Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in hospice, palliative care and end-of-life issues – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

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Compilation of Media Watch 2008, 2009, 2010, 2011 ©

Compiled & Annotated by Barry R. Ashpole

Europe-wide poll: Scroll down to <u>International</u> and 'Quality of life more important than length of time left' (p.6), published in the *Daily Telegraph*.

Canada

Withholding and withdrawing life-sustaining treatment

End-of-life reports call for better education

MANITOBA | *Winnipeg Free Press* – 25 March 2011 – The Winnipeg Regional Health Authority [WRHA] released two reports ... on the sensitive issue of end-of-life care. ^{1,2} The reports were sparked by Samuel Golubchuk's controversial battle to live his final days on his own terms. ³ The 85-year-old died in Grace Hospital on 24 June 2008, before a court could resolve whether the elderly man's Orthodox Jewish beliefs trumped guidelines that give doctors the final say on withdrawing life-support. The reports recommend better public education on the issue and improved communication between health providers, patients and their families. The reports recommend that improved communication is needed to clarify patient and family wishes as early as possible. They also recommend increasing access to mediation and ethics support services for patients, families and staff to help resolve disagreements in a timely and respectful manner. Both reports raise the issue of whether there should be a legislated or internal review process to resolve end-of-life care issues between patients, families and health providers as an alternative to pursuing the matter in the courts. http://www.winnipegfreepress.com/breakingnews/WRHAs-end-of-life-reports-call-for-better-education-118653749.html

- 1. Withholding/Withdrawing Life-Sustaining Treatment, WRHA Board Working Group Report, December, 2010. http://www.wrha.mb.ca/healthinfo/reports/files/EndOfLife-BoardReport.pdf
- 2. Report of the WRHA Working Group on withholding and withdrawing life-sustaining treatment, March 2011. http://www.wrha.mb.ca/healthinfo/reports/files/EndOfLife-Report.pdf
- 3. 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. http://www.nationalpost.com/news/canada/story.html?id=2738063

N.B. Noted in Media Watch dated 29 March 2010.

Baby Joseph doing well after tracheotomy

ONTARIO | *Toronto Star* – 25 March 2011 – A Windsor ... baby at the centre of a controversy over treatment of the terminally ill is doing well after a tracheotomy [at a St. Louis, Missouri, hospital]. The tracheotomy had been a point of dispute between ... [Joseph Maraachli's] ... parents and doctors in London [Ontario], who'd kept Joseph alive since October with a feeding tube and a ventilator. London doctors wanted to remove Joseph from life support because they believed medical tests showed the infant was in a vegetative state from which he couldn't recover. The parents asked London doctors to perform a tracheotomy in the hope of extending his life as they did with an older sibling who died of the same rare neurological disorder. London doctors refused to perform a tracheotomy because they believed it would only serve as an affront to a patient who they believed would die regardless. The doctors sought and received the backing of an expert panel appointed by the Ontario Health Ministry, a finding supported as reasonable by a London court. http://www.torontosun.com/news/canada/2011/03/25/17753626.html

From Media Watch dated 21 March 2011:

ONTARIO | Vancouver Sun (British Columbia) – 14 March 2011 – 'Baby Joseph to get tracheotomy by the end of the week: U.S. doctors.' A terminally ill Ontario baby at the centre of a heated debate over end-of-life medical care will undergo a tracheotomy ... in hopes he could be transferred to a nursing facility closer to home, said the Missouri hospital that accepted Joseph Maraachli. http://www.vancouversun.com/life/Baby+Joseph+tracheotomy+week/4435461/story.html

Are we in denial about the growing issue of elder care?

GLOBE & MAIL | Online article – 24 March 2011 - Senator Sharon Carstairs has had it. Over the past 16 years, there has been no fiercer a Canadian advocate of better care for the elderly. She has spearheaded two ground-breaking Senate reports on aging, and remains in demand as a speaker, preaching the need for action. Yet even now, with the first baby boomers turning 65 this year, almost nothing is being done to prepare for the demographic bulge of seniors. There is no comprehensive plan, no national program, not even a firm commitment to deal with frail elders already trapped in the system, many of whom are doomed to spend their final days in misery. With a sigh and trace of despair in her voice, Senator Carstairs says she is giving up. This fall, she will retire. "The passion is still with me, but I'm tired," says the former leader of the Manitoba Liberal Party. "You can only do this so long. I give speeches, speeches, speeches ... and we continue to do badly." http://www.theglobeandmail.com/life/health/n ew-health/health-policy/are-we-in-denialabout-the-growing-issue-of-eldercare/article1955902/

Extract from Globe & Mail

Palliative-care facilities also fall far short. Although the situation has improved in recent years, only about 30% of those who would like the option get it. And the number of annual deaths is projected to increase from about 250,000 to 430,000 by 2031. "If we can't care for our dying," Senator Carstairs asks, "what kind of a society are we?"

