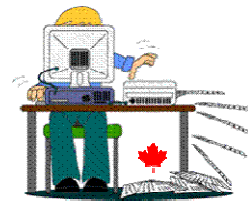


Media Watch...

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

Continuing coverage of Massachusetts General Hospital study: Scroll down to U.S.A. and 'New impetus for palliative care' (p.4), an OpEd published in the *Boston Globe*.

Canada

Lawsuit could set precedent about end-of-life decisions

ONTARIO | *Toronto Star* – 4 September 2010 – While [Joy] Wawrzyniak and her father, Douglas (Dude) DeGuerre, had repeatedly requested he receive life-saving treatment in case of a medical emergency, doctors unilaterally overruled those wishes without consent or consultation ... [a \$1 million] lawsuit [against Sunnybrook Health Sciences Centre] claims. The highly charged allegations, which have not been proved in court, set the stage for renewed public debate over the largely unsettled ethical and legal questions surrounding end-of-life protocols in Canada, experts say. "The million-dollar question at the heart of this is whether it is a medical decision or a family/patient decision," says Dr. Kerry Bowman, a bioethicist at the University of Toronto... "That question has largely been unanswered from a legal and ethical perspective in this country." There is, however, an emerging consensus that final decisions must be negotiated with families, he says. Not so fast, says Dr. Michael Gordon, a geriatrician and medical program director of palliative care at Baycrest Centre for Geriatric Care. "If you cannot convince the family member, then you still have to make your responsible, professional decision. Otherwise, you're abrogating your professional responsibility." Subjecting a dying person to CPR if you believe there is virtually no hope of survival is, he says, "a terrible way to practise medicine. It's inhumane. It's an assault." <http://www.thestar.com/news/gta/article/856741--lawsuit-could-set-precedent-about-end-of-life-decisions?bn=1>

From Media Watch dated 29 March 2010:

NATIONAL POST | Online report – 29 March 2010 – '**Crisis in the ICU.**' The doctor for a dying Jewish man at the heart of an emotional court battle has spoken out about the case for the first time, calling for a public inquiry to help clear up the growing debate over who should decide the care of gravely ill patients.¹

<http://www.nationalpost.com/news/canada/story.html?id=2738063>

1. *AMERICAN JOURNAL OF BIOETHICS*, 2010;10(3):50-53.

'The case of Samuel Golubchuk and the right to live.' Samuel Golubchuk was unwittingly at the center of a medical controversy with important ethical ramifications. <http://www.informaworld.com/smp/content-content=a919856613~db=all>

'We need a war on pain'

It's time society faced death head-on, neuroscientist says

QUEBEC | *Montreal Gazette* – 3 September 2010 – As the Olympics of Pain wraps up in Montreal and Quebecers prepare to debate the controversial issue of physician-assisted suicide or euthanasia ... neuroscientist Kathleen Foley says it's about time society faced death head-on. In an interview with the *Gazette* at the [recent] 13th World Congress on Pain in Montreal, Foley, of the renowned Memorial Sloan-Kettering Cancer Centre in New York and adviser to the World Health Organization cancer and palliative care unit, said euthanasia has fallen off the radar of most countries. She also addressed the need to improve care for the dying on a

global scale and said the so-called "war on drugs" has limited patient access to pain relief. <http://www.montrealgazette.com/health/need+pain/3476677/story.html>

Specialist Publications

Of particular interest:

'Inadequate pain management: Myth, stigma and professional fear' (p.11), a commentary in the *Post Graduate Medical Journal*.

- INTERNATIONAL ASSOCIATION FOR THE STUDY OF PAIN | Press release – 3 September 2010 – Health care providers and researchers in the field of pain management are calling for governments worldwide to recognize the rights of people to the access of reasonable care for acute and chronic pain. The Declaration of Montreal emphasizes that management of acute pain is inadequate for more than 50% of people in developed countries and 90% of people in developing countries, while chronic non-cancer pain ... occurs in at least one in five people worldwide. <http://www.prnewswire.com/news-releases/health-care-professionals-and-advocates-from-84-countries-to-issue-declaration-that-access-to-pain-management-is-a-fundamental-human-right-102137469.html>

