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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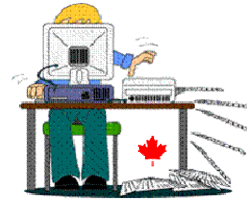

Compilation of Media Watch 2008, 2009, 2010 ©

Compiled & Annotated by Barry R. Ashpole

Moral wisdom: Scroll down to Specialist Publications and 'Pitfalls of legal regulation to improve end-of-life care: The example of artificial nutrition and hydration' (p.9) published at Online Journal of Health Ethics.

Canada

Letter to the editor

Cancer a complex disease

ALBERTA | *Edmonton Journal* – 22 July 2010 – As medical oncologists at the Cross Cancer Institute, we wish to clarify some statements made recently in the *Journal* about cancer patients.[1,2] Cancer is an incredibly complex disease process; it is not a single illness. Depending on the type and extent of cancer that a person has, treatment may be very useful even if it is not curative. With modern chemotherapy and better supportive treatments to manage side-effects, many patients with Stage IV cancer can expect improvements in both quality and length of life. However, some patients with advanced cancer cannot receive treatment, either because they are too ill or because there are not useful treatments for their particular type of cancer – these patients are best served by supportive and palliative care. Edmonton has some of the finest palliative care services in the world, and they are typically provided in the community; referral to the ... Institute is not required in order for these pain and symptom control services to be accessed. http://www.edmontonjournal.com/health/Cancer+complex+disease/3307222/story.html

1. **'Woman's agonizing death prompts cancer-care changes.'** The death of a woman who felt abandoned while waiting for chemotherapy treatments from the ... Institute has spurred Alberta Health Services to fast-track a new system to guide patients through cancer treatment. http://www.edmontonjournal.com/health/Woman+agonizing+death+prompts+cancer+care+changes/3285216/story.html

2. **'Home chemotherapy eases patients' anxiety.'** Chris Corrigan believes his life has been lengthened by getting chemotherapy treatment at home rather than at the ... Institute. http://www.edmontonjournal.com/health/Home+chemotherapy+eases+patients+anxiety/3289603/story.html

From Media Watch dated 14 June 2010:

- ALBERTA | CBC News (Edmonton) – 7 June 2010 – **'Chemo denied to some at Edmonton clinic.'** A shortage of oncologists is forcing doctors at the Cross Cancer Institute in Edmonton to limit chemotherapy for gastrointestinal patients to those who would have a chance at full recovery if they received the treatment. http://www.cbc.ca/canada/edmonton/story/2010/06/07/edmonton-oncololgist-shortage-cross-cancer-chemotherapy.html

Economist Intelligence Unit Quality of Death Index

There are a lot better places to die than Canada

GLOBE & MAIL | Online OpEd – 21 July 2010 – Britain is the best place in the world to die. While that statement may lend itself to all manner of snide commentary, it is based on the results of the newly created Quality of Death Index, which ranks countries according to their provision of end-of-life care. Britain topped the index, prepared by the Economist Intelligence Unit, because it takes hospice and palliative care seriously: It has decided, as a matter of public policy, that the quality of death is as important as the quality of life.[1] The care itself is good and publicly funded. Health-care providers are trained in palliation, painkillers are used liberally at the end of life and there is a high degree of doctor-patient transparency (meaning the wishes of patients and families are respected). Canada didn't fare so well on the index. It is renowned for its technical abilities – using medication and other techniques such as music therapy to lessen pain and suffering – but scored a middling ninth out of 40 countries. There are four principal reasons for the mediocre showing: End-of-life care is poorly co-ordinated; it is expensive (many services and drugs needed at the end of life are not covered by medicare); patient-centred care is lacking (meaning the wishes of patients are not respected nearly enough) and there is a shortage of policy leadership (with the exception of the tireless work of Senator Sharon Carstairs, the issue is ignored by politicians).[2] The Canadian Hospice Palliative Care Association, in a [recent] report ... also underscored these issues.[3] http://www.theglobeandmail.com/life/health/there-are-a-lot-better-places-to-die-than-canada/article1647604/

1. *The Quality of Death: Ranking End of-life-care Across the World*, Economist Intelligence Unit, July 2010 http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

   N.B. The EIU study was commissioned by the Singapore-based Lien Foundation: http://www.lienfoundation.org/ Publication of the Quality of Death Index is reported on in detail in Media Watch dated 19 July 2010 (pp.1,2 & 3).