Senator Carstairs authored, or chaired a senate committee that published:

Raising the Bar: A Roadmap for the Future of Palliative Care in Canada, 2010.

http://sen.parl.gc.ca/scarstairs/PalliativeCare/PalliativeCare_e.asp

Still Not There: Quality End of Life Care, 2005. http://sen.parl.gc.ca/scarstairs/PalliativeCare/Still%20Not%20There%20June%202005.pdf

Quality End-of-Life Care: The Right of Every Canadian, Report of the Senate Subcommittee to Update Of Life & Death, 2000.

http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/uoda-e/reo-e/reofiniun00-e.htm

Ontario hospices looking for end-of-life financial relief

ONTARIO | Stoney Creek News - 22 March 2011 – Ontario's hospice officials are warning the provincial government if the Liberals don't increase their funding in this year's budget, beds will start closing. "If we don't get an increase, some hospices will have to close beds," said Rick Firth, executive director of the Hospice Association of Ontario. "A lot of facilities have exhausted their reserves. They are very lean, with very efficient budgets now." Beth Ellis, executive director of the Dr. Bob Kemp Hospice echoed those comments, saying hospices in Ontario are in a funding "crisis" and if they don't receive a boost in government funding, some will close. The [Dr. Bob Kemp] hospice, like the other 23 facilities across Ontario, receives about 40% of provincial funding to cover its \$1.9 million operating budget. The provincial money to hospices, said Firth, was initially intended to cover 100% the cost of personal support services that involves nurses. But, said Firth, the cost of nursing has increased since the initial funding began, taking larger chunks out of the hospices' operating budget. Hospices have provided a vital service to the Ontario health care program, say Firth and Ellis, relieving significant care and cost to Ontario's hospitals. "We have done everything the health ministry has asked of us," said Ellis. Hospice provides a bed at a cost of about \$439 per day, compared to a hospital's cost of \$850 per day for an acute bed. A Health Ministry spokesperson said he couldn't say if there will be any funding increase to hospices in this year's budget. http://www.stonevcreeknews.com/news/articl e/231775

Funding issues in the provision and delivery of end of life care

AUSTRALIA (NEW SOUTH WALES) | Advocate – 23 March 2011 – 'Families 'crying out for palliative care funding.' Dr. Yvonne McMaster is protesting against "a rationing of services" for the terminally ill after palliative care community funding was cut by \$1.2 million. http://hornsby-advocate.whereilive.com.au/news/story/families-crying-out-for-palliative-care-funding-wahroonga-doctor/

IRELAND | *Irish Times* (Dublin) – 22 March 2011 – 'Hospice has big interest bill but no inpatients.' The €22 million St Francis Hospice was built mainly with private money, though €10 million was borrowed from a bank and it now has to be paid back. Father Eugene Kennedy said the hospice cannot accept residential patients until the Government approves funding to pay the staff.http://www.irishtimes.com/newspaper/health/2011/0322/1224292769916.html

U.K. | BBC News (Humberside) – 21 March 2011 – 'Council funding cuts hit Hull's Dove House hospice.' Hull City Council announced that it would start charging the hospice for removing and recycling unwanted items donated by the public [at a cost to the hospice of £50,000 to £70,000 a year]. http://www.bbc.co.uk/news/ukengland-humber-12805030

U.K. | The Chester Standard – 21 March 2011 – 'Hospice of Good Shepherd desperate for funds.' If ... [£250,000] ... is not raised it is feared the Hospice of the Good Shepherd, which has suffered a steep drop in donations caused by the recession, will be faced with "extreme" hardship. http://www.chesterfirst.co.uk/news/100310/hospic e-of-good-sheperd-desperate-for-funds.aspx

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.

U.S.A.

