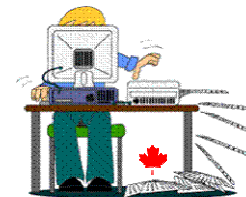


Media Watch...

is intended as an advocacy tool and change document. The weekly report is international in scope and distribution – to 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 inform discussion and encourage further inquiry.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012 ©

Compiled & Annotated by Barry R. Ashpole

'The single biggest problem in communication is the illusion that it has taken place.'¹

Scroll down to **Specialist Publications** and 'Misunderstandings about prognosis: An approach for palliative care consultants when the patient does not seem to understand what was said' (p.8), in *Journal of Palliative Medicine*.

1. George Bernard Shaw (1856-1950).

Canada

Family-friendly firms top up compassionate care leave

GLOBE & MAIL | Online report – 10 December 2012 – Compassionate care benefits work much the same way as EI [Employment Insurance] maternity or parental leave. It was enacted by the Government of Canada in 2004 so employees would not have to quit or lose their jobs when called on to temporarily care for or support a gravely ill or dying family member. Employees apply for approval while employers grant a leave of absence without pay for up to eight weeks. After a two-week waiting period, a maximum of six weeks of EI benefits are paid to employees who meet the eligibility criteria, which includes a letter from the attending physician saying that the individual concerned has a serious medical condition with significant risk of death occurring within 26 weeks. Compassionate care top-up payments are an option that many Family-Friendly Top Employers are choosing to make to cover some or all of the difference between the payment received from EI and the employee's normal base salary. <http://www.theglobeandmail.com/report-on-business/careers/top-employers/family-friendly-firms-top-up-compassionate-care-leave/article6100744/>

N.B. Compassionate Care Benefit website (last updated 19 September 2012):
http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

[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/pg/file/owner/MediaWatch>

Supreme Court hears Ontario end-of-life care case

ONTARIO | CBC News (Toronto) – 10 December 2012 – Who gets to decide when medical treatments are no longer worth pursuing and should be ended? The doctors? The patients? In the case of those who can't speak for themselves, their surrogate decision-makers? Is discontinuing care when doctors deem all hope of recovery is gone the equivalent of allowing a patient to die – or hastening a death? In the coming weeks, the Supreme Court of Canada's justices will be mulling over these questions and what the law says about them as they craft a judgment in ... *Brian Cuthbertson, et al. vs. Hassan Rasouli*... The Ontario case was argued on Monday before the court in a three-hour hearing. Chief Justice Beverley McLachlin closed the proceedings by saying the court was reserving judgment. No hint

was given as to how soon a decision might come. <http://www.cbc.ca/news/canada/story/2012/12/10/can-supreme-court-end-of-life-case.html>

Specialist Publications

Of related interest:

'Best interests at end of life: An updated review of decisions made by the Consent & Capacity Board of Ontario' (p.10), in *Journal of Critical Care*.

'Hospital is refused permission to withhold "futile" treatment if patient's condition deteriorates' (p.9), in *British Medical Journal*.

- *GLOBE & MAIL* | Online OpEd – 10 December 2012 – **'Rasouli case may help reduce misunderstanding about role of palliative care.'** <http://www.theglobeandmail.com/commentary/rasouli-case-may-help-reduce-misunderstanding-about-role-of-palliative-care/article6144053/>

N.B. Scroll down to [U.S.A.](#) and 'Terminal health care measures: Who decides in Canada?'

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *Vancouver Sun* – 10 December 2012 – **'Range of intervener groups granted status at landmark right-to-die case.'** The B.C. Court of Appeal has granted advocacy groups representing both sides of the right-to-die debate intervener status as it examines a ruling that struck down Canada's ban on assisted suicide. The federal government is appealing a ruling from earlier this year that concluded the Criminal Code provisions that prohibit assisted suicide violate the Charter of Rights & Freedoms. The Court of Appeal has scheduled a hearing March 2013. <http://www.vancouversun.com/health/Range+intervener+groups+granted+status+landmark+rightto+die/7677495/story.html>

U.S.A.

Terminal health care measures: Who decides in Canada?