2. *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*, Senator Sharon Carstairs, June 2010 http://sen.parl.gc.ca/scarstairs/PalliativeCare/PalliativeCare_e.asp

3. The author of the OpEd refers to a yet to be released report, *Quality of End-of-Life Care? It Depends on Where You Live ... and Where You* Die. Personal communication with Canadian Hospice Palliative Care Association, 22 July 2010 ***BRA***.

   From Media Watch dated 24 May 2010:

   - CANADIAN CANCER SOCIETY | Press release – 19 May 2010 – **'Dying cancer patients need more support.'** The type and quality of care and services to ensure a cancer patient dies with dignity in the setting of their choice depends on where the person lives in Canada, according to a special report about end-of-life care in Canadian Cancer Statistics 2010, released by the Canadian Cancer Society. http://www.cancer.ca/Canada-wide/About%20us/Media%20centre/CW-Media%20releases/CW-2010/Canadian%20Cancer%20Statistics%202010.aspx?sc_lang=en

Hospice integration will dissolve local organizations

ONTARIO | *Northumberland News* – 21 July 2010 – In the face of ongoing funding challenges, local hospice services will be integrated into one county-wide body in an effort to improve efficiency. The Central East Local Health Integration Network (LHIN) is currently working with Hospice Northumberland Lakeshore, Palliative Care Campbellford and Community Care Northumberland on a plan that would dissolve the two hospice providers and integrate the service into Community Care."The question is, given what's happening with these organizations at the current time, are they going to be able to carry on?" said Katie Cronin-Wood, communications lead for the LHIN, citing financial and operational challenges such as staffing and volunteer recruitment. "Truthfully, we don't know, but with integration we have the ability to maintain and maybe enhance services." Jim Wrigley, executive director of Hospice Northumberland Lakeshore, notes this is not a new concept. The boards of the two hospices have been in talks for quite some time about a possible merging or integration. "This is not coming out of the blue," he explained. http://www.northumberlandnews.com/news/article/158674

U.S.A.

Helping patients face death, she fought to live

NEW YORK TIMES | Online article – Accessed 25 July 2010 – Over the last decade, palliative care has become standard practice in hospitals across the country. Born out of a backlash against the highly medicalized death that had become prevalent in American hospitals, it stresses the relief of pain; thinking realistically about goals; and recognizing that, after a certain point, aggressive treatment may prevent patients from enjoying what life they had left. Dr. [Desiree] Pardi had gone into the field because she thought her experience as a patient would make her a better doctor. Now she came face to face with all the ambiguities of death, and of her profession. http://www.nytimes.com/2010/04/04/health/04doctor.html?_r=3&scp=3&sq=palliative+care+aggressive+cancer&st=nyt

Hospice helps pets, too

LOUISIANA | *Advocate* – 20 July 2010 – Henry Griffin, 92, sat on the front porch of his house in Broadmoor, his two dachshunds nearby. One of them, Amber, wiry and graying, is the elderly mother of Cé Cé, a more rotund, friskier version. Both are good company for Griffin, who is a patient of Hospice of Baton Rouge. "I've always had a dog here," Griffin said. Now, through a new national grant program, the hospice's patient care volunteer who visits Griffin weekly will be able to bring dog food and treats for the dogs and keep an eye on them. In June, the non-profit Hospice of Baton Rouge received a start-up grant of $1,500 from Pet Peace of Mind, a program of Banfield Charitable Trust. http://www.2theadvocate.com/features/98805704.html

