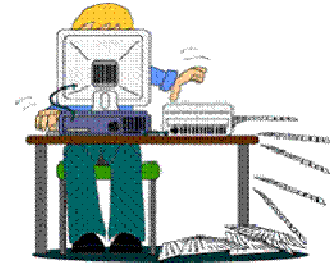


Media Watch

...is distributed weekly to colleagues active or with a special interest in **hospice and palliative care, and end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to inform discussion and encourage further inquiry. Following is an annotated listing of recent articles, reports, etc., with links to the original source.

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Compiled & Annotated by Barry R. Ashpole

Communications and the quality of patient care: Scroll down to [Specialist Publications](#) (p.7) and 'Pathways linking clinician–patient communication to health outcomes.'

Canada



Hospice palliative care: A human right

CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION (CHPCA) | Press release – 1 May 2009 – Hospice palliative care has been identified in an international declaration as a human right, yet not even half of all Canadians who need it, have access to it. During National Hospice Palliative Care Week (3-9 May), CHPCA is encouraging all levels of government to support improved access to hospice palliative care for all Canadians.
<http://www.newswire.ca/en/releases/archive/May2009/01/c7372.html>

U.S.A.

End-of-life bill shows mercy to suffering families

NEW YORK | *Buffalo News* – 1 May 2009 – Fewer than 25% of New Yorkers have completed a health care proxy form naming someone to act on their behalf, should they be unable to voice their wishes. The proposed Family Health Care Decisions Act would ensure the rights of all New Yorkers – and specifically those incapacitated patients in hospices, hospitals and residential care facilities – ensuring that they can live with dignity and receive health care that is in their best interests and is consistent with their own wishes and beliefs.
<http://www.buffalonews.com/149/story/657616.html>

Links

Links are confirmed as being active before Media Watch is distributed; however, links often remain active for only a limited period of time. Please alert this office if you encounter any difficulty.

Health care for those near the end of life

Personal experience weighs on Obama in health policy debate

WASHINGTON DC | *New York Times* – 30 April 2009 – In the weeks before he was elected president, Barack Obama confronted a life crisis all too common in families across America. His grandmother, who already had a diagnosis of terminal cancer, fell and broke her hip, possibly because of a mild stroke. The question became whether to replace her hip even though she was dying. Mr. Obama discussed the episode in an interview with *The New York Times Magazine* to point out one of the thorniest issues involved in overhauling health care: Much of the spending on medical care in the U.S. goes to people in their final months of life.¹ If society is to rein in health costs, at what point are expensive operations like Ms. Dunham's hip replacement surgery no longer affordable? <http://www.nytimes.com/2009/05/01/us/politics/30web-baker.html?ref=global-home>

1. **'After the great recession,'** *New York Times Magazine*, 28 April 2009

Caregivers struggle even more during recession, study finds

FLORIDA | *Orlando Sentinel* – 28 April 2009 – A new study shows family caregivers are facing increased financial and emotional hardships as they struggle to continue providing care to loved ones with chronic illnesses or disabilities.¹ The survey reveals that more than 40% of caregivers have taken a pay cut or have been forced to work fewer hours as a result of the recession; 15% of caregivers have lost their jobs as a result of the downturn; 21% of caregivers say that they and their loved ones have moved in together to cut costs; and, nearly half of all caregivers have exhausted their savings. <http://www.orlandosentinel.com/news/local/ori-loccaregivers-struggle-recessio042809apr28.0.6894119.story>

1. *Evercare Survey of The Economic Downturn and Its Impact on Family Caregiving*, April 2009
http://evercarehealthplans.com/pdf/EVC_Caregivers_Economy_Report_FINAL_4_28_09.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MONTANA | Associated Press – 28 April 2009 – **'Amicus (friends of the court) briefs filed in assisted suicide case.'** Three friend-of-the-court briefs ask the Montana Supreme Court to reverse a lower-court ruling that Montanans have a constitutional right to physician-assisted suicide. <http://www.kpax.com/Global/story.asp?S=10265667>

International

Calls for terminally-ill to have greater choice of where to die

U.K. (SCOTLAND) | *Herald* – 29 April 2009 – Charities called for greater choice for terminally ill patients after the first Scottish Government report of its kind revealed more than half of all cancer patients die in hospital. The inaugural *Place of Death* report found half of the 75,000 deaths from cancer in Scotland between 2003-2007 were in ... acute hospitals and only around a quarter of deaths were at home. The report found that it was likely that lack of facilities for caring for people at home who suffer difficulties or related complications in their dying days mean people are ending their lives in hospital when they'd rather be at home. But social reasons, such as the need to provide respite to a carer, were also cited. The report also found 17% of cancer deaths were in hospices, and the remainder died in other institutions such as care homes and private hospitals. http://www.theherald.co.uk/news/news/display.var.2504840.0.Calls_for_terminallyill_patients_to_have_greater_choice_of_where_to_die.php