WASHINGTON D.C. | *Washington Times* – 16 December 2012 – Last Monday, the Canadian Supreme Court took up the case of Hassan Rasouli, a 60-year old comatose Toronto man whose family and doctors disagree about whether he should be kept alive on life support. Canada's Health Care Consent Act will be interpreted. The Court will decide the meaning of "treatment" and whether or not it includes the withdrawal of life-sustaining measures. Canadian analysts offer that the Court will have to comment on the policy debate about end-of-life decisions. The court could rule in favor of the doctors and grant them unilateral power to withdraw life support, or it could conclude that the family must give their consent before doctors can allow the withdrawal of life support. <http://communities.washingtontimes.com/neighborhood/leading-edge-legal-advice-everyday-matters/2012/dec/15/terminal-health-care-measures-who-decides-canada/>

Cutting the high cost of end-of-life care

CNN MONEY MAGAZINE | Online article – 12 December 2012 – You've gotten the phone call no one wants to receive: A close family member has been diagnosed with a life-threatening illness, or one battling a terminal condition has begun to fail. And so begins a medical saga that could last weeks, months, or years, during which you will face some of the most difficult choices you'll ever make. And while no one wants to think about money at such times, they are also expensive ones – for families and for the country. One out of every four Medicare dollars, more than \$125 billion, is spent on services for the 5% of beneficiaries in their last year of life. Yet even with Medicare or private insurance, you're likely to face a big bill. A recent Mount Sinai School of Medicine study¹ found that out-of-pocket expenses for Medicare recipients during the five years before their death averaged about \$39,000 for individuals, \$51,000 for couples, and up to \$66,000 for people with long-term illnesses like Alzheimer's. For more than 40% of these households, the bills exceeded their financial assets. Says study co-author Amy Kelley, an assistant professor of geriatrics: "Many people are shocked by the high out-of-pocket health care costs near the end of life." <http://money.cnn.com/2012/12/11/pf/end-of-life-care-duplicate-2.moneymag/>

1. 'Out-of-pocket spending in the last five years of life,' *Journal of General Internal Medicine*, published online, 5 September 2012. [Noted in Media Watch, 10 September 2012.] <http://www.springerlink.com/content/427m88565153p76k/>

Psychiatrists to take new approach in bereavement

NATIONAL PUBLIC RADIO | Online report – 6 December 2012 – A panel of psychiatrists recently voted on changes for the fifth edition of the Diagnostic & Statistical Manual of Mental Disorders [DSM-5]. DSM-5 guides diagnoses and treatments for millions of people. Among the changes is removal of the so-called "bereavement exclusion" for depression diagnoses. <http://www.npr.org/2012/12/06/166682774/psychiatrists-to-take-new-approach-in-bereavement#commentBlock>

[Specialist Publications](#)

Of related interest:

'Grief reactions in dementia carers: A systematic review' (p.9), in *International Journal of Geriatric Psychiatry*.

[International](#)

Liverpool Care Pathway: Watchdogs must be informed about 'inappropriate' use

U.K. | *The Daily Telegraph* – 14 December 2012 – Health watchdogs must be informed when doctors or loved-ones think the Liverpool Care Pathway [LCP] has been used "inappropriately," the Care Quality Commission [CQC] has stated. Doctors and nurses must also "work together as a team" with the patient and their loved-ones, to come to a decision about when to use the approach to end-of-life care. The statement, issued by the CQC, is intended to "set out our expectations of the responsibility of clinical and other staff" regarding use of the controversial pathway. Designed to ease the suffering of those close to death, the LCP is now used in most NHS [National Health Service] hospitals. But in recent months many relatives have complained that they were not informed their loved-ones were put on it in the last hours or days. Some doctors have concerns that if used badly it can result in additional suffering, while others are worried it could hasten death and so amounts to a form of euthanasia. Most doctors reject these charges. <http://www.telegraph.co.uk/health/healthnews/9746446/Liverpool-Care-Pathway-watchdogs-must-be-informed-about-inappropriate-use.html>

N.B. See Media Watch of 3 December 2012 (p.6) for representative sample of press coverage of the controversy surrounding the LCP.