From Media Watch dated 28 December 2009:

- OREGON | *The Oregonian* – 23 December 2009 – **'Hospice offers patients free care for their pets.'** The Banfield Charitable Trust has awarded Mt. Hood Hospice a grant to initiate a Pet Peace of Mind program which will provide in-home pet care such as dog-walking, litter box maintenance, transportation to and from vet appointments and financial assistance with pet food, grooming... http://www.oregonlive.com/clackamascounty/index.ssf/2009/12/sandy_hospice_offers_patients.html

Demystifying the process of dying

OHIO | *Canton Repository* – 19 July 2010 – What do physicians and hospice nurses know about dying that we don't? Much that would make the impending death of a loved one easier to understand and endure. For many, witnessing the process creates a miasma of conflicting emotions. Fear. Helplessness. Uncertainty. Hospice and palliative, or comfort, care for patients nearing the end of life smoothes the way for patients and their loved ones. "My mantra is, dying is all about spirituality," said Dr. Kevin F. Dieter, associate medical director of Summa palliative care and hospice services in Akron. "The first thing we have to acknowledge is that patients are near the end of life. We need to validate to them what's going on. They are waiting for us to tell them because they need to get things wrapped up. The end of life can be a time of healing, reconciliation and closure. But unless you know you're dying, those things can't happen." http://www.cantonrep.com/carousel/x1005405810/Demystifying-the-process-of-dying

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.

The risk of out-of-pocket health care expenditure at end of life

NATIONAL BUREAU OF ECONOMIC RESEARCH | Online posting – July 2010 – There is conflicting evidence on the importance of out-of-pocket medical expenditures as a risk to financial security, particularly at older ages. The authors revisit this question, focusing on health care spending near the end of life using data from the Health & Retirement Study for the years 1998-2006. They address difficulties with missing values for various categories of expenditures, outliers, and variations across individuals in the length of the reporting period. Spending in the last year of life is estimated to be $11,618 on average, with the 90th percentile equal to $29,335, the 95th percentile $49,907, and the 99th equal to $94,310. These spending measures represent a substantial fraction of liquid wealth for decedents. Total out-of-pocket expenditures are strongly positively related to wealth and weakly related to income. The authors find evidence for a mechanism by which wealth could plausibly buy health: large expenditures on home modifications, helpers, home health care, and higher-quality nursing homes, which have been shown elsewhere to improve longevity. http://www.nber.org/papers/w16170

- *NEW YORK TIMES* | Online report – 20 July 2010 – **'Dying is expensive.'** In case there were any doubts, a new study finds that dying is very expensive. The paper ... looks at how much people spend on out-of-pocket health care costs in the last year of their lives. This last year of care is generally expected to be quite expensive (it is, after all, the year when people are so ill that they're on the verge of death). http://economix.blogs.nytimes.com/2010/07/16/dying-is-expensive/

Of related interest:

- *EUROPEAN JOURNAL OF AGEING* | Online article – 14 July 2010 – **'Counselling for dementia caregiver – predictors for utilization and expected quality from a family caregiver's point of view.'** Family caregivers most frequently expressed a wish for advice about further 'support offers' by qualified counsellors. In order to increase the rate of utilization, family caregivers must be convinced of the relevant advantages of using caregiver counselling. Counselling services should provide information about further support offers and give practical help in filling out application forms. http://www.springerlink.com/content/1103507145203102/

- *NEW YORK TIMES* | Online report – 16 July 2010 – **'Cuts in home care put elderly and disabled at risk.'** Since the start of the recession, at least 25 states ... have curtailed programs that include meal deliveries, housekeeping aid and assistance for family caregivers, according to the Center on Budget & Policy Priorities. That threatens to reverse a long-term trend of enabling people to stay in their homes longer. http://www.nytimes.com/2010/07/21/us/21aging.html

