Canada

End of life decisions – Should they be made by doctors or family?

EPOSTMEDIA | Online article – 28 December 2011 – A couple of recent cases have sparked an interest in the way loved ones have the deciding factor as to whether or not patients remain in care after physicians say they have no chance of surviving off of life-support. The Supreme Court of Canada has agreed to make the choice whether the end of life decisions should be made by doctors despite objections by the family. One case that has brought this to light is that of Baby Joseph Maraachli. He passed away 3 months ago after a high profile case when London Health Science Centre would not perform a tracheotomy allowing the child to go home to die. This very emotional case was closely followed by many who were happy when the child was transferred to St. Louis Hospital where he received the procedure. A new case is now the focus for who should make end of life decisions. A comatose Ontario man is the subject. Although he has no clue what is happening, his family is fighting to keep him alive as they believe he is getting better. http://epostmedia.com/end-of-life-decisions-should-they-be-made-by-doctors-or-family/378607/

Extract from ePostMedia article:

Dr. Laura Hawryluck ... believes it is not right to pass the end of life decisions onto ill-informed patients and representatives. In an affidavit to the court, Hawryluck wrote "It would create a situation where medically uneducated and uninformed patients and substitute decision-makers could demand treatments not in accordance with standards of medical care."

From Media Watch dated 26 December 2011:

Assisted (or facilitated) death

Representative sample of recent news media coverage:


From Media Watch dated 26 December 2011:


From Media Watch dated 31 October 2011:

- **QUEBEC** | Canadian Press – 24 October 2011 – *Committee on assisted suicide likely to recommend more palliative care.* Quebec's committee examining physician-assisted suicide is running behind schedule and wants more time to reach a consensus on its recommendations to the provincial government. [http://www.winnipegfreepress.com/canada/breakingnews/committee-on-assisted-suicide-likely-to-recommend-more-palliative-care-132495373.html](http://www.winnipegfreepress.com/canada/breakingnews/committee-on-assisted-suicide-likely-to-recommend-more-palliative-care-132495373.html)

**U.S.A.**

Physicians clueless about end-of-life care

- **CALIFORNIA** | *The Union* (Nevada County) – 30 December 2011 – Recently I had the opportunity of accompanying a dear friend to a major teaching university for an appointment. My friend was in hospice care, after five operations for cancer. We were met by the surgeon with the statement "I hear you are in hospice care; why did you do that?" And later "hospice is where you go to die in a week or two." I took responsibility for my friend being on hospice and at one point in the conversation the surgeon, in response to my question, said "his care is your responsibility now." I tried to educate this surgeon about hospice care and how it can work with traditional medicine for the best of the patient. At our next visit, my friend told the physician that he felt his spirit and his body were battling, one wanting to live and one wanting to die, and "what does that mean?"

The surgeon responded with a "deer in the headlights" look and said he had never been asked that question before and did not know what it meant. I found this extremely telling about our medical providers and a stark example of the disconnect between "curing" and recognizing when the dying process has begun. [http://www.theunion.com/article/20111230/OPINION/111239998/1024](http://www.theunion.com/article/20111230/OPINION/111239998/1024)

**Specialist Publications**

Of particular interest:

'Assessing attitudinal barriers toward end-of-life care' (p.5), published in the *American Journal of Hospice & Palliative Medicine.*
The unspoken diagnosis: Old age

NEW YORK TIMES | Online article – 27 December 2011 – Dr. Alexander K. Smith is a brave man. It has taken physicians a very long time to accept the need to level with patients and their families when they have terminal illnesses and death is near – and we know that many times those kinds of honest, exploratory conversations still don’t take place. Now Dr. Smith, a palliative care specialist at the University of California ... and two co-authors are urging another change, one they acknowledge would “radically alter” the way health care professionals communicate with their very old patients. In a recent article¹ ... they suggested offering to discuss “overall prognosis,” doctorspeak for probable life expectancy and the likelihood of death, with patients who don’t have terminal illnesses. The researchers favor broaching the subject with anyone who has a life expectancy of less than 10 years or has reached age 85.


From Media Watch dated 26 December 2011:

• U.S. NEWS & WORLD REPORT | Online report – 21 December 2011 – 'Most sick or disabled seniors want docs to say how long they have.' Life expectancy is a topic many disabled seniors want to talk about with their doctors but very few have that discussion, a new study finds.¹ http://health.usnews.com/health-news/family-health/boomer-health/articles/2011/12/21/most-sick-or-disabled-seniors-want-docs-to-say-how-long-they-have

¹. ''Knowing is better": Preferences of diverse older adults for discussing prognosis,’ Journal of General Internal Medicine, published online 30 November 2011. http://www.springerlink.com/content/xjq36814q4355820/

Media Watch Online

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

Canada

ONTARIO | Hamilton Niagara Halimand 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.mhpc.ca/Physicians/resources.htm?mediawatch=1

U.S.A.


