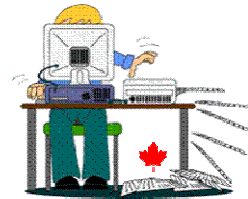


Media Watch...

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.

12 December 2011 Edition | Issue #231



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Compiled & Annotated by Barry R. Ashpole

U.K. National Council for Palliative Care survey: Scroll down to [International](#) and 'Staff shortage' for terminally ill' (p.5), from Associated Press.

[Canada](#)

Economics of end-of-life care

Hospices dispute fee for patients who live longer than expected

BRITISH COLUMBIA | *Times-Colonist* (Victoria) – 6 December 2011 – [The B.C. Hospice & Palliative Care Association] is taking issue with a provincial policy that bills patients a \$30 per day fee for living longer than expected. The province has a long-standing policy in place to reassess palliative-care patients when they improve under care. "The idea of charging a fee to people who are designated as hospice/palliative care (is something) I've really struggled with over the years," said Fraser Black, medical director at Victoria Hospice. "The last thing these patients and families need to be worried about is finances." The fee is applicable to people who are in hospice residential beds, not in acute beds or tertiary palliative-care beds. The policy has been in place for more than a decade, but it has not been consistently enforced. <http://www.timescolonist.com/health/Hospices+dispute+patients+live+longer+than+expected/5821772/story.html>

Impoverished veterans

Feds to slash 36% from Last Post Fund budget

TORONTO SUN | Online report – 5 December 2011 – Veterans Affairs plans to shave \$4million – or 36% – from the \$11 million budget of federal program that ensures impoverished ex-soldiers are buried with dignity. But Veterans Ombudsman Guy Parent and other stakeholders have been sounding the alarm that the Last Post Fund is already badly underfunded – to the tune of \$12 million a year. The federal government has been aware of problems with its burial assistance program for vets since at least 2009. That year, a federal audit raised concerns about the program and listed seven recommendations that included boosting funding, reducing red tape, and extending the program to all veterans – not just those who fought in the Second World War and Korean War. <http://www.torontosun.com/2011/12/05/feds-to-slash-36-from-last-post-fund-budget>

Resource allocation

Keeping ailing folks at home: Current system just doesn't work

NOVA SCOTIA | *Chronicle-Herald* (OpEd) – 5 December 2011 – In its 'Continuing Care Strategy for Nova Scotia,'¹ the provincial government has indicated that providing home care, respite, and palliative care in homes and communities is a main focus of its long-term care strategy. The implication is that, with improved home care, we won't need as many long-term care beds because people will be able to stay in their homes right to the ends of their lives. And, in an ideal world, that would certainly be the case. But the idea of shifting care from long-term care beds to the home scares me – a lot – because I'm highly sceptical that there will be enough support (both physical and financial) provided to family caregivers to actually make home care a feasible choice. <http://thechronicleherald.ca/hcw/39541-keeping-ailing-folks-home-current-system-just-doesn%E2%80%99t-work>

1. *Continuing Care Strategy for Nova Scotia: Shaping the future of Continuing Care*, Nova Scotia Health, 2011. http://www.gov.ns.ca/health/ccs_strategy/Continuing_Care_Strategy.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *Globe & Mail* – 7 December 2011 – **"Good death' in Swiss clinic held up as model.** Kathleen (Kay) Carter achieved the kind of "good death" that applicants in a right-to-die case say should be a right for all Canadians – the only problem was that she had to leave the country to get it. <http://www.theglobeandmail.com/life/health/end-of-life/good-death-in-swiss-clinic-held-up-as-model/article2263912/>
- QUEBEC | *Montreal Gazette* (OpEd) – 7 December 2011 – **'Assisted-suicide panel failed to present balanced arguments.'** Responding to the Royal Society of Canada's Expert Panel Report on End-of-Life Decision Making,¹ which recommended the legalization of euthanasia and physician-assisted suicide, a *Gazette* editorial called for "a national debate on life-and-death issues."² In deciding where we stand on this issue, it's important for Canadians to understand the weaknesses of the report. It is not "a careful, balanced review of various pros and cons of decriminalization of physician-assisted death from well-reasoned ethical and legal standpoints" required in the panel's mandate. <http://www.montrealgazette.com/health/Assisted+suicide+panel+failed+present+balanced+arguments/5826773/story.html>
 1. *Royal Society of Canada Expert Panel: End of Life Decision Making*, November 2011 (noted in Media Watch dated 21 November 2011). http://www.rscsrc.ca/documents/RSCEndofLifeReport2011_EN_Formatted_FINAL.pdf
 2. 'We need a national debate on life-and-death issues,' *Montreal Gazette* (OpEd), 24 November 2011 (noted in Media Watch dated 28 November 2011). <http://www.montrealgazette.com/news/need+national+debate+life+death+issues/5758661/story.html>

U.S.A.

