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 and research.

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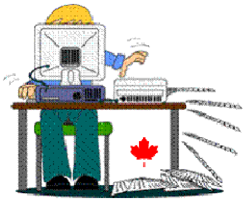


Compiled & Annotated by Barry R. Ashpole

Dependent elderly experiences of economic life: Scroll down to Specialist Publications and 'Care and value at the end of life' (p.10), published in *Poetic* (the Journal of Empirical Research on Culture, the Media and the Arts).

Canada

A Toronto hospice's biggest hurdle isn't finding land or staff. It's the city itself.

ONTARIO | *Globe & Mail* – 27 April 2012 – It took eight long years of unanswered door knocks and gentle letdowns before the Toronto Commandery Hospice was finally gifted provincial funding for nursing staff and a plot of land... Now that they've got those crucial parts in place ... [the] ... organization faces its most difficult hurdle: navigating through city bylaws. And for the organizers of a much-needed residential hospice, that hasn't been easy. There's no zoning for hospices in Toronto's bylaws, and the ones that do exist are generally near hospitals or in an existing building. http://m.theglobeandmail.com/news/national/toronto/globe-to/a-toronto-hospices-biggest-hurdle-isnt-finding-land-or-staff-its-the-city-itself/article2416446/?service=mobile

Hassan Rasouli case

Vegetative patient now able to give 'thumbs up,' fuelling debate over life support

ONTARIO | *Globe & Mail* (Toronto) – 25 April 2012 – A hospital patient deemed vegetative is now able to make a "thumbs up" gesture – a sign to family that he is aware, but not yet strong enough to persuade doctors to drop a recommendation to withdraw life support. The symbol marks a dramatic turn for Hassan Rasouli, 60, who until recently was in a persistent vegetative state. An affidavit filed with Canada's top court says he's now minimally conscious, and doctors' reports say he can "voluntarily control" certain behaviours – suggesting he may be aware but trapped in a paralyzed body. This new diagnosis seems certain to inflame an already divisive ethical debate about who decides to withdraw life support. And it raises the discomfiting notion – the stuff of relatives' nightmares – of a patient being aware but unable to communicate when the machines are turned off. The case before the Supreme Court of Canada was begun by two doctors from Sunnybrook Health Sciences Centre, Brian Cuthbertson and Gordon Rubenfeld, who saw no medical purpose in keeping Mr. Rasouli on life support and proposed shifting him to palliative care. http://www.theglobeandmail.com/news/national/vegetative-patient-now-able-to-give-thumbs-up-fuelling-debate-over-life-support/article2413296/?from=sec431

Cont.

From Media Watch, 26 December 2011:

- ONTARIO | *Globe & Mail* – 22 December 2011 – **'Supreme Court to hear Rasouli ... case.'** http://www.theglobeandmail.com/life/health/end-of-life/supreme-court-to-hear-rasouli-end-of-life-case/article2281641/

From Media Watch, 1 November 2010:

- ONTARIO | *Globe & Mail* – 29 October 2010 – **'Vegetative patients may be aware, newly-recruited researcher says.'** http://www.theglobeandmail.com/news/national/vegatative-patients-may-be-aware-newly-recruited-researcher-says/article1779227/

Québec commission

Dying with dignity

QUÉBEC | CBC Radio 1 ('C'est la vie') – 24 April 2012 – A special commission of Québec's National Assembly spent two years looking into issues around end of life care, assisted suicide and euthanasia.[1] The two women who chaired those hearings say that what they heard changed their lives. Members of the National Assembly Maryse Gaudreault (Liberal) and Véronique Hivon (Parti Québécois) talk about that experience. http://www.cbc.ca/cestlavie/episode/2012/04/19/april-22nd-and-24th-2012/

1. 'La Commission spéciale sur la question de mourir dans...' (noted in Media Watch, 26 March 2012): http://www.gouv.qc.ca/portail/quebec/pgs/commun/actualites/actualite/asurveiller_120323_soins-palliatifs/?lang=en; an English translation of the Committee's recommendations (noted in Media Watch, 23 April 2012): http://www.cspcp.ca/english/DWD%20Recommendations.pdf.

