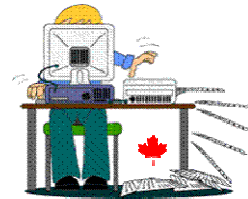


Media Watch...

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

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

Compiled & Annotated by Barry R. Ashpole

The human condition: Scroll down to [Specialist Publications](#) and 'Drama and empathy in medical education' (p.8), published in *Literature Compass*.

With this issue, Media Watch begins its 5th year of publication.

Canada

Rights and responsibilities

A pressing question of life, death

ALBERTA | *Edmonton Journal* (OpEd) – 9 July 2011 – How we die, and under whose terms, are issues that loom large in hospitals and are increasingly brought to Canadian courts. Recent judicial processes in other provinces have implications for Alberta. Last week, a terminally ill woman in British Columbia joined a legal attempt to make assisted suicide permissible. It is uncertain how quickly the B.C. Supreme Court will hear her case. Meanwhile, the Ontario Court of Appeal last week decided a case concerning a Toronto man who has been in intensive care for months. Since October, the health care team has wanted to discontinue Hassan Rasouli's treatment. They regarded it as medically without benefit because he is in a persistent vegetative state, but the family wants it continued. The court held that such disputes must go to an Ontario committee, the Consent & Capacity Board. In the first case, the B.C. woman is seeking a physician's help to end her life. In the second, the Ontario family is rejecting the physicians' judgment that their loved one's life has come to an end. In both cases, the parties asked the courts to help decide. As these disputes are adjudicated, many Alberta physicians are worried about what the future holds for their patients. We have no board in Alberta to resolve these disputes, two similar cases have been litigated here, and in many cases litigation has been threatened. <http://www.edmontonjournal.com/pressing+question+life+death/5077037/story.html>

From Media Watch dated 4 July 2011:

- ONTARIO | *Globe & Mail* – 29 June 2011 – '**Doctors can't make life-support decisions on their own: Court.**' Ontario's top court has ruled doctors must get approval from a provincial medical board when their decision to withdraw life-support treatment goes against the wishes of a patient's family. <http://www.theglobeandmail.com/news/national/doctors-cant-make-life-support-decisions-on-their-own-court/article2080320/>

N.B. Of related interest: Scroll down to [U.S.A.](#) and '**How long should Texas docs treat untreatable patients? The debate that won't go away**' (p.3).

Coma research no joke: London scientist to try to detect emotional response in coma patients

ONTARIO | *London Free Press* – 8 July 2011 – People in a comatose state may someday have their own say on whether to live or die, thanks to research pioneered by a London neuroscientist. Adrian Owen of the University of Ontario is weeks away from testing whether people in a coma understand and react emotionally to jokes. The tests build on a study [by] Owen and former colleagues at Cambridge University in England.¹ Owen's team scanned the brains of healthy adults as they were told jokes, puns and sentences that lacked humor. The jokes activated parts of the brain used when experiencing pleasure, and the funnier the joke, the greater the brain activity. <http://www.lfpress.com/news/london/2011/07/07/18390366.html>

1. 'The relationship between humor and semantic ambiguity,' *Journal of Neuroscience*, 2011;31(26): 9665-9671. <http://www.jneurosci.org/content/31/26/9665.abstract?sid=b27fb324-5836-4ce6-aa0e-fc03b8533fca>

From Media Watch dated 1 November 2010:

- ONTARIO | *Globe & Mail* – 29 October 2010 – **'Vegetative patients may be aware, newly-recruited researcher says.'** Adrian Owen has pioneered a new way to communicate with seemingly unconscious patients by putting them in a brain imager and asking them to think particular kinds of thoughts. <http://www.theglobeandmail.com/news/national/vegetative-patients-may-be-aware-newly-recruited-researcher-says/article1779227/>

Therapy helps dying patients tend to unfinished business, Canadian study says

MANITOBA | *PostMedia News* – 6 July 2011 – Canadian researchers have come up with a list of questions to help terminally ill people share their memories, hopes and regrets as they look back on their lives. And a new study¹ ... conducted by those researchers in Winnipeg shows that their approach, called dignity therapy, helps terminally ill patients tend to any unfinished business and find peace in their final days. Dignity therapy asks terminally ill people about their wishes, lessons learned and how they want to be remembered: "What are the most important roles you had in life?" "Are there specific things you want your family to know or remember about you?" "When did you feel most alive?" The conversations with therapists are recorded and transcribed to create a permanent record, which the person can share with loved ones or leave in their will. "Dignity therapy really tries to look at what are the sources, what are the things that might cause or undermine dignity toward the end of life," said Harvey Chochinov ... psychiatry professor at the University of Manitoba. "Some of the areas we found were, for example, a loss of sense of meaning, a loss of sense of purpose, feeling that one's life wouldn't have made a difference." <http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadian+study+says/5060980/story.html>