Learning from each other to help the dying

U.K. (SCOTLAND) | *Scotsman* (OpEd) – 29 April 2009 – What value is there in comparing the experiences of dying in two very different countries? One where specialist palliative care is available free, the other where cancer was not a national priority, where there were no specialists, or easy access to chemotherapy, or good pain relief. Palliative care has a long way to go in Africa and Edinburgh University is working there to improve services. But we in Scotland can learn much from Africa about caring for those nearing the end of life. Physical care is critical, but so too is the care of patients' spiritual and social needs. Good palliative care can be delivered best in the community, we need to rebuild our communities and talk about death as a path we all must tread. <http://news.scotsman.com/opinion/Dr-Liz-Grant-Learning-from.5215284.jp>

Of related interest:

- U.S. | *Bedlam Farm Journal* (Editorial) – 30 April 2009 – **'Hospice Journal: Izzy, Jean, on the edge of life.'** I am always a bit taken aback by the grace, humor and acceptance I find in hospice work. <http://blog.bedlamfarm.com/index.cfm/2009/4/30/Hospice-Journal-Izzy-Jean-on-the-edge-of-life>

Chinese face rising cost of dying

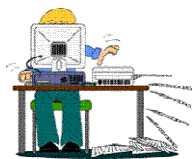
CHINA | *Financial Times* (U.K.) – 28 April 2009 – Public outrage erupted this month in China over profiteering in the funeral industry, and the outcry even spilled into the state-controlled press during the recent traditional tomb-sweeping festival (Qing Ming Jie – 清明節), when Chinese honour the dead. <http://www.ft.com/cms/s/0/d9020796-338c-11de-8f1b-00144feabdc0.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SINGAPORE | *Straits Times* – 30 April 2009 – The police disallowed pro-euthanasia group Exit International from holding a talk ... on the grounds it would promote what is a criminal offence in Singapore. http://www.straitstimes.com/Breaking%2BNews/Singapore/Story/STIStory_370846.html
- U.K. (SCOTLAND) | *The Christian Institute* – 29 April 2009 – **'Euthanasia will be debated in the Scottish Parliament.'** A Member of the Scottish Parliament, Margo Macdonald has gained enough support from colleagues to have a full debate on assisted suicide in the Scottish parliament. <http://www.christian.org.uk/news/20090429/euthanasia-will-be-debated-in-the-scottish-parliament/>
- U.K. | *Telegraph & Argus* – 28 April 2009 – **'Undercliffe woman takes suicide law fight to House of Lords.'** A woman who suffers from Multiple Sclerosis would like the option of an assisted death should her suffering become unbearable. Recently, the Court of Appeal had expressed the opinion that although a prosecution is unlikely, they would not rule for a prosecuting policy to clarify the law. Debbie Purdy will challenge this judgement in a House of Lords appeal scheduled for 2 June. http://www.thetelegraphandargus.co.uk/news/4325189.Debbie_gets_date_for_legal_challenge/

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.

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

No heroic measures: How soon is too soon to stop?

ANNALS OF THORACIC SURGERY, 2009;87(1):11-8. Cardiothoracic surgeons ... base most decisions on clinical judgment developed and honed during years of training and experience. Some decisions, however, are based on more than weighing scientific evidence and outcome probabilities, and they require value judgments on such matters as the desirability of alternative outcomes. Among the most difficult judgments ... are those that conflict with the views of the patient or the patient's proxy ... decision maker. In cases of critical illness with low survival probability, discordant judgments about withdrawing life support are often based on perceived acceptability of the projected quantity and quality of life if the patient survives. The surgeon and the proxy or surrogate might find themselves on either of the opposing sides of the issue.

<http://ats.ctsnetjournals.org/cgi/reprint/87/1/11>

End-of-life care for people with a learning disability

North Staffordshire palliative care project bears fruit

COMMUNITY CARE (U.K.) | Online report – 28 April 2009 – A guide to help social care professionals provide end-of-life care for people with a learning disability has been published by Mencap (a U.K. advocacy group) and Keele University. The free guide is the result of a two-year palliative care project set up ... in 2006, which developed and tested best practice in end-of-life care. <http://www.communitycare.co.uk/Articles/2009/04/28/111362/learning-disabilities-end-of-life-care-guide-published.html>

1. *Living and dying with dignity: The best practice guide to end-of-life care for people with a learning disability*, Mencap, April 2009. <http://www.mencap.org.uk/document.asp?id=9750>