From Media Watch dated 19 October 2009:

- *PALLIATIVE MEDICINE* | Online article – 16 October 2009 – **'Costs associated with resource utilization during the palliative phase of care.'** This [Canada-wide] study aimed to evaluate prospectively the resource utilization and related costs during the palliative phase of care in five regions across Canada. http://pmj.sagepub.com/cgi/content/abstract/0269216309346546v1

N.B. Scroll down to **Worth Repeating** and **'"They don't know what they don't know" – Supporting family caregivers at the end of life'** (p.11), published in the *Journal of the American Medical Association* in 2004.

International

Views sought on end of life care in Darlington

U.K. | BBC News – 24 July 2010 – The health trust and Darlington and Durham councils are developing a joint strategy on palliative care, health and social care. It covers a range of options, aimed at improving end-of-life care, and once finalised will be reviewed and updated annually. People are being invited to comment on the areas it covers. http://www.bbc.co.uk/news/uk-england-10749991

National palliative care performance indicators: Results of the 2008 performance indicator data collection

AUSTRALIAN INSTITUTE OF HEALTH & WELFARE | Online report – 19 July 2010 – Of the 227 agencies that responded to the survey, 147 agencies reported delivering care to clients mostly in the community setting and 52 agencies reported that they provided care mostly in an inpatient setting (admitted patients in hospital). The remaining 28 agencies reported that similar proportions of time were spent on delivering services in community and inpatient settings. Information collected for the first time showed that most agencies are relatively small with 61% employing 10 staff or fewer, and 45% providing care for 100 or fewer patients through the year. Performance against the national palliative care performance indicators in 2008 differed from that found in the previous survey. For example, there was a drop in the proportion of regions reporting that they met the requirements of ... strategic plans, down from 63% in 2007 to 45% in 2008. http://www.aihw.gov.au/publications/index.cfm/title/10770

Specialist Publications

Of particular interest:

'Care of the dying in Australia's busiest hospital: Benefits of palliative care consultation and methods to enhance access' (p.8) for the findings of an audit published in the *Journal of Palliative Medicine.*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | *Herald* – 22 July 2010 – **'Legalising euthanasia wins huge support.'** Legalising euthanasia has won huge support from readers of the ... reflecting the earlier findings of scientific public opinion polls. By last night, 82% of nzherald.co.nz poll respondents said euthanasia should be legalised. http://www.nzherald.co.nz/health/news/article.cfm?c_id=204&objectid=10660398

  - *NEW ZEALAND DOCTOR* | Online report – 20 July 2010 – **'Former GP fights for voluntary euthanasia.'** A former GP who has terminal cancer is urging doctors to join him in lobbying the New Zealand Medical Association to accept euthanasia as ethical. http://nzdoctor.co.nz/news/2010/july-2010/20/former-gp-fights-for-voluntary-euthanasia.aspx

- U.K. (SCOTLAND) | *Herald* (OpEd) – 21 July 2010 – **'A question of life and death: But who should decide?'** For those whose personal morality is shaped by the laws of their faith, the uncompromising answer is that life is given by God and can only be ended at a moment determined by its creator. That view has to be respected by any legal system. But so too must the secular views of those who want the freedom to make what they believe to the ultimate in personal judgments; to decide when their existence is no longer tolerable. In essence that is what ... Margo MacDonald has argued in the Scottish Parliament; should her Parkinsonism lead to a situation she cannot tolerate, she wants to be allowed to arrange her own death. These decisions in themselves are wrapped in complexities. http://www.heraldscotland.com/comment/ruth-wishart/a-question-of-life-and-death-but-who-should-decide-1.1042584

- U.K. | *Guardian* – 19 July 2010 – **''Locked-in' syndrome man demands right to die.'** Tony Nicklinson, 54, seeks to force the Director of Public Prosecutions to issue guidance against murder prosecutions for some 'mercy killing' families. http://www.guardian.co.uk/society/2010/jul/19/locked-in-syndrome-die-dpp

