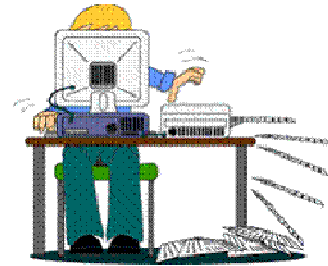


Media Watch

...is distributed weekly to colleagues active or with 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. Following is an annotated listing of recent articles, reports, etc., with links to the original source.

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Compilation of Media Watch 2008, 2009 ©

Compiled & Annotated by Barry R. Ashpole

Rediscovering the human essence of "being with our patients." Scroll down to [Journal Articles](#) and 'Cultural challenges in caring for our patients in advanced stages of cancer.'

Canada: National

Crown to appeal Quebec man's acquittal in assisted suicide case

CANADIAN PRESS | Online newswire report – 29 December 2008 – The Crown is appealing the acquittal of the Quebec man found not guilty of helping his ailing uncle commit suicide. Stephan Dufour was charged with aiding or abetting Chantal Maltais to kill himself in September 2006. <http://www.google.com/hostednews/canadianpress/article/ALeqM5ivllsHXP6oDgpwAnr7USwgKSqfCw>

- QUEBEC | *Montreal Gazette* (Editorial) – 31 December 2008 – '**Assisted suicide acquittal sets dangerous precedent.**' The Crown is right to appeal jury's decision in death of disabled man. <http://www.canada.com/montrealgazette/features/viewpoints/story.html?id=56246481-e492-46c3-b7e0-3fb2fa128b38>

End-of-life decisions: Reprise of the Samuel Golubchuk case

Death was a battle

MANTIOBA | *Winnipeg Free Press* – 28 December 2008 – Samuel Golubchuk died 24 June, just days after his children Miriam Geller and Percy Golubchuk sang to him in the Grace Hospital intensive care unit (ICU) to celebrate his 85th birthday. The court injunction Golubchuk's children sought to keep him alive died with him, and the question of who gets to decide when someone dies hasn't been fully answered. Six months after his death, the medical system is still abuzz – health officials are only halfway through a review of Golubchuk's case that they hope will shed light on how to better handle conflict between patients and physicians. An independent arbitrator is an option they might consider. Miriam and Percy aren't included in that review and said physicians brushed off their concerns the first day their father was admitted in the ICU. They allege the medical system failed, and set a dangerous precedent for patients and families. When doctors and patients clash, Percy said, patients' rights are overruled. "The main issue is human rights and freedom of religion." http://www.winnipegfreepress.com/local/death_was_a_battle.html

Canada: Provinces

Palliative Care Services of Greater Fort Erie closes its doors after 25 years

ONTARIO | *Niagara Falls Review* – 31 December 2008 – Palliative Care Services of Greater Fort Erie has ceased operations. The non-profit agency has closed its doors after 25 years of serving residents of Fort Erie, Ridgeway and Crystal Beach. George Fletcher, president of the board of directors, said the organization was not being utilized to its fullest extent due to depletion of resources and the emergence and growth of groups that offer similar services.

<http://www.niagarafallsreview.ca/ArticleDisplay.aspx?e=1369367>

U.S.A.

Medicaid hospice benefit

Unprecedented budget crises

FLORIDA | *Highlands Today* (Editorial) – 30 December 2008 – The state of Florida is facing an unprecedented budget crisis. Our lawmakers will be meeting in special session in early January, where they will need to make difficult decisions to address the pressing needs of our state. One area of the budget under consideration is the Medicaid hospice benefit. Because of that, I am writing on behalf of some of our most vulnerable citizens, the terminally ill and their families that receive dedicated end of life care from hospice organizations across the state. The demographics of hospice patients might surprise you. Along with our aging population and cancer patients, hospice organizations also care for children, teens, young and middle-aged adults, heart disease patients, Alzheimer's patients and kidney disease patients. Anyone of any age diagnosed with a terminal illness is able to receive hospice care, where healthcare professionals and trained volunteers address all medical, emotional, social and spiritual needs. Hospice care also saves the state money. <http://www2.highlandstoday.com/content/2008/dec/30/good-shepherd-hospice/>

Of related interest:

- CONNECTICUT | Associated Press – 2 January 2009 – **'Hospice coverage among new laws.'** Connecticut loses standing as one of the last states that does not cover hospice services. http://www.boston.com/news/local/connecticut/articles/2009/01/01/clean_contracting_hospice_coverage_among_new_laws/
- MASSACHUSETTS | *Gloucester Daily Times* – 3 January 2009 – **'Encouraging doctors to utilize hospice care.'** Despite a dramatic increase in hospice care, it remains underutilized for patients with life-limiting illnesses. http://www.gloucestertimes.com/puopinion/local_story_002184321.html
- *MCKNIGHT'S LONG TERM CARE NEWS* | Online report – 5 January 2009 – **'Congressional Budget Office analyzes long-term care policies.'** The agency released a report highlighting the projected costs and ramifications of more than 100 healthcare policies, including many proposed for long-term care. <http://www.mcknights.com/Congressional-Budget-Office-analyzes-long-term-care-policies/article/123486/>

Links & Back Issues of Media Watch

Please alert this office if you encounter any difficulty. Every effort will be made to find an alternative means of access. Alternatively, copy/paste the URL into the address bar of your browser. All links are confirmed as being active before Media Watch is distributed; they remain active, however, for only a limited period of time.

Back issues of Media Watch are held on file for a limited time and available on request.

End-of-life care and the prison system

State debates easing medical parole rules

KENTUCKY | *Courier-Journal* – 28 December 2008 – The State Department of Corrections has released 1,851 inmates from prisons since May as part of an effort to save \$30 million over two years. Yet state officials have been reluctant to loosen the rules for releasing on parole or (to) home incarceration dozens of Kentucky State Reformatory inmates diagnosed with such serious illnesses as terminal cancer and organ failure, whose treatment costs taxpayers thousands of dollars a year. State law requires medically paroled inmates be diagnosed as having less than a year to live and that they be completely dependent on others for their care. <http://www.courier-journal.com/article/20081228/NEWS01/812280452/1008/rss01#pluckcomments>

International

Economic impact of caring for patients during their last years of life

U.K. (England) | Rand Organization (Press release) – 3 January 2009 – A new study points to the potential for end of life care services to reduce expenditures associated with hospitalizations, at the same time accommodating the expressed preferences of many patients.¹ The purpose of the study was to provide an estimation of the current economic impact of caring for patients during their last years of life in England ... and, to underscore the potential benefits of an expansion of end of life care services. <http://www.thematuremarket.com/SeniorStrategic/RAND-10455-5.html>

1. ***The potential cost savings of greater use of home- and hospice-based end of life care in England***, National Audit Office. http://www.rand.org/pubs/technical_reports/2008/RAND_TR642.pdf

National Health Service end-of-life drugs rule change

U.K. | BBC News – 2 January 2009 – The National Institute for Health & Clinical Excellence is to extend the threshold at which the drugs are deemed cost-effective. But this will only be in certain circumstances, for instance in people who have less than two years to live. The rules affect decisions for England, Wales and Northern Ireland. It is thought one or two treatments a year will be affected by the change. The charity Macmillan Cancer Support estimated 10,000 cancer patients a year could benefit. <http://news.bbc.co.uk/2/hi/health/7808644.stm>

Quotable Quotes

One lives in the hope of becoming a memory. Antonio Porchia, Italian poet, 1885-1968

Media Watch Posted on Palliative Care Network-e Website

The mission of the Palliative Care Network-e (PCNE-e) is to promote education amongst health care professionals and provide a platform to exchange information and materials.

Links: PCN-e <http://www.pcn-e.com/>; Media Watch <http://www.pcn-e.com/MW.htm>.

Palliative Care Network (PCN) is a volunteer initiated project. Using widely available internet technology, the project provides a platform to teach, interact, and exchange ideas with colleagues in places around the world where the knowledge gap is wider than the technology gap. The PCN directory gives health care professionals worldwide access to colleagues to provide educational support.

PCN link: <http://www.palliativecarenetwork.com/Aboutushtml.html>

Expressions of grief

Shorn of the rituals of old, death maroons us in grief

U.K. | *The Guardian* (Editorial) – 2 January 2009 – The pain of bereavement is worsened by isolation, but few of us now know how to speak about their own – or others' – loss. My father died just before Christmas. He was nearly 80; he had been ill. Intellectually and rationally there should have been nothing startling about his death. It is part of the pattern of things. Yet I have been as stunned by his death, and the utter absence of him, as if I never knew that human beings had a lifespan. I did understand that people die. I didn't understand how the loss would feel. Perhaps it's something one can never grasp until it has happened, because the imagination refuses to go there. But it's also that death has been so removed from our daily experience that it has become almost embarrassingly private. We have gone from the strict and public mourning rituals of the Victorian era, with widows in heavy black clothes for a year and a day, and men wearing black armbands to signify loss, to having no mechanisms to signal our sadness at all.