Program at Vacaville's California Medical Facility gives special care to terminally ill inmates

CALIFORNIA | *The Reporter* (Vacaville) – 27 March 2011 – [Alfredo] Garcia's second conviction makes him ineligible for parole until 2015. But his nine-year prison sentence will likely be cut short as a result of a much weightier sentence – one not imposed by the courts. Garcia has stage four cancer... Doctors have given him six months to live. "As the time keeps going down, I keep getting weaker and the cancer keeps on getting stronger," he said, his voice breaking with emotion. "And I don't want to die here." Located just off the prison's main thoroughfare, "here" for Garcia and other terminal inmates is Corridor-X, also known as the hospice unit. California Medical Facility's hospice has the distinction of being the first such program in the country to serve inmates within a correctional facility and is the only licensed hospice facility in the state. http://www.thereporter.com/ci 17712023

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of (p.13).

Home funerals a spiritually fulfilling option for families

TENNESSEE | *The Commercial Appeal* (Memphis) – 26 March 2011 – When a loved one dies, most of us assume that the body must be embalmed and set in a metal casket inside a concrete vault for burial. Not true. Those are options, not legal requirements. Embalming is not required in any state (there are a few exceptions). Neither a casket nor a vault is a legal requirement. Licensed morticians are not required to transport a body. And home funerals are legal in Tennessee, Arkansas, Mississippi and more than 40 other states. Home funerals aren't new, though they have become rare in recent decades. For thousands of years, bodies were prepared at home for burial, and then buried without embalming in shrouds or wooden caskets without vaults. http://www.commercialappeal.com/news/2011/mar/26/guest-commentary-home-funerals-a-spiritually-for/

What to expect when a loved one receives a terminal diagnosis

HUFFINGTON POST | Online article – 23 March 2011 – A terminal diagnosis throws not only the person who gets the diagnosis (the patient) into a crisis, but his or her family and other loved ones as well. We all know someone (probably many people) who received a diagnosis that could have proved quickly fatal a generation or two ago. Not so, today. Although people do die suddenly and unexpectedly, today this is more the exception than the rule. Sometimes the diagnosis itself may come quickly and unexpectedly, as was true for one man who saw his doctor for persistent sores on his tongue, only to be diagnosed with cancer within two days. For others, the diagnosis is finally rendered only after a series of tests that can take weeks. In either case, this is where the crisis begins, for the patient and the family alike. And this is key: Unlike

sudden death, which was once the norm and which led to what we could call "traditional grief," the process that begins with a terminal diagnosis marks the start of a lengthy process that we've called "the new grief." http://www.huffingtonpost.com/josephnowinski-phd/grieving-process b 838702.html

Specialist Publications

Of particular interest:

'Courageous conversations: Exploring matters of life and death in geriatric rehabilitation' (p.8), published in *Topics in Geriatric Rehabilitation*.

Massachusetts Expert Panel on End of Life Care

At end of life - more planning, more counseling, more dignity

MASSACHUSETTS | Boston Globe – 23 March 2011 – Most people can't control how or when death comes, but can prepare for certain scenarios – hospital, nursing home, or hospice – and pass their wishes along to doctors and loved ones. But most people don't want to think about end-of-life care. Bay State health officials hope to change that with a common-sense series of recommendations that all sides of the end-of-life debate can support. Massachusetts led the nation by embracing the principle that every citizen deserves full access to affordable health care. Now, public health officials hope to lead the way on a related principle: that when it comes to end-of-life medical decisions, every citizen has the right to understand all available options, and the right to a health care system that respects the balance they choose to strike between prolonging life and maintaining its quality. That principle ... [is] ... presented in a report by a Massachusetts panel of end-of-life experts, and embraced ... by the administration of Governor Deval Patrick. http://www.boston.com/bostonglobe/editorial opinion/editorials/articles/2011/03/23/at end of life more planning more counseling more dignity/

 Patient Centered Care & Human Mortality: The Urgency of Health System Reforms to Ensure Respect for Patients' Wishes and Accountability for Excellence in Care, Report & Recommendations of the Massachusetts Expert Panel on End of Life Care, October 2010. http://www.mass.gov/lhqcc/docs/expert_panel/final_expert_panel_report.pdf

From Media Watch dated 21 March 2011:

MASSACHUSETTS | Patriot Ledger (Quincy) – 16 March 2011 – 'End-of-life care in Massachusetts needs improvement, panel says.' State officials and health care experts want people talking about an issue that affects everyone: If you fall ill, how do you want to spend the last days of your life? http://www.patriotledger.com/lifestyle/50 plus/x32326773/End-of-life-care-in-Massachusetts-needs-improvement-panel-says

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

Ontario | Mississauga Halton Palliative Care Network: http://www.mhpcn.ca/Physicians/resources.htm (Scroll down to 'Newsletters/Media Updates')

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/news.htm

Assisted (or facilitated) death

Representative sample of recent news media coverage:

IDAHO | Associated Press (Boise) – 22 March 2011 – **'Lawmakers advance bill to outlaw assisted suicide.'** Legislation to make assisted suicide a felony is headed to the Idaho House [of Representatives] – its final hurdle in the 2011 session. The measure cleared the House State Affairs Committee on Tuesday [15 March 2011]. If it becomes law, those found guilty face five years in prison. http://www.necn.com/03/22/11/Lawmakers-advance-bill-to-outlaw-assiste/landing politics.html?&blockID=3&apID=c0add996878d4a91a7b07adbafc8603e

International

Alzheimer's Disease International: Conference

Effective elder care starts at home, experts say

INDIA | Globe & Mail (Canada) - 27 March 2011 – Waves of elderly patients set to hit hospitals worldwide have prompted two novel solutions from doctors in Toronto [Canada] and India who have found that the way forward often comes by looking back. Mount Sinai Hospital in Toronto will open an Acute Care for Elders unit next month. And as part of its new geriatric program, it has specialists and family physicians doing house calls to keep seniors home longer, thus avoiding unnecessary hospitalizations. And at the annual conference ... a physician from Goa in India said ... that an experiment to train lay people as home-care advisers meant they could intervene in troubling situations with the elderly - such as wandering – that helped struggling families. The ... low-cost, low-tech approaches from

geriatricians Samir Sinha of Mount Sinai and University Health Network and Dr. Dias take place continents apart. But they reveal how solutions come in simpler forms: workers trained to prevent problems and to red flag others.http://www.theglobeandmail.com/life/health/dementia/effective-elder-care-starts-at-home-experts-say/article1958956/

Extract from Globe & Mail

The ... two low-cost, low-tech approaches from geriatricians Samir Sinha of Mount Sinai and University Health Network and Dr. Dias take place continents apart. But they reveal how solutions come in simpler forms: workers trained to prevent problems and to red flag others.

Europe-wide poll

Quality of life more important than length of time left

U.K. | Daily Telegraph – 24 March 2011 – The majority surveyed in a Europe-wide poll said being in pain would be their biggest concern if they knew they were going to die, ahead of becoming a burden on others. The majority of people surveyed in England also said that having physical suffering relieved would be more important to them than remaining positive or ensuring loved ones were not distressed. Professor Irene Higginson, Professor of Palliative Care & Policy at King's College, London, said: "There needs to be a fundamental shift in the approach to delivering end-of-life care across Europe. Although individuals' priorities and needs will differ, it is absolutely clear that people value highly the quality of the time they have left. What we need to see is a step-change in the way policy-makers and clinicians across Europe look at end-of-life care, and ensure that people's priorities and needs inform planning and delivery of these services." http://www.telegraph.co.uk/health/healthnews/8401422/Quality-of-life-more-important-than-length-of-time-left.html

Cont.

From Media Watch dated 14 March 2011:

■ U.S. | National Journal & The Regence Foundation press release – 8 March 2011 – 'Americans choose quality over quantity at the end of life, crave deeper public discussion of care options.' A national poll ... finds that more than 70% of Americans believe enhancing the quality of life – not just extending the length of it – should be a priority at the end of life. The poll ... shows over-whelming majorities also want a more open public dialogue about the issues and options surrounding end-of-life care ... http://www.sys-con.com/node/1744606