Defining a role for palliative care

Heart failure patients, caregivers have unmet care needs

EMAXHEALTH (U.S.) | Online report – 27 April 2009 – Heart failure patients and their caregivers want to know what to anticipate with the illness, get more help with symptom relief and have increased communication with members of the medical team providing care, researchers reported at the recent American Heart Association's Scientific Forum on Quality of Care & Outcomes Research in Cardiovascular Disease & Stroke. Most teams treating heart failure are medically focused. There is little guidance on the emotional, financial, spiritual and social impact of heart failure. This study helps define a role for palliative care in addressing the needs of heart failure patients and their caregivers." <http://www.emaxhealth.com/2/80/30657/heart-failure-patients-caregivers-have-unmet-care-needs.html>

Of related interest:

- *CURRENT CARDIOLOGY REPORTS*, 2009;11(3):184-191. **'End-of-life care in heart failure.'** End-of-life care should be planned with the patient and family and should incorporate comprehensive symptom management, bereavement support, and spiritual support. http://www.current-reports.com/article_frame.cfm?PubID=CR11-3-1-04&Type=Abstract
- *EUROPEAN JOURNAL OF HEART FAILURE*, 2009;11(5):433-443. **'Palliative care in heart failure: A position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology.'** Heart failure patients may have generic palliative care needs, such as refractory multifaceted symptoms, communication and decision making issues, and the requirement for family support. This document describes recommendations in the area of delivery of quality care to patients and families, education, treatment coordination, research and policy. <http://eurjh.oxfordjournals.org/cgi/content/abstract/11/5/433>

Palliative care in rural and remote regions

Assessing the suitability of host communities for secondary palliative care hubs

HEALTH & PLACE, 2009;15(3):649-908. Recent Canadian end-of-life care frameworks have largely failed to consider the unique challenges of delivery in rural and remote regions. In the British Columbia urban areas are well-served for specialized palliative care; however, rural and remote regions are not. The authors present a location analysis model designed to determine appropriate locations to allocate palliative care services. Secondary palliative care hubs (PCH) are introduced as an option for delivering these services in rural and remote regions.

http://www.sciencedirect.com/science?_ob=MIimg&_imagekey=B6VH5-4VJBTW4-1-7&_cdi=6057&_user=10&_orig=browse&_coverDate=09%2F30%2F2009&_sk=999849996&_view=c&_wchp=dGLbVlb-zSkWA&_md5=879a08bf0a1e28d6730aafc2d1cea094&_ie=/sdarticle.pdf

From Media Watch dated 03.23.09.

- *CANADIAN JOURNAL OF RURAL MEDICINE*, 2009;14(1):10-15. **'Use of palliative care services in a semirural program in British Columbia.'** Although specialized palliative care services in rural areas are scarce, many people who are dying, and their families, want to remain in their homes or within their own community. <http://www.cma.ca/multimedia/staticContent/HTML/N0/I2/cjrm/vol-14/issue-1/pdf/pg10.pdf>

From Media Watch dated 12.29.08.

- *CANADIAN JOURNAL OF RURAL MEDICINE*, 2008;13(3):139-40. **'Palliative care is a rural medicine issue.'** The increasing number of people relocating to rural areas upon retirement and the process of aging-in-place in such communities are amplifying the need for palliative care in these settings. <http://www.cma.ca/multimedia/staticContent/HTML/N0/I2/cjrm/vol-13/issue-3/pdf/pg139.pdf>

Racism and black-white relationships in end-of-life care in the U.S.

ILLNESS, CRISIS & LOSS, 2009;17(2):113-124. Despite the almost sacred nature of end-of-life care in hospitals, hospice programs, and nursing homes, there is every reason to think that racism and the racial system are often present in black-white relationships in end-of-life care in the U.S. This speculative essay explores expressions of the racial system that might occur in end-of-life care, from the perspectives of Euro-Americans and African Americans as patients, family members of patients, and care providers. The racial system operates in ways that bruise some people and that make it difficult for those who are advantaged by the system to understand the system and their place in it; and so, ideally one way for end-of-life care facilities to deal with potential difficulties in black-white relationships is to provide contexts for dealing with bruises and obliviousness. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,8;journal,1,42;linkingpublicationresults,1:103734,1>

Exploring the literature surrounding the transition into palliative care

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2009;15(4):186-189. This article explores the current literature surrounding transitions into palliative care. Transitions in care have become more frequent and complex in the Canadian healthcare system. Plagued with difficulty, fear and misunderstanding, the transition into palliative care is one of the most confusing and traumatic transitions a patient and family can face. Despite this, however, transitions into palliative care have been commonly overlooked in transitional research. A scoping review of the existing literature on transitions and palliative care was conducted and three key areas complicating the transition into palliative care were noted: the intrinsic nature of the transitions, the timing of the transition, and the lack of information surrounding this transition. This article highlights a need for further research into the complicated area of transitions into palliative care. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=41967;article=IJPN_15_4_186_189

Understanding best practice within nurse intershift handover: What suits palliative care?

