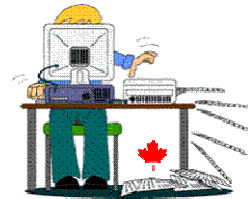


Media Watch...

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

Improving support for family and friends: Scroll down to [Specialist Publications](#) and 'Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: Community facilitator pilot' (p.10), published in *Palliative Medicine*.

Canada

Province to provide free drug coverage to all palliative home care patients

NOVA SCOTIA | Halifax News Net – 23 September 2011 – Palliative home care patients will now receive drug coverage at no cost to help them manage their symptoms, Health & Wellness Minister Maureen MacDonald announced. "This is about giving Nova Scotians the option to spend their last days in a setting of their choice, including the comfort of their own home," said MacDonald. "It will also remove any financial burden families may face when paying for medications in order to keep their loved ones at home." This option has been available in some parts of Nova Scotia. Government will fund this coverage in all areas of the province. There will be no co-payment fees, alleviating some of the pressure on families who are trying to make the choice between hospitalization and staying at home. <http://www.halifaxnewsnet.ca/News/2011-09-23/article-2758102/Province-to-provide-free-drug-coverage-to-all-palliative-home-care-patients/1>

End of life care needs attention

BRITISH COLUMBIA | *Victoria News* (OpEd) – 21 September 2011 – Fear of dying is common in western culture. Even the word "died" is often watered down to more gentle phrases such as passed away, passed on, or crossed over. Those words indicate not only a desire to ease the pain of losing a loved one, but soften the path from life to death. It's ironic, then, that in British Columbia we put relatively little money into making a person's final days and weeks more comfortable. http://www.bclocalnews.com/vancouver_island_south/victoria_news/opinion/130162578.html

[Specialist Publications](#)

Of particular interest:

'Palliative care: An enforceable Canadian human right?' (p.9), published in the *McGill Journal of Law & Health*.

Report shows that \$1 of every \$20 invested in cancer research was focused on survivorship and palliative and end-of-life care

CANADIAN CANCER RESEARCH ALLIANCE | Press release – 20 September 2011 – The first-ever detailed examination of Canada's investment in cancer survivorship research and palliative and end-of-life care cancer research was released by the Canadian Cancer Research Alliance [CCRA] and the Canadian Partnership Against Cancer [CPAC],¹ which is funded by Health Canada. This study found that the investment in these two emerging and related areas of research represented nearly 5% of the overall cancer research investment in Canada, or about \$18.5M annually, for the 2005-2008 period. By comparison, this was roughly half of what was invested in cancer risk and prevention

research; the investment in treatment research was nearly five times greater. <http://www.prnewswire.com/news-releases/report-shows-that-1-of-every-20-invested-in-cancer-research-was-focused-on-survivorship-and-palliative-and-end-of-life-care-130183238.html>

Extract from CCRA & CPAC study

Research in the palliative and end-of-life care has been challenging in Canada, given considerable provincial differences in organization and delivery of care, and the lack of a national palliative and end-of-life care strategy.

1. *Investment in Research on Survivorship and Palliative and End-of-Life Care, 2005-2008*, a special section of *Cancer Research Investment in Canada, 2008*, The Canadian Cancer Research Alliance, September 2011. http://www.ccra-acrc.ca/PDF%20Files/Surviv_2005-08_EN.pdf

From Media Watch dated 2 May 2011:

- CBC NEWS | Online report – 26 April 2011 – '**Deadliest cancers in research funding gap: Report.**' Research on some of the deadliest cancers in Canada is underfunded relative to their toll in lives taken, according to a new report.¹ <http://www.cbc.ca/news/health/story/2011/04/25/cancer-charity-intelligence.html>
 1. *Cancer in Canada: Framing the Crisis and Previewing the Opportunity for Donors*, Charity Intelligence Canada, April 2011. <http://www.charityintelligence.ca/?page=24>

Hassan Rasouli Case

When family and doctors disagree on when to end life

ONTARIO | *Toronto Star* – 20 September 2011 – In 2010, Hassan Rasouli had surgery to remove a brain tumour. Unfortunately, there were complications and his doctors say Rasouli is now in a permanent vegetative state. According to them, he will never regain consciousness or be able to survive without the help of a machine that breathes for him. They think it's medically inappropriate to keep him on a ventilator and want it turned off. His physician wife, however, disagrees with the diagnosis and still hopes for a miracle. Unable to agree whether to "pull the plug," the wife and doctors went to court. Most of us now die in hospital. Decisions to provide or withhold life support are made every day across Canada.