New program transitions seniors from hospital to home or long-term care

ONTARIO | *Kitchener Record* – 31 August 2010 – A new local program to transition elderly patients from hospital to home or long-term care was unveiled as part of this year's initiatives in the provincial Aging at Home Strategy. The Waterloo Wellington Local Health Integration Network received \$18.7 million to fund local programs to help seniors live independently at home or in the community. The new transition program is among 21 programs being funded locally, most continuing from the first two years of the province-wide strategy that's intended to relieve pressure on emergency rooms and hospitals by reducing the number of unnecessary hospital visits and stays by

seniors. Over four years, the province is providing \$1.1 billion for the local health networks to expand home care and support services for seniors to reduce the number of hospital beds filled by alternate level of care patients, who no longer need to be in hospital, but are waiting for care in the community. <http://news.therecord.com/News/Local/article/771199>

The Ontario Hospital Association indicates that hospital patients who are awaiting access to appropriate care elsewhere occupy almost 19% of hospital beds in the province.

- ONTARIO | *Ottawa Citizen* – 1 September 2010 – **'Cash no cure for nursing home gridlock.'** Funding in Eastern Ontario aimed at keeping seniors in their homes ... has increased nearly four-fold over the past three years. However, the region continues to have Ontario's longest waits for nursing-home beds, leading critics to question whether the money is being spent in the right place. <http://www.ottawacitizen.com/health/Cash+cure+nursing+home+gridlock/3466880/story.html>

N.B. Ontario Ministry of Health & Long Term Care press release on the expansion of the Aging at Home Strategy: <http://www.news.ontario.ca/mohltc/en/2010/08/aging-at-home-strategy-expands.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *Montreal Gazette* – 5 September 2010 – **'Right-to-die debate takes centre stage in Quebec.'** The national debate on euthanasia and helping end the life of someone who wants to die is about to be rekindled by public hearings kicking off this week in Quebec. <http://www.montrealgazette.com/news/Right+debate+takes+centre+stage+Quebec/3485522/story.html>
 - QUEBEC | *Montreal Gazette* – 2 September 2010 – **'Better palliative care would end euthanasia debate, group says.'** Instead of debating the decriminalization of euthanasia, what Quebec needs is better palliative care, says a group representing the province's retired public-sector employees. <http://www.montrealgazette.com/health/Better+palliative+care+would+euthanasia+debate+group+says/3471969/story.html>
 - QUEBEC | *Montreal Gazette* – 2 September 2010 – **'Polls are useless.'** It's not surprising that the question... "Do you believe decriminalizing euthanasia and assisted suicide is the right way to help people die with dignity?" – received the response it did.¹ <http://www.montrealgazette.com/opinion/letters/Polls+useless/3471994/story.html>
1. QUEBEC | *Montreal Gazette* – 22 August 2010 – **'71% of Quebecers want euthanasia legalized.'** The question asked [in the newspaper's poll]: "Do you believe decriminalizing euthanasia and assisted suicide is the right way to help people die with dignity?" While 71% answered "yes," only 16% answered "no." <http://www.montrealgazette.com/news/Quebecers+want+euthanasia+legalized/3427946/story.html>

N.B. Noted in Media Watch dated 23 August 2010. Euthanasia, consenting to a lethal dose of medicine, and assisted suicide, ending the life of someone who wants to die, are currently illegal under the federal Criminal Code ...but, a provincial committee will seek public input on the issue beginning this month.

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.

U.S.A.

New impetus for palliative care

MASSACHUSETTS | *Boston Globe* (OpEd) – 1 September 2010 – All too often, patients with terminal illnesses turn to the pain medication and counseling of palliative care only after enduring wrenching treatments that have little chance of extending their lives. But what if palliative care began immediately after the diagnosis and while the disease is still being treated? The answer, according to a study at Massachusetts General Hospital, is that patients treated this way enjoy a higher quality of life and live longer.^{1,2} In addition, they are more likely than patients not receiving palliative care to forgo 11th hour therapies. The outcome took experts by surprise, but not entirely. As Brigham and Women's surgeon Atul Gawande noted in a recent article in *The New Yorker*, a study of Medicare patients found survival times for terminal patients receiving hospice care were about equal or longer than those of patients getting more aggressive treatment.³ http://www.boston.com/bostonglobe/editorial_opinion/editorials/articles/2010/09/01/new_impetus_for_palliative_care/

