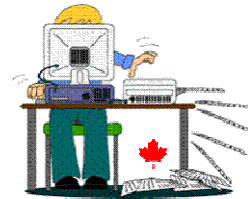


Media Watch...

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

Access to end of life care: Scroll down to [U.S.A.](#) and 'Looking for a place to die' (p.2), published in the *New York Times*.

Canada

Supreme Court to hear Rasouli end-of-life case

GLOBE & MAIL | Online report – 22 December 2011 – The debate over whether doctors need consent before taking a patient off life support will be heard by the Supreme Court of Canada. The country's top court has granted leave to appeal to the doctors of Hassan Rasouli, a man who has been in a coma at Toronto's Sunnybrook Health Sciences Centre since October 2010. His doctors diagnosed him as being in a "permanently vegetative state" and recommended he be taken off life support, but his wife and substitute decision-maker, Parichehr Salasel, strongly opposed. Now the doctors have turned to the Supreme Court in hopes of disconnecting Mr. Rasouli from the medical machines that are keeping him alive. The outcome of the case could set a national precedent on protocol for end-of-life care when physicians and families don't see eye-to-eye. The issue is fraught: Medical technology can now keep patients technically alive, so their loved ones sometimes keep them connected to

machines for months or years, even when doctors advise against it. It's even more contentious in a public health-care system, since health professionals must also consider the best way to allocate resources. http://www.theglobeandmail.com/life/health/end-of-life/supreme-court-to-hear-rasouli-end-of-life-case/article2281641/?utm_medium=Feeds%3A%20RSS%2FAtom&utm_source=Home&utm_content=2281641

Extract from *Globe & Mail* report

..the Supreme Court's decision will have a major impact on the country's doctors, medical ethicists, lawyers and, of course, families of patients. As it stands, all provinces but New Brunswick require consent from the patient or substitute decision-maker for medical treatment, and Ontario is the only one with a tribunal that makes decisions on a patient's behalf.

N.B. The Rasouli case has generated significant media attention in Canada (see Media Watch 2011 issues dated 5 December (p.2); 21 November (p.2); 26 September (p.2, p.9); 25, 11 & 4 July (p.1 in each issue); 23 May (p.2); and, 11 April (p.7).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CANADIAN ASSOCIATION FOR RETIRED PERSONS (CARP) | Online posting – 20 December 2011 – **'End of life/Elder abuse poll report.'** Seven-in-ten CARP members agree with legalized physician-assisted suicide for the terminally ill, both now and last year, and regardless of whether or not Canada has an effective, comprehensive and compassionate system of palliative and end of life care.¹ <http://www.carp.ca/2011/12/21/end-of-lifeelder-abuse-poll-report/>

1. 'End Of life/Elder abuse poll report,' CARP, December 2011. <http://www.carp.ca/wp-content/uploads/2011/12/End-Of-Life-Report.pdf>

U.S.A.

Physician Orders for Life Sustaining Treatment

For terminally ill, new law gives final say on medical care

NEW JERSEY SPOTLIGHT | Online report – 22 December 2011 – Legislation that encourages patients to decide if they want aggressive medical care at the end of life was signed into law by Gov. Chris Christie on Wednesday, moving New Jersey in line with more than 30 other states that provide residents with a relatively new planning document called the 'Physician Orders for Life Sustaining Treatment' or POLST. <http://www.njspotlight.com/stories/11/1222/0122/>

Looking for a place to die

NEW YORK TIMES | Online OpEd – 21 December 2011 – The patient was a fairly young woman and she'd had cancer for as long as her youngest child had been alive. That child was now walking and talking and her mother's cancer had spread throughout her body to the point where there were no more curative options. Aggressive growth of the disease in her brain had stripped her of her personality and her memories. She had another child, too, a few years older, and a husband whose drawn eyes and tense frame bore the strain of trying to keep it all together. Extended family lived far away and couldn't be brought closer. The husband and kids lived more than an hour's drive from the hospital. No one could say for sure how long she would live, but continued hospital care was clearly pointless. Nor could she go home: she needed more attention than her family could provide. Her physician, the husband, the palliative care team, we nurses ... agreed she needed inpatient hospice care, and that it should be provided close to home. The problem was, she had no place to go. There was a hospice facility near her house, but it would accept her only if she would die within six days. <http://www.nytimes.com/2011/12/22/opinion/looking-for-a-place-to-die.html>

Of related interest:

- CALIFORNIA | *Sacramento Bee* – 18 December 2011 – **'Terminally ill woman to stay in foreclosed home until she dies.'** [Luther & Claire Findlay's] ... situation shows what can happen when a medical crisis meets the foreclosure crisis and the spiralling effects of the recession. As a result, they represent an especially desperate economic reality: bankrupt, facing terminal illness and, until recently, coping with the stress of possible homelessness. The Findleys' dual medical and financial crises brought them to the brink of homelessness in what doctors say are Claire's final months of life and left them pleading for help. "It's a terrible, terrible case," said Margaret Reilly, Sacramento region program manager for the Health Insurance Counseling & Advocacy Program. <http://www.sacbee.com/2011/12/18/4130567/terminally-ill-woman-to-stay-in.html>

N.B. *Sacramento Bee* article is profiled on MSNBC Photo-blog at:
<http://photoblog.msnbc.msn.com/news/2011/12/22/9614385-facing-twin-tragedies-terminal-illness-and-foreclosure?pc=25&sp=25>

Prognosis

Most sick or disabled seniors want docs to say how long they have

U.S. NEWS & WORLD REPORT | Online report – 21 December 2011 – 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 It included 60 elderly patients with an average age of 78 who had multiple illnesses and disabilities and lived in a community-based, long-term care program in San Francisco. None of the patients had been diagnosed with a specific terminal illness. Interviews with the patients revealed that 75% would want a conversation about their prognosis if their doctor felt they had less than a year to live, while 65% would welcome such a dialogue if they likely had fewer than five years to live. However, only one of the 60 patients reported having such a discussion with a doctor, said the researchers at the San Francisco Veterans Affairs Medical Center and the University of

California... Wanting to prepare for death, making the most of their remaining time and making medical or life decisions were among the most common reasons the patients gave for wanted to discuss their prognosis. <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>

Specialist Publications

Of particular interest:

'Issues in prognostication for hospital specialist palliative care doctors and nurses: A qualitative inquiry' (p.6), published in *Palliative Medicine*.

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 Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx>

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

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

U.S.A.

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

International

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

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

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

International

Palliative care in Zambia: "People are not dead until they have died"

ZAMBIA | Street News Service (Glasgow, Scotland) – 19 December 2011 – Prevention and access to anti-retroviral medicines (ARV's) have been the main focus in the battle against HIV/Aids. But what about those who are already infected and, despite ARV's, have to deal with sickness and pain? Zambian health workers are now being trained in palliative care, learning to take care of both the physical and the emotional pain that comes with the disease. The Palliative Care Association of Zambia, formed in 2005, is now working to make good quality palliative care more widely available. This is not only for people who are very close to death, as people often assume. "Palliative care starts from the moment you are told: this disease cannot be cured," says Njekwa Lumbwe, national coordinator of the association. "With ARV's you can prolong life, but it should also be a quality life." <http://www.streetnewsservice.org/news/2011/december/feed-310/palliative-care-in-zambia-%E2%80%9Cpeople-are-not-dead-until-they-have-died%E2%80%9D.aspx>

N.B. Street News Service is the news agency of the International Network of Street Papers, a charity organisation that unites 112 street papers in 40 countries.

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

A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia

AGE & AGEING | Online article – 8 December 2011 – Four studies were included. All took place in nursing homes. Three studies reported formal processes of capacity assessment; only up to 36% of participants were judged to have capacity. Three studies reported positive findings in terms of documentation of patient pre-ferences for care. Two studies reported significant reductions in hospitalisation rates; a third found increased use of hospice services in the intervention group. There is limited evidence for the effectiveness of ACP [advance care planning] in people with cognitive impairment/dementia in terms of ACP documentation and health-care use. In terms of capacity to discuss ACP, nursing home settings may be too late for people with dementia. <http://ageing.oxfordjournals.org/content/early/2011/12/07/ageing.afr148.abstract>

Of related interest:

- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online article – 20 December 2011 – '**Advance directives and personal identity: What is the problem?**' The personal identity problem expresses the worry that due to disrupted psychological continuity, one person's advance directive could be used to determine the care of a different person. Even ethicists, who strongly question the possibility of the scenario depicted by the proponents of the personal identity problem, often consider it to be a very potent objection to the use of advance directives. <http://jmp.oxfordjournals.org/content/early/2011/12/20/jmp.ih.r055.abstract>

Religiosity and death attitudes and engagement of advance care planning among chronically ill older adults

RESEARCH ON AGING | Online article – 15 December 2011 – Greater reported religiosity was significantly associated with reported ACP [advance care planning] discussions with the doctor. Less fear of death was significantly associated with self-reported completion of a living will. Religiosity and fears of death should be considered in future ACP studies. <http://roa.sagepub.com/content/early/2011/12/14/0164027511423259>

Policies of withholding and withdrawal of life-sustaining treatment in critically ill patients on cardiac intensive care units in Germany: A national survey