Yet surprisingly, until June when the Ontario Court of Appeal ruled in the Rasouli case, the law was unclear as to who decides whether to withdraw life support. <http://www.thestar.com/opinion/editorialopinion/article/1057057--when-family-and-doctors-disagree-on-when-to-end-life>

Specialist Publications

Of particular interest:

'Vegetative patient dispute forces rethink of term 'treatment' (p.9), published in *The Medical Post*.

An "inner voice" in patients

Research shows patients in 'vegetative state' can communicate with brain waves

POST MEDIA NEWS | Online report – 18 September 2011 – Neuroscientist Adrian Owen has discovered that some people who have been written off can actually understand and communicate. Owen asked one such man to imagine playing tennis when he wanted to answer "Yes" to a question, and to think of his home for "No." The man's face never flickered in response to commands. Yet under a scanning technique known as functional magnetic resonance imaging, different areas of his brain flared with activity, lighting the same language and movement-planning regions that are active when healthy people hear those commands. The discovery of an "inner voice" in patients who are effectively buried alive has far-reaching consequences for how doctors diagnose and treat unconscious patients with traumatic brain injuries or cardiac arrest. Ethicists say Owen's discovery raises highly charged questions about what society deems is appropriate life support and whether to consult severely disabled patients on their care. <http://www.vancouversun.com/health/Research+shows+patients+vegetative+state+communicate+with+brain+waves/5421577/story.html>

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/>

U.S.A.

Palliative care in Georgia: A closer look

GEORGIA | WABE News (Atlanta) – 20 September 2011 – WABE reported on a recent study from the University of Georgia¹ that found the state's hospitals do lag behind in the number of programs that specialize in palliative care, a type of care that treats the symptoms and pain associated with incurable illness. The authors of the study said that the main reason Georgia is deficient is simply a widespread lack of knowledge: of what palliative care is, and why it may be helpful. <http://www.publicbroadcasting.net/wabe/news.newsmain/article/1/0/1854586/Atlanta./Palliative.Care.in.Georgia.A.Closer.Look>

1. 'A state-wide status report on hospital-based palliative care programs,' *Journal of Palliative Medicine*, 2011;14(7):806-809 (noted in Media Watch dated 18 July 2011). <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0489?prevSearch=allfield%253A%2528Georgia%2529&searchHistoryKey=>



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>

Changes in controversial organ donation method stir fears

WASHINGTON POST | Online article – 19 September 2011 – Surgeons retrieving organs for transplant just after a donor's heart stops beating would no longer have to wait at least two minutes to be sure the heart doesn't spontaneously start beating again under new rules being considered by the group that coordinates organ allocation in the U.S. The organization is also poised to eliminate what many consider a central bulwark protecting patients in such already controversial cases: an explicit ban on even considering anyone for those donations before doctors and family members have independently decided to stop trying to save them. Proponents say the changes strengthen the transplant system by aligning the rules with other regulatory bodies and better ensure that the wishes of donors and their loved ones are honored without sacrificing necessary protections. Critics,

however, say the move heightens the risk that potential donors will be treated more like tissue banks than like sick people deserving every chance to live, or to die peacefully.

http://www.washingtonpost.com/national/health-science/changes-in-controversial-organ-donation-method-stir-fears/2011/09/15/gIQAly9agK_print.html

Extract from *Washington Post* article

The National Academy of Sciences concluded in 1997 that DCD [donation after cardiac death] was ethical as long as tight rules are followed: The decision to withdraw care must be independent of the decision to donate organs, and before removing any organs, surgeons must wait at least five minutes after the heart stops to make sure it doesn't spontaneously start beating again.

From Media Watch dated 12 September 2011:

- *CLINICAL ETHICS*, 2011;6(3):122-126. **'Supporting organ donation through end-of-life care: Implications for heart-beating donation.'** New protocols have been developed for donors after circulatory death involving early assessment of donor status and pre-mortem supporting treatment in appropriate cases where there is evidence that the patient wished to be an organ donor. These donors are now making an increasingly marked impact on overall deceased donor numbers in the U.K. <http://ce.rsmjournals.com/content/6/3/122.abstract>

From Media Watch dated 31 May 2010:

JOURNAL OF MEDICINE & PHILOSOPHY, 2010;35(3):223-241. **'Death revisited: Rethinking death and the dead donor rule.'** Because successful transplantation requires that organs be removed from cadavers shortly after death to avoid organ damage due to loss of oxygen, there has been keen interest in knowing precisely when people are dead so that organs could be removed. The authors explore the ongoing debate over definitions of death, particularly over brain death or death determined using neurological criteria, and the relationship between definitions of death and organ transplantation. <http://jmp.oxfordjournals.org/cgi/content/abstract/35/3/223>

N.B. This issue of *Journal of Medicine & Philosophy* contains several articles on the dead donor rule. Contents page: <http://jmp.oxfordjournals.org/current.dtl>

[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/>

International

End-of-life care not up to standard: Study

SINGAPORE | *Asia One* – 21 September 2011 – Terminally ill patients in Singapore are rarely consulted as to whether they wish to continue receiving medical treatment, a study conducted at the National University Hospital said. It was found that many are still being forced to undergo aggressive treatments right until the very end, which often causes unnecessary pain while doing little to avert death. While in the West, patients are usually consulted if possible before resuscitation is carried out, in Singapore, even when the patients are aware and able to communicate their wishes, this decision is rarely discussed with them. Of those resuscitated, the paper reported that only 4% had been consulted although this percentage may include those who were unconscious or insensible. <http://health.asiaone.com/Health/News/Story/A1Story20110921-300752.html>



From Media Watch dated 12 September 2011:

- SINGAPORE | *Straits Times* – 6 September 2011 – **'Subsidy dearth for end-of-life home care.'** The dying would like to spend their last days at home, but the current health-care system makes it difficult for those without the financial means to do so. This was one of the findings that emerged in a recent study¹ conducted by the National University of Singapore's Centre for Biomedical Ethics. http://www.straitstimes.com/BreakingNews/Singapore/Story/STIStory_709910.html
 1. *What Doctors Say About Care Of The Dying*, Lien Foundation, September 2011. http://www.lienfoundation.org/pdf/news/What_Doctors_Say_About_Care_of_the_Dying.pdf

Of related interest:

- UNITED ARAB EMIRATES | *Gulf News* – 21 September 2011 – **'Country lacks supportive care for the terminally ill, doctor says.'** Despite the increasing number of people in the country with life-limiting diseases like cancer, renal and cardiovascular diseases, there is a distinct lack of palliative care facilities that work to improve the terminally ill patients' quality of life, a leading health care professional. <http://gulfnews.com/news/gulf/uae/health/country-lacks-supportive-care-for-the-terminally-ill-doctor-says-1.870604>

Hospice could pull off a Scottish first with green projects

U.K. (SCOTLAND) | *Paisley Daily Express* – 20 September 2011 – Charity bosses are channelling their energies into ambitious plans to make their hospice the first in Scotland to boast solar panels and underground heating. <http://www.paisleydailyexpress.co.uk/renfrewshire-news/2011/09/20/hospice-could-pull-off-a-scottish-first-with-green-projects-87085-29448950/>

Dying – Doing it Better

U.K. | National Council for Palliative Care online report – 19 September 2011 – The Council's new Impact Report describes recent activities and sets out why public support is needed as much as ever. Every minute someone in the U.K. dies, but too many people are still not receiving the type of end of life care that they need or having their end of life wishes met. That is why the work of the National Council for Palliative Care and of the Dying Matters Coalition remains so important. <http://www.ncpc.org.uk/news/67>

Economic trends

Chronic disease to cost \$47 trillion by 2030...

USA TODAY & WORLD REPORT | Online report – 19 September 2011 – Unless current health trends are reversed, five common, non-infectious diseases – cancer, diabetes, heart disease, lung disease and mental health problems – will cost the world \$47 trillion in treatment costs and lost wages [according to the World Economic Forum].¹ Non-communicable diseases have the potential to not only bankrupt health systems but to also put a brake on the global economy. <http://yourlife.usatoday.com/health/medical/story/2011-09-19/Chronic-disease-to-cost-47-trillion-by-2030-WEF-says/50466138/1>

1. 'The Global Economic Burden of Non-communicable Diseases,' World Economic Forum (Geneva, Switzerland) and the Harvard School of Public Health (Boston, Massachusetts, U.S.A.), September 2011. http://www3.weforum.org/docs/WEF_Harvard_HE_GlobalEconomicBurdenNonCommunicableDiseases_2011.pdf