N.B. The Canadian Society of Palliative Care Physicians has adopted a position statement opposing assisted suicide and euthanasia. http://www.cspcp.ca/english/WebStoryFINAL4.pdf

Provinces should enshrine patient rights in a charter, law experts say

ONTARIO | *Toronto Star* – 23 April 2012 – Canadian provinces should enshrine patient rights in a charter with independent enforcement.[1] Colleen Flood, Faculty of Law, University of Toronto, told the *Toronto Star*, patients who feel they have been treated unjustly for whatever reason shouldn't have to hire a lawyer to have their grievances heard but rather have access to an independent adjudicator. http://www.thestar.com/news/canada/article/1166257--provinces-should-enshrine-patient-rights-in-a-charter-law-experts-say

1. 'A patient charter of rights...' *Canadian Medical Association Journal*, published online 23 April 2012. http://www.cmaj.ca/content/early/2012/04/23/cmaj.111050

From Media Watch, 26 September 2011:

- *MCGILL JOURNAL OF LAW & HEALTH*, 2011;5(1):106-160. **'Palliative care: An enforceable Canadian human right?'** http://mjlh.mcgill.ca/pdfs/vol5-1/MJLH%20Vol%20V.,%20No.%201%20-%20Shariff.pdf

Corrections & Clarifications

Noted in Media Watch, 16 April 2012 (p.2), was publication of the report of the Quebec Ombudsman on home care in the province. At the time, only the French language copy of the report ('Chez soi: toujours le premier choix? L'accessibilité aux services de soutien à domicile pour les personnes présentant une incapacité significative et persistante') was available. An English language version is now available online at: http://www.protecteurducitoyen.qc.ca/fileadmin/medias/pdf/rapports_speciaux/2012-03-30_rapport_chez_soi_EN.pdf

Worth repeating

The ethics of caring for the dying

ONTARIO | *Toronto Star* (OpEd) – 23 April 2012 – The poignant story of 89-year-old Daniel Harkins' dying alone at Toronto East General Hospital in a recent *Toronto Star* series is a stark reminder of what awaits more Canadians if we don't improve care for dying patients. At one extreme, we have frail, elderly people dying on gurneys waiting for care that never comes; at the other, some patients get so much treatment it's as if the medical well will never run dry. Those in the middle are left with a mishmash of uncoordinated treatments that may include feeding tubes, intravenous lines and other questionable therapy. Information from studies collected by the University of Toronto's Joint Centre for Bioethics shows that most terminally ill patients want to die in peace, without suffering, having strengthened relationships with loved ones. They don't want treatment that will unnecessarily prolong life. Yet up to 80% of caregivers report giving dying patients too much treatment, and almost half of families disagree with caregivers over crucial issues like pain relief and the amount of information families need to make decisions. Physicians believe families are overwhelmed by too much information; families think they don't get enough. Meanwhile patients get lost in the shuffle, abandoned to an increasingly dysfunctional system.http://www.thestar.com/news/insight/article/1166285--the-ethics-of-caring-for-the-dying

Specialist Publications

Of particular interest:

'Is a determination of medical futility ethical?' (p.11), published in *Professional Case Management.*

N.B. This article was originally published in the *Toronto Star* 10 June 2002. Abstracts of each article in the series at: http://pqasb.pqarchiver.com/thestar/results.html?st=advanced&QryTxt=Daniel Harkins.

U.S.A.

Respite programs for family caregivers face cuts despite growing need

KAISER HEALTH NEWS | Online article – 26 April 2012 – Family caregivers provide 80% of long-term care needs in the U.S., but many need time away from that job so they can continue to care for their loved ones. Respite can provide short-term relief through several options, including a paid home care worker or providing temporary stays for patients at a residential care facility or adult day care center. Some families pick up the cost of such care out-of-pocket, but many must rely on state and community programs. However, as states face tough budget decisions, such programs are increasingly on the chopping block. "These services have just come under pretty serious attack at the state level," said Jill Kagan, program director of the Access to Respite Care and Help National Respite Network & Resource Center. "The current economic climate that we're in and that every state is facing has made it really difficult to expand any services at all." http://capsules.kaiserhealthnews.org/index.php/2012/04/respite-programs-for-family-caregivers-face-cuts-despite-growing-need/

Specialist Publications

Of particular interest:

'Survey highlights frustration of caregivers' (p.8), posted by the American Academy of Family Physicians.

Cont.