Europe

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

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

International

Australasian Palliative International Link: http://www1.petermac.org/apil/links.htm (Scroll down to 'Media Watch')

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

International Palliative Care Resource Center: http://www.ipcrc.net/archive-global-palliative-care-news.php
Robert Packer Hospital starts 'No One Dies Alone' program

PENNSYLVANIA | Morning Times (Sayre) – 27 December 2011 – The Pastoral Services department at the Robert Packer Hospital will now sponsor a program that places volunteers at the bedside of terminal patients who would otherwise be alone called "No One Dies Alone." The program was implemented about a month ago ... and will provide a compassionate companion to "patients who are on comfort care, are on a 'do not resuscitate' status, and are expected to die soon and have no family or friends present." http://www.morning-times.com/news/2011-12-27/Front_Page/Robert_Packer_Hospital_starts_No_One_Dies_Alone_pr.html

Many seriously ill get too much care: Docs, nurses

REUTERS HEALTH | Online report – 27 December 2011 – A third of doctors working in intensive care units (ICUs) believe one or more of their patients is getting inappropriate care, with slightly fewer nurses sharing the sentiment, a European poll shows.¹ In most cases, ICU staff felt they were giving too much medical care to their patients. "What this study shows is that a striking number of ICU physicians and nurses on any given day are providing care they perceive to be inappropriate," Dr. Scott Halpern, who wrote an editorial about the findings, told Reuters Health. "What it doesn't tell us is why they are doing it," he said. While patient and family preferences about life-and-death medical decisions have been at the center of discussion for years, Halpern said, there hasn't been much focus on what clinicians think. Nevertheless, that could have a big impact on the quality of the care they deliver. "We live in a society where life-support and aggressive care are provided by default," said Halpern, who studies critical care at the University of Pennsylvania Medical Center in Philadelphia. When providers feel their efforts are too aggressive, he added, "that may highlight situations where the goals of care could usefully be changed toward comfort measures in a more timely fashion." The new findings are based on information from more than 1,600 doctors and nurses at hospitals in Europe and Israel.


From Media Watch dated 21 November 2011:

• CRITICAL CARE MEDICINE | Online article – 10 November 2011 – 'Integrating palliative care in the surgical and trauma intensive care unit: A report from the Improving Palliative Care in the Intensive Care Unit Project Advisory Board and the Center to Advance Palliative Care.' http://journals.lww.com/ccmjournal/Abstract/publishahead/Integrating_palliative_care_in_the_surgical_and.98189.aspx
**International**

**Pilot project**

**Dying at home supported by Arthur Rank [Hospice Charity]**

U.K. (ENGLAND) | Cambridge News – 27 December 2011 – A National Health Trust (NHS) has joined forces with a hospice charity to launch a pilot scheme which supports people with a terminal illness who want to die at home. The two-year pilot scheme is funded by Arthur Rank Hospice Charity and builds on a smaller service it has been helping Cambridgeshire Community Services NHS Trust to provide. The funding is enabling the trust to recruit nurses and healthcare assistants to the Hospice at Home team, which provides specialist end-of-life care to enable people to die with dignity. [http://www.cambridge-news.co.uk/Health-and-Beauty/Health-News/Dying-at-home-supported-by-Arthur-Rank-23122011.htm](http://www.cambridge-news.co.uk/Health-and-Beauty/Health-News/Dying-at-home-supported-by-Arthur-Rank-23122011.htm)

**Father left to die after docs decided not to resuscitate**

U.K. (SCOTLAND) | Evening Times (Glasgow) – 26 December 2011– A dad was left to die in a Glasgow hospital after doctors gave him a "do not resuscitate" order – without asking his family. Staff at Glasgow Royal Infirmary did not help the dying man, after medics took the decision themselves that he should not be resuscitated, if his breathing or heart failed. His family said the decision was never discussed with them and they were never made aware how serious their father's condition was. [http://www.eveningtimes.co.uk/news/father-left-to-die-after-docs-decided-not-to-resuscitate-1.1141280](http://www.eveningtimes.co.uk/news/father-left-to-die-after-docs-decided-not-to-resuscitate-1.1141280)

**Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- U.K. | The Guardian – 1 January 2012 – *End the ban on assisted suicide, report will urge the government.* Helping terminally ill people to commit suicide should be made legal under strict new safeguards, a major independent report is expected to recommend this week. The eagerly awaited advice from the Commission on Assisted Dying, chaired by Lord Falconer, a former lord chancellor, is likely to criticise the current legal framework and suggest that, in some cases, those who encourage or assist another to die should no longer be threatened with prosecution. The report is expected to recommend that assisted dying be legalised only for a very limited category of terminally ill patients and under procedures that are rigorously monitored. It is likely to suggest tight controls on how and when lethal medicines are prescribed for use in assisted suicide. Procedures to ensure that those involved are made fully aware of all the palliative and social care available to them are also likely to be spelt out. [http://www.guardian.co.uk/society/2012/jan/01/assisted-dying-ban-report?newsfeed=true](http://www.guardian.co.uk/society/2012/jan/01/assisted-dying-ban-report?newsfeed=true)

