euthanasia and the extent to which legal safeguards are followed. <http://www.sciencedirect.com/science/article/pii/S0277953612003772>

Barry R. Ashpole
Beamsville, Ontario CANADA

'phone: 905.563.0044
e-mail: barryashpole@bellnet.ca