Map & Chart: Tracking killer chronic diseases

CANADA | CBC News – 19 September 2011 – Heart and lung disease, diabetes and cancer comprise two-thirds of deaths around the globe, according to the World Health Organization. This phenomenon represents a marked shift away from death from once potent and vast communicable diseases, such as malaria and tuberculosis. <http://www.cbc.ca/news/intercitatives/who-2011/#>

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

The effect on survival of continuing chemotherapy to near death

BMC PALLIATIVE CARE | Online article – 21 September 2011 – 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. Moreover, patients receiving chemotherapy near the end of life were much less likely to enter hospice or were more likely to be admitted within only 3 days of death. <http://www.biomedcentral.com/content/pdf/1472-684x-10-14.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/all/>

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>

Working together. An interdisciplinary approach to dying patients in a palliative care unit

JOURNAL OF MEDICAL ETHICS | Online article – 24 September 2011 – The authors' research focuses on the analysis of the process by which the development of knowledge in multi-professional practice is built to establish more information on recurrent patterns in the interaction and connect them to the specific context that these are shaped by. In this sense they underline how components of knowing are shared among team members in constructing medical prognosis and analyse the connection among language processes, cognitive activities and social structures. <http://jme.bmj.com/content/early/2011/09/24/jme.2010.040980.abstract>

Pediatric palliative care gains recognition

JOURNAL OF THE NATIONAL CANCER INSTITUTE (U.S.) | Online article – 20 September 2011 – Palliative care is not commonly associated with pediatrics, but pediatric palliative care programs are growing throughout the country – not as children die, but as they live longer with serious illnesses. A study published in ... *Pediatrics* showed that 70% of children were alive one year after their first consultation in a palliative care program.¹ According to Chris Feudtner MD, the director of research at the Pediatric Advanced Care Team at the Children's Hospital of Philadelphia ... unlike adults in palliative care programs, who have an average lifespan of two weeks, children often need ongoing care. "There are plenty of people who are re-admitted, which means we have to have a staff ready to handle new incident and prevalent cases," he said. But many palliative care programs are understaffed, with just one physician who may be part-time, along with a nurse, and maybe a social worker and a chaplain who

are usually volunteers, Feudtner explained. <http://jnci.oxfordjournals.org/content/early/2011/09/20/jnci.djr401.short?rss=1>

Increased access to palliative care and hospice services: Opportunities to improve value in health care

MILBANK QUARTERLY, 2011;89(3):343-380. Palliative care and hospice services improve patient-centered outcomes such as pain, depression, and other symptoms; patient and family satisfaction; and the receipt of care in the place that the patient chooses. Some data suggest that, compared with the usual care, palliative care prolongs life. By helping patients get the care they need to avoid unnecessary emergency department and hospital stays and shifting the locus of care to the home or community, palliative care and hospice reduce health care spending for America's sickest and most costly patient populations. <http://www.milbank.org/quarterly.html>

1. 'Pediatric palliative care patients: A prospective multicenter cohort study,' *Pediatrics*, 2011;127(6): 1094-1101 (published online 9 May 2011 and noted in Media Watch dated 16 May 2011 <http://pediatrics.aappublications.org/content/early/2011/05/05/peds.2010-3225.abstract>

Of related interest:

- *JOURNAL OF PEDIATRIC NURSING* | Online article – 12 September 2011 – '**Integrative review: Parent perspectives on care of their child at the end of life.**' Recurring themes included poor communication/lack of information, strained relationships/inadequate emotional support, parental need to maintain parent/child relationships in life and death, quality of care continues after the death of the child, influence of services/planning on parent/child impacts quality of life, and the difficult decision to terminate life support. No studies were identified that focused on parents' perspectives on the care their child received at the end of life. <http://www.sciencedirect.com/science/article/pii/S0882596311005343>
- ACT (U.K. Association for Children's Palliative Care) | Online posting – 19 September 2011 – '**Using Telehealth to support care at home in children's palliative care.**' ACT has developed an information sheet for professionals faced with ... providing care to children and families in remote areas. <http://www.act.org.uk/news.asp?itemid=1687&itemTitle=New+ACT+Telehealth+information+sheet§ion=94§ionTitle=News>

Professional education

Changing the face of death: A pedagogic intervention

JOURNAL OF PROFESSIONAL NURSING, 2011;27(5):315-319. A study was undertaken to explore whether alumni from years 2001 to 2007 at our school of nursing perceive that the end-of-life (EOL) undergraduate education they received: a) prepared them to provide quality care to the dying and their loved ones; and, b) contributed to changes in their way of being in the world, generally speaking. There were statistically significant differences between those who had taken an EOL elective while in nursing school and those who had not. This exploration of nurse alumni perceptions, from a school of nursing that purportedly has strong advocacy for EOL education, offers a snapshot view of issues relevant to the integration of EOL education in nursing schools. [http://www.professionalnursing.org/article/S8755-7223\(11\)00039-1/abstract](http://www.professionalnursing.org/article/S8755-7223(11)00039-1/abstract)