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/

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

Physician-patient communication

OpenNotes: Doctors and patients signing on

ANNALS OF INTERNAL MEDICINE, 2010;153(2):121-125. Few patients read their doctors' notes, despite having the legal right [in the U.S.] to do so. As information technology makes medical records more accessible and society calls for greater transparency, patients' interest in reading their doctors' notes may increase. Inviting patients to review these notes could improve understanding of their health, foster productive communication, stimulate shared decision making, and ultimately lead to better outcomes. Yet, easy access to doctors' notes could have negative consequences, such as confusing or worrying patients and complicating rather than improving patient-doctor communication. To gain evidence about the feasibility, benefits, and harms of providing patients ready access to electronic doctors' notes, a team of physicians and nurses have embarked on a demonstration and evaluation of a project called OpenNotes. http://www.annals.org/content/153/2/121.full?aimhp

- U.S. | *Wall Street Journal* – 20 July 2010 – **'The pros and cons of opening doctors' notes to patients.'** Patients typically have no idea what their doctor jots down about them after an office visit, and rarely read those notes, even though they have the legal right to do so. Now, an ambitious project called OpenNotes aims to change that, by giving patients access to the notes recorded after every medical encounter. http://blogs.wsj.com/health/2010/07/20/the-pros-and-cons-of-opening-doctors-notes-to-patients/

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 19 July 2010 – **'Communication practices in physician decision-making for an unstable critically ill patient with end-stage cancer.'** Shared decision-making has become the standard of care for most medical treatments. However, little is known about physician communication practices in the decision making for unstable critically ill patients with known end-stage disease. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0053

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.

Effect of an end-of-life planning intervention on the completion of advance directives in homeless persons

ANNALS OF INTERNAL MEDICINE, 2010;153(2):76-84. Both a simple and complex intervention successfully engaged a diverse sample of homeless persons in advance care planning. One-on-one assistance significantly increased the completion rate. Homeless persons can respond to an intervention to plan for end-of-life care and can express specific preferences for care or a surrogate decision maker, but additional studies are needed to assess the effect of these directives on subsequent care. http://www.annals.org/content/153/2/76.abstract

From Media Watch dated 6 April 2009:

- MISSOURI | *Kansas City Star* – 1 April 2009 – **'A last kindness to the homeless.'** She's known ... as the case manager of death. It's a title Jan Brown, the intensive case manager for the Kansas City Rescue Mission, is proud to hold. http://www.kansascity.com/news/local/story/1119812.html

U.K. is ranked top out of 40 countries on quality of death thanks to hospice network

BRITISH MEDICAL JOURNAL | Online report – 16 July 2010 – A new quality of death index [published by the Economist Intelligence Unit (EIU) has shown substantial variations in end of life care in different countries across the world, with the U.K. ranking top because of its hospice care network and statutory involvement in the care of people who are dying. http://www.bmj.com/cgi/content/extract/341/jul16_1/c3836

N.B. The EIU study was commissioned by the Singapore-based Lien Foundation: Publication of the Quality of Death Index is reported on in detail in Media Watch dated 19 July 2010 (pp.1,2 & 3). Foundation website: http://www.lienfoundation.org/

A history of resolving conflicts over end-of-life care in intensive care units in the U.S.