Virginia launches registry for advance health directives

VIRGINIA | *Virginia-Pilot* (Norfolk) – 8 December 2011 – Virginia has launched a registry in which state residents can file advance health directives online, so medical providers can know their wishes during an emergency. The online registry ... allows people to name a medical power of attorney and describe what type of health care they desire in an emergency or a situation where they are incapacitated. People can also download important directives such as do-not-resuscitate orders and permission for organ donation. The service is free for all Virginia residents. <http://hamptonroads.com/2011/12/virginia-launches-advance-health-directive-registry>

Occupy elder care: Why caregivers are bad advocates

FORBES | Online OpEd – 7 December 2011 – Why are caregivers for the elderly such bad advocates? There are 40-60 million Americans caring for loved ones yet their needs are widely ignored by the political system. Thus, politicians rarely rouse themselves to do much to help, and when budget-cutting time comes, what little assistance there is often ends up on the block. Interestingly, advocates for people with disabilities and their caregivers are very good at this. The Americans with Disabilities Act is just one example of how they have influenced policy. Why? In part it is because people with disabilities can be powerful advocates for themselves while the frail elderly often cannot. <http://www.forbes.com/sites/howardgleckman/2011/12/07/occupy-elder-care-why-caregivers-are-bad-advocates/>

U.S. hospice care revealed as \$14billion market

BLOOMBERG NEWS | Online article – 6 December 2011 – Hospice care, once chiefly a charitable cause, has become a growth industry, with \$14 billion in revenues, 1,800 for-profit providers and a base of Medicare-covered patients that doubled to 1.1 million from 2000 to 2009. Compensation based on enrolment numbers, pay to nursing-home doctors who double as hospice medical directors, and gifts to the nursing facilities have helped fuel the boom, according to an examination of 1,000 pages of court documents and interviews with more than 45 current and former hospice employees, patients and family members. <http://www.bloomberg.com/news/2011-12-06/hospice-care-revealed-as-14-billion-u-s-market.html>

Cost, confusion rife in end-of-life care

PENNSYLVANIA | *Philadelphia Tribune* (OpEd) – 6 December 2011 – Every medical study ever conducted has concluded that 100% of all Americans will eventually die. This comes as no great surprise, but the amount of money being spent at the very end of people's lives probably will. As we prepare for a decision from the Supreme Court, in all the discussion of health-care reform, there is one issue that has received almost no attention, but has the potential to save billions of dollars and untold suffering if it is effectively addressed. I'm talking about futile treatments at or near the end of life. <http://www.phillytrib.com/healtharticles/item/1807-cost-confusion-rife-in-end-of-life-care.html>

From Media Watch dated 7 November 2011:

- FLORIDA | *Miami Herald* – 2 November 2011 – **'Daughter's complaint puts focus on Medicare payment to for-profit hospice.'** In the past five years, hospice services have been the fastest-growing Medicare service – climbing an average of 10% per year, a Medicare spokeswoman says. <http://www.miamiherald.com/2011/10/09/2446620/daughters-complaint-puts-focus.html>

From Media Watch dated 10 October 2011:

- CALIFORNIA | *Sacramento Business Journal* – 7 October 2011 – **'End-of-life care ... for profit.'** Rapid growth by for-profit companies that dominate the national market has heightened competition and increased options for care – but also has raised questions for some about whether it's appropriate for a commercial enterprise to make money off of the most vulnerable of patients. <http://www.bizjournals.com/sacramento/print-edition/2011/10/07/first-health-care-story.html>

From Media Watch dated 8 August 2011:

- FLORIDA | *Florida Trend* (St. Petersburg) – 1 August 2011 – **'Hospices in Florida: From cause to commerce.'** Between 2000 and 2007, the number of non-profit hospices nationally has remained at around 1,200, while the number of for-profit hospices more than doubled, from 725 to 1,660. <http://www.floridatrend.com/article.asp?aID=55369&mostread=true>