1. *NEW ENGLAND JOURNAL OF MEDICINE* | Online article – 18 August 2010 – '**Palliative care – a shifting paradigm.**' Physicians tend to perceive palliative care as the alternative to life-prolonging or curative care – what we do when there is nothing more that we can do – rather than as a simultaneously delivered adjunct to disease-focused treatment. <http://www.nejm.org/doi/full/10.1056/NEJMe1004139>
2. *NEW ENGLAND JOURNAL OF MEDICINE* | Online article – 18 August 2010 – '**Early palliative care for patients with metastatic non-small-cell lung cancer.**' Early palliative care led to significant improvements [for the patient] in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life, but longer survival. <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>

A doctor's and a nurse's perspective on end-of-life-care

"There comes a point where we almost use medicine to ... torture old people by trying to keep them alive when really they are ready to die." Iona Heath, president of the U.K. Royal College of General Practitioners, speaking at the recent New Zealand Royal College of General Practitioners Conference in a report posted 2 September on TVNZ. <http://tvnz.co.nz/health-news/elderly-care-more-nursing-fewer-drugs-3755059>

"Watching this patient suffer ... because of what we did to him in the name of helping him was agonizing." Theresa Brown, an oncology nurse and author of an online article posted 1 September 2010 on CNN. <http://edition.cnn.com/2010/OPINION/08/31/brown.hospice.care/?hpt=Sbin#fbid=YSn-qpkaDyn&wom=false>

N.B. The journal articles were noted in Media Watch dated 23 August 2010.

3. *THE NEW YORKER* | Online article – 2 August 2010 – '**What should medicine do when it can't save your life?**' Although not everyone has embraced its rituals [i.e. hospice] those who have are helping to negotiate an *ars moriendi* for our age. But doing so represents a struggle – not only against suffering but also against the seemingly unstoppable momentum of medical treatment. http://www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande?currentPage=all

N.B. Noted in Media Watch dated 2 August 2010:

Memorial Hospital lays off 47, cuts hospice care

MISSISSIPPI | WLBT News – 1 September 2010 – Memorial Hospital [Gulfport] announced ... that 47 workers had been laid off due to an \$11 million budget shortfall. The hospital is also cutting hospice care services. Of the 47 people laid off at Memorial Hospital, officials say 16 were with hospice care. <http://www.wlbt.com/Global/story.asp?S=13074888>

Assisted (or facilitated) death

Representative sample of recent news media coverage:



Al Pacino recently received an Emmy Award for Best Actor for his portrayal of right-to-die activist Jack Kevorkian in an HBO biopic, 'You Don't Know Jack.' [Cartoon: Mike Thompson, *Detroit Free Press*]

Specialist Publications

Of particular interest:

'The irony of supporting physician-assisted suicide' (p.10), a commentary in *Medicine, Health Care & Philosophy*.

'Strange deathbedfellows' and 'Hospice and physician-assisted death: Collaboration, compliance, and complicity' (p.10), commentaries on the legal and moral questions of Oregon's Dying with Dignity law in *The Hastings Report*.

International

Hospital deaths relatives want change in law

U.K. | BBC News – 1 September 2010 – The families of patients who died at a Hampshire hospital after being given "potentially hazardous" levels of drugs are petitioning for a law change. An inquest held last year into the deaths of 10 Gosport War Memorial Hospital patients in the 1990s found drugs to be a factor in five cases. Dr. Jane Barton prescribed the drugs and was later found guilty of misconduct. Relatives are at Downing Street [the Prime Minister's official London residence] to ask that doctors are forced to consult more widely before "end of life" care. They want more to be done to safeguard patients, who are often elderly and vulnerable.
<http://www.bbc.co.uk/news/uk-england-hampshire-11151196>

Committee wants G5 ward closure to be put on ice

U.K. | *The News* (Portsmouth) – 27 August 2010 – Councillors sitting on Portsmouth City Council's health overview and scrutiny committee ... voted unanimously to ask Portsmouth Hospitals NHS [National Health Services] Trust to defer the closure of the end-of-life care ward ... at Queen Alexandra Hospital ... and hold a public meeting. Councillors voiced their anger at not being consulted about plans to replace the ward with a mobile nurse team to work with patients throughout the hospital. <http://www.portsmouth.co.uk/newshome/Committee-wants-G5-ward-closure.6498319.jp>