Of related interest:

- OREGON | *The Lundy Report* – 27 April 2012 – **'Portland's Housecall Providers selected as national demonstration site.'** A non-profit, has been selected as a demonstration site for the national health care study Independence at Home ... developed in response to a growing body of evidence that suggests that many patients with multiple health concerns ... enjoy a higher quality of life and make fewer hospital and emergency room visits when they receive medical care in their residence.http://www.thelundreport.org/resource/portland%E2%80%99s_housecall_providers_selected_as_national_demonstration_site

Don't be shocked when you meet a grieving child

ILLINOIS | *Chicago Tribune* – 24 April 2012 – A new New York Life Foundation/National Alliance for Grieving Children survey[1] of kids at bereavement programs across the U.S., billed as the first study of its kind, suggests that young people are still struggling with less-than-helpful reactions. Among the study's findings: While kids identified strongly with key statements such as "The death of my loved one is the worst thing that ever happened to me" and "You never stop missing your loved one," when they were asked to choose just one statement that applied to them the most, the largest group of kids (32%), chose "People don't have to give me special treatment; I just want to be treated like everyone else." http://www.chicagotribune.com/news/local/ct-talk-schoenberg-column-0424-20120424,0,2535133.story

1. 'Childhood loss can create a heavy burden borne in isolation; friends, family and school key to...' http://www.newyorklife.com/nyl/v/index.jsp?contentId=150910&vgnextoid=4738a9dd34816310VgnVCM100000ac841cacRCRD

"Undercover" investigation

Dying is expensive...

TIME MAGAZINE | Online report – 24 April 2012 – The funeral home business is rife with exploitative practices, despite fairly strict federal regulations governing the industry. In fact, a recent round of undercover visits to funeral homes by the Federal Trade Commission has confirmed that none of us should wait until it's too late to learn about the business of death. Because those making arrangements are generally coping with the loss of a loved one, consumers tend to let down their guard when it comes to making decisions about funerals. And given how expensive a funeral can be – the total cost often exceeds $10,000 – the stakes are high and opportunities for abuse ample. http://moneyland.time.com/2012/04/24/dying-is-expensive-the-ftc-funeral-home-abuses/

Hospice care trickles down to pets

FLORIDA | *Daily Commercial* (Leesburg) – 23 April 2012 – Cornerstone Hospice is extending its care to patients' companions: The ones with paws and feathers. "Pet Peace of Mind is really part of patient care; we just have to do this program because our pets really are our family," said Lisa Gray, volunteer manager, who adores her three dogs and two horses and under-stands patients' passion for their beloved pets. Hospice patients in Lake and Sumter counties will be able to receive funds for pet food, litter and routine vaccines through Pet Peace of Mind. The program also allows pet-loving volunteers to assist with dog walking and transportation to veterinarian appointments. http://www.dailycommercial.com/News/LakeCounty/042312HospicePets-

Specialist Publications

Of particular interest:

'Reflections on the International Symposium on Veterinary Hospice Care' (p.11), published in *Veterinary Practice News.*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHUSETTS | *Boston Globe* – 29 April 2012 – **'Dying wishes expected to be decided on November ballot.'** It's not often that voters face a moral question like the one expected on November's ballot: Should terminally ill patients have the right to get a fatal prescription? It's up to the people of Massachusetts. http://www.bostonglobe.com/magazine/2012/04/27/massachusettts-death-with-dignity-act-that-would-legalize-physician-assisted-suicide-expected-decided-november-ballot/ljEGuMYnF1TAKgRTTMKYNO/story.html
    - MASSACHUSETTS | *Boston Globe* – 27 April 2012 – **'How the Death with Dignity Act works.'** http://bostonglobe.com/magazine/2012/04/27/how-death-with-dignity-act-works/VhJHCiCScliBiFgJ2AjUNO/story.html

International

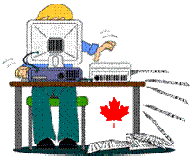
Kerala: A destination to die for

INDIA (KERALA) | *Economic Times* – 29 April 2012 – Kerala's listing as one of the 50 must-see destinations of a lifetime by the *National Geographic Traveller*, and its accolades on socio-economic indicators couch a well-kept secret about the state: that it is a great place to die as well. Keralites are displaying a sobriety in funeral rituals that may have to do with its high literacy and an awareness about eco-friendly and inexpensive funerals.http://economictimes.indiatimes.com/news/news-by-industry/et-cetera/kerala-a-destination-to-die-for/articleshow/12914771.cms

> **N.B.** The palliative care initiative in Kerala has generated significant media attention in recent years: See Media Watch dated 26 March 2012 (p.5); 30 January 2012 (p.7); 12 September 2011 (p.6), 5 September 2011 (p.7); 29 August 2011 (p.2); 9 May 2011 (p.3); 2 February 2011 (p.6): and, 10 January 2011 (p.6). http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf.