Bigger roles for chaplains on patient medical teams

WALL STREET JOURNAL | Online article – 6 December 2011 – Chaplains are seeking bigger roles in hospitals and in some cases joining the medical-care team, as new research shows positive spiritual guidance and discussion can help improve a patient's medical outcome. As interest rises in the links between religion, spirituality and health, there is a new push to establish chaplaincy in the medical mainstream and apply more rigorous scientific research. Medical schools are adding courses on spirituality and health, and training residents to consider patients' spiritual needs. Studies indicate as many as 40% of patients with serious illnesses ... struggle with spiritual concerns, which can harm emotional and physical well-

being, says George Fitchett, the Department of Religion, Health & Human Values at Rush University Medical Center Chicago.

http://online.wsj.com/article/SB10001424052970204826704577074462494881428.html?mod=googlenews_wsj

Specialist Publications

Of particular interest:

'Incorporating spirituality in end-of-life nursing care' (p.7), published in the *End of Life Journal*.

International

Spot-check on quality of care

Leeds hospice wins praise from Care Quality Commission

U.K. (ENGLAND) | *Yorkshire Evening Post* – 9 December 2011 – A Leeds hospice has won praise from the Care Quality Commission (CQC) after its first random spot-check. An inspector said staff at St. Gemma's Hospice treated patients with "safe and appropriate care" and respect – and reportedly said that if all services were the same, she would be "out of a job." The St Gemma's report is split into six outcomes – respecting and involving people who use services; care and welfare of people who use services; safeguarding people who use services from abuse; cleanliness and infection control; supporting staff; and assessing and monitoring the quality of service provision. http://www.yorkshireeveningpost.co.uk/news/latest-news/central-leeds/leeds_hospice_wins_praise_from_care_quality_commission_1_4044881

From Media Watch dated 28 November 2011:

- U.K. (ENGLAND) | *Public Finance* – 22 November 2011 – **'Care Quality Commission launches spot checks on home care providers.'** The ... Commission will carry out spot inspections of 250 home care providers next year to root out 'bad practice' in the sector. The 'themed' inspections will focus on the respect, care and welfare of people who receive care services in their own homes, as well as the support given to staff. <http://www.publicfinance.co.uk/news/2011/11/cqc-launches-spot-checks-on-home-care-providers/>

Of related interest

- U.K. (ENGLAND) | BBC News – 11 December 2011 – **'Plans for greater scrutiny of elderly care in England.'** Plans to "radically drive up" standards of social care in England to protect the elderly have been unveiled by the government. They include an online "good care guide" to allow family members to rate and review care homes and providers. Committees featuring relatives of care users will also be formed to scrutinise services that do not meet standards. <http://www.bbc.co.uk/news/health-16125463>

'Staff shortage' for terminally ill

U.K. (ENGLAND) | Associated Press – 6 December 2011 – Specialist care of the dying may be put at risk in the future because of a recruitment crisis, a health charity has warned. An ageing nursing workforce combined with staff shortages could pose serious problems for specialist care of the terminally ill, the National Council for Palliative Care said. A survey by the charity has shown that the number of specialist palliative care nurses fell by 6.9% from 2008 to 2010. The study also showed an average vacancy rate among specialist palliative care nurses of 8.7% and among specialist palliative care consultants of 7.8%. Almost four out of 10, or 39.2%, of specialist palliative care nurses were over the age of 50, as were 44.7% of social workers, 36.3% of physiotherapists and 25.3% of occupational therapists. More than a quarter ... of specialist palliative care consultants were aged over 50. The findings come as the number of people dying each year is predicted to increase from about 500,000 to 586,000 in England and Wales by 2030. <http://www.google.com/hostednews/ukpress/article/ALeqM5jse0kQtHb4LXUI8UHF6a2r3TeCMw?docId=N0282741323167975213A>

1. Specialist Palliative Care Workforce Survey & Specialist Palliative Care Longitudinal Survey of English Cancer Networks, National Council for Palliative Care, December 2011. <http://ncpc.org.uk/library?keyword=workforce&date1=07%2F12%2F2011&date2=07%2F12%2F2011>
1

National Health Service hospitals warned over 'do not resuscitate' orders

U.K. (ENGLAND) | *Daily Telegraph* – 5 December 2011 – Hospitals have been ordered to improve the way they record their decisions on whether or not to resuscitate patients amid fresh evidence of a failure to create a proper dialogue about those decisions with patients and relatives. <http://www.guardian.co.uk/society/2011/dec/05/nhs-hospitals-warned-resuscitate-orders?newsfeed=true>