From Media Watch dated 2 August 2010:

- U.K. | *The News* (Portsmouth) – 28 July 2010 – **'Ward for terminally ill patients to shut...'** When the ward closes the staff will instead form a special palliative care team which will work throughout the hospital. <http://www.portsmouth.co.uk/newshome/Ward-for-terminally-ill-patients.6443818.jp>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (SCOTLAND) | *Herald* – 5 September 2010 – **'Is there such a thing as a 'good death'? It is time we found out.'** Few people talk about the idea of the "good death", except sometimes to console themselves after some loved one has died that, as passings go, theirs wasn't so terribly bad. <http://www.heraldscotland.com/comment/vicky-allan/is-there-such-a-thing-as-a-good-death-it-is-time-we-found-out-1.1052849>
- *IRISH TIMES* | Online letter – 4 September 2010 – **'Euthanasia is no solution to suffering.'** In Ian O'Doherty's impassioned piece on euthanasia ... he touches on a number of crucial issues regarding death and dignity. ¹<http://www.independent.ie/opinion/columnists/ian-odoherty/ian-odoherty-why-let-a-whale-die-with-dignity-but-not-a-person-2322888.html>
 1. **'Why let a whale die with dignity, but not a person?'** Two stories appeared ... yesterday – separate yet connected in a way that many people won't realise. <http://www.independent.ie/opinion/columnists/ian-odoherty/ian-odoherty-why-let-a-whale-die-with-dignity-but-not-a-person-2322888.html>
- U.K. (SCOTLAND) | *Scotsman* – 3 September 2010 – **'Margo MacDonald wins backing in bid to permit 'dignified dying.'** [Member of the Scottish Parliament] Margo MacDonald's bid to legalise assisted suicide has been given a boost after the Humanist Society of Scotland launched a campaign backing her proposal. <http://news.scotsman.com/scotland/Margo-MacDonald-wins-backing-in.6510854.jp>
- U.K. (SCOTLAND) | *Scotsman* – 3 September 2010 – **'Margo is willing to amend her bill on assisted dying.'** Margo MacDonald says she is willing to amend her own bill on assisted dying to make improvements to the proposed legislation. <http://news.scotsman.com/health/Margo-is-willing-to-amend.6511247.jp>
- SWITZERLAND | SwissInfo.com – 2 September 2010 – **'Swiss want a say on how to end their lives.'** Most Swiss are in favour of assisted suicide, and would support direct active euthanasia – a practice currently outlawed. But a Zurich University survey into public attitudes on these issues ... also found a lack of support for "death tourism" where foreigners come to Switzerland to end their lives. http://www.swissinfo.ch/eng/swiss_news/Swiss_want_a_say_on_how_to_end_their_lives.html?cid=28250486
- U.K. | *The Guardian* – 2 September 2010 – **'Two arrested over assisted suicide.'** Friends are believed to have helped Douglas Sinclair, 76, who had multiple system atrophy, travel to Switzerland to die. <http://www.guardian.co.uk/society/2010/sep/02/two-arrested-over-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/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/search/?tag=Media+Watch>

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>

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

End-of-life experiences

Reaching out for compassion, communication, and connection – meaning of deathbed visions and coincidences

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 27 August 2010 – A recent study shows that the greatest fear of many Britons is to die alone. More than half the complaints received by the U.K. National Health Service (NHS) concern end-of-life care, with an emphasis on spiritual matters. Much has been written on the spiritual needs of the dying, but many doctors and nurses still find this a difficult area to approach. They lack the confidence and/or training to recognize or discuss spiritual aspects of death and dying or to affirm the spiritual needs of the dying person. The authors' end-of-life experience (ELE) research suggests that deathbed visions (DVs) and deathbed coincidences (DCs) are not uncommon, and that the dying process appears to involve an instinctive need for spiritual connection and meaning, requiring compassionate understanding and respect from those who provide end-of-life care. <http://ajh.sagepub.com/content/early/2010/08/16/1049909110374301.abstract>

From Media Watch dated 12 October 2009:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 8 October 2009 – **'Deathbed phenomena: Its role in peaceful death and terminal restlessness.'** Dying patients and their caregivers frequently experience ... deathbed phenomena ... [including] ... visions of past deceased relatives or friends, religious figures, and a visionary language pertaining to travel. Collective research supports mounting evidence that deathbed visions typically yield peaceful deaths. <http://ajh.sagepub.com/cgi/content/abstract/1049909109347328v1>