The umbrellas of hope

INDIA (KERALA) | IBN Live – 26 April 2012 – The 286 patients of the Institute of Palliative Medicine are eagerly looking forward to the monsoon season as each drop of rain is going to fill their lives with a lot of hope. The reason, the 14,000 umbrellas made by them, some lying on the beds and some confined to wheel chairs, will be unfolded to drench the monsoon rains.http://ibnlive.in.com/news/the-umbrellas-of-hope/252986-60-116.html



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

The challenge of inspecting home care

U.K. | *The Guardian* – 25 April 2012 – Care provided in people's homes provides a challenge for regulators. How do you check up on a service being delivered behind closed doors, often to people who are vulnerable or find it hard to communicate? People may feel that it is an intrusion if you observe them in such an intimate setting. People's privacy and dignity are included in the standards that we assess, so we have to be mindful of our presence and its impact on people. And you can't be assured that the care you observe is a true reflection of that which is normally delivered. Reports by the Equality & Human Rights Commission[1] and Which?[2] found examples of good home care, and we heard positive comments from people about their home care services last year. However, those reports and our own work suggest that too many people receive home care that isn't good enough and – worryingly – that some people do not feel able to report poor services. http://www.guardian.co.uk/social-care-network/2012/apr/25/challenge-inspecting-home-care?newsfeed=true

1. 'Close to home: An inquiry into older people and human rights in home care,' Equality & Human Rights Commission, November 2011 (noted in Media Watch, 28 November 2011). http://www.equalityhumanrights.com/uploaded_files/homecareFI/home_care_report.pdf

2. 'Which? exposes failings in home care system,' Which?, March 2012 (noted in Media Watch, 19 March 2012). http://www.which.co.uk/news/2012/03/which-exposes-failings-in-home-care-system-281517/

Of related interest:

- U.K. | *Northampton Chronicle & Echo* – 26 April 2012 – **'Northampton General Hospital plans care review after report says one in four deaths could have been in comfort of home.'** The review of the notes of 237 patients who died at Northampton General Hospital, many of whom were frail and elderly with cancer or dementia, found that hospital care was not needed for 25% of them. http://www.northamptonchron.co.uk/news/health/northampton-general-hospital-plans-care-review-after-report-says-one-in-four-deaths-could-have-been-in-comfort-of-home-1-3773673

Deathless data

What happens to our digital property after we die?

THE ECONOMIST | Online article – 21 April 2012 – Digital assets may include software, websites, downloaded content, online gaming identities, social-media accounts and even e-mails. In Britain alone holdings of digital music may be worth over £9 billion ($14 billion [U.S.]). A fifth of respondents to a Chinese local-newspaper survey said they had over 5,000 yuan ($790) of digital property. And value does not lie only in money. "Anyone with kids under 14 years old probably has two prints of them and the rest are in online galleries," says Nathan Lustig of Entrustet, a company that helps people manage digital estates. Service providers have different rules – and few state them clearly in their terms and conditions. Many give users a personal right to use an account, but nobody else, even after death. Facebook allows relatives to close an account or turn it into a memorial page. Gmail (run by Google) will provide copies of e-mails to an executor. Music downloaded via iTunes is held under a licence which can be revoked on death. Apple declined to comment on the record on this or other policies. All e-mail and data on its iCloud service are deleted on the death of the owner. http://www.economist.com/node/21553011

From Media Watch, 11 October 2011:

U.K. | *Daily Telegraph* – 13 October 2011 – **'Britons leave Internet passwords in wills.'** http://www.telegraph.co.uk/technology/news/8824216/Britons-leave-internet-passwords-in-wills.html.