INTERACTIVE CARDIOVASCULAR THORACIC SURGERY | Online article – 22 December 2011 – Concerning medical reasons, cranial computed tomography with poor prognosis, multi-organ failure and failure of assist device therapy were the three most frequently cited medical reasons for [withholding and/or withdrawal] WH/WD life-sustaining treatment. Overall, 32.6% of persons answered that ethical aspects influence their decision-making processes. Poor expected quality of life (48.8%), the patient's willingness to limit medical care (40.7%) and the families' choice (27.9%) were the top three reported ethical reasons. There was a significant difference regarding the perception of the three involved professional groups concerning the decision-making parameters: multi-organ failure, failure of assist device therapy, cardiac index, poor expected quality of life, the patient's willingness to limit medical care, intraoperative course, opinion of family members and whether decision-making process are done collaboratively.
<http://icvts.oxfordjournals.org/content/early/2011/12/22/icvts.ivr119.full>

Compassionate care enhancement: Benefits and outcomes

INTERNATIONAL JOURNAL OF PATIENT CENTRED MEDICINE, 2011;1(4):808-813. This review of outcome studies demonstrates that compassionate care benefits patients with regard to elected treatment adherence, wound healing, satisfaction, and well-being; it benefits physicians with regard to lowered depression rates, elevated meaning, lower burnout, and more diligent technical care; it benefits healthcare systems that establish reputational gains at no greater use of time or resources; it benefits medical students with regard to their diminished complaints of abusive clinical environments and maladaptive team interactions. There is no doubt that compassionate care has many dimensions of beneficial impact.
<http://www.ijpcm.org/index.php/IJPCM/article/view/153>

Of related interest:

- *PALLIATIVE MEDICINE* | Online article – 16 December 2011 – '**Understanding compassion satisfaction, compassion fatigue and burnout: A survey of the hospice palliative care workforce.**' The results of [this] survey indicate a significant negative correlation between compassion satisfaction and burnout, and between compassion satisfaction and compassion fatigue, and a significant positive correlation between burnout and compassion fatigue. Results indicate that health care systems could increase the prevalence of compassion satisfaction through both policy and institutional level programs to support HPC professionals in their jurisdictions.
<http://pmj.sagepub.com/content/early/2011/12/16/0269216311431311.abstract>

The findings of the Dartmouth Atlas Project: A challenge to clinical and ethical excellence in end-of-life care

JOURNAL OF CLINICAL ETHICS, 2011;22(3):267-76. The Dartmouth Institute for Health Policy & Clinical Practice Atlas Project¹ found "staggering variations" in the quality and quantity of end-of-life care provided to Medicare patients with severe chronic illness across the U.S. Particularly concerning is the finding that more care is provided to patients who live in "high-supply" areas, irrespective of the effectiveness of care, and that more care often equalled inappropriate care that increased patients' suffering at the end of life. Patients in "lower supply" areas typically received better, more appropriate levels of care and reported higher levels of satisfaction with the care they received. http://www.clinicalethics.com/single_article/7rleqieb8eA.html

1. *Trends & Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness*, Dartmouth Institute for Health Policy & Clinical Practice, April 2011 (noted in Media Watch dated 18 April 2011). http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf

The emergence of thanatology and current practice in death education

JOURNAL OF DEATH & DYING, 2012;64(2):157-169. Thanatology is a recent field that contemplates death studies and employs an interdisciplinary approach to practice. This science emerged in a historical context marked by intense social, economic, and political changes that contributed to the concept of death being excluded from social life. This literature review aims to outline the history and evolution of thanatology in Western society, delineating the contextual circumstances that led to its origin and drawing special attention to current works on death education. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue.4,5;journal,1,253;linkingpublicationresults,1:300329,1>

Hospital staff opinions concerning loved ones' understanding of the patient's life-limiting disease and the loved ones' need for support

JOURNAL OF PALLIATIVE MEDICINE | Online article – 23 December 2011 – The aim of this study was to investigate the opinions of nurses, assistant nurses, and doctors about whether the patient's loved ones understand that the patient has a life-limiting disease, and if they talk about these matters with the patient or staff. The study was quantitative in design with data collected by means of a semi-structured questionnaire. The study was conducted at geriatric, oncology, and urology wards at a university hospital in western Sweden. Results indicate a perception that loved ones understand the seriousness and consequences of the disease. Professional caregivers perceived an association between the loved ones' understanding of the fatal disease and their ability to cope with the situation. In addition, the study found that follow-up activities after the patient's death are mostly lacking. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0297>

Family Communication Patterns Theory

The impact of family communication patterns on hospice family caregivers: A new typology