CRITICAL CARE MEDICINE, 2010;38(8):1623-629. Conflict at the end of life in intensive care units in the U.S. is relatively rare because most families and physicians agree about how patients should be treated. Nevertheless, conflict still exists over some patients whose families insist on care that physicians consider inappropriate and hence inadvisable, and over other patients whose families object to care that physicians prefer to provide. When such conflict occurs, mediation between families and physicians is usually successful in resolving it. Consultation from ethics committees also may be helpful in achieving resolution, and one state actually allows such committees to adjudicate disputes. Physicians who act unilaterally against family wishes run the risk of malpractice suits, although such suits usually are unsuccessful because the physicians are not shown to have violated standards of care. http://journals.lww.com/ccmjournal/Abstract/2010/08000/A_history_of_resolving_conflicts_over_end_of_life.1.aspx

Of related interest:

- *CANCER*, 2010;116(12):3061-3070. **'Characteristics of patients who refuse do-not-resuscitate orders upon admission to an acute palliative care unit in a comprehensive cancer center.'** The authors conducted a retrospective study to determine the frequency and predictors of refusals of DNR in advanced cancer patients admitted to an acute palliative care unit. DNR refusal ... is low, more frequent in patients with more pain and nausea and no advance directives, and associated with longer survival. This study demonstrates possible predictors of complicated DNR discussions. http://www3.interscience.wiley.com/journal/123339148/abstract

Pediatric palliative care

CURRENT PROBLEMS IN PEDIATRIC & ADOLESCENT HEALTH CARE, 2010;40(6):120-151. Rather than defining pediatric palliative care in terms of a patient base, severity of disease, or even a general philosophy of care, palliative care can best be understood as a specific set of tasks directed at mitigating suffering. By understanding these tasks; learning to identify predictable times and settings of suffering; and, learning to collaborate with multidisciplinary specialists, use communication skills, and identify clinical resources, the pediatrician can more effectively support children with life-threatening illnesses and their families. The authors define palliative care as a focus of care integrated in all phases of life and as a set of interventions aimed at easing suffering associated with life-threatening conditions. They detail an approach to these interventions and discuss how they can be implemented by the pediatrician with the support of specialists in hospice and palliative medicine. They discuss common and predictable times of suffering when these interventions become effective ways to treat suffering and improve quality of life. http://www.cppah.com/article/S1538-5442(10)00070-2/abstract

From Media Watch dated 12 July 2010:

- *VIRTUAL MENTOR*, 2010;12(7):519-521. **'Pediatric palliative care: Born of necessity.'** Given the number of children who die of terminal illness each year, as well as the many children living with life-limiting conditions, why are so few of them receiving the benefits of palliative care? http://virtualmentor.ama-assn.org/2010/07/fred1-1007.html

Care of the dying in Australia's busiest hospital: Benefits of palliative care consultation and methods to enhance access

JOURNAL OF PALLIATIVE MEDICINE, 2010;13(7):855-860. Hospital-based palliative care consultative teams assist with decision-making, symptom management, patient and family support, and discharge planning for those with advanced illness. However, there is evidence to suggest that many patients dying within acute hospitals receive no specialist palliative care input. http://www.liebertonline.com/doi/abs/10.1089/jpm.2009.0339

Palliative care beyond that for cancer in Australia

MEDICAL JOURNAL OF AUSTRALIA, 2010;193(2):124-126. Australian health system care for dying people needs systematic change so that people who may require palliative care in the foreseeable future are systematically identified, and have proactive care plans developed to meet their complex needs. This can be done in general practice and aged care, as shown by a model for such care in the U.K. The authors explain the need for system change, and propose steps by which this might be achieved. http://mja.com.au/public/issues/193_02_190710/mit10505_fm.html

Of related interest;

- *AGE & AGEING* | Online article – 20 July 2010 – **'The palliative care needs of acute stroke patients: A prospective study of hospital admissions.'** Despite a mortality rate of approximately 30% in acute stroke, little is known about the palliative care needs of this group of patients. http://ageing.oxfordjournals.org/cgi/content/abstract/afq077

- *CURRENT OPINION IN NEPHROLOGY & HYPERTENSION* | Online article – 16 July 2010 – **'Should there be an expanded role for palliative care in end-stage renal disease?'** There is a large unmet need to alleviate the physical, psychosocial, and existential suffering of patients with ESRD [end-stage renal disease]. More fully integrating palliative care into ESRD management by improving end-of-life care training, eliminating structural and financial barriers to hospice use, and identifying optimal methods to deliver palliative care are necessary if we are to successfully address the needs of an aging ESRD population. http://journals.lww.com/co-nephrolhypertens/Abstract/publishahead/Should_there_be_an_expanded_role_for_palliative.99877.aspx