National End of Life Care Programme

Transforming end of life care in acute hospitals: Feedback from a focus group of pilot site representatives looking at factors that have influenced progress during the first phase

U.K. (ENGLAND) | National Health Service (NHS) – 13 December 2012 – In 2010 'The route to success in end of life care – achieving quality in acute hospitals' was published. As a result, the Transform Programme was set up by the National End of Life Care Programme (NEoLCP) to provide practical support for managers and clinicians in acute Trusts delivering end of life care. Twenty-five acute trusts (43 hospitals) signed up to take part in the first phase pilots. To support these Trusts NEoLCP and the NHS Institute for Innovation & Improvement developed a 'How to' guide in 2012 using service improvement methodology which included five key enablers and key metrics to implement best practice for end of life care in acute hospitals. Whilst each of the pilot sites provides regular returns on progress against implementation of the five key enablers it was thought timely to bring together a focus group to discuss some of the practical issues that had helped and sometimes hindered progress. This short report reflects the views expressed by those participating in the focus group and should complement the more formal progress reports.

http://www.endoflifecareforadults.nhs.uk/assets/downloads/EoLC_Transform_Report_Final.pdf

We live 'longer but sicker' as chronic diseases rise

U.K. | BBC News – 13 December 2012 – People around the world are living longer but with higher levels of sickness, according to the largest ever study of the global burden of disease.¹ High blood pressure, smoking and drinking alcohol have become the highest risk factors for ill health. They replace child malnourishment, which topped the list in 1990. But some researchers have criticised the way the data was put together, and suggested it is based on poor evidence. The five-year project, involving almost 500 authors, found heart disease and stroke caused around one in four deaths – almost 13 million – worldwide in 2010. The burden of HIV/Aids remains high - accounting for 1.5 million deaths that year. While the age people can expect to live to has increased around the world, the gap in life expectancy between countries with the highest and lowest figures was broadly unchanged since 1970. <http://www.bbc.co.uk/news/health-20715310>

1. 'Global Burden of Disease Study 2010,' *The Lancet*, 13 December 2012. <http://www.thelancet.com/themed/global-burden-of-disease>



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>

A good death: The role of local government at the end of life

U.K. | *The Guardian* – 10 December 2012 – In recent years, social care has undergone an important shift towards personalisation, giving people a say in the care they receive rather than offering a one-size-fits-all service. But despite major strides forward this tailored care does not always extend to the end of life. Research shows that 70% of adults would like to be cared for and die in their own home. But the great majority of us still die in hospital; today, two out of 10 are able to fulfil this final wish. Progress has certainly been made since the Department of Health's publication of an end-of-life care strategy in 2008, but recent reports show that this progress has been patchy across the country. Working with Home Group, the Local Government Information Unit [LGIU] surveyed 91 upper tier councils to ask them about their arrangements for end of life care. Housing is an essential piece of the jigsaw when it comes to helping people die in their own homes. The Good Death project,¹ established by Public Health North East and managed by Home Group, has brought together housing, health and social care ser-

vices to make practical arrangements for residents to enable them to remain in their own homes for as long as possible at the end of life. <http://www.guardian.co.uk/local-government-network/2012/dec/10/good-death-local-government-end-of-life-care>

The LGIU survey found

Six out of 10 councils thought that their existing end-of-life care arrangements would not be sufficient in future.

Four out of 10 thought that health and wellbeing boards should lead on end-of-life care in future.

However, only three out of 10 said that their shadow health and wellbeing boards had identified end-of-life care as a priority.

Only a quarter of respondents said that housing departments were engaged with social care on end-of-life care issues, despite the often crucial role of housing in supporting quality of life outcomes.