From Media Watch dated 17 October 2011:

- U.K. | *Daily Telegraph* – 15 October 2011 – **'Elderly patients condemned to early death by secret use of do not resuscitate orders.'** Elderly patients are being condemned to an early death by hospitals making secret use of "do not resuscitate" orders, an investigation has found. <http://www.telegraph.co.uk/health/elderhealth/8829350/Elderly-patients-condemned-to-early-death-by-secret-use-of-do-not-resuscitate-orders.html>

From Media Watch dated 12 September 2011:

- U.K. | *Daily Mail* – 6 September 2011 – **'Do not resuscitate: They're the fateful words meaning doctors won't try to save you if you collapse in hospital. But could they go on YOUR file without you being asked?'** Throughout England and Wales, bereaved relatives have discovered that the decision not to resuscitate had been taken without either the patient or their family being consulted. <http://www.dailymail.co.uk/health/article-2034160/Do-resuscitate-Theyre-fateful-words-meaning-doctors-wont-try-save-you-collapse-hospital.html?ito=feeds-newsxml>

N.B. The issue of do not resuscitate orders has in recent months generated significant media attention in the U.K. (see Media Watch dated 5 September and 29 August 2011, p.5 and p.2, respectively).

[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>

Initiatives in children's hospice

Precious time with sick babies

U.K. (WALES) | *Western Mail* (Cardiff) – 5 December 2011 – Tŷ Hafan has developed a new palliative care service to support families with very sick newborn babies. It comes after the South Wales [and the region's only] children's hospice had a number of referrals from families with babies diagnosed with a life-threatening illness. The hospice has supported some families through pregnancy, after diagnosis, and others following the birth of their child. It has also arranged for some parents, such as Angela Newman and Stephen Price [see sidebar right], to bring their critically-ill baby out of hospital and to the hospice to die. <http://www.walesonline.co.uk/news/health-news/2011/12/05/precious-time-with-sick-babies-91466-29893352/>

Hospice where parents and their sick children can 'just be a family'

Katie was the baby Angela and partner Stephen thought they might never have, after suffering two miscarriages. Sadly Katie died just days after she was born with an under-developed heart. But rather than passing away in a busy neonatal unit surrounded by machines, wires and hospital staff, Katie died in her father's arms in the peaceful surroundings of the Tŷ Hafan children's hospice. <http://www.walesonline.co.uk/news/wales-news/2011/12/05/hospice-where-parents-and-their-sick-children-can-just-be-a-family-91466-29893353/>

N.B. Tŷ Hafan: <http://www.tyhafan.org/what-is-ty-hafan/>

Of related interest:

- U.K. | BBC News – 5 December 2011 – **'Little Harbour children's hospice ready for families.'** Cornwall's first children's hospice will open to families this week after a four-year campaign to raise £5million. Little Harbour ... will cater for six terminally-ill children and their families at a time. The charity Children's Hospice South West started the campaign in September 2007 and reached its target in September 2011. <http://www.bbc.co.uk/news/uk-england-cornwall-16027407>

Specialist Publications

Of particular interest:

'Parents' experiences with life-threatening fetal diagnosis' (p.11), published in the *Journal of Palliative Medicine*

Quotable Quotes

It's still unclear who needs whom more, whether sick children need us more, or whether we need them most. They help us to compare our trivial trials with true suffering; to see what is really important, and what is ephemeral and of no value at all. Patriarch Kirill Gundyayev of Moscow and all the Russias, November 2010, on a visit to Russia's only children's hospice. <http://www.youtube.com/watch?v=IK7NL7k8hFY>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | *Daily Telegraph* (U.K.) – 6 December 2011 – **'Mobile euthanasia teams being considered by Dutch government.'** In a written answer to questions from Christian Union MPs, Edith Schippers, the health minister, said that mobile units "for patients who meet the criteria for euthanasia but whose doctors are unwilling to carry it out" was worthy of consideration. <http://www.telegraph.co.uk/news/worldnews/europe/netherlands/8938917/Mobile-euthanasia-teams-being-considered-by-Dutch-government.html>