Men set to live as long as women, figures show

U.K. | BBC News – 23 April 2012 – The gap between male and female life expectancy is closing. [Research shows] ... men languishing far behind for decades, but now starting to get closer to women. If current trends continue ... both sexes could, on average, be living to the age of 87 in 2030. http://www.bbc.co.uk/news/health-17811732

Of related interest:

- EUROPE | Eurostat data – 19 April 2012 – **'Men and women unequal in life expectancy.'** In all European Union member states women have a longer life expectancy than men at age 65... http://www.europolitics.info/social/men-and-women-unequal-in-life-expectancy-art332084-26.html

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- EUROPE | Euro News ('Talk') – 26 April 2012 – **'Should the European Commission make a decision on assisted suicide?'** Should those suffering from incurable diseases have the right to assisted suicide? At the moment this issue varies from country to country, and some have yet to decide. http://www.euronews.com/2012/04/26/should-the-european-commission-make-a-decision-on-assisted-suicide/

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/CurrentNewsandEvents/tabid/88/Default.aspx (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/inthenews.html

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

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.palliativecareconsultation.ca/?q=mediawatch

U.S.A.

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

Europe

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

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

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/ (Scroll down to 'What's New: Reading List Update')

International

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

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

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

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

The impact of a program in mindful communication on primary care physicians

ACADEMIC MEDICINE | Online article – 24 April 2012 – In addition to structural transformations, deeper changes are needed to enhance physicians' sense of meaning and satisfaction with their work and their ability to respond creatively to a dynamically changing practice environment. The purpose of this research was to understand what aspects of a successful continuing education program in mindful communication contributed to physicians' well-being and the care they provide.http://journals.lww.com/academicmedicine/Abstract/publishahead/The_Impact_of_a_Program_in_Mindful_Communication.99638.aspx

From Media Watch, 23 April 2012.

- QUEBEC | *Montreal Gazette* – 19 April 2012 – **'McGill's mindfulness meditation teaches doctors coping skills.'** It's not easy to work with critically ill children and stressed-out parents. Doctors who work in pediatric-palliative care do it every day. Conversations with parents are often tense; frustrations can boil over... Pediatrician Stephen Liben knew he needed to figure out how to cope better with the stress. The director of pediatric-palliative care at the Montreal Children's Hospital was finding himself angry or defensive in heated moments with parents. A calm doctor is a better doctor.http://www.montrealgazette.com/health/Physicians+healing+themselves/6482206/story.html

Extract from *Academic Medicine* article...

Participants reported three main themes:

1) Sharing personal experiences from medical practice with colleagues reduced professional isolation;

2) Mindfulness skills improved the participants' ability to be attentive and listen deeply to patients' concerns, respond to patients more effectively, and develop adaptive reserve; and,

3) Developing greater self-awareness was positive and transformative, yet participants struggled to give themselves permission to attend to their own personal growth.

Survey highlights frustration of caregivers

AMERICAN ACADEMY OF FAMILY PHYSICIANS | Online posting – 24 April 2012 – According to the Institute of Medicine, the proportion of Americans who are age 65 years and older is projected to increase from 12% in 2005 to 20% by 2030. This aging of America's patient population has focused greater attention on care and treatment of the elderly, as well as their family caregivers, who are reporting burnout in increasing numbers. In fact, a recent study[1] ... found that nearly three out of four Americans who provide care for a family member or friend who is disabled or elderly or who has physical or mental limitations said caregiving had at least some impact on their health. http://www.aafp.org/online/en/home/publications/news/news-now/health-of-the-public/20120424newfdcontent.html

Hospice and palliative care access issues in rural areas

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 24 April 2012 – All individuals deserve to have access to quality end-of-life care. In rural communities within the U.S., significant barriers limit access to hospice and palliative care. They include issues related to geography and supply, health care system eligibility criteria, limitations of the available workforce, educational deficits, and differences in cultural values. This article examines the barriers and potential solutions to address the gaps in hospice and palliative care services in rural communities. Strategies are proposed to strengthen hospice and palliative care delivery models to enhance earlier referrals and provide better facilitation and transition to hospice and palliative care. http://ajh.sagepub.com/content/early/2012/04/22/1049909112444592.abstract

Cont.