1. 'Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomised controlled trial,' *Lancet Oncology*, published online 7 July 2011. [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(11\)70153-X/abstract](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(11)70153-X/abstract)

[Specialist Publications](#)

Of particular interest:

'Restorative justice, euthanasia, and assisted suicide: A new arena for restorative justice and a new path for end of life law and policy in Canada' (p.10), published in the *Alberta Law Review*.

U.S.A.

Burial fees surge on high costs, low revenue

WALL STREET JOURNAL | Online article – 9 July 2011 – The Grand County Cemetery Maintenance District [Utah], running low on funds, is turning to a new revenue tactic: raising the prices of plots and burials as much as 400%. The proposed rate increase is just one of the controversies breaking out nationwide as cities and counties increase burial fees at publicly owned cemeteries to offset rising costs and declining or stagnant tax revenues.

<http://online.wsj.com/article/SB10001424052702304793504576432001758352050.html>

Of related interest:

- U.K. | *The Independent* – 9 July 2011 – **'Funeral prices to soar 50% as Church feels effect of downturn.'** The Church of England is planning to increase the cost of funerals by nearly 50% to bring consistent pricing across its parishes and raise extra revenue at a time of continued economic hardship. <http://www.independent.co.uk/news/uk/home-news/funeral-prices-to-soar-50-per-cent-as-church-feels-effect-of-downturn-2309504.html>

How long should Texas docs treat untreatable patients? The debate that won't go away

TEXAS | *Dallas Observer* – 8 July 2011 – Last week, just outside of Houston, a little boy's parents were scrambling. Doctors at Texas Children's Hospital had told them there was nothing more they could do for the boy, 14-year-old Jordan Allen, whose brain is dotted with inoperable tumors. He was on a ventilator and in a coma, and further treatment would have done him more harm than good, the doctors believed. They thought it was time to let him go. The parents disagreed. And that disagreement guaranteed the family's place at the center of a decade-old fight pitting Texas doctors and hospitals against lawmakers and activists, over how long is too long to care for a patient who appears certain to die. The fight dates back to 1999, and focuses on a narrow but emotionally volatile and unique section of the Texas's advance-directives law. Under that law, doctors have the right to halt treatment when they no longer believe they're acting in a patient's best interest. If the patient's family disagrees, the case goes before a hospital ethics panel. It's a process unique to Texas, experts say, the only state

to offer a "legal safe harbor" for doctors who end treatment to medically futile patients.

http://blogs.dallasobserver.com/unfairpark/2011/07/how_long_should_texas_docs_tre.php

From Media Watch dated 16 May 2011:

Sensitive topic of futile medical care faces long road in Legislature

TEXAS | *Statesman* (Austin) – 8 May 2011 – For the fourth consecutive session, Texas legislators are struggling with the delicate issue of how and when doctors can allow patients to die by withholding life-sustaining treatment against the wishes of family members. It's a nuanced, difficult question that can be ill-suited to the blunt-force nature of lawmaking. And true to form, tackling the issue ... has split allies, produced odd political alliances and resulted, thus far, in a stalemate.

<http://www.statesman.com/news/texas-politics/sensitive-topic-of-futile-medical-care-faces-long-1463003.html>

Of related interest:

- U.S. NEWS & WORLD REPORT | Online report – 5 July 2011 – **'Medical futility trend seen in neonatal deaths.'** Most deaths that occur in neonatal intensive care units at U.S. hospitals are due to withdrawal of life support and the withholding of lifesaving measures, a new study reveals.¹
<http://health.usnews.com/health-news/managing-your-healthcare/healthcare/articles/2011/07/05/medical-futility-trend-seen-in-neonatal-deaths>

1. 'How infants die in the neonatal intensive care unit,' *Archives of Pediatrics & Adolescent Medicine*, 2011; 165(7):630-634. <http://archpedi.ama-assn.org/cgi/content/abstract/165/7/630>