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

Technology and end of life care

How technology can connect doctors and caregivers

AMERICAN MEDICAL NEWS | Online article – 5 December 2011 – With more than 29% of the U.S. population acting as a caregiver to someone else, chances are that physicians eventually will be faced ... with questions about how they can work with caregivers to ensure the health of the person receiving care. The majority of caregivers spend an average of 20 hours per week providing care, in addition to holding down a full-time job. To help make things more efficient, many are turning to technology that not only will supplement the care they are providing in person, but also will help them stay organized and connected with the care recipient's physicians or fellow caregivers. <http://www.ama-assn.org/amednews/2011/12/05/bisa1205.htm>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 4 December 2011 – **'Assessing the readiness of hospice volunteers to utilize technology.'** Despite the use of technology, communication problems with volunteers hindered the coordinator's ability to manage scheduling, training, and volunteer assignments for patient care. Coordinators and volunteers felt comfortable utilizing technology but were less comfortable using technology in the patients' home. <http://ajh.sagepub.com/content/early/2011/11/23/1049909111429559.abstract>

Incorporating spirituality in end-of-life nursing care

END OF LIFE JOURNAL | Online article – Accessed 9 December 2011 – Recent U.K. health policy has acknowledged the importance of spiritual assessment. However, spiritual assessment within the context of end-of-life care presents fundamental problems for practitioners, as it is not clear what is meant by the term 'spirituality' or how relevant it is in an age purported to be increasingly secular. This article aims to explore spirituality in the context of life-limiting disease. <http://endoflifejournal.stchristophers.org.uk/clinical-practice-development/incorporating-spirituality-in-end-of-life-nursing-care>

Reflections on palliative care from the Jewish and Islamic tradition

EVIDENCE-BASED COMPLEMENTARY & ALTERNATIVE MEDICINE | Online article – Accessed 6 December 2011 – All healthcare providers are likely to encounter Muslim patients, yet many lack basic knowledge of the Muslim faith and of the applications of Islamic teachings to palliative care. Similarly, some of the concepts underlying positive Jewish approaches to palliative care are not well known. The authors outline Jewish and Islamic attitudes toward suffering, treatment, and the end of life. They discuss other religions' approaches to treatments deemed unnecessary by medical staff, and consider some of the cultural reasons that patients and family members might object to palliative care, concluding with specific suggestions for the medical team. <http://www.hindawi.com/journals/ecam/2012/693092/>

From Media Watch dated 28 March 2011:

- *JOURNAL OF MEDICAL ETHICS* | Online article – 23 March 2011 – **'Disclosure of terminal illness to patients and families: Diversity of governing codes in 14 Islamic countries.'** Codes for 14 Islamic countries were located. Five codes were silent regarding informing the patient, seven allowed concealment, one mandated disclosure and one prohibited disclosure. Five codes were silent regarding informing the family, four allowed disclosure and five mandated/recommended disclosure. The Islamic Organization for Medical Sciences code was silent on both issues. <http://jme.bmj.com/content/early/2011/03/22/jme.2010.038497.abstract>

N.B. Several articles on the Islamic faith and end-of-life care that have been noted in past issues of Media Watch are footnoted (p.10).

Cont.

From Media Watch dated 4 October 2011:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 27 September 2010 – **'Caring for the dying patient from an Orthodox Jewish perspective.'** This article describes end-of-life guidelines for hospital health care professionals caring for Orthodox Jewish patients and their families. Religious perspectives on advance directives, comfort care and pain control, nutrition and hydration, do not resuscitate/do not intubate (DNR/DNI), and extubation are often unfamiliar to the American medical community. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0088>

Meeting the needs of Somali patients at the end of life

MINNESOTA MEDICINE (U.S.) | Online article – Accessed 5 December 2011 – Given the large number of Somali refugees living in Minnesota, it is likely that Minnesota physicians will encounter Somali patients, some of whom will have serious illnesses. Although our knowledge of Somali expectations about health care is growing, little has been written about the Somali people's views of treatment for life-threatening illnesses or their ideas about end-of-life care.