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online article – 22 December 2011 – As patients transition to hospice/palliative care, family members face the challenge of engaging in conversations about prognosis and death. Although conversations about death and dying are optimal during hospice care, few families are able to speak openly and candidly about disease and illness and little is known about the impact of family communication patterns on the primary caregiver's stress and ability to cope. Family Communication Patterns Theory was used as a framework to investigate caregiver concerns related to family roles and responsibilities during hospice care. http://journals.lww.com/jhpn/Abstract/publishahead/The_Impact_of_Family_Communication_Patterns_on.99993.aspx

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Online editorial – 21 December 2011 – '**Death can be a friend.**' Would you like to die the way your patients do, doctor? We suspect that many of you will answer no. Too many people are dying undignified graceless deaths in hospital wards or intensive care units, with doctors battling against death way past the point that is humane. Because too many doctors have forgotten that death is a friend, people are kept alive when all that makes life valuable has gone. Denying the inevitable comes with a heavy price. We believe that doctors and their patients need to adopt a much more positive attitude to death to reduce suffering and costs. <http://www.bmj.com/content/343/bmj.d8008>
- *PALLIATIVE MEDICINE* | Online article – 21 December 2011 – '**Issues in prognostication for hospital specialist palliative care doctors and nurses: A qualitative inquiry.**' Two major themes [emerged]: difficulties of prognostication; benefits of prognostication. Eleven sub-themes [emerged]: difficulties (non-malignant disease; communicating uncertainty; seeking definitive prognosis; participants' feelings; confidence in prognostication; estimating prognosis; dealing with reaction of prognosis; prognostic error); benefits (patient informed decision-making prioritizing needs and care; family-prioritizing commitments; services accessing funding and services planning patient care). <http://pmj.sagepub.com/content/early/2011/12/21/0269216311432898.abstract>

The nurse advocate in end-of-life care

THE OCHSNER JOURNAL, 2011;11(4):325-329. End-of-life nursing encompasses many aspects of care: pain and symptom management, culturally sensitive practices, assisting patients and their families through the death and dying process, and ethical decision making. Advocacy has been identified as a key core competency for the professional nurse, yet the literature reveals relevant barriers to acquiring this skill. Challenges exist, such as limitations in nursing school curricula on the death and dying process, particularly in multicultural settings; differing policies and practices in healthcare systems; and various interpretations of end-of-life legal language. Patricia Benner's conceptual model of advocacy behaviors in end-of-life nursing provides the framework in which nurses can become effective patient advocates. Developing active listening and effective communication skills can enhance the nurse-patient trust relationship and create a healing environment. <http://www.ochsnerjournal.org/doi/abs/10.1043/1524-5012-11.4.325>

N.B. This issue of *The Ochsner Journal* includes several articles on different aspects of end-of-life care. Contents page: <http://www.ochsnerjournal.org/toc/ochs/11/4>

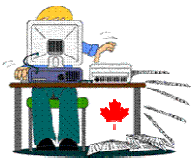
Editorial

Back to basics: Researching equity in palliative care

PALLIATIVE MEDICINE, 2012;26(1):5-6. Recent debate on the provision of palliative care as an international human right has included the assertion that there should be equity of access to services for all, without discrimination. Few would argue with the merits of such an aim. Few also would argue that current evidence points to serious inequalities; at a global level, the lack of palliative care provision in many settings remains a fundamental issue. However, even within countries with well-developed palliative care, differential access has been reported for patients as a result of characteristics including age, ethnicity and socioeconomic status. This has led to the widespread assumption that there is inequitable provision of care. This may indeed be the case. However, for the presence of inequity to be determined, a few key theoretical concepts need to be understood. <http://pmj.sagepub.com/content/26/1/5.extract>

Of related interest:

- *PALLIATIVE MEDICINE* | Online article – 16 December 2011 – **'Using observation as a data collection method to help understand patient and professional roles and actions in palliative care settings.'** Observational studies can be challenging to carry out: the authors focus on the potentially problematic areas of sampling, consent and ethics, data collection and recording, data management and analysis. They conclude that qualitative observational data collection methods can contribute to theoretical and conceptual development and the explanation of social processes in palliative care. This contribution to understanding care structures and processes should improve understanding of patients' experiences of their care journey and thus impact on care outcomes. <http://pmj.sagepub.com/content/early/2011/12/16/0269216311432897.abstract?rss=1>



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>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *PALLIATIVE MEDICINE*, 2012;26(1):23-33. **'Attitudes of U.K. doctors towards euthanasia and physician-assisted suicide: A systematic literature review.'** U.K. doctors appear to oppose the introduction of voluntary euthanasia and physician assisted suicide, even when one considers the methodological limitations of included studies. Attempts to minimise bias in included studies varied. Further studies are necessary to establish if subgroup variables other than degree of religiosity influence attitudes, and to thoroughly explore the qualitative themes that appeared.
<http://pmj.sagepub.com/content/26/1/23.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.

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