Poll: Most support end-of-life options

OREGON | *Portland Tribune* – 6 July 2011 – Oregon's reputation as a leader in end-of-life care is supported by a survey of Pacific Northwest residents released by the Portland's Regence Foundation and the *National Journal*. A poll of 1,200 registered voters in Oregon and Washington found that residents of the only two states that allow physician assisted suicide – Oregon and Washington – are also more open to other end-of-life options such as hospice care. The poll asked whether enhancing the quality of life for seriously ill patients is more important than extending life as long as possible. In a February nationwide poll conducted for the *National Journal*, 71% of respondents said they supported enhanced quality of life. In [the most recent] poll, 83% of Washington residents and 85% of Oregon residents chose quality of life instead of length. http://portlandtribune.com/news/story.php?story_id=130999312475709400

From Media Watch dated 28 June 2011:

- OREGON | *The Oregonian* (Portland) – 22 June 2011 – **'Oregon's end-of-life care far from norm.'** Medical care at the end of life continues to vary drastically across the U.S. As far as researchers can tell, extreme use of hospitals and specialists in some regions doesn't improve survival or quality of life. http://www.oregonlive.com/health/index.ssf/2011/06/oregons_end-of-life_care_far_f.html

Of related interest:

- NEW JERSEY | Associated Press – 10 July 2011 – **'Lawmakers send Governor Christie two measures to help residents with end-of-life care decisions.'** One bill would mandate that the state create a document that enables patients to indicate their preferences regarding life-sustaining treatment. The other creates an advisory council that would conduct a comprehensive study on the quality and cost-effectiveness of end-of-life care services and how easily they can be accessed. <http://www.therepublic.com/view/story/2d6fd7b4b4f546d9acce81cd962fce6/NJ-XGR--Legislative-Preview/>

International

Governments urged to improve care for the dying

AUSTRALIA | *Sydney Morning Herald* – 4 July 2011 – Palliative Care Australia (PCA) ... called on state and federal governments to do more to ensure those with terminal illnesses have a say in how they die. PCA said a survey had found that despite most people preferring to die at home, the number able to do so had dropped to just 16% in the past 50 years. Twenty per cent died in hospices, 10% in nursing homes and the remainder in hospitals. Releasing a national palliative care consensus statement,¹ the PCA's president Dr. Scott Blackwell said many terminally ill people were not aware of the services available to them at the end of their lives. The PCA statement lists eight priority areas, including for all Australians to have reasonable access and resources to support them to die in the location of their choice. <http://news.smh.com.au/breaking-news-national/govts-urged-to-improve-care-for-the-dying-20110705-1gzgd.html>

1. 'National Palliative Care Consensus Statement & Call to Action,' Palliative Care Australia, July 2011. http://pallcare.org.au/Portals/46/Palliative_Care_Consensus_Statement_final.pdf

Of related interest:

- AUSTRALIA (NEW SOUTH WALES) | *The Manly Daily* – 9 July 2011 – **'Heed our wishes.'** The right to die in the comfort of your own home, surrounded by loved ones. To most people this is a basic human entitlement. The reality, however, is that more terminally-ill patients on the northern beaches are being deprived of that right because of funding cutbacks to palliative care services. <http://manly-daily.wherelive.com.au/news/story/heed-our-wishes/>

The middle England issue: Report aims to fix elderly care

POLITICS U.K. | Online report – 4 July 2011 – Those who lose their assets to pay for social care may be protected if the government accepts the findings of a major report into the issue.¹ Andrew Dilnot's report on elderly care argues that spending on people's care costs should be capped at £35,000, although it accepts any level between £25,000 and £50,000. Together with a higher means-tested threshold the plans would ensure that no-one spends over 30% of their assets on care costs. Critics of the scheme suggest that this is not an ideal moment to go to the Treasury requesting funding. The proposals would cost somewhere in the region of the projected savings from public sector pensions. If elderly care costs were capped at £50,000 it would cost the government £1.3 billion, while a £25,000 cap would come in at £2.2 billion. Analysts expect the Treasury's objections to be tempered by the fact that social care relates so directly to middle England. <http://www.politics.co.uk/news/2011/07/04/the-middle-england-issue-report-aims-to-fix-e>