Of related interest:

- *HEALTH & PLACE* | Online article – 3 April 2012 – **'Variation in geographic access to specialist inpatient hospices in England & Wales.'** The authors identify that subset of small areas in which accessibility ... is relatively poor yet the potential 'demand' for hospice services is above average. While urban areas are relatively well served, large parts of England & Wales have poor access to hospices, and there is a risk that the needs of those living in relatively deprived areas may be un-met. http://www.sciencedirect.com/science/article/pii/S135382921200057

From Media Watch, 23 January 2012:

- *PALLIATIVE MEDICINE* | Online article – 16 January 2012 – **'Resource utilization and cost analyses of home-based palliative care service provision: The Niagara West End-of-Life Shared-Care...'** http://pmj.sagepub.com/content/early/2012/01/16/0269216311433475.abstract

From Media Watch, 30 May 2011:

- *RURAL & REMOTE HEALTH* | Online article – 19 May 2011 – **'Developing rural palliative care: Validating a conceptual model.'** http://www.rrh.org.au/articles/printviewnew.asp?ArticleID=1717

From Media Watch, 21 March 2011:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 14 March 2011 – **'A shared care model pilot for palliative home care in a rural area: Impact on symptoms, distress, and place of death.'** http://www.jpsmjournal.com/article/S0885-3924(11)00031-5/abstract

Treatment intensity at the end of life in older adults receiving long-term dialysis

ARCHIVES OF INTERNAL MEDICINE, 2012;172(8):661-663. Life expectancy after the initiation of long-term dialysis is often severely limited in the elderly, and it is becoming increasingly clear that many older patients who are receiving dialysis experience a significant burden of concomitant illness, functional limitation, and symptoms. Such considerations have fostered a growing interest in end-of-life care and advanced care planning in this population. Relatively little is known about the contemporary patterns and determinants of end-of-life care among older patients who are receiving long-term dialysis. http://archinte.ama-assn.org/cgi/content/extract/172/8/661

End-of-life preferences in advanced cancer patients willing to discuss issues surrounding their terminal condition

EUROPEAN JOURNAL OF CANCER CARE | Online article – 22 April 2012 – Eighty-eight advanced cancer patients were interviewed through End of Life Preferences Interview, a 23-item interview covering a wide range of end-of-life care issues. In total, 100% of responders expressed the will to receive some kind of information on the disease process and/or the treatments proposed. Approximately 77% declared to be willing to talk about what it is important at the end of life in case of worsening of their conditions and 31% prefer to be left alone in difficult moments. Approximately 67% choose home as the preferred place of death and 63% think it is preferable to die in a state of unconsciousness induced by drugs. About half of responders declare to believe in any kind of life after death and 40% consider very important to find any meaning at the end of life. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2354.2012.01347.x/abstract

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 24 April 2012 – **'Importance and timing of end-of-life care discussions among gynecologic oncology patients.'** Patients expressed that addressing end of life care is an important part of their treatment. Most patients were familiar with advanced directives (73.0%), do not resuscitate/do not intubate (88.5%), and hospice (97.5%). Designating someone to make decisions was significantly related to disease status. http://ajh.sagepub.com/content/early/2012/04/22/1049909112444156.abstract

Palliative care in dementia – Delphi consensus procedure begins

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online posting – 22 April 2012 – More than 80 experts in palliative and dementia care from about 25 countries across Europe and elsewhere are being invited to evaluate a set of recommendations on palliative care in dementia. The recommendations represent best practice and are based on evidence where available. Additionally, because of the limited evidence base, the evaluation is given shape in a Delphi consensus procedure that aims at a broad consensus on how to provide optimal care for older people with progressive dementia. The experts' feedback will help to revise the recommendations where necessary. It will also inform on possible remaining areas where international consensus is not achieved. http://eapcnet.wordpress.com/2012/04/22/palliative-care-in-dementia-delphi-consensus-procedure-begins/

Of related interest:

- *NURSING TIMES* (U.K.) | Online report – 29 April 2012 – **'Hospitals 'failing to deliver' appropriate end-of-life care to dementia patients.'** Many patients with dementia who die in hospital still fail to receive sufficiently structured end of life care, a study in the North West has suggested. http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/hospitals-failing-to-deliver-appropriate-end-of-life-care-to-dementia-patients/5044318.article

Do-not-resuscitate orders in the last days of life

JOURNAL OF PALLIATIVE MEDICINE | Online article – 26 April 2012 – Veterans with a family member present at time of death and those who received pastoral care visits were more likely to have DNR orders [on the medical records examined]. African American veterans and veterans who died unexpectedly were less likely to have DNR orders. Compared with those dying on a general medicine unit, veterans dying in the emergency department or an intensive care unit (ICU) and veterans dying during a procedure or in transit were less likely to have DNR orders. Results suggest that the DNR process might be improved by interventions that target ICU settings, facilitate transitions to less intensive locations of care, ensure the involvement and availability of pastoral care staff, and create environments that support the presence of family members. http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0321