1. 'A good death: The role of the local authority in end of life care,' Local Government Information Unit, November 2012. [Noted in Media Watch, 3 December 2012.] <http://www.lgiu.org.uk/wp-content/uploads/2012/11/A-Good-Death-the-role-of-the-local-authority-in-end-of-life-care.pdf>

Of related interest:

- U.K. | *The Daily Telegraph* – 14 December 2012 – '**National Health Service owes families thousands over care home costs.**' Families are losing tens of thousands of pounds because they are unaware that the NHS should have paid the care home costs of loved-ones, lawyers are warning. <http://www.telegraph.co.uk/health/healthnews/9746138/NHS-owes-families-thousands-over-care-home-costs.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | RTÉ News (Dublin) – 13 December 2012 – '**Judgment on right-to-die case due in January.**' The High Court will deliver judgment on 10 January in the case of Wicklow woman who took a landmark case challenging the ban on assisted suicide. After a six-day hearing, High Court President Mr. Justice Nicholas Kearns said there was much to think about and consider. The specially convened three-judge court hopes to deliver judgment next month, he said. <http://www.rte.ie/news/2012/1213/assisted-suicides-palliative-care-marie-fleming.html>

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

Medical specialists' motivations for referral to specialist palliative care: A qualitative study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Published online – 14 December 2014 – The decision to refer a patient to palliative care is complex and often highly variable between medical specialists. The authors examine medical specialists' motivations and triggers underpinning decision-making around referral to palliative care in order to facilitate improvements in referral practices. The major motivations/triggers identified were: a) disease-based (e.g., pain management and symptom control); b) pre-emptive/strategic (e.g., anticipation of need, preparatory objective); c) crisis/parallel (e.g., physical and psychosocial issues); and, d) team-based (e.g., referral as policy/team strategy). In order to improve the care and quality of life of patients and family caregivers, further work is needed to develop streamlined practices that are sensitive to physical and psychosocial considerations, and patient/family caregiver desires.

<http://spcare.bmj.com/content/early/2012/12/14/bmjspcare-2012-000376.abstract>

Of related interest:

- *THE ONCOLOGIST* | Published online – 7 December 2012 – '**Access to palliative care before death among patients treated at a comprehensive cancer center.**' Palliative care (PC) is a critical component of comprehensive cancer care. Previous studies on PC access have mostly examined the timing of PC referral. The proportion of patients who actually receive PC is unclear. The authors determined the proportion of cancer patients who received PC at our comprehensive cancer center and the predictors of PC referral. They found a majority ... did not access PC before they died. PC referral occurs late in the disease process with many missed opportunities for referral. <http://theoncologist.alphamedpress.org/content/early/2012/12/04/theoncologist.2012-0192.abstract>
- *THE GERONTOLOGIST* | Published online – 7 December 2012 – '**Palliative care for long-term care residents: Effect on clinical outcomes.**' A palliative care consult service in a long-term care facility resulted in a more favorable course of treatment and clinical outcomes for participating residents... [and] ... was effective in reducing ER visits and depression, and promoted more appropriate care resulting in more favorable clinical outcomes toward the resident's end of life. <http://gerontologist.oxfordjournals.org/content/early/2012/12/04/geront.gns154.abstract?sid=8780ce31-3bbb-43ea-906a-acb04a7dced1>
- *JOURNAL OF ONCOLOGY PRACTICE* | Published online – 14 December 2012 – '**If palliative care is the answer, what is the question?**' We as oncologists are privileged to be participants in the difficult transition of our patients from actively living to the ritual of dying. "On our watch" we, as a team, can offer realistic expectations, foster hope, identify willing family members, friends, and community resources, acting as a valued guide and no longer as a scientific expert. <http://jop.ascopubs.org/content/early/2012/12/13/JOP.2012.000789.full.pdf+html>
- *JOURNAL OF ONCOLOGY PRACTICE* | Published online – 11 December 2012 – '**Inpatient hospitalization of oncology patients: Are we missing an opportunity for end-of-life care?**' On the basis of our data, an unscheduled hospitalization for a patient with advanced cancer strongly predicts a median survival of fewer than 6 months. The authors believe that hospital admission represents an opportunity to commence and/or consolidate appropriate palliative care services and end-of-life care. <http://jop.ascopubs.org/content/early/2012/12/07/JOP.2012.000698>
- *NATURE REVIEWS CLINICAL ONCOLOGY* | Published online – 11 December 2012 – '**Palliative care: Gaps between ideal and reality.**' It is recognized that palliative care is a crucial part of the treatment trajectory for patients with advanced-stage cancer. The National Consensus Project and National Quality Forum released a set of clinical practice guidelines and preferred practices. <http://www.nature.com/nrclinonc/journal/vaop/ncurrent/full/nrclinonc.2012.224.html>