1. *Fairer Care Funding*, The Report of the Commission on Funding of Care & Support, July 2011. <https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf>

From Media Watch dated 4 July 2011:

- U.K. | *The Telegraph* – 1 July 2011 – **'100,000 terminally ill 'do not get proper palliative care.'** Almost 100,000 terminally ill people do not get proper care, according to a Government review which concluded that a new funding system would save millions of pounds and better serve individuals.¹ <http://www.telegraph.co.uk/health/healthnews/8610266/100000-terminally-ill-do-not-get-proper-palliative-care.html>
- 1. *Palliative Care Funding Review: Funding the Right Care & Support for Everyone*, July 2011. <http://palliativecarefunding.org.uk/wp-content/uploads/2011/06/PCFRFinal%20Report.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BULGARIA | Novinite.com – 7 July 2011 – **'Bulgaria parliament committee resolutely rejects euthansai bill.'** The Health Committee of the Bulgarian Parliament almost unanimously rejected a draft bill to legalize euthanasia in Bulgaria tabled last week by socialist MP, law professor Lyuben Kornezov. http://www.novinite.com/view_news.php?id=130028

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.hpcconnection.ca/newsletter/inthenews.html>

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

U.S.A.

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

International

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

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>

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

Improving cultural competency among hospice and palliative care volunteers: Recommendations for social policy

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 4 July 2011 – This case study of 14 hospice and palliative care volunteers looked for recommendations and suggestions on how to increase cultural competency among hospice volunteers. Findings reveal that volunteers have very specific and diverse recommendations on how they prefer to be briefed and educated on cultural competency issues surrounding their patients. Findings also reveal hospice volunteers want more cultural competency training and acknowledge the importance of being culturally competent. This article concludes with ... recommendations for increasing cultural competency in hospice and palliative care for both volunteers and agencies and discusses the top four future trends in cultural competency for hospice care. <http://ajh.sagepub.com/content/early/2011/07/02/1049909111414863.abstract>

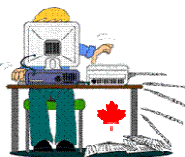
Veterinary medicine's perspective on end of life care (for animals)

Compassionate care survey probes end-of-life care practices

DVM NEWSMAGAZINE – July 2011 – Almost half of the veterinarians surveyed are having end-of-life discussions with pet owners more than 11 times per month. One of the survey's goals was to measure "some of the formalized policies that are out there regarding end-of-life care." Topics like communication, hospital procedures and practices, and compassion fatigue were all addressed in the survey. As part of its effort to better understand current practices, an advisory council was assembled and asked to weigh in and talk about the issues surrounding end-of-life care for most veterinarians and veterinary technicians. <http://veterinarynews.dvm360.com/dvm/Veterinary+news/Virbacs-compassionate-care-survey-probes-end-of-li/ArticleStandard/Article/detail/729103>

Narratives of 'terminal sedation' and the importance of the intention-foresight distinction in palliative care practice

BIOETHICS | Online article – 4 July 2011 – The authors report findings from a qualitative study of 18 Australian palliative care medical specialists, using in-depth interviews to address the use of sedation at the end of life. In contrast to their colleagues in acute medical practice, these Australian palliative care specialists were almost unanimously committed to distinguishing their actions from euthanasia. This commitment appeared to arise principally from the need to maintain a clear professional role, and not obviously from an ideological opposition to euthanasia. While some respondents acknowledged that there are difficult cases that require considered reflection upon one's intention, and where there may be some 'mental gymnastics,' the nearly unanimous view was that it is important, even in these difficult cases, to cultivate an intention that focuses exclusively on the relief of symptoms. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2011.01895.x/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>

Prevalence, course and associations of desire for hastened death in a U.K. palliative population: A cross-sectional study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – 4 July 2011 – The objective of this study was to determine the prevalence, severity and remission of desire for hastened death (DHD) in a U.K. representative sample of patients with advanced disease receiving palliative care and to examine the associations of desire for death. The prevalence of DHD was at the lower end of that seen in previous studies using similar samples. More severe DHD was uncommon and for most part remitted to some extent during the study. The provision of symptom control and timely detection and intervention for depression coupled with a focus on optimising function, instilling hope and preserving dignity are likely to contribute to alleviation of DHD in patients with advanced illness. <http://spcare.bmj.com/content/early/2011/07/04/bmjspcare-2011-000011.abstract>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 4 July 2011 – **'Best practices for the non-pharmacological treatment of depression at the end of life.'** This literature review summarizes the current research on non-pharmacological management of depressive symptoms for patients nearing the end of their lives. Based on the current research, it is recommended that psychotherapy be used first-line in patients with approximately 6 months or more to live, and that semi-psychotherapeutic techniques be first-line in patients with 6 months or less to live. <http://ajh.sagepub.com/content/early/2011/07/02/1049909111413889.abstract>