Of related interest:

- *JOURNAL OF MEDICAL ETHICS* | Online article – 24 September 2011 – **'The role of the principle of double effect in ethics education at U.S. medical schools and its potential impact on pain management at the end of life.'** This study demonstrates that a significant minority of ethics educators believe, contrary to current evidence, that opioids are 'likely' to cause significant respiratory depression that could hasten death in terminally ill patients. Yet, many of those who do not feel this is likely still rely on the principle of double effect to justify this possibility, potentially (and unknowingly) contributing to clinical misperceptions and underutilisation of opioids at end-of-life. <http://jme.bmj.com/content/early/2011/09/24/medethics-2011-100105.abstract>

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.

Palliative care: An enforceable Canadian human right?

MCGILL JOURNAL OF LAW & HEALTH, 2011;5(1):106-160. This article lays out a series of approaches for establishing an enforceable human right to palliative care in Canada. The article first examines international human rights instruments to which Canada is a signatory, and concludes that they offer limited assistance to palliative care advocates. This article then examines two promising [Canadian] Charter [of Human Rights & Freedoms] challenges. The first based on section 15, argues that since palliative care is provided unevenly to those who require it, the equality provisions in the Charter could compel equitable provision of palliative care to Canadians with life-limiting illnesses. The second is based on section 7, and argues that failure to provide palliative care may impose an unacceptable level of psychological stress on those at the end of their life. The article concludes with a look at the limitations of a Charter challenging, including justification under section 1 of the Charter, and the lack of empirical evidence necessary to conclusively prove the arguments advanced under sections 15 and 7.

http://works.bepress.com/cgi/viewcontent.cgi?article=1014&context=darcy_macpherson&sei-redir=1#search=%22http%3A%2F%2Fworks.bepress.com%2Fcgi%2Fviewcontent.cgi%3Farticle%3D1014%26context%3Ddarcy_macpherson%22

Hassan Rasouli Case

Vegetative patient dispute forces rethink of term 'treatment'

THE MEDICAL POST (Canada) | Online article – 21 September 2011 – Words are what law is made of. So it comes as no surprise that judges often interpret words and decide what they mean. A good example is a recent case from the Ontario Court of Appeal involving the word "treatment." The case has gotten a lot of press, since it deals with the perennial and difficult question of how a doctor can legally pull the plug on someone who has entered a permanent vegetative state. The story began when the patient in question underwent a brain operation to remove a benign tumour. Tragically, bacterial meningitis set in, and the infection laid waste to his brain. He ended up on life support. Doctors at Sunnybrook Health Sciences Centre in Toronto decided they should pull the plug because the patient had been effectively rendered a vegetable, and therefore his condition could not possibly improve. The patient's wife, who is not a physician, felt her husband was not vegetative. She said that when she was at his bedside, he was aware of his surroundings and responsive. Only she and her family appear to have witnessed this. Her "medical opinion" became important because she was also the patient's substitute decision-maker, and therefore her consent was required for any medical treatment. The legal question then became whether pulling the plug was a form of "treatment under the [Ontario] Health Care Consent Act. <http://www.canadianhealthcarenetwork.ca/physicians/magazines/the-medical-post/september-20-2011/vegetative-patient-dispute-forces-rethink-of-term-treatment-18209>

From Media Watch dated 12 September 2011:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online report – 6 September 2011 – **'Physicians appeal Rasouli ruling to Supreme Court.'** Dr. Brian Cuthbertson and Dr. Gordon Rubinfeld, physicians at the Sunnybrook Health Sciences Centre in Toronto, Ontario, sought leave to appeal from the Supreme Court in August to overturn lower court decisions that prohibit them from withdrawing mechanical ventilation from a 59-year-old mechanical engineer in a persistent vegetative state. <http://www.cmaj.ca/site/earlyreleases/4theRecord.xhtml>

N.B. The Rasouli case has in recent months generated significant media attention in Canada (see Media Watch dated 25, 11 & 4 July 2011, p.1 in each issue, and 23 May and 11 April 2011, p.2 and p.7, respectively).

Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: Community facilitator pilot

PALLIATIVE MEDICINE | Online article – 19 September 2011 – Although the unit of care in palliative care is defined as the patient and their family, there are few rigorous studies on how to improve support for family and friends as they take on the role of caregiver for someone at the end of life. In a quasi-experimental design, two communities were included: one received standard specialist palliative care support and one additionally was allocated to a community network facilitator who assessed caregivers' needs and helped mobilize the caregiver's own support network or initiated contact with other community supports in three planned visits. At 8 weeks, participants in the intervention arm showed significant within-group improvement in caregiver fatigue, sufficient support from others, decreased resentment in the role, greater confidence in asking for assistance and were better able to find resources and support. <http://pmj.sagepub.com/content/early/2011/09/17/0269216311421834.abstract>

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Online article – 19 September 2011 – '**Assessing and helping carers of older people.**' Identifying carers is important because many do not recognise themselves as such, and care responsibilities can affect their health and financial and social aspects of their lives. Comprehensive carer assessment may not be feasible but doctors can identify carers, briefly assess their needs, develop a care plan in collaboration with the carer, and refer where needed. <http://www.bmj.com/content/343/bmj.d5202>

From Media Watch dated 19 September 2011:

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2011;1(2):129-133. '**Compassionate community networks: Supporting home dying.**' How may communities be mobilised to help someone dying at home? This article outlines the thinking behind an innovative compassionate community project being developed at Weston-Super-Mare, U.K. <http://spcare.bmj.com/content/1/2/129.abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *SOUTHERN MEDICAL JOURNAL*, 2011;104(10):676-681. '**"Murder or mercy?" An innovative module helping U.K. medical students to articulate their own ethical viewpoints regarding end-of-life decisions.**' This module was designed to equip U.K. medical students to respond ethically and sensitively to requests encountered as qualified doctors regarding ... assisted dying. http://journals.lww.com/smajournalonline/Abstract/2011/10000/Murder_or_Mercy_An_Innovative_Module_Helping_UK.2.aspx
- *JOURNAL OF MEDICAL ETHICS* | Online article – 24 September 2011 – '**"Unbearable suffering": a qualitative study on the perspectives of patients who request assistance in dying.**' Medical, psycho-emotional, socio-environmental and existential themes contributed to suffering. Especially fatigue, pain, decline, negative feelings, loss of self, fear of future suffering, dependency, loss of autonomy, being worn out, being a burden, loneliness, loss of all that makes life worth living, hopelessness, pointlessness and being tired of living were constituent elements of unbearable suffering. Only patients with a psychiatric (co)diagnosis suffered unbearably all the time. <http://jme.bmj.com/content/early/2011/09/24/jme.2011.045492.abstract>
- *BRITISH MEDICAL JOURNAL* | Online report – 12 September 2011 – '**Dutch doctors complain about long wait for judgments in cases of euthanasia.**' Doctors in the Netherlands who carry out voluntary euthanasia must wait up to eight months before knowing whether they face a criminal investigation after an "enormous" rise in numbers of cases has swamped an already stretched reporting system. The Dutch Medical Association describes the situation as "serious," with "unrest" among doctors. One doctor had written complaining that his euthanasia report this summer would not be considered until April. <http://www.bmj.com/content/343/bmj.d5768.short>

Worth Repeating

Existential pain – an entity, a provocation, or a challenge?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2004;27(3):241-250. "Existential pain" is a widely used but ill-defined concept. Therefore the aim of this study was to let hospital chaplains, physicians in palliative care, and pain specialists respond to the question: "How would you define the concept existential pain?" In many cases, existential pain was described as suffering with no clear connection to physical pain. Chaplains stressed significantly more often the guilt issues, as well as various religious questions. Palliative physicians (actually seeing dying persons) stressed more often existential pain as being related to annihilation and impending separation, while pain specialists (seeing chronic patients) more often emphasized that "living is painful." Thirty-two percent of the physicians stated that existential suffering can be expressed as physical pain and provided many case histories. Thus, "existential pain" is mostly used as a metaphor for suffering, but also is seen as a clinically important factor that may reinforce existing physical pain or even be the primary cause of pain, in good agreement with the current definition of pain disorder or somatization disorder. [http://www.jpmsjournal.com/article/S0885-3924\(03\)00516-5/abstract](http://www.jpmsjournal.com/article/S0885-3924(03)00516-5/abstract)

Barry R. Ashpole
Beamsville, Ontario CANADA

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