Interpreting educational evidence for practice: Are autopsies a missed educational opportunity to learn core palliative care principles?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Published online – 14 December 2014 – U.K. policy requires undergraduate medical curricula to equip students to care for dying patients. The educational potential of autopsy attendance during authentic early experience to learn about the social context of death and dying has not been fully explored. In this paper the author: 1) explores how meaning is created from autopsies in authentic early experience; 2) compares views of students, curriculum designers and pathology supervisors; and, 3) identifies actual/potential learning about death and dying. The autopsy enabled students to learn about death and dying in a social context. Variance between groups in perceptions of autopsy experiences may reduce educational value. Autopsies were considered by students to be opportunities for 'meeting' real people, albeit dead ones, and learning from them. Tensions between lay and medical perspectives influenced learning. Increasing communication and collaboration between medical school curriculum designers and disciplines such as Palliative Medicine as well as Pathology could address concerns regarding student/doctor competencies to deal with death and dying. Further research is needed to evaluate changes in curriculum design and to establish if similar concerns are found in other settings. <http://spcare.bmj.com/content/early/2012/12/14/bmjspcare-2012-000330.abstract>

Updated 17 December 2012

Media Watch Online

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Links,' then to 'Media Watch')

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>

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/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

International

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

A systematic review of the prevalence of signs of impending death and symptoms in the last 2 weeks of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Published online – 14 December 2012 – Twelve articles, representing 2416 patients, in multiple settings were analyzed. Of the 43 unique symptoms, those with the highest prevalence were: dyspnea (56.7%), pain (52.4%), respiratory secretions/death rattle (51.4%), and confusion (50.1%). Overall prevalence may be useful in anticipating symptoms in the final days and in preparing families for signs of impending death. <http://ajh.sagepub.com/content/early/2012/12/10/1049909112468222.abstract>

The incidence of deathbed communications and their impact on the dying process

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Published online – 14 December 2012 – The purpose of this study was to determine the incidence of deathbed communications (DBC) during the 30 days before death and their impact on the dying process. In all, 89% of the hospice nurses reported patients who experienced a DBC had a peaceful and calm death, with only 40.5% reporting a peaceful and calm death without the DBC. These DBCs have a positive impact on the dying process but are underreported in patient records and under described in textbooks. <http://ajh.sagepub.com/content/early/2012/12/07/1049909112467529.abstract>

Of related interest:

- *WESTERN JOURNAL OF EMERGENCY MEDICINE* | Published online – Accessed 15 December 2012 – 'Death notification in the Emergency Department: The survivors and the physicians.' <http://escholarship.org/uc/item/0245p245#page-1>

"In the Beginning...": Tools for talking about resuscitation and goals of care early in the admission

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Published online – 12 December 2012 – The authors propose two novel strategies... The first, SPAM (determine Surrogate decision maker, determine resuscitation Preferences, Assume full care, and advise them to expect More discussion especially with clinical changes), helps clinicians discover patient preferences and decision maker during routine admissions. The second, UFO-UFO (Understand what they know, Fill in knowledge gaps, ask about desired Outcomes, Understand their reasoning, discuss the spectrum Feasible Outcomes), helps patients with poor or uncertain prognosis or family–team conflict. <http://ajh.sagepub.com/content/early/2012/12/10/1049909112468609.abstract>

Of related interest:

- *JOURNAL OF CLINICAL ONCOLOGY* | Published online – 10 December 2012 – 'Randomized controlled trial of a video decision support tool for cardiopulmonary resuscitation decision making...' <http://jco.ascopubs.org/content/early/2012/12/04/JCO.2012.43.9570.abstract>

Misunderstandings about prognosis: An approach for palliative care consultants when the patient does not seem to understand what was said

JOURNAL OF PALLIATIVE MEDICINE | Published online – 12 December 2012 – Called in after discussions about prognosis between referring clinicians and patients, palliative care consultants sometimes find that the patient does not seem to understand what the referring clinician believes he or she explained. However, holding a more explicit discussion about prognosis may compromise the palliative care clinician's rapport with both the patient and the referring clinician. The authors therefore propose a two-part approach to explore apparent prognostic misunderstandings: first, generate a differential diagnosis for why the patient and referring clinician have different reports of what was said, and second, cultivate a partnership with the referring clinician to provide a unified patient care plan. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0142>