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2009;15(4):190-196. The authors identify and appraise what is known about best practice within nurse intershift handover and evaluate the implications for practice within a specialist palliative care inpatient unit. Three main themes emerged within the literature (reviewed): purpose; type; and content of handover. Five sub-categories emerged that may be significant in meeting the demands of specialist palliative nursing. These were: 1) clinical decision-making; 2) staff support; 3) maintaining confidentiality while handling sensitive information; 4) patient involvement; and, 5) type of information exchange. All themes are presented within this article. The literature review suggests that traditional verbal nursing handover may be the most advantageous handover method within inpatient specialist palliative care, though attention to structure and focus is vital. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=41968;article=IJP_N_15_4_190_196

Assisted (or facilitated) death

Objectivity in evaluations for assisted suicide

JOURNAL OF FORENSIC PSYCHOLOGY PRACTICE, 2009;9(1):70-81. Recent literature has emphasized the important role that psychologists can play in evaluating patients' competency and decision-making processes in cases of assisted suicide. It is often assumed that psychologists will be objective when conducting evaluations or that current training standards will neutralize potential sources of bias. Yet, providing service to patients who are seeking an assisted suicide may give rise to a number of relational and intra-psychic issues that could influence the evaluation process and its outcomes. Psychologists should not be involved in cases of assisted suicide until they are adequately trained to be cognizant of the psychodynamic issues, particularly their own counter-transference, that are likely to emerge within this unique clinical situation. They offer suggestions for augmenting previously recommended training procedures to account for these issues. <http://www.informaworld.com/smpp/content~content=a908604908~db=all>

Of related interest:

- *CRITICAL CARE MEDICINE*, 2009;37(4):1206-1209. **'Why not physician-assisted death?'** Our collective repudiation of physician-assisted death, in all its forms, has complex origins that are not necessarily rational. If great care is taken to ensure that a request for physician-assisted death is persistent despite exhaustion of all available therapeutic modalities, then an argument can be made that our rejection constrains unnecessarily the liberty of a small number of patients. <http://www.ccmjournal.com/pt/re/ccm/abstract.00003246-200904000-00003.htm;jsessionid=J51QmHb2Vn8DSkWPJwYJLdKxGCJgTpVhR0QmVL6mjCTFz0VcBDyQ!-1862535748!181195628!8091!-1>
- *IRISH HEALTH* | Online OpEd – 28 April 2009 – **'Euthanasia is growing issue...'** A survey by the Irish Association of Suicidology found 48% of those questioned agreed that people with incurable illness should be allowed to commit suicide in a dignified manner. <http://www.irishhealth.com/article.html?id=15436>
- *PSYCHOSOMATICS*, 2009;50(1):1-7. **'Differentiating suicide from life-ending acts and end-of-life decisions...'** Technological advances continue to yield life-prolonging treatments that complicate the occurrence of death ... (and) until recently, refusal to submit to recommended care was considered suicide. <http://psy.psychiatryonline.org/cgi/content/abstract/50/1/1>

Something Missed or Overlooked?

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

Affective forecasting and advance care planning

JOURNAL OF HEALTH PSYCHOLOGY, 2009;14(3):447-456. That sicker people evaluate quality of life in future health status more positively, compared to healthier people, is viewed as an instance of affective forecasting error and explained by Prospect Theory, which holds that two prospects (poor health versus death) are more distinguishable when they are imminent than when distant. <http://hpq.sagepub.com/cgi/content/abstract/14/3/447>

Failure to provide adequate pain relief

MEDSCAPE TODAY (U.S.) | Online OpEd – 24 April 2009 – There is hardly any risk of liability for malpractice based on the failure to provide patients with adequate pain relief, despite almost universal recognition that standards of practice require the provision of adequate pain relief. Two highly respected scholars in pain management and legal liability have both concluded that the principles of liability could support malpractice by a physician who under treats pain, but neither could reference a single reported precedential legal opinion in which liability under such circumstances has actually been recognized. <http://www.medscape.com/viewarticle/591048>

How does communication heal?