Dying with dementia: What we know after more than a decade of research

JOURNAL OF ALZHEIMER'S DISEASE | Online article – 30 August 2010 – Although recent studies indicate encouraging trends of improved palliative care [for patients with dementia], little evidence supports effectiveness of specific treatments. As of January 2010, at least 45 studies, almost all performed after 2000, have reported on treatment, comfort, symptom burden, and families' satisfaction with care. Over half of these studies were in U.S. settings, and most were small or retrospective. Few randomized trials and prospective observational studies have been performed so far, but several promising studies have been completed recently or are underway in various countries. Guidelines for care and treatment, still mostly consensus-based, support the benefits of advance care planning, continuity of care, and family and practitioner education. <http://iospress.metapress.com/content/454w7q4vx7q48453/>

Nursing contributions to the development of palliative care programs

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2010;12(5):319-325. Demand for expert palliative and end-of-life care has far outpaced the availability of specialty trained healthcare providers and the unique programs required to address this need. This article describes a palliative and end-of-life care professional education course and discusses successful nurse-led team projects initiated after the course. Two-person interdisciplinary healthcare teams from nationwide cancer centers were trained to recognize and care for the special needs of the palliative and end-of-life patient population. Following a 3-day course, 199 teams returned to their institutions to implement customized goals for improving patient care. Long-term follow-up evaluation provided examples of teams with nurse members ... successful in initiating palliative care culture changes and in developing/fine tuning palliative and end-of-life care programs. http://journals.lww.com/jhpn/Abstract/2010/09000/Nursing_Contributions_to_the_Development_of_10.aspx

"At the foot of a very long ladder"

Discussing the end of life with older people and informal caregivers

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 3 September 2010 – This article reports findings from one approach of engaging older members of the general public and informal caregivers in discussions about end-of-life care. Listening events were delivered across the United Kingdom using principles of focus group conduct to facilitate discussions among older people, informal caregivers, and representatives from community groups in four workshops. Participants discussed their feelings, experiences, and concerns about the end of life, guided by the booklet *Planning for Choice in End-of-Life Care*, which was piloted in an earlier study.¹ Three themes arose: communicating about end-of-life issues, factors that influence individuals' concerns about death and dying, and advance care planning. The heterogeneity of stories told not only illustrates how people's responses and needs at the end of life vary greatly but also reveals shared reactions, experiences, and some confusion. The stories also demonstrate people's

willingness to engage with concerns associated with the end of life and their conviction that this is an important area of community action and development.
[http://www.jpsmjournal.com/article/S0885-3924\(10\)00524-5/abstract](http://www.jpsmjournal.com/article/S0885-3924(10)00524-5/abstract)

Architect's perspective

Palliative care unit design: Patient and family preferences

DESIGN & HEALTH | Online article – Accessed 2 September 2010 – The primary purpose of this qualitative study was to identify what palliative care patients and their families perceive to be important elements in the design of a palliative care unit for end-of-life care. Secondary objectives included exploring whether differences in preferences and perceptions exist between patients and family members. This study looked at the palliative care population of Bridgepoint Hospital in Toronto, Canada, and evaluated patient and family preferences for room design and layout, as well as preference for private versus shared accommodations.
<http://www.worldhealthdesign.com/Palliative-Care-Unit-Design.aspx>

1. *Planning for Choice in End-of-Life Care*, The Peer Education Project Group, Help the Aged, 2006
<http://policy.helptheaged.org.uk/NR/rdonlyres/2E92D357-BBDA-4142-AADE-A74742F77C6D/0/planningforchoice140108.pdf>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 27 August 2010 – **'Residents' practices and perceptions about do not resuscitate orders and pronouncing death: An opportunity for clinical training.'** Although most residents discuss DNR status with patients and families, only a quarter are observed in such discussions by attending physicians and only a third feel comfortable with this aspect of clinical care. Developing a structured residency program curriculum to address resident skills in end-of-life care would benefit residency training.
<http://ajh.sagepub.com/content/early/2010/08/16/1049909110374599.abstract>
- *THE HASTINGS REPORT*, 2010;40(5):36-45. **'Can we improve treatment decision-making for incapacitated patients?'** Clinical practice relies on patients to make their own treatment decisions, typically in consultation with a clinician. This approach is intended to respect those who can make decisions but poses a dilemma for incapacitated patients, such as those with advanced Alzheimer disease.
<http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=4860>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 3 September 2010 – **'Measuring families' perceptions of care across a health care system: Preliminary experience with the family assessment of treatment at end-of-life short form (FATE-S).'** Interviews were completed with 2827 family members. Overall, the survey showed excellent psychometric characteristics, with good homogeneity ... and strong evidence of discriminant validity.
[http://www.jpsmjournal.com/article/S0885-3924\(10\)00517-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(10)00517-8/abstract)