Deathbed experiences

Going into the light

IRELAND | *Irish Times* (Dublin) – 22 March 2011 – Given that many of us shy away from talking about death and dying, it is not surprising that we know so little about what happens in the last hours of a person's life. But an unusual new study, funded by the Irish Hospice Foundation, aims to break through the taboo of the deathbed. 'Capturing the invisible: exploring Deathbed Experiences in Irish Palliative Care' ... examines the strange visions that often accompany the dying process, asking members of the Irish Association of Palliative Care to report their experiences. The results are startling. In one frequently reported scenario, the dying person spoke of seeing deceased relatives or religious figures, or of experiencing a radiant white light in the room. Perhaps because they defy explanation, these deathbed phenomena are rarely discussed by healthcare professionals, despite being a familiar occurrence. MacConville says education about such experiences could raise awareness of the phenomena and help palliative care professionals to normalise them for patients and families as a common and even comforting part of dying. http://www.irishtimes.com/newspaper/health/2011/0322/1224292769193.html

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

Call for better end-of-life care training

U.K. (SCOTLAND) | The Herald (Glasgow) 22 March 2011 – The Care Commission [i.e., the Scottish Commission for the Regulation of Care] said that care homes for older people were increasingly involved in looking after people in their final days and should take advantage of the latest training and best practice. The [Commission's recent] report¹ ... recommends that care services should seek support through working with staff in other agencies such as the National Health Service, local authorities, and the third sector. While care homes in Scotland are making progress in how they deliver good palliative and end-oflife care, they can do much more to ensure

people receive the standard of care that meets their needs, expectations and wishes. http://www.heraldscotland.com/life-style/reallives/call-for-better-end-of-life-care-training-1.1091715

Specialist Publications

Of particular interest:

'Educational needs assessment, development of learning objectives, and choosing a teaching approach' (p.11), published in the *Journal of Palliative Medicine*.

1. Improving the Quality of Care in Scotland: An overview of Care Commission findings 2002 to 2010 http://www.carecommission.com/images/stories/documents/publications/reviewsofqualitycare/carecommission_quality_of_care_review_2002-10_final.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

THE AUSTRALIAN | Online report – 25 March 2011 – "Unproductive burdens' still have a right to live.' There was a moment during the last national debate on euthanasia that deserves to be revisited by a new generation of legislators, a moment that crystallised fears that the so-called right to die would come to be felt by the frailest among us more as a "duty to die." http://www.theaustralian.com.au/national-affairs/commentary/unproductive-burdens-still-have-a-right-to-live/story-e6frgd0x-1226027674393

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

Geriatricians' views of advance decisions and their use in clinical care in England: Qualitative study

AGE & AGEING | Online article – 23 March 2011 – An anticipatory decision document records a person's wishes regarding medical treatment at a time when they have capacity to make choices, to be enacted when this capacity is lost. In England & Wales an advance decision to refuse treatment (ADRT), a legally binding document, is currently rarely used. Geriatricians held positive views on anticipatory decisions in principle. In practice, they reported being highly likely to follow a decision which was in line with their clinical view. However. geriatricians expressed concerns in relation to patient understanding of the role and limits of these documents. Participants [in this study expressed discomfort in following

an ADRT which, in their professional opinion, did not represent the patient's best interests, despite it being a legally binding document. http://ageing.oxfordjournals.org/content/early/2011/03/22/ageing.afr025.abstract

Extract from Age & Ageing

A conflict between doctors' beneficence and patients' autonomy was apparent, with geriatricians differing in their views on how ADRTs should fit into medical decision-making; particularly how far anticipatory decisions can represent ongoing patient autonomy.

Of related interest:

TOPICS IN GERIATRIC REHABILITATION, 2011;27(1):81-86. 'Courageous conversations: Exploring matters of life and death in geriatric rehabilitation.' Death, dying, loss, and grief are aspects of the human condition, constituting important topics not routinely discussed within personal and professional relationships. This article focuses on the importance of awareness and preparation for these often challenging conversations. An overview of the knowledge, values, and skills needed to effectively discuss topics of dying, grief, and loss with clients and families is provided. http://journals.lww.com/topicsingeriatricrehabilitation/Abstract/2011/01000/Courageous Conversations Exploring Matters of 10.aspx

N.B. This issue of *Topics in Geriatric Rehabilitation* includes several articles on palliative care. Contents page: http://journals.lww.com/topicsingeriatricrehabilitation/pages/currenttoc.aspx

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/

Hope in action facing cardiac death: A qualitative study of patients with life-threatening disease