Hospital based palliative care in sub-Saharan Africa: A six month review from Malawi

BMC PALLIATIVE CARE | Online article – 9 July 2011 – The World Health Organisation recognises the importance of palliative care in an African setting. Despite this services are often patchy and inconsistent and many operate at health centre and / or community level. Few reports from hospital based palliative care services in sub-Saharan Africa exist in the current literature. As part of its activities Tiyanjane Clinic has been providing hospital based palliative care to patients at Queen Elizabeth Central Hospital, a large government tertiary referral institution, in the Southern region of Malawi since 2003, caring for patients with HIV, cancer and other non-malignant palliative diagnoses. The palliative care population in this setting is relatively young, especially among patients with HIV related diagnoses. HIV and cancer are the main diagnostic groups. Pain is the most commonly reported symptom, with oral morphine frequently required. Health workers require access to and knowledge of oral morphine in order to provide appropriate assistance to patients under their care. <http://www.biomedcentral.com/content/pdf/1472-684x-10-12.pdf>

From Media Watch dated 14 March 2011:

- *BMC PALLIATIVE CARE* | Online article – 9 March 2011 – **'End of life care in sub-Saharan Africa: A systematic review of the qualitative literature.'** This article aims to synthesize qualitative research on EoL care in sub-Saharan Africa to inform policy, practice and further research. <http://www.biomedcentral.com/content/pdf/1472-684x-10-6.pdf>

Germany has adopted a charter for the care of the critically ill and the dying

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2011;18(4):176-178. In Germany, in 2010, over 50 medical and socio-political institutions consensually adopted a charter for the care of the critically ill and the dying. The charter contains five key principles pertaining to the areas of ethics, standards of care, training and education of professionals, research, and international networking. http://www.eapcnet.eu/LinkClick.aspx?fileticket=mg9e_y4c73w%3d&tabid=676

N.B. Germany was rated 8th in *The Quality of Death: Ranking End-of-life-Care Across the World*, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Drama and empathy in medical education

LITERATURE COMPASS, 2011;8(7):443-454. Increasingly, undergraduate and graduate programs in medical humanities are exploring the ability of the arts to elucidate the human condition as it relates to patient care. At the University of California, Davis, students and faculty from both the Department of Medicine and English Literature have convened for informal readings of scenes from dramatic works. This paper discusses the use of excerpts from Eugene O'Neill's *Long Day's Journey into Night* and Berry Barta's *Journey into That Good Night* in a medical education setting. Medical students participated in staged readings of these plays, which were filmed and then screened for a group of 30 medical students in order to elicit discussion. Topics included how individuals deal with illness differently and how prospective physicians could address similar clinical scenarios. Medical students contributed to a fluid, evolving project in which they oftentimes struggled to play a character but appreciated the opportunity to do so and to observe their peers in a similar fashion. Future plans for the project include further staged readings and presentations to larger groups of students with the intent of incorporating these activities into the medical school curriculum. <http://onlinelibrary.wiley.com/doi/10.1111/j.1741-4113.2011.00778.x/full>

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

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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.

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/world/world/>

How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness

PALLIATIVE MEDICINE | Online article – 7 July 2011 – This systematic review updates an earlier effectiveness review to determine both the effectiveness of subsequently published intervention studies, and the current state of science. Thirtythree studies met inclusion criteria. From the original review, an encouraging increase was identified in the number of evaluations (from 8 to 33), in carer-specific interventions (from 6 to 17) and in the robustness of the study design (an increase from 2 to 12 studies with before/after measures, comparison groups and prospective data). The evidence suggests a rapid increase in the number of robust intervention studies. However, the range of models remains narrow in relation to caregivers' needs and preferences. <http://pmj.sagepub.com/content/early/2011/07/06/0269216311409613.abstract>

Of related interest:

- *COCHRANE REVIEWS* | Online report – 6 July 2011 – '**Hospital at home: Home-based end of life care.**' The authors systematically reviewed the literature to see if the provision of end of life home care reduces the likelihood of dying in hospital and what effect this has on patients' symptoms, quality of life, health service costs and care givers compared with inpatient hospital or hospice care. <http://www2.cochrane.org/reviews/en/ab009231.html>

Developing a national quality register in end-of-life care: The Swedish experience

PALLIATIVE MEDICINE | Online article – 7 July 2011 – The register received status as a National Quality Register in 2006. More than 30,000 deaths in nursing facilities, hospital wards, palliative in-patient units and private homes were registered during 2010, representing 34% of all deaths in Sweden and 58% of the cancer deaths. [The authors] have shown that it is feasible to establish a national quality register in end-of-life care and collect data through a web-based system. Ongoing data analyses will show in what way this initiative can lead to improved quality of life for patients and their families. <http://pmj.sagepub.com/content/early/2011/07/06/0269216311414758.abstract>

N.B. Sweden was rated 16th in *The Quality of Death: Ranking End of-life-Care Across the World*, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Cancer patients' preferences for control at the end of life

QUALITY HEALTH RESEARCH | Online article – 6 July 2011 – This study explored the meaning of control and control preferences in a group of racially and ethnically diverse patients with an advanced cancer diagnosis. [The authors] uncovered two themes: a) preferences for everyday control over treatment decisions, family issues, final days of life, and arrangements after death, vs. b) awareness that cancer and death are controlled by a higher power. Although the sample included non-Hispanic Whites, African Americans, and Hispanics, participants shared common views that are characteristic of American cultural norms regarding the value of autonomy. <http://qhr.sagepub.com/content/early/2011/07/05/1049732311415287.abstract>

Of related interest:

- *QUALITY HEALTH RESEARCH* | Online article – 6 July 2011 – '**Interviews on end-of-life care with older people: Reflections on six European studies.**' The authors offer a set of reflections from six end-of-life care studies conducted with older people in four European countries: Belgium, Germany, the Netherlands, and the U.K. They identify as major challenges accessing people, the introduction of end-of-life issues in an interview, managing emotions, the presence of companions, and reciprocity. Formal ethical review committees rarely take into account these complex issues. <http://qhr.sagepub.com/content/early/2011/07/05/1049732311415286.abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *ALBERTA LAW REVIEW* (Canada) | Online article – Accessed 4 July 2011 – **'Restorative justice, euthanasia, and assisted suicide: A new arena for restorative justice and a new path for end of life law and policy in Canada.'** This article examines the current Canadian legal approach to euthanasia and assisted suicide, highlights some of the problems with it, and offers a novel alternative to the current traditionally criminalized prohibitive regime. The authors first describe a restorative justice approach and explain the differences between such an approach and the traditional approach currently in use. They then explain how a restorative justice approach could be implemented in the arena of assisted death, acknowledging the potential challenges in implementation. <http://www.albertalawreview.com/index.php/alr/article/view/158>

N.B. Available is **'Assisted (or Facilitated) Death: The Debate in Canada,'** which summarizes notable developments (as reported in past issues of Media Watch) – highlighting also those in other countries – that inform discussion of the issue in Canada. Contact information at foot of this page.

Worth Repeating

'When your child dies you don't belong in that world any more'

Experiences of mothers whose child with an intellectual disability has died

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES, 2008;21(6):546-560. Individuals with intellectual disability are at higher risk of premature death compared with individuals without intellectual disability, and therefore parents of people with intellectual disability are more likely to outlive their children. However, there has been relatively little research investigating the bereavement experiences of parents of deceased children with intellectual disability. Five themes emerged from the analysis: loss, benefit finding, coping, sources of support and medical relationships. An analysis ... indicated similarities and differences between the experiences of the mothers. In particular, continuing in their caring role by working within the world of intellectual disability following the death of their child was important to all of the mothers. Support from similarly bereaved parents was the most useful source of support, although it was not always readily accessible. Implications for theory and practice are described including suggestions that service providers should aim to maintain links with families after the death of their child, a parent-to-parent programme that enables parents to contact others in a similar situation might be beneficial, and further research into the functions of coping strategies and supports in loss would be worthwhile. <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2008.00427.x/full>

Barry R. Ashpole
Beamsville, Ontario CANADA

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