<http://www.guardian.co.uk/commentisfree/2009/jan/02/death-grief-bereavement>

Of related interest:

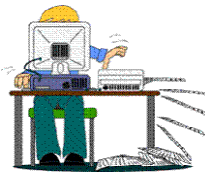
- U.S. | *New York Times* – 2 January 2009 – **'Rough crossing.'** The foundational condition of being human is that we're going to die. Almost as basic a truth is that we seem incapable of believing it. <http://www.nytimes.com/2009/01/04/books/review/Cohen-t.html?ref=books>

National Health Service shows 'deteriorating level of compassion'

U.K. | *Daily Mail* – 30 December 2008 – National Health Service (NHS) hospitals are suffering from a deterioration in the level of compassion shown to patients by clinical staff, the head of a health think tank warns. Niall Dickson, chief executive of the King's Fund, blamed work pressures, shorter stays in hospital and the greater complexity of medical challenges for staff behaving in a less feeling way. He told the BBC that compassion should be a key priority for the boards of every NHS hospital. <http://www.dailymail.co.uk/health/article-1103003/NHS-shows-deteriorating-level-compassion.html>

- U.K. | BBC News – 30 December 2008 – **'Compassion 'key to good health care.'** Amanda Platt still burns with indignation when she recalls her late father-in-law's dying days in the care of the National health Service. <http://news.bbc.co.uk/2/hi/health/7797548.stm>
- U.K. | *Daily Telegraph* – 30 December 2008 – **'Dying World War II hero 'stripped of human dignity' by hospital care, family say.'** A decorated Second World War hero aged 101 was sent home to die by a hospital in a taxi wearing a nappy and a set of ill fitting pyjamas, clutching a bag of soiled clothing. <http://www.telegraph.co.uk/news/4029829/Dying-World-War-Two-hero-stripped-of-human-dignity-by-hospital-care-family-say.html>

Barry R. Ashpole



My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses and facilitating workshops for frontline care providers.

Gordon Brown rules out change in law on assisted dying

U.K. | *The Times* – 30 December 2008 – Gordon Brown made plain that he would block any move to relax the law on assisted suicide, less than a month after he first revealed that he opposed new legislation. In a radio interview, the Prime Minister said that he was not prepared to consider any measures that might put vulnerable people under pressure to agree to end their own lives. The law should make "absolutely clear" that it recognised the value of human life, he said. Asked if he would support laws to permit euthanasia or assisted suicide, Mr Brown responded: "I am totally against laws on that . . . It is not really for us to create any legislation that would put pressure on people to feel they had to offer themselves because they were causing trouble to a relative or anyone else. I think we have got to make it absolutely clear that the importance of human life is recognised." <http://www.timesonline.co.uk/tol/news/politics/article5419080.ece>

- AUSTRALIA | *Advertiser* – 2 January 2009 – '**Adventurer wants right to die.**' Arts entrepreneur Kym Bonython is urging the state's politicians to give him the right to die. <http://www.news.com.au/adelaidenow/story/0,27574,24863965-2682,00.html>
- ITALY | BBC News – 2 January 2009 – '**Vatican divorces from Italian law.**' Vatican legal experts say there are too many laws in Italian civil and criminal codes, and that they frequently conflict with Church principles. http://news.bbc.co.uk/2/hi/middle_east/7807501.stm
- U.K. (Scotland) | *News of the World* – 3 January 2009 – '**Pensioners take euthanasia fight to Scottish Parliament.**' Militant retired have lodged a petition at Holyrood calling for a referendum on assisted death. http://www.newsoftheworld.co.uk/scottish/scottish_news/116451/OAPs-battle-for-right-to-die.html