Pitfalls of legal regulation to improve end-of-life care: The example of artificial nutrition and hydration

ONLINE JOURNAL OF HEALTH ETHICS, 2010;6(1). Biomedical advances nowadays enable physicians to keep patients hovering at the brink of death for many years. These new technologies have evoked challenging ethical dilemmas that test society's moral resources. But some have been unwilling to patiently search for new moral wisdom, believing a bold stance is required and they are using legal means to achieve their goal. Attempts to legalize physician assisted suicide and euthanasia are one example, and the literature is replete with analyses of these practices. Far less attention has been paid to opposite attempts at legally enforcing life-sustaining medical interventions. In the mid-1990s ... 'Nebraskans for Humane Care' sought to amend the Nebraska Constitution to require that nutrition and hydration is administered to any person and with any means available. The ... text of the proposed amendment is critically analyzed, revealing the serious consequences that adoption of such legal regulation of medical treatment can have. http://test2.ojhe.org/index.php/ojhe/article/viewFile/131/158

Of related interest:

- *JOURNAL OF MEDICINE AND THE PERSON* | Online article – 19 July 2010 – **'Basic human needs in end-of-life care.'** We are all persons in need. Do we recognize this need in the persons we care for and then, do we provide that need? This paper uses case examples of our failure to recognize basic human needs in the provision of nutrition and hydration at the end of life - in these instances far too much food and water was given. Sources of basic human needs are reviewed and a model is presented to aid clinicians in better matching patients needs to their current clinical reality. http://www.springerlink.com/content/4127816505524540/

The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care

PALLIATIVE MEDICINE | Online article – 22 July 2010 – Spirituality was a broader term that may or may not encompass religion. A 'spirit to spirit' framework for spiritual care-giving respects individual personhood. This was achieved in the way physical care was given, by focusing on presence, journeying together, listening, connecting, creating openings, and engaging in reciprocal sharing. Affirmative relationships supported patients, enabling them to respond to their spiritual needs. The engagement of family caregivers in spiritual care appears underutilized. Relationships formed an integral part of spirituality as they were a spiritual need, caused spiritual distress when broken and were the way spiritual care was given. Barriers to spiritual care include lack of time, personal, cultural or institutional factors, and professional educational needs. http://pmj.sagepub.com/content/early/2010/07/19/0269216310375860.full.pdf+html

Cont.

Media Watch Online

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

Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx

Ontario | HPC Consultation Services: http://www.hpcconnection.ca/newsletter/inthenews.html

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/

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/media-watch-provides-global-roundup-of-end-of-life-issues-n-96.htm

Of related interest:

- *ANNALS OF LONG TERM CARE*, 2010;18(7):1524-7929. **'Palliative and end-of-life care in LTC: Practical implications of understanding spirituality and religion.'** A consensus conference ... recently published a report with recommendations for integrating spiritual care and improving palliative care. This brief review offers a step-wise implementation of these recommendations in long-term care. http://www.annalsoflongtermcare.com/content/palliative-and-end-life-care-ltc-practical-implications-understanding-spirituality-and-relig

  N.B. This article is the third in a series on palliative care. Part I appeared in the April issue, and Part II appeared in the May issue of the journal. Journal archive page: http://www.annalsoflongtermcare.com/issues/past

From Media Watch dated 19 July 2010:

- *AUSTRALASIAN MEDICAL JOURNAL*, 2010;3(6):364-369. **'"Diagnosing" and "managing" spiritual distress in palliative care: Creating an intellectual framework for spirituality useable in clinical practice.'** This paper describes the central role of addressing spirituality. By understanding the dynamics of spirituality, and the essential role of developing a meaningful and trusting relationship with a patient, it is possible to assist them to use their deepest beliefs to make this most difficult part of life's journey tolerable, and perhaps even to derive profound benefits from it. http://www.doaj.org/doaj?func=abstract&id=562322&recNo=12&toc=1