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

**Assessing attitudinal barriers toward end-of-life care**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 28 December 2011 – Due to the rapid influx of palliative care and hospice services over the last decade, there has been an increase in the number of medical professionals interacting with terminal patients. One of the challenges with this growth becomes how to integrate these services into already busy practices along with providing physicians the education and tools they need to provide quality care. While there is no shortage of articles focusing on the educational needs of physicians ... less is known about the level of anxiety physicians feel about interacting with dying patients and their families. [http://ajh.sagepub.com/content/early/2011/12/04/1049909111429558.abstract](http://ajh.sagepub.com/content/early/2011/12/04/1049909111429558.abstract)
Perceptions of hospice support

An exploration of parents' and young people's perspectives of hospice support

**CHILD: CARE, HEALTH & DEVELOPMENT, 2012;38(1):32-40.** The aim of the study was to investigate parents' and young people's perceptions of hospice support and identify how support could be improved. A mixed-method approach was used involving a postal survey of families and in-depth qualitative interviews with a purposively sampled sub-sample of parents and young people. Families [i.e., study participants] were highly satisfied with the support provided in terms of quality of care; interpersonal qualities of the staff; the individualized, family-focused approach; accessibility of support and involvement in decision making. Young people valued the opportunity to meet with other young people and take part in different activities. For parents the provision of a break from caring was the main way in which they were supported although they felt they wanted more of this form of support. 

[Link to article]

Of related interest:

- **AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE** | Online article – 28 December 2011 – 'Views of hospice and palliative care among younger and older sexually diverse women.' The aim of the present study was to explore end-of-life health care attitudes among younger and older sexually diverse women. Results indicated that lesbian women held significantly more positive beliefs about hospice services and the role of alternative medicines in health care. 

[Link to article]

- **NURSING TIMES (U.K.)** | Online OpEd – 28 December 2011 – 'Death and dying: A community perspective.' After working for nearly 4 years within a hospice setting at Wheatfields ... I was quietly focused in my thinking that, just as hospitals are the places where people should give birth, so hospices are the best place to die. 

[Link to article]

**What is palliative care? Depends on who you ask and who you tell**

**AMERICAN ACADEMY OF HOSPICE & PALLIATIVE MEDICINE (AARP)** | Online article – 30 December 2011 – 'Palliative care: It's not what you think.' That headline over a recent article in AARP Bulletin was both good and bad. The good news is that AARP Bulletin published an accurate and positive story about palliative care that helped spread information to millions of readers age 50 and older. The bad news is that the headline speaks: What the public thinks about palliative care is still often contrary to the facts. What they think is that palliative care is for patients who are dying. Or worse, they may believe that palliative care means giving up, providing less care, and hastening death. Many have no idea what palliative care is. 

[Link to article]

**Biosketch**

**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: 

[Link to biosketch]
Expressions of loss and separation

**DSM-5: Proposed changes to depressive disorders**

*CURRENT MEDICAL RESEARCH & OPINION* | Online article – 28 December 2011 – Proposed changes for Diagnostic & Statistical Manual of Mental Disorders-5 [due to be published in 2013] include the creation of several new categories of depressive disorder. Some nosologists have expressed concern that the proposed changes could yield many "false positive diagnoses" in which normal distress is mislabeled as a mental disorder. The author critically examines ... proposed DSM-5 expansions in the scope of depressive and grief disorders [including]: a new mixed anxiety/depression category; elimination of the major depression bereavement exclusion; elimination of the adjustment disorder bereavement exclusion, thus allowing the diagnosis of sub-syndromal depressive symptoms during bereavement as adjustment disorders; a new category of adjustment disorder related to bereavement for diagnosing pathological non-depressive grief. [http://informahealthcare.com/doi/abs/10.1185/03007995.2011.653436?prevSearch=allfield%253A%2528DSM-5%2529&searchHistoryKey=](http://informahealthcare.com/doi/abs/10.1185/03007995.2011.653436?prevSearch=allfield%253A%2528DSM-5%2529&searchHistoryKey=)

From Media Watch dated 7 March 2011:

- **QUEBEC | THE MCGILL DAILY (University of McGill, Montreal) | Online article – 3 March 2011 – 'To medicalize mourning.'** Over the past 25 years in the Diagnostic & Statistical Manual of Mental Disorders (DSM) has expanded to allow room for a number of "new" disorders. Included in this growing group is "Complicated Grief," or "Prolonged Grief Disorder," which is being considered for a spot in the DSM-V, due out in 2013. [http://www.mcgilldaily.com/2011/03/to-medicalize-mourning/](http://www.mcgilldaily.com/2011/03/to-medicalize-mourning/)