A measure of palliative care in nursing homes

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 27 August 2010 – Efforts to improve care for nursing home residents stand to be enhanced by measures to assess the degree to which staff provide palliative care. As the incidence of death in nursing homes increases with the aging population, the gap in measurement must be addressed. To that end, the authors report the development and psychometric testing of a nursing home palliative care survey. The PCS [Palliative Care Survey] measures the extent to which the nursing home staff engage in palliative care practices and have knowledge consistent with good end-of-life care. Both practice and knowledge are an essential foundation to providing good end-of-life care to nursing home residents. Efforts to improve care for the dying in nursing homes have been slowed by an absence of measurement tools that capture care processes; a gap, which the PCS reported here, helps fill. [http://www.jpsmjournal.com/article/S0885-3924\(10\)00501-4/abstract](http://www.jpsmjournal.com/article/S0885-3924(10)00501-4/abstract)

- *PALLIATIVE MEDICINE* | Online article – 3 September 2010 – **'A comparison of palliative care outcome measures used to assess the quality of palliative care provided in long-term care facilities: A systematic review.'** The Family Perceptions of Care Scale is considered by the authors as the most suitable outcome measure for use in LTC facilities. Quality of Dying in Long-term Care scale and the Toolkit Interview were also considered suitable for measuring the quality of palliative care... <http://pmj.sagepub.com/content/early/2010/09/02/0269216310378786.abstract>

From Media Watch dated 11 January 2010:

- AMERICAN ASSOCIATION OF HOMES & SERVICES FOR THE AGING | Online press release – 5 January 2010 – **'Research finds few nursing homes participate in end-of-life care programs.'** Although 25% of all deaths in America occur in nursing homes, fewer than 20% of homes participate in end-of-life care programs, according to a new research report from the Institute for the Future of Aging Services. <http://www.aahsa.org/article.aspx?id=10765>

1. The research was published in the *American Journal of Hospice & Palliative Care Medicine* and noted in Media Watch dated 20 April 2009. Abstract of **'Nursing home participation in end-of-life programs'** is available at: <http://ajh.sagepub.com/cgi/content/abstract/1049909109333933v1>

Including the perspective of the adolescent in palliative care preferences

JOURNAL OF PEDIATRIC HEALTH CARE, 2010;24(5):286-291. Improving communication with an adolescent with a life-limiting or life-threatening disease is key to providing comprehensive care and support. A pediatric hospital in the [U.S.] Midwest uses a communication tool (CCCT) to facilitate conversations about the adolescent's wishes, beliefs, values, preferences and goals. Information gathered in a CCCT conversation becomes a key intervention to providing compassionate, appropriate care that is directed toward quality of life consistent with the adolescent's and family's goals. <http://www.jpedhc.org/article/PIIS0891524509002107/abstract>

From Media watch dated 1 February 2010:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 22 January 2010 – **'Adolescents with life-threatening illnesses.'** Adolescents with life-threatening illnesses must rely on their parents, due to legal aspects of decision making, and they also face potential loss of peer interaction as they spend more time in hospitals and away from their friends. Adolescents may also be concerned with fertility, reproduction, and sexuality, issues that are often not addressed in palliative care programs. <http://ajh.sagepub.com/cgi/content/abstract/1049909109358310v1>