Care and value at the end of life

POETIC (Journal of Empirical Research on Culture, the Media and the Arts) | Online article – 17 April 2012 – How we care for dependent people is an important test of how we make decisions about value in our society. These are not just decisions about budgetary prioritisation, but about how different conceptions of value are to be reconciled. This paper discusses the interaction between cultures of economic circulation and cultures of care with respect to the dependent elderly. It focuses on the ways in which the dependent elderly themselves experience economic life, particularly as it relates to their care. The paper begins by showing how the economic experience of elderly people is distinctive. It explores how elderly people interact with markets in care and with modern caring institutions. It ... [draws] ... out implications for the future of elder care and for our understanding of how life is valued in modern market economies. http://www.sciencedirect.com/science/article/pii/S0304422X12000113

Highlights of *Poetic* article

► Elderly people experience economic life differently to other people.
► Self-interested market exchange cannot adequately motivate elder care.
► The dependent elderly increasingly interact with institutions, not individuals.
► Accounting struggles to capture important issues surrounding institutional care.
► Good care requires an economically persuasive articulation of the value of life.

Is a determination of medical futility ethical?

PROFESSIONAL CASE MANAGEMENT, 2012;17(3):103-106. Medical futility is a timely topic and one fraught with ethical implications. Medical futility is a term used to describe medical interventions that are expected to result in little or no benefit to a patient. This editorial examines some considerations and applications of medical futility to a specific patient or treatment, the ramifications of the use of the term futility, and its effects on physician-patient communication and the role of the health care administrator. Invoking medical futility is fraught with areas of vulnerability and implications in ethical decision making. Of concern is whether the treatment will cause more harm than good (nonmaleficence), whether it respects patients' goals and desires (autonomy), and whether the interests of patients, society, and the organization are served (justice).http://journals.lww.com/professionalcasemanagementjournal/Abstract/2012/05000/Is_a_Determination_of_Medical_Futility_Ethical_.1.aspx

Pen-pushing rather than palliating

Palliative care's becoming an elaborate game of Cluedo

PULSE (U.K.) | Online OpEd – 27 April 2012 – Ah, remember terminal care in the good old days? Armed only with a prior knowledge of the patient and a syringe driver of morphine, and mercifully untroubled by outside interference, you really felt you were achieving something (note for confused younger readers – this was before the word 'achievement' became inextricably linked with the acronym 'QOF' [Quality & Outcomes Framework]). Now, I know that only tedious old farts would say, "It's not like that now," but, hey, it's not like that now. It's become yet another tick-box exercise where judgement and compassion have been supplanted by regulations and bureaucracy. I know this because I have: a) a patient dying of lung cancer; and, b) two forms sitting on my desk. They're not the only forms I've had to complete – I've signed the Liverpool Care Pathway, the drug regime (in triplicate) and so on, the net effect being I'm pen-pushing rather than palliating. But these two forms are the most vexing. http://www.pulsetoday.co.uk/comment-blogs/-/blogs/13850755/palliative-care-s-becoming-an-elaborate-game-of-cluedo

N.B. Cluedo is a popular murder/mystery-themed deduction board game.

No matter the species

Reflections on the International Symposium on Veterinary Hospice Care

VETERINARY PRACTICE NEWS | Online report – 27 April 2012 – The first pet hospice conference's purpose was to merge the medical aspects of end-of-life care with the psychosocial and spiritual aspects. According to Kathryn D. Marocchino, PhD., president and founder of the Nikki Hospice Foundation, this collaborative meeting was the first of its kind and brought together a diverse group of health care workers. Marocchino organized the symposium at the University of California, Davis. Hospice professionals like Dr. Marrochino, hospice volunteers, nursing and medical staff, psychologists, grief counselors, social workers, bereavement facilitators, death educators, veterinary chaplains, pastoral counselors, animal-health care workers, shelter and Society for the Prevention of Cruelty to Animals staff, animal communicators, pet cemetery personnel, pet massage therapists and pet-sitters including interested lay people assembled to discuss the medical and emotional aspects of hospice care. This unusual group of human-animal bond oriented people sat side by side with general practitioners, specialists, holistic veterinarians, registered technicians, animal nurses, students, practice managers and philanthropists who maintain private or non-profit pet hospice facilities. http://www.veterinarypracticenews.com/vet-practice-news-columns/bond-beyond/reflections-on-the-international-symposium-on-veterinary-hospice-care.aspx

Cont.