- *JOURNAL OF PALLIATIVE MEDICINE*, 2010;13(7):869-875. **'The competencies required by professional hospice palliative care spiritual care providers.'** This article describes a Canadian Community of Practice process to develop an occupational analysis-based competency profile for the professional hospice palliative care spiritual care provider utilizing a modified Developing a Curriculum methodology. http://www.liebertonline.com/doi/abs/10.1089/jpm.2009.0429

Hospital-based palliative care consultation: Effects on hospital cost

PALLIATIVE MEDICINE | Online article – 19 July 2010 – In this observational study, the average daily total direct hospital costs were $464 a day lower for the 606 patients receiving palliative compared to the 2715 receiving usual care. Palliative care patients were 43.7% points less likely to be admitted to ICU during the hospitalization than usual care patients. Palliative care for patients hospitalized with advanced disease results in lower costs of care and less utilization of intensive care compared to similar patients receiving usual care.
http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0038

The ties that bind: A reflection on physician grief

SUPPORTIVE CARE IN CANCER | Online article – 18 July 2010 – Physician grief remains a prevalent yet largely unacknowledged problem in the medical profession. Several techniques can be employed to improve coping in physicians that deal frequently with patients approaching the end of life that can be integrated into medical training programs and physician practices.
http://www.springerlink.com/content/n3604u13974g562n/?p=abb2b4a2e46644ce90b8b76fa5500cb7&pi=1

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online article – 23 July 2010 – **'Doctor-cared dying instead of physician-assisted suicide: A perspective from Germany.'** Euthanasia and PAS [physician assisted suicide] as practices of direct medical killing or medically assisted killing of vulnerable persons as "due care" is to be strictly rejected. The authors propose a more holistically-oriented palliative concept of a compassionate and virtuous doctor-cared dying ... embedded in an ethics of care.
  http://www.springerlink.com/content/p53194l74h7n5881/?p=9ed992ade41e47fa88804f86e703bff9&pi=2

Cont.

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online article – 21 July 2010 – **'The role of religion in the debate about physician-assisted dying.'** This paper explores the role of religious belief in public debate about physician-assisted dying and argues that the role is essential because any discussion about the way we die raises the deepest questions about the meaning of human life and death.http://www.springerlink.com/content/q5070031vm533535/?p=9ed992ade41e47fa88804f86e703bff9&pi=0

Worth Repeating

"They don't know what they don't know"

Supporting family caregivers at the end of life

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2004;291(4):483-491. The amorphous relationship between physicians and the families of patients at the end of life presents both challenges and opportunities for which physicians may be unprepared. Families play important roles in the practical and emotional aspects of patient care and in decision making at the end of life. At the same time, family members may carry significant burdens as a result of their work. Through the perspectives of the wife, daughter, and home care nurse of a patient who died from pancreatic cancer, the authors illustrate the range of family caregiver experiences and suggest potentially helpful physician interventions. They describe five burdens of family caregiving (time and logistics, physical tasks, financial costs, emotional burdens and mental health risks, and physical health risks) and review the responsibilities of physicians to family caregivers. Based on available evidence, the authors identify five areas of opportunity for physicians to be of service to family members caring for patients at the end of life, including promoting excellent communication with family, encouraging appropriate advance care planning and decision making, supporting home care, demonstrating empathy for family emotions and relationships, and attending to family grief and bereavement. In caring well for family caregivers at the end of life, physicians may not only improve the experiences of patients and family but also find greater sustenance and meaning in their own work. http://jama.ama-assn.org/cgi/content/abstract/291/4/483?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=foregiveness+at+the+end+opf+life&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

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