Pathways linking clinician–patient communication to health outcomes

PATIENT EDUCATION & COUNSELING, 2009;74(3):295-301. Although prior research indicates that features of clinician-patient communication can predict health outcomes weeks and months after the consultation, the mechanisms accounting for these findings are poorly understood. While talk itself can be therapeutic ... more often clinician-patient communication influences health outcomes via a more indirect route. Proximal outcomes of the interaction include patient understanding, trust, and clinician-patient agreement. These affect intermediate outcomes (e.g., increased adherence, better self-care skills) which, in turn, affect health and well-being. Seven pathways through which communication can lead to better health include: 1) increased access to care: 2) greater patient knowledge and shared understanding: 3) higher quality medical decisions: 4) enhanced therapeutic alliances: 5) increased social support; 6) patient agency and empowerment; and, 7) better management of emotions. Future research should hypothesize pathways connecting communication to health outcomes and select measures specific to that pathway. <http://linkinghub.elsevier.com/retrieve/pii/S0738399108006319>

Of related interest:

- *PSYCHO-ONCOLOGY*, 2009;18(5):500-507. **'Time-related communication skills from the cancer patient perspective.'** How do cancer patients describe and explain the effects of health care communication upon their experience of time? The authors of this study found time a meaningful and symbolic construct for cancer patients and describe clinician time-related attitudes and behaviors as significant factors in shaping the impact of clinical encounters on their overall psychosocial cancer experiences. <http://www3.interscience.wiley.com/journal/121372669/abstract>

Quotable Quotes

Start doing the things you think should be done, and start being what you think society should become. Do you believe in free speech? Then speak freely. Do you love the truth? Then tell it. Do you believe in an open society? Then act in the open. Do you believe in a decent and humane society? Then behave decently and humanely.

Adam Michnik, Polish historian, journalist, political activist.

Pediatricians' perceptions of and preferred timing for pediatric palliative care

PEDIATRICS, 2009;123(5):e777-e782. Despite recommendations to refer children to palliative care early in the course of illness, most pediatricians define palliative care as similar to hospice care and refer patients once curative therapy is no longer an option. Creating a more-practical definition of care, one that emphasizes an array of services throughout the course of an illness, as opposed to hospice care, may increase earlier palliative care referrals for children with life-limiting illnesses. <http://pediatrics.aappublications.org/cgi/content/abstract/123/5/e777>

Flirting with death: The effects on relationships of surviving a life-threatening illness

PSYCHODYNAMIC PRACTICE (OpEd), 2009;15(1):77-83. Over the course of twenty years' experience counselling more than 600 clients, the author came across many relationships which seem to have been severely compromised by one partner nearly dying. In some cases, the partner of the ill client has withdrawn affection and become cold; in others, the partner has found a lover – ex- or new, temporary or permanent. All of the clients concerned were people with considerable experience of the world. All of them were confused and puzzled by the way the partner reacted to their illness. Some of them had not made the link to their own illness until it was uncovered in counselling. The author suggests that life-threatening illness can be experienced as a flirtation with death, producing something of the same feelings of betrayal in the healthy partner, and, in some cases, some of the same reactions as any other threat of abandonment. <http://www.informaworld.com/smpp/content~content=a909228859~db=all>

The context of religious and spiritual care at the end of life in long-term care facilities

SOCIOLOGY OF RELIGION | Online journal article – 27 March 2009 – Despite the increasing numbers of Americans who die in nursing homes and residential care or assisted living facilities, and the importance of religious and spiritual needs as one approaches death, little is known about how these needs are met for dying individuals in long-term care institutional settings. This study compared receipt of religious and spiritual help in four types of settings. Data were also available for religious affiliation of the facilities, size, and provision of religious and hospice services. <http://socrel.oxfordjournals.org/cgi/content/abstract/srp012>

Worth Repeating

Nurses' experiences with hospice patients who refuse food and fluids to hasten death

NEW ENGLAND JOURNAL OF MEDICINE, 2003;349(4):359-365. Voluntary refusal of food and fluids has been proposed as an alternative to physician-assisted suicide for terminally ill patients who wish to hasten death. There are few reports of patients who have made this choice. Nurses who responded to a survey reported that patients chose to stop eating and drinking because they were ready to die, saw continued existence as pointless, and considered their quality of life poor. On the basis of the hospice nurses' reports, the patients who stopped eating and drinking were older than 55 patients (in Oregon) who died by physician-assisted suicide, less likely to want to control the circumstances of their death, and less likely to be evaluated by a mental health professional. On the basis of reports, patients in hospice care who voluntarily choose to refuse food and fluids are elderly, no longer find meaning in living, and usually die a "good" death within two weeks after stopping food and fluids. <http://content.nejm.org/cgi/content/abstract/349/4/359>

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