Telehealth in palliative care in the U.K.: A review of the evidence

JOURNAL OF TELEMEDICINE & TELE CARE | Online article – 2 September 2010 – Telehealth was being used by a range of health professionals in oncology care settings: specialist palliative care, hospices, primary care settings, nursing homes and hospitals as well as patients and carers. The most common applications were: out-of-hours telephone support, advice services for palliative care patients, carers and health professionals, videoconferencing for interactive case discussions, consultations and assessments, and training and education of palliative care and other health-care staff. <http://jtt.rsmjournals.com/cgi/content/abstract/jtt.2010.091108v1>

From Media Watch dated 28 June 2010:

- *TELEMEDICINE & E-HEALTH* | Online article – 24 June 2010 – '**Comparing face-to-face and telehealth-mediated delivery of a psychoeducational intervention: A case comparison study in hospice.**' This case study compared the delivery of a psychoeducational intervention with hospice caregivers, delivered in person and via videophone. This study demonstrates the feasibility of using telehealth tools to deliver interventions in hospice and identified ways or protocols that can be adapted for telehealth delivery. <http://www.liebertonline.com/doi/abs/10.1089/tmj.2010.0013>

A personal account

The irony of supporting physician-assisted suicide

MEDICINE, HEALTH CARE & PHILOSOPHY | Online article – 14 August 2010 – Under other circumstances, I would have written an academic paper rehearsing the arguments for and against legalization of physician-assisted suicide: autonomy and the avoidance of pain and suffering on the pro side, the wrongness of killing, the integrity of the medical profession, and the risk of abuse, the "slippery slope," on the con side. I've always supported the pro side. What this paper is, however, is a highly personal account of the challenges to my thinking about right-to-die issues. In November 2008, my husband suffered a C2/C3 spinal cord injury ... leaving him ventilator-dependent, almost completely paralyzed, and in the hospital – but fully alert and profoundly self-reflective. This is a detailed portrait of a man whose life involves extraordinary suffering but also luminous experience some of the time. It only makes the question harder: What if he wanted to die? <http://www.springerlink.com/content/41450356g02j6425/>

Of related interest:

- *THE HASTINGS REPORT*, 2010;40(5):3. '**Strange deathbedfellows.**' When talking to a variety of audiences about my experience around Oregon's law, I am often asked, "How and why do hospices allow physician-assisted death to happen?" I respond, "How can they prevent it?" <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=4847>
- *THE HASTINGS REPORT*, 2010;40(5):26-35. '**Hospice and physician-assisted death: Collaboration, compliance, and complicity.**' An examination of fifty-five Oregon hospices reveals that both legal and moral questions prevent hospices from collaborating fully with physician-assisted death. <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=4859>



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.

National survey of the current provision of specialist palliative care services for patients with end-stage renal disease

NEPHROLOGY DIALYSIS TRANSPLANTATION | Online article – 2 September 2010 – The majority of SPC [specialist palliative care] services accept ESRD [end-stage renal disease] patients, but limited numbers are referred. Respondents [to this national survey] indicated that this barrier could be addressed by closer collaboration and better communication and education between renal and SPC services. Other initiatives to enable delivery of SPC to increased numbers of ESRD patients include the use of specific referral and clinical care guidelines and expansion of joint MDT [multi-disciplinary team] meetings and out-patient clinics. <http://ndt.oxfordjournals.org/cgi/content/abstract/qfg530>

End of life care is compromised as 'crucial' services are denied funds

NURSING TIMES (U.K.) | Online report – 31 August 2010 – Primary care trusts [PCTs] spent just a quarter of the funds they were given to pay for end of life care on direct nursing provision to support patients dying at home. The Department of Health's second report into progress on the previous government's 2008 end of life care strategy details what the £72m, which was given to PCTs to pay for the strategy, was spent on in 2009-2010.¹ The report shows £6m went towards rapid response 24 hour community services, £3m was paid to support Marie Curie or Macmillan nurses, and £8.6m was spent on specialist palliative care teams. In total, around a quarter of the total pot was spent directly on services that provide nursing care to patients wanting to die at home. <http://www.nursingtimes.net/whats-new-in-nursing/primary-care/end-of-life-care-is-compromised-as-crucial-services-are-denied-funds/5018738.article>

1. *End of Life Strategy: Second Annual Report*, National Health Service, Department of Health, 2010 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalassets/dh_118955.pdf
- *HEALTH SERVICE JOURNAL* (U.K.) | Online report – 1 September 2010 – '**Poor data reporting skews palliative care spending picture.**' A government report has pointed to significant variations in the amount primary care trusts spend on end of life care. <http://www.hsj.co.uk/news/finance/poor-data-reporting-skews-palliative-care-spending-picture/5018781.article>