Hospital is refused permission to withhold "futile" treatment if patient's condition deteriorates

BRITISH MEDICAL JOURNAL | Published online – 10 December 2012 – A High Court judge has refused to give a hospital trust caring for a man deemed minimally conscious by clinicians a declaration that it need not offer him "futile and burdensome" treatment if his condition deteriorated. The unnamed trust wanted a declaration that it need not give David James, a 68 year old former musician, cardiopulmonary resuscitation, renal replacement treatment, or invasive support for chronic low blood pressure in an attempt to keep him alive. But at the Court of Protection Mr. Justice Peter Jackson refused the declaration, which was strongly opposed by James's family. <http://www.bmj.com/content/345/bmj.e8404>

Care management role in end-of-life discussions

CARE MANAGEMENT JOURNALS, 2012;13(4):180-183. End-of-life care discussions should occur early on in the patient's disease process and often requires a great deal of coordination between multiple caregivers. There are also ethical, cultural, social, and spiritual considerations during this very important time in the disease process. Research suggests that we are not doing an adequate job of addressing end-of-life care with our patients and that a great deal of money and resources are being spent in the last days of life when there may be no clinical indication to do so. <http://www.ingentaconnect.com/content/springer/cmanj/2012/00000013/00000004/art00001>

The Death of Ivan Ilyich and the concept of 'total pain'

CLINICAL MEDICINE, 2012;12(6):601-602. *The Death of Ivan Ilyich* by Leo Tolstoy [1886] is well known for its remarkable insight into the suffering of a dying man and can be considered a 'medical classic.' But can a reading of this short story over a hundred years later give any insight into contemporary medical practice or is it an historical curiosity? One interpretation is to consider the story a depiction of a man experiencing 'total pain,' a concept central to the practice of modern palliative care in which 'the sense of hopelessness and fear of impending death may add to and exaggerate the pain, which contributes to the overall suffering of the patient.' But is such an interpretation warranted? <http://www.clinmed.rcpjournal.org/content/12/6/601.full>

Of related interest:

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2012;26(4):334-340. "What is killing me most": Chronic pain and the need for palliative care in the Eastern Cape, South Africa.' <http://informahealthcare.com/doi/abs/10.3109/15360288.2012.734897>

Grief reactions in dementia carers: A systematic review

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY, 2013;28(1):1-17. Supporting dementia carers is an identified target of the U.K. government, yet we know little about such family carers' grief before and after the death of the person with dementia for whom they care. The authors systematically review the existing literature on characteristics, prevalence, predictors and associations of grief in dementia carers before and after death. Carers experience anticipatory grief as multiple losses for themselves (companionship, personal freedom and control) and the person with dementia. Anticipation and ambiguity about the future, anger, frustration and guilt are core features. Anticipatory grief is greatest in moderate to severe stage dementia and spouse carers, especially when the person with dementia is institutionalised. There was poor quality evidence about the prevalence of grief; studies reported anticipatory grief between 47% and 71%, and complicated grief after death is estimated around 20%. Carer depression increases with anticipatory grief. Being a spouse carer and being depressed are the strongest predictors of complicated and normal grief after death. <http://onlinelibrary.wiley.com/doi/10.1002/gps.3795/abstract>

End of life care in Pakistan: Some ethical issues

JOURNAL OF THE COLLEGE OF PHYSICIANS & SURGEONS PAKISTAN, 2012;22(12):745-746. The interplay between the patients, families, and health care providers at the end of life has changed dramatically over the last century. Medicine, about a century ago, used to be an interaction between a patient and a doctor, dispensed out of a black bag, mostly harmless but at the same time, useless. Over this time span, health care has become highly technical, very effective and complex with interplay of multidisciplinary teams. In Pakistan, where formal ethics education is lacking and a faulty health care system predominantly exists, some of these issues are magnified. <http://www.jcpsp.pk/archive/2012/Dec2012/01.pdf>

Best interests at end of life: An updated review of decisions made by the Consent & Capacity Board of Ontario