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH & WELL-BEING | Online article – 18 March 2011 – The findings showed that hope could enhance coping and diminish existential distress when patients were confronted with mortality and other existential challenges. Hope was observed as three types of dynamic work: to shift perception of mortality from overwhelming horror toward suppression or peaceful acceptance, to foster reconciliation instead of uncertainty when adapting to the new phase of life, and to establish go-ahead spirit instead of resignation as their identity. Meaning of life could, hence, be sustained in spite of serious threats to the persons' future, everyday life, and self-conception. The work of hoping could be supported or disturbed by relationships with family, friends, and health care professionals. Hope can be regarded as an active, dynamic state of existential coping among patients with life-threatening disease. Physicians may support this coping and thereby provide personal growth and alleviation of existential distress by skilfully identifying, acknowledging, and participating in the work of hoping performed by the patient. https://www.ijghw.net/index.php/qhw/article/viewFile/5917/7969

Of related interest:

- JOURNAL OF LANGUAGE & SOCIAL PSYCHOLOGY | Online article 14 March 2011 'Hope and the act of informed dialogue: A delicate balance at end of life.' The author focuses on an examination of the research on hope at end of life and tries to reconcile it with the concomitant need for acknowledgment of impending terminality and the communication that should accompany this. http://jls.sagepub.com/content/early/2011/03/01/0261927X10397150.abstract
- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article 14 March 2011 –

 'Perspectives on death and an afterlife in relation to quality of life, depression, and hopelessness in cancer patients without evidence of disease and advanced cancer patients.' [In this study] patients without evidence of disease and advanced cancer patients did not differ in attitudes or emotions toward death, but the relationship between these attitudes and emotions and aspects of quality of life varied. When there is no evidence of disease, negative emotions play the most important role, whereas in the advanced cancer situation, attitudes toward death and an afterlife ... become more prominent. http://www.jpsmjournal.com/article/S0885-3924(11)00013-3/abstract

Barriers to optimal palliative care of lung transplant candidates

JOURNAL OF HEART & LUNG TRANSPLANTATION, 2011;30(4):S28. Provision of palliative and end-of-life care is of special importance for patients awaiting lung transplantation. However, lung transplant program practices may be at odds with palliative care principles. The authors examined perceived barriers to delivery of palliative care to lung transplant candidates and sought strategies to improve such care. Barriers that were considered at least moderate by 50% of respondents were classified as significant: unrealistic patient/family expectations about survival until and after transplant; patient/family unwillingness to plan end-of-life care; patient concerns about inappropriate care or abandonment after enrollment in a palliative care program; and, family disagreements about care goals. Among program policy

barriers the requirement for weight loss or gain was identified. Clinician barriers included competing time demands and seemingly contradictory goals of transplantation and palliative care. Helpful strategies included routine advanced care planning assistance for listed patients, access to palliative care consultants, training of transplant physicians in symptom management and regular meetings between transplant physicians, nurses, patients and families. http://www.jhltonline.org/article/S1053-2498(11)00071-4/abstract

Worth Repeating

Of particular interest:

'Jewish tradition provides pathway out of grief' (p.13), published in the *Guelph Mercury* (Ontario, Canada).

Disclosure of terminal illness to patients and families: Diversity of governing codes in 14 Islamic countries

JOURNAL OF MEDICAL ETHICS | Online article – 23 March 2011 – The consistency of codes governing disclosure of terminal illness to patients and families in Islamic countries has not been studied. Codes for 14 Islamic countries were located. Five codes were silent regarding informing the patient, seven allowed concealment, one mandated disclosure and one prohibited disclosure. Five codes were silent regarding informing the family, four allowed disclosure and five mandated/recommended disclosure. The Islamic Organization for Medical Sciences code was silent on both issues. http://jme.bmj.com/content/early/2011/03/22/jme.2010.038497.abstract

From Media Watch dated 17 May 2010

■ JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2010;12(3):156-163. 'Considering faith within culture when caring for the terminally ill Muslim patient and family.' This article presents an overview of the Islamic faith within the cultural context and highlights considerations that may empower nurses to deal with challenges of caring for the dying Muslim patients and their families.http://journals.lww.com/jhpn/Abstract/2010/05000/Considering Faith Within Culture When Caring for.5.aspx

From Media Watch dated 4 January 2010:

JOURNAL OF THE ISLAMIC MEDICAL ASSOCIATION OF NORTH AMERICA, 2009;41(3):109-113. 'Do not resuscitate: A case study from the Islamic viewpoint.' It is encouraged for Muslim patients to have a living will, but they are discouraged from putting in a DNR order that covers all situations. In other words, they should be full code if there is a reasonable chance of recovery. http://jima.imana.org/article/view/4477/41 3-109

From Media Watch dated 6 April 2009:

- U.K. | New Statesman 3 April 2009 'Death and Islam.' [In the Islamic faith] death is divinely willed and when it arrives it should be readily accepted. There should, therefore, be no reasoning by the bereaved as to why they have lost their loved one. http://www.newstatesman.com/blogs/the-faith-column/0000/00/holy-qur-muslims-life-death
- THE NETHERLANDS | Islam in Europe 31 March 2009 'Muslims refusing pain management treatment.' Palliative care for Muslims is often hindered by cultural barriers and prejudices. Muslims are often afraid of pain management since it makes one drowsy, and in the Koran it says one must be alert before Allah. http://islamineurope.blogspot.com/2009/03/netherlands-muslims-refusing-pain.html

A new set of quality indicators for palliative care: Process and results of the development trajectory

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 24 March 2011 – In some countries (the U.S. in particular), quality indicators for palliative care have already been developed. However, these quality indicators often cover one specific setting or target group, for example, palliative cancer care or palliative home care. This article describes the development and initial testing of a set of quality indicators for palliative care, applicable for all settings in which palliative care is being provided for adult patients in The Netherlands. As a result of ... [this three-phase project] ... a set of quality indicators for palliative care has been developed, consisting of 33 indicators for palliative patient care and 10 indicators for support for relatives before and/or after the patient's death. http://www.ipsmjournal.com/article/S0885-3924(11)00051-0/abstract

Educational needs assessment, development of learning objectives, and choosing a teaching approach

JOURNAL OF PALLIATIVE MEDICINE | Online article – 25 March 2011 – This article discusses some of the components involved with determining and providing necessary educational experiences. These steps apply to various educational needs and settings such as development of curriculum for training programs, clinical staff development, courses in continuing medical education, and identifying learning needs throughout practice. A needs assessment is a first step in this process and can be applied to determining revisions in curriculum, identifying needs in clinical staff development, and to self-identifying individual learner status. The identified curriculum needs are linked to the development of learning objectives and outcome statements that identify the knowledge, skills, and attitudes that learners are expected to demonstrate. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0232

Advance directives in an oncologic intensive care unit: A contemporary analysis of their frequency, type and impact

JOURNAL OF PALLIATIVE MEDICINE | Online article – 18 March 2011 – The authors' objective was to provide a contemporary analysis of the prevalence, types, and impact of advance health care directives in critically ill cancer patients. The prevalence of living wills (LW) in patients admitted to the authors' oncologic intensive care unit (ICU) is low. More than half of the remaining patients had a designated health care proxy (HCP). Older age and white race were associated with the presence of LWs. The presence of LWs or HCPs did not influence ICU care, end of life (EOL) management or outcomes. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0397

From Media Watch dated 15 November 2010:

U.S.A. | PBS TV (FRONTLINE) – 10 November 2010 – 'Facing death: How far would you go to sustain the life of someone you love, or your own?' In 'Facing death,' FRONTLINE ... takes a measure of today's complicated end-of-life decisions. In this ... ground-breaking film, doctors, patients and families speak with remarkable candor about the increasingly difficult choices people are making at the end of life. http://www.pbs.org/wgbh/pages/frontline/facing-death/

From Media Watch dated 23 November 2009:

■ U.S.A. | CBS TV (60 Minutes) – 22 November 2009 – 'The cost of dying.' Last year, Medicare paid \$50 billion just for doctor and hospital bills during the last two months of patients' lives – that's more than the budget of the Department of Homeland Security or the Department of Education. It has been estimated that 20-30% of these medical expenditures may have had no meaningful impact. http://www.cbsnews.com/video/watch/?id=5737138n

A novel approach to hospital palliative care: An expanded role for counselors

JOURNAL OF PALLIATIVE MEDICINE | Online article – 16 March 2011 – A large tertiary hospital in central Georgia has found a novel approach to hospital palliative care. It is unique in that the approach has a strong counseling base in providing the palliative service, rather than major reliance on advance practice nurses or palliative physicians. The Medical Center of Central Georgia employs master's prepared counselors who spend the hours needed to assist families in making difficult end-of-life decisions. The growth of the program over seven years is staggering with the outcomes far exceeding even the predicted volume from the Center to Advance Palliative Care. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0432