<http://www.minnesotamedicine.com/CurrentIssue/MeetingtheNeedsOfSomaliPatientsattheEndof.aspx>

Knowing loved ones' end-of-life health care wishes: Attachment security predicts caregivers' accuracy

HEALTH PSYCHOLOGY, 2011;30(6):814-818. Very little is known about the factors that make caregivers more or less accurate as surrogate decision makers for their loved ones. Previous research suggests that in low stress situations, individuals with high attachment-related anxiety are attentive to their relationship partners' wishes and concerns, but get overwhelmed by stressful situations. Individuals with high attachment-related avoidance are likely to avoid intimacy and stressful situations altogether. The authors hypothesized that both of these insecure attachment patterns limit surrogates' ability to process distressing information and should therefore be associated with lower accuracy in the stressful task of predicting their loved ones' end-of-life health care wishes. Surrogates [i.e., the subjects of this study] high on either type of insecure attachment dimension were less accurate in predicting their loved ones' end-of-life health care wishes. It is interesting to note that even though surrogates' attachment-related anxiety was associated with lower accuracy of end-of-life health care wishes of their loved ones, it was associated with higher accuracy in the non-stressful task of predicting their loved ones' everyday living conditions. <http://psycnet.apa.org/journals/hea/30/6/814/>

From Media Watch dated 7 November 2011:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2011;42(5):777-782. **'Responding to surrogate requests that seem inconsistent with a patient's living will.'** Clinicians may feel conflicted when a patient's legal decision maker is making decisions that seem inconsistent with a patient's living will. The authors provide evidence-based information to help clinicians consider whether a surrogate's inconsistent decisions are ethically appropriate. Surrogates are not flawless translators of their loved one's preferences; they are influenced by their own hopes and the current clinical context. [http://jpsmjournal.com/article/S0885-3924\(11\)00427-1/abstract](http://jpsmjournal.com/article/S0885-3924(11)00427-1/abstract)

End-of-life care in France

Impact of an intensive communication strategy on end-of-life practices in the intensive care unit

INTENSIVE CARE MEDICINE | Online article – 30 November 2011 – Since the 2005 French law on end of life and patients' rights, it is unclear whether practices have evolved. The authors investigated whether an intensive communication strategy based on this law would influence practices in terms of withholding and withdrawing treatment, and outcome of patients hospitalised in intensive care. <http://www.springerlink.com/content/c83271461q254054/>

'Death rounds' shown to help students cope

IRISH MEDICAL TIMES | Online article – 8 December 2011 – 'Death rounds' are a useful way of helping neurology residents to deal with the emotional issues surrounding death, as well as helping them learn basic end-of-life care, suggests new research.¹ Attempting to address a finding that neurology residents were often unprepared to care for dying patients, neurologists in a U.S. teaching hospital introduced 'death rounds' – informal, clinical case discussions devoted to residents' responses to, and experiences with, the death of patients. "Death rounds typically consists of three-to-five case discussions among 10 to 15 team members, including medicine interns, neurology residents and attendings," the study authors wrote. "The facilitator first reads aloud the names of all patients who died in the inpatient service during the preceding month and residents choose to discuss cases they found particularly memorable." The team was encouraged to focus on the details of quality of the dying process rather than on medical aspects of the deaths and the facilitator urged them to view the dying process as a natural part of care, not as a reason to search for errors. <http://www.imt.ie/clinical/2011/12/death-rounds-shown-to-help-students-cope.html>

1. 'Coping with death and dying on a neurology inpatient service : Death rounds as an educational initiative for residents,' *Archives of Neurology*, 2011;68(11):1395-1397. <http://archneur.ama-assn.org/cgi/content/short/68/11/1395>

End of life care in Belgium

The use of palliative care services associated with better dying circumstances: Results from an epidemiological population-based study in the Brussels metropolitan region

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2011;42(6):839-851. Although numerous studies have shown that most patients prefer to spend their final days at home if possible, many patients will instead die in nursing homes or hospitals. In this issue, Joachim Cohen and colleagues report on the results of a population-based mortality follow-back study in Brussels in which they found that only 12% of patients died at home. However, they also report that only 27% of patients' physicians were aware of their patients' preferences regarding site of care. Most importantly, they report that 66% of patients who wanted to die at home were able to do so. [http://jpsmjournals.com/article/S0885-3924\(11\)00161-8/abstract](http://jpsmjournals.com/article/S0885-3924(11)00161-8/abstract)

Of related interest:

- *PALLIATIVE MEDICINE* | Online article – 5 December 2011 – '**Social-cultural factors in end-of-life care in Belgium: A scoping of the research literature.**' Various socio-cultural factors influence the provision of EoL care in Belgium. This country provides a unique opportunity to witness how euthanasia is put into practice when legalized, in a context where palliative care is also highly developed and where many health care institutions have Catholic affiliation, providing an important example to others. Attention to how the socio-cultural context affects EoL care adds to the current evidence base of service provision, which is essential in the further development of EoL care. <http://pmj.sagepub.com/content/early/2011/12/05/0269216311429619.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>

Ethical decisions in palliative care: How well are palliative care teams prepared to make them?