JOURNAL OF CRITICAL CARE, 2013;28(1):22-27. To increase understanding of the notion of "best interests" in end of life disagreements through an updated review of decisions made by the Consent & Capacity Board of Ontario. There was a significant increase (235%) in decisions from this tribunal between 2009 and 2011. "Best interests" test is used when no prior expressed wishes are known to the surrogate decision-makers. The authors found substitute decision makers (SDMs) rely on an appeal to their own values or religion in their interpretation of best interests; physicians rely on clinical conditions; board emphasizes alignment with Health Care Consent Act. In the more recent cases, they found that SDMs report patients value suffering; SDMs have unrealistic hope for recovery and can communicate and get direction from the incapable patient; SDMs need education on their role and responsibility as SDM; and, SDMs need time to provide consent, and that most proposed treatment plans that were sources of conflict included "palliative care." <http://www.sciencedirect.com/science/article/pii/S0883944112003152>

Of related interest:

- *IRISH MEDICAL TIMES* | Published online – 13 December 2012 – '**Legal move is pending on advance directives.**' It is the intention of the Department of Health to include legislative provisions for advance healthcare directives in the forthcoming Assisted Decision-Making (Capacity) Bill. <http://www.imt.ie/news/latest-news/2012/12/legal-move-is-pending-on-advance-directives.html>

The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: A validation study

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Published online – 13 December 2012 – Family carers need to be supported in their central role of caring for patients at the end of life, but brief practical tools to assess their support needs have been missing. CSNAT domains comprehensively covered carer support needs ... [and] ... scores showed clear and consistent positive correlations with strain and distress and negative correlations with preparedness for caregiving and global health. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00750-6/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00750-6/abstract)

Intentional sedation to unconsciousness at the end of life: Findings from a national physician survey

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Published online – 10 December 2012 – The terms "palliative sedation" and "terminal sedation" have been used to refer to both proportionate palliative sedation, in which unconsciousness is a foreseen but an unintended side effect, and palliative sedation to unconsciousness, in which physicians aim to make their patients unconscious until death. It has not been clear to what extent palliative sedation to unconsciousness is accepted and practiced by U.S. physicians. Although there is a widespread support among U.S. physicians for proportionate palliative sedation, intentionally sedating dying patients to unconsciousness until death is neither the norm in clinical practice nor broadly supported for the treatment of primarily existential suffering. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00748-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00748-8/abstract)

[From a month or two back](#)

Caring and coping: Depending on the favored child

THE NEW YORK TIMES | Online report – 20 October 2012 – In the decade they've been sorting through the thorny tangle of family relationships and how they influence elder care, the sociologists J. Jill Suitor and Karl Pillemer have learned a lot about the effects of mothers' favoritism. You think mothers don't have favorites? Or at least won't admit that they feel closer to one child than another? That was the prevailing wisdom in 2003 when Dr. Pillemer ... and Dr. Suitor ... began arranging face-to-face interviews with hundreds of older mothers in the Boston area. But the women, who had two or more children and were then 65 to 75, surprised the researchers with their willingness, in the great majority of cases, to acknowledge that, yes, there was one child they felt closest to emotionally. That was the child they wanted to care for them if they grew ill or frail. The latest of the Suitor/Pillemer studies¹ ... shows that favoritism has consequences for elderly mothers' well-being, too. This wave of interviews, seven years after the first, focused on the 234 mothers, now 72 to 82, who had become ill or disabled and required assistance from their children within the past two years. Three-quarters of the time, the child previously named as the preferred caregiver did help. But when another child played that role instead, the mother was more likely to be depressed. For the elderly mothers, "this violates their sense of control," Dr. Pillemer said. "They had a preference, it didn't occur, and they were unhappy about that."

<http://newoldage.blogs.nytimes.com/2012/10/20/depending-on-the-favored-child/>

1. 'The role of violated caregiver preferences in psychological well-being when older mothers need assistance,' *The Gerontologist*, published online 8 August 2012.
<http://gerontologist.oxfordjournals.org/content/early/2012/08/03/geront.gns084.abstract?sid=37aea42d-476a-4822-b835-d1342e8a37e2>

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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.

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