Inadequate pain management: Myth, stigma and professional fear

POST GRADUATE MEDICAL JOURNAL, 2010;86(1018):453-458. The ability to effectively relieve pain has been available to health professionals for generations. It should be a primary concern in treating patients but is still often given a low priority or ignored completely. Apathy toward the suffering experienced may be mixed with a fear of the use of the common analgesics. Our own prejudices and ignorance can also contribute. Failures in the primary education of health professionals may be the single most important cause and the identity of the remedy. Raising the profile of pain as an essential educational topic and, more broadly, realising that this is a major public health matter are the way forward. <http://pmj.bmj.com/content/86/1018/453.abstract>

Of related interest:

- *HOME HEALTHCARE NURSE*, 2010;28(8):458-468. '**7 Tools to assist hospice and home care clinicians in pain management at end of life.**' Assessing pain at end of life is often a challenge for the home health clinician, especially in different age groups or in the presence of severe cognitive impairment, language barriers, or communication difficulties. The task of assessing and monitoring the severity of pain and measuring the effectiveness of treatment measures is essential for effective pain management. This article provides home health clinicians with some practical skills and essential tools to assess and record pain intensity as the first step for effective pain management. http://journals.lww.com/homehealthcareonline/Abstract/2010/09000/7_Tools_to_Assist_Hospice_and_Home_Care_Clinicians.3.aspx

Moral distress experienced by health care professionals who provide home-based palliative care

SOCIAL SCIENCE & MEDICINE | Online article – 26 August 2010 – Health care providers regularly encounter situations of moral conflict and distress in their practice ... [resulting in] unfavorable outcomes for both health care providers and those in their care. This study examined the experience of moral distress from a broad range of health care occupations that provide home-based palliative care as the initial step of addressing the issue. Most participants [in this study] described at least two critical incidents. Analyses ... revealed 11 issues ... which clustered into three themes: a) the role of informal caregivers; b) challenging clinical situations; and, c) service delivery issues. Findings suggest that the training and practice environments for health care providers need to be designed to recognize the moral challenges related to day-to-day practice. http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-50W1TKN-1&_user=10&_coverDate=08%2F26%2F2010&_rdoc=1&_fmt=high&_orig=search&_origin=search&_sort=d&_docanchor=&_view=c&_searchStrId=1446258130&_rerunOrigin=sch

olr.google.acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=f38f5f715eb3d61394a07a388624cada&searchtype=a

Quotable Quotes

If doctors feel that their beliefs, religious or otherwise, are influencing their ability to fulfil their professional obligations, then they must have the professional integrity and self-awareness to acknowledge this, and remove themselves from any situation in which their values are incompatible with delivering the standards of care demanded of them. The Lancet, 2010;376(9743):743.

[http://www.lancet.com/journals/lancet/article/PIIS0140-6736\(10\)61359-1/fulltext](http://www.lancet.com/journals/lancet/article/PIIS0140-6736(10)61359-1/fulltext)

N.B. Commentary on 'The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care,' *Journal of Medical Ethics* online article of 25 August 2010 (noted in Media Watch dated 30 August 2010).

http://jme.bmj.com/content/early/2010/07/22/jme.2010.036194.short?q=w_jme_ahead_tab

Worth Repeating

The principle of double effect as a guide for medical decision-making

MEDICINE, HEALTH CARE & PHILOSOPHY, 2008;11(4):465-473. Many medical interventions have both negative and positive effects. When health care professionals cannot achieve a particular desired good result without bringing about some bad effects also they often rely on double-effect reasoning to justify their decisions. The principle of double effect is therefore an important guide for ethical decision-making in medicine. At the same time, however, it is a very controversial tool for resolving complex ethical problems that has been criticized by many authors. For these reasons ... in this paper [the author examines] whether the principle of double effect can serve as a basis for ethical decisions in medicine. The conclusion reached in this article is that even though this principle has desirable effects on clinical conduct, it is only an unreliable guide and physicians and nurses cannot feel secure in continuing to use this principle for ethical guidance. <http://www.springerlink.com/content/k865177172821181/>

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