JOURNAL OF PALLIATIVE CARE & MEDICINE | Online article – Accessed 5 December 2011 – Making decisions related to health care issues is a demanding task. These decisions are influenced by many combined factors related to the patient, their relatives, and the professional as an individual and as a team member, beyond other factors considering the team as a whole. When these decisions are concerned to [sic] palliative and end-of-life care, ethical dilemmas or problems may occur (e.g., decisions related to place of care and death, decisions regarding therapeutic interventions for symptom control, decisions about withholding and/or withdrawing treatments, decisions considering truth disclosure and communication, decisions considering patients' autonomy and self-determination, decisions related to the justice and resource distribution). Besides these problems, even though palliative care principles reject interventions in order to postpone or hasten death, issues such as medical futility, euthanasia and physician assisted suicide need to be reflected and discussed. <http://omicsgroup.org/journals/JPCM/JPCM-1-e101.pdf>

Of related interest:

- *AMERICAN JOURNAL OF BIOETHICS*, 2011;11(2):13-16. **'Reason giving: When public leaders ignore evidence.'** Discussion of bioethics-related policy, given its value-laden nature, can result in heated and emotional discourse. Political leaders significantly affect public deliberations surrounding bioethical issues, and as policy experts, they should be held accountable to a set of virtues needed for deliberative democracy. The authors examine two prominent examples, Sarah Palin decrying "death panels" in the U.S. ... and Thabo Mbeki denying HIV as the cause of AIDS in South Africa. <http://www.tandfonline.com/doi/abs/10.1080/15265161.2011.626995>
- *CHEST*, 2011;140(6):1625-1632. **'The ethics and reality of rationing in medicine.'** Rationing is the allocation of scarce resources, which in health care necessarily entails withholding potentially beneficial treatments from some individuals. Rationing is unavoidable because need is limitless and resources are not. How rationing occurs is important because it not only affects individual lives but also expresses society's most important values. This article discusses: 1) the inevitability of rationing of social goods, including medical care; 2) types of rationing; 3) ethical principles and procedures for fair allocation; and, 4) whether rationing ICU care to those near the end of life would result in substantial cost savings. <http://chestjournal.chestpubs.org/content/140/6/1625.abstract>
- *CLINICAL ETHICS*, 2011;6(4):167-171. **'Challenging some myths about the right to life at the end of life: Not an absolute right.'** The present article focuses upon the myth that the right to life is an absolute right, always requiring the preservation of life. It identifies three distinct situations in which state authorities may be justified in declining to take intervening action in order to save a life. It argues that the right to life encompasses recognition of the impossibility and undesirability of preserving human life in all circumstances and that recognition of this fact will render the right more useful in a health-care context. <http://ce.rsmjournals.com/content/6/4/167.abstract>
- *DEATH STUDIES*, 2012;36(1):23-40. **'Death competence: An ethical imperative.'** The authors argued that death competence, defined as specialized skill in tolerating and managing clients' problems related to dying, death, and bereavement, is a necessary prerequisite for ethical practice in grief counseling. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2011.553503>
- *EUROPEAN JOURNAL OF HEALTH LAW*, 2011;18(5):531-547. **'Parents as decision-makers – do the attitudes of Norwegian doctors conform to law?'** This study indicates that doctors may permit parental/surrogate decision-making to a greater extent than justified by law, sometimes in contravention of the child's best interests, which should be a fundamental guideline in all decisions that concern children. The authors conclude that Norway needs a precedent decision from the Supreme Court that confirms the right of judicial review of end-of-life decisions, and which applies the principle of the child's best interests as a fundamental guideline in the final decision. <http://www.ingentaconnect.com/content/mnp/ejhl/2011/00000018/00000005/art00005>

Cont.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2011;42(6):961-966. '**Denying a patient's final will: Public safety vs. medical confidentiality and patient autonomy.**' Especially when caring for patients approaching the end of life, physicians and nursing staff feel committed to fulfilling as many patient desires as possible. However, sometimes a patient's "final will" may threaten public safety. <http://www.sciencedirect.com/science/article/pii/S0885392411005112>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 7 December 2011 – '**Organ donation after cardiac death from withdrawal of life support in patients with amyotrophic lateral sclerosis.**' Patients may legally and ethically refuse life-sustaining care. These patients [i.e., case studies] considered their lives to be more burdensome than beneficial near the end of their lives, both carefully planned the time and circumstance of their deaths, and both fulfilled a long-standing desire to donate their organs. This study describes a potential opportunity for patients with progressive neurologic illness. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0239>