**N.B.** This issue of Media Watch lists several articles on the proposed change to DSM-5.

**Timely referral to end-of-life care**

**Effect of early palliative care on chemotherapy use and end-of-life care in patients with metastatic non-small-cell lung cancer**

*JOURNAL OF CLINICAL ONCOLOGY* | Online article – 27 December 2011 – Prior research shows that introducing palliative care soon after diagnosis for patients with metastatic non–small-cell lung cancer (NSCLC) is associated with improvements in quality of life, mood, and survival. Participants received either early palliative care integrated with standard oncology care or standard oncology care alone. Although patients with metastatic NSCLC received similar numbers of chemotherapy regimens in the sample, early palliative care optimized the timing of final chemotherapy administration and transition to hospice services, key measures of quality end-of-life care. [http://jco.ascopubs.org/content/early/2011/12/20/JCO.2011.35.7996.abstract](http://jco.ascopubs.org/content/early/2011/12/20/JCO.2011.35.7996.abstract)

Cont.
Navigating the emotional terrain

Suffering among carers working in critical care can be reduced by an intensive communication strategy on end-of-life practices

INTENSIVE CARE MEDICINE, 2012;38(1):55-61. The implementation of an active, intensive communication strategy regarding end-of-life care in the ICU was associated with a significant reduction in the rate of burnout syndrome and depression in a stable population of caregiving staff.

http://icmjournal.esicm.org/journals/abstract.html?v=38&j=134&i=1&a=2413_10.1007_s00134-011-2413-z&doi

Dementia deaths in hospice: A retrospective case note audit

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2011;17(12):581-585. Population prevalence studies suggest that very few people with dementia access hospice services in the U.K. The literature further suggests that hospice staff may be inadequately prepared to care for people with dementia. A retrospective internal case note audit covering a 3-month period of referrals was undertaken in one hospice in the south of England as part of work to establish staff education requirements arising from patient make-up. Of the 288 case notes audited, 9% of the patients had either been diagnosed with dementia or suffered with dementia as a co-morbidity.

http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=88511;article=IJPN_17_12_581_585
Geritalk: Communication skills training for geriatric and palliative medicine fellows

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online article – 28 December 2011 –
Expert communication is essential to high-quality care for older patients with serious illness. Although the importance of communication skills is widely recognized, formal curricula for teaching communication skills to geriatric and palliative medicine fellows is often inadequate or unavailable. The current study drew upon the educational principles and format of an evidence-based, interactive teaching method to develop an intensive communication skills training course designed specifically to address the common communication challenges that geriatric and palliative medicine fellows face. http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03787.x/abstract

Technology in end-of-life care

Organizational factors associated with the use of telehospice

JOURNAL OF TELEMEDIATE & TELECARE | Online article – 23 December 2011 – The authors investigated organizational factors associated with the use of telehospice (defined as the use of video technology by hospices). The investigation was based on the 2007 National Home and Hospice Care Survey. There were 695 hospice agencies, of which 6% used telehospice. Most of the variables that were significantly associated with the use of telehospice were related to characteristics of the agency director. If the director had at least a Masters degree or had a longer tenure as director of the agency, there was a higher likelihood that the agency used telehospice. If the director was a nurse, the likelihood that telehospice was used was considerably lower. Organizations with inter-agency contracts were less likely to use telehospice. http://jtt.rsmjournals.com/content/early/2011/12/22/jtt.2011.110803.abstract

End-of-life care for children and adults with intellectual and developmental disabilities


Of related interest:


Worth Repeating

The withholding of truth when counselling relatives of the critically ill: A rational defence

CLINICAL ETHICS, 2008;3(1):42-45. In cases of sudden, life-threatening illness where the chance of survival appears negligible to the admitting physician, this opinion is not always revealed during the initial meeting with the patient's relatives. Reasons as to why this withholding of the truth may be acceptable are explored through review of available evidence and personal reflection. Factors identified include: the importance of hope in families' coping mechanisms, and the instinct to preserve it; the fallibility of physicians' perception of poor prognosis in the early phase of illness; the need to avoid large swings in relatives' expectations that occur when patients appear to rally during initial resuscitation; and the adverse effect that an atmosphere of hopelessness can have on the provision of medical care. A strategy for the staged disclosure of information and the confirmation of hopelessness is then described, the aim being to find a compromise between providing a true opinion about a patient's prognosis, and regard for the opposing factors described. http://www.ce.rsmjournals.com/content/3/1/42.short
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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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.

Barry R. Ashpole                                      telephone: 905.563.0044
Beamsville, Ontario, Canada                          e-mail: barryashpole@bellnet.ca