From Media Watch, 16 April 2012:

- *NEW YORK TIMES* | Online OpEd – 9 April 2012 – **'An ethical quandary, no matter the species.'** http://www.nytimes.com/roomfordebate/2012/04/09/the-ethics-of-spending-25000-on-pet-health-care/an-ethical-quandary-no-matter-the-species

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- NZDOC.CO.NZ | Online report – 27 April 2012 – **'Euthanasia is unethical...'** In the wake of a public discussion ... about euthanasia and assisted suicide the New Zealand Medical Association [NZMA] has reiterated its stance against doctors helping patients to end their lives. Even if the law changed, euthanasia is unethical and cannot be condoned by the NZMA as a professional body, NZMA chair Paul Ockelford says. http://www.nzdoctor.co.nz/news/2012/april-2012/27/euthanasia-is-unethical-nzma.aspx

- *EUROPEAN RESPIRATORY JOURNAL* | Online article – 20 April 2012 – **'Expressed wishes and incidence of euthanasia in advanced lung cancer patients.'** One in five of patients had expressed a wish for euthanasia; and 3 in 4 of these had made an explicit and repeated request. One in two of these received euthanasia. Of the patients who had expressed a wish for euthanasia but had not made an explicit and repeated request, none received euthanasia. Patients with a palliative treatment goal at inclusion were more likely to receive euthanasia. Death was preceded by an end-of-life decisions with possible life-shortening effects in 62.9% of patients. To conclude, advanced lung cancer patients who expressed a euthanasia wish were often determined. Euthanasia was performed significantly more among patients whose treatment goal after diagnosis was exclusively palliative. http://erj.ersjournals.com/content/early/2012/04/19/09031936.00182611.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.

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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.

Worth Repeating

From critical care to comfort care: The sustaining value of humour

JOURNAL OF CLINICAL NURSING, 2008;17(8):1088-1095. Research in health care commonly identifies the value of humour for enabling communication, fostering relationships, easing tension and managing emotions. Other studies identify situations involving serious discussion, life-threatening circumstances and high anxiety as places where humour may not be appropriate. The authors' demonstrate humour is significant even where such circumstances are commonplace. Common themes ... include the value of humour for team work, emotion management and maintaining human connections. Humour served to enable co-operation, relieve tensions, develop emotional flexibility and to "humanise" the health-care experience for both caregivers and recipients of care. Humour is often considered trivial or unprofessional; this research verifies that it is neither. The value of humour resides, not in its capacity to alter physical reality, but in its capacity for affective or psychological change which enhances the humanity of an experience, for both care providers and recipients of care. In the present era which emphasises technology, efficiency and outcomes, humour is crucial for promoting team relationships and for maintaining the human dimension of health care. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2007.02090.x/abstract;jsessionid=42FBD215316B08577D4AC1E63EC520FB.d04t04?userIsAuthenticated=false&deniedAccessCustomisedMessage=

Extract of an article authored by Canadian physician and palliative care pioneer Dr. Elizabeth Latimer, who died 28 April 2012 following a sudden illness, aged 68.

An exchange of gifts

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2000;162(13:1859-1860. The hospital often seemed to her to be separate from the rest of life, like an island or a ship, a world unto itself. This insular quality had the effect of intensifying the sense of community, of shared purpose, within. Her hospital, she sometimes called it — and she really felt that in some ways it was. Eighteen years of caring for its seriously ill and dying patients. About three hundred a year…over five thousand in all. Could it be possible? Each person, each story, unique. A rich legacy. She felt privileged to receive some of the lessons of living from those who, facing illness and death, had gained a crystal-clear perspective on what was valuable in life and what was irrelevant distraction. Lately, she found herself caring for family members of previous patients. This made more acute not only her sense of the passage of time, but also her sense of death as inescapable in the human community of which she, too, was a part. http://www.cmaj.ca/content/162/13/1859.full.pdf+html?sid=c7978691-97c4-47de-901b-a77ea78cea19

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