"My baby is a person"

Parents' experiences with life-threatening fetal diagnosis

JOURNAL OF PALLIATIVE MEDICINE, 2011;14(12):1302-1308. Diagnosis of a lethal fetal diagnosis (LFD) early in pregnancy is devastating for parents. Those who choose to continue with the pregnancy report intense emotional reactions and inconsistent, often insensitive treatment by health care providers. This ... study sought to clarify the experiences and needs of families in order to design responsive perinatal palliative care services, and to establish the feasibility and acceptability of conducting intensive interviews of pregnant women and their partners during their pregnancy with a LFD. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0165>

Media Watch: Editorial Practice

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

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Something Missed or Overlooked?

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

The care of the very old in the last three days of life

JOURNAL OF PALLIATIVE MEDICINE, 2011;14(12):1339-1344. As life expectancy has increased, the age at which people are dying has also increased. There is limited knowledge of the experience of dying of the very old. We sought to examine the last 3 days of life for the very old, dying in a palliative care unit, focusing upon symptom burden and medications prescribed. The very old appear to have a distinct experience of palliative inpatient care with shorter admissions, and lower requirements for medication. Reasons for lower medication requirements are discussed, and the need for future prospective studies in this area is highlighted. A better understanding of the needs of this population at end of life will enable adequate service planning and improved care. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0308>

Call for research on nurse role in palliative care prescribing

NURSING TIMES (U.K.) | Online article – 1 December 2011 – The National Institute for Health & Clinical Excellence last week published draft guidance on strong opioid prescribing in palliative care.¹ It highlighted that many patients were concerned about side effects, becoming addicted to the drugs or that they implied "the final stages of life" – all of which affected adherence. The guidance promotes good communication between clinicians and patients as "essential." It said clinicians should ask patients about their concerns and offer access to frequent pain control reviews and information on who to contact out of hours, particularly during initiation of treatment. Patients should also be advised that nausea or drowsiness may occur when starting opioids or at dose increase, but is "likely to be transient." But the document also said research was needed to "determine how to address the main concerns of patients, the level of information they require and the best time and methods to deliver this." This should examine "the benefits of greater involvement in this process by specialist nurses," it said. <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/call-for-research-on-nurse-role-in-palliative-care-prescribing/5038843.article>

1. 'Opioids in palliative care: Safe and effective prescribing of strong opioids for pain in palliative care of adults,' National Institute for Health & Clinical clinical guideline (Draft for consultation), December, 2011 <http://www.nice.org.uk/nicemedia/live/12953/57394/57394.pdf>

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/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation Services: <http://www.hpconnection.ca/newsletter/inthenews.html>

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

U.S.A.

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

International

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

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

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

Reduced use of chemotherapy at the end of life in an integrated-care model of oncology and palliative care

TUMORI, 2011;97(5):573-577. When there is little hope of a clinical benefit, too delayed a withdrawal from chemotherapy might be detrimental for a patient's quality of life. The authors evaluated appropriately timed cessation of chemotherapy ... after integration of a Supportive & Palliative Care Unit. [This] integration decreased chemotherapy use in the last 30 days of life. A careful evaluation of prognostic factors of advanced cancer patients and provision of appropriate supportive and palliative cares can reduce the use of futile anticancer chemotherapy and preserve a patient's quality of life. [http://www.tumorionline.it/allegati/00989_2011_05/fulltext/06-Magarotto\(573-577\).pdf](http://www.tumorionline.it/allegati/00989_2011_05/fulltext/06-Magarotto(573-577).pdf)

From Media Watch dated 26 September 2011:

- *BMC PALLIATIVE CARE* | Online article – 21 September 2011 – **'The effect on survival of continuing chemotherapy to near death.'** [In this study] receipt of chemotherapy was associated with a 2-month improvement in overall survival. However, based on three different statistical approaches, no additional survival benefit was evident from continuing chemotherapy within 14 days of death. <http://www.biomedcentral.com/content/pdf/1472-684x-10-14.pdf>

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