Spiritual dimensions of surgical palliative care

SURGICAL CLINICS OF NORTH AMERICA, 2011;91(2):305-315. The spiritual dimensions of surgical palliative care encompass recognition of mortality (physician and patient); knowledge of moral and ethical dilemmas of medical decision making; respect for each individual and for all belief systems; responsibility to remain physically and psychologically present for the patient and family; and knowledge of when chaplains, palliative care professionals, or social workers should be consulted. Certain aspects of surgical palliative care distinguish it from palliative care in other medical disciplines such as the two definitions (palliative procedure and palliative care), treating a disproportionate share of patients who suffer unforeseen tragic events, and the surgical system. http://www.surgical.theclinics.com/article/S0039-6109(10)00193-3/abstract#article-footnote-1

Of related interest:

SURGICAL CLINICS OF NORTH AMERICA, 2011;91(2):277-292. 'Surgical palliative care: Recent trends and developments.' Palliation has been an essential, if not the primary, activity of surgery during much of its history. However, it has been only during the past decade that the modern principles and practices of palliative care developed in the nonsurgical specialties in the United States and abroad have been introduced to surgical institutions, widely varied practice settings, education, and research. http://www.surgical.theclinics.com/article/S0039-6109(11)00003-X/abstract

N.B. This issue of *Surgical Clinics of North America* includes several articles on palliative care. Contents page: http://www.surgical.theclinics.com/issues?issue-key=S0039-6109(11)X0002-6

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.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

MENTAL HEALTH PRACTICES, 2011;14(6):32-34. 'The right to die: A discussion of 'rational suicide' Media debate about cases of 'rational suicide' has failed to reach a conclusion for or against the practice. Most of the cases in the public eye have concerned people with terminal illnesses, but it is apparent that some physically well people consider their lives to be unbearable and decide to end them. This article discusses the complexity of interactions and interventions with clients, and the myriad ethical and legal issues that must be considered by mental health professionals in deciding whether rational suicide can be morally acceptable.
http://mentalhealthpractice.rcnpublishing.co.uk/resources/archive/GetArticleByld.asp?ArticleId=836

Worth Repeating

Jewish tradition provides pathway out of grief

CANADA | Guelph Mercury (Guelph, Ontario) - 11 March 2011 - Jewish tradition provides for a gradual release from grief, with four periods of mourning. It fits the normal cycle of bereavement so closely that some maintain that the laws of mourning are descriptive rather than prescriptive. According to Jewish ways, seven close relatives are considered mourners and follow the rules for the bereaved. These are the father, mother, spouse, son, daughter, brother and sister. Grief is most intense between death and burial of the beloved, with burial usually within a day, or two in special circumstances. With this in mind major religious requirements are cancelled. The second stage of mourning is the "Shiva" - seven days of mourning following interment. Mourners stay home. They express grief by not shaving or grooming and saying the Kadish, the consoling prayer recited throughout the year of mourning. Isolated from the outside world, this inward retreat relaxes them. During this week the mourner sits at home and doesn't conduct business. do house chores or other activities. Family and the community see to meals and other needs. People come to offer comfort and express sympathy. The visitor speaks about the lost loved one and their good qualities. This caring environment allows grief to be expressed. While visitors may drop by throughout the day, prayer services are held in the home in the morning and at sunset. Being together sharing a common bond through prayer and talking about the person who passed away, the visitor also has the opportunity to respond to the loss. Next is the "Shloshim," the 30 days, including shiva, following burial. The bereaved is encouraged to leave the house and return to work. Still, it's recognized that more time must pass to assume full normal social relations. The mourner continues to recite the Kadish and doesn't attend social events. The fourth period is the next 11 months. The inner hurt remains, but everyday life resumes. This is not the time for entertainment such as parties. In Jewish tradition after a year mourners are expected to resume their life and to mourn annually on the date of the death. While the loss remains in their heart, graduated mourning raises mourners from the abyss of despair to the ups and downs of normal daily life. http://www.guelphmercury.com/living/article/500474--jewish-tradition-provides-pathwayout-of-grief

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