Journal Articles

Palliative care in Brazil

Conceptions about palliative care: Literature review

ACTA PAULISTA DE ENFERMAGEM, 2008;21(3). This literature review aimed to identify the conceptions of palliative care mentioned in Brazilian journals. In total, 47 articles were selected, published from 2000 to 2006. The conceptions found refer to the concept of palliative care, understood as integral care for individuals in terminal conditions, emphasizing the physical, psychosocial and spiritual aspects of the individual and the family; quality of life; care-based on a humanistic approach and valuation of life; pain and symptom control; ethical issues about life and death; multidisciplinary approach; dying as a natural process; the priority of care over cure; communication, spirituality and mourning support. These conceptions are considered highly important in palliative care; however, there is a lack of services and centers to deliver these types of care. http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002008000300020

Pulmonary and critical care

Meeting physicians' responsibilities in providing end-of-life care

CHEST, 2008;133(3):775-786. Despite many clinical examples of exemplary end-of-life care, a number of studies highlight significant shortcomings in the quality of end-of-life care that the majority of patients receive. In part, this stems from inconsistencies in training and supporting clinicians in delivering end-of-life care. This review describes the responsibilities of pulmonary and critical care physicians in providing end-of-life care to patients and their families. While many responsibilities are common to all physicians who care for patients with life-limiting illness, some issues are particularly relevant to pulmonary and critical care physicians. <http://www.chestjournal.org/cgi/content/abstract/133/3/775>

Does a patient-held quality-of-life diary benefit patients with inoperable lung cancer?

JOURNAL OF CLINICAL ONCOLOGY, 2009;27(1):70-77. The authors examined the effect of weekly completion of a patient-held quality-of-life (QOL) diary in routine oncology practice for palliative care patients. In a pragmatic randomized controlled trial, 115 patients with inoperable lung cancer were randomly assigned to receive either standard care or a structured QOL diary ... that they completed at home each week for 16 weeks. Patients were encouraged to share the QOL information with health professionals involved in their care. The authors conclude that the regular completion of a QOL questionnaire without appropriate feedback to health care professionals and without the provision of appropriate support may have a negative impact on inoperable lung cancer patients. <http://jco.ascopubs.org/cgi/content/short/27/1/70?rss=1>

The process of grief and letting go of life

Between utter despair and essential hope

JOURNAL OF CLINICAL ONCOLOGY, 2009;27(1):146-149. Denial marks the beginning of a longer process of grief and letting go of life. Patients tend to perceive a diagnosis of cancer as if they were in a movie. Professional experience educates: it is most often of no use to try to drag patients, or their family members, out of this movie. Psychologists and doctors conscientiously have to know that, although the diagnosis and facts may be explained more than once, even then patients often do not accept the facts. At some time, the patient will get over this state of shock. The time for a first psychic consolidation of reality awareness will come. Severe and prolonged denial may cause lost chances for the patient to do things that would be important, missed opportunities may occur by not adequately planning, which may hurt the patient and family members. <http://jco.ascopubs.org/cgi/reprint/27/1/146>

Cultural challenges in caring for our patients in advanced stages of cancer

JOURNAL OF CLINICAL ONCOLOGY, 2009;27():157-158 (Letter to the editor). We have greatly advanced in our ability to control symptoms such as pain, fatigue, and malnutrition. Now we need to improve our ability to positively affect other aspects of our cancer patients' suffering during the advanced stages of their illness. This is a difficult task, as there are many barriers to overcome. Yet, if we consider that real progress in today's medicine came about when molecular biologists and clinicians began to speak to and understand each other, we can foresee how progress in palliative medicine will be achieved when technical advances, new skills, adequate financial resources, effective policy changes, and social, emotional, psychological, and spiritual support for patients and their caregivers that support the dignity of both are fully integrated. Achieving this goal requires balancing clinical art with science while paying due attention to cross-cultural differences that influence patients' and physicians' attitudes toward health care matters. After proper cultural assessment of each patient, the team may suggest the most appropriate approach to accompany patients and assist them in their decision-making process. Though the importance of cultural sensitivity for oncologists is now increasingly recognized and teaching and training in cultural competence are mandatory in some countries, we also need to develop culturally competent health care systems to address effectively different social, racial, and cultural realities of the communities for which they provide care. Palliative and end-of-life care for a patient born and living in an Anglo-Saxon country may be different from that of a patient in a Latin or Islamic country, as patients' relationships with individual physicians and with institutions, preferences and practices of truth telling, attitudes toward screening, prevention and clinical trials, decision-making styles, and end-of-life choices are all subject to cultural variability. Additional research on how cultural diversity influences patients' and families' preferences in regard to palliative care in oncology is needed to meet the needs of different communities and individual patients. So-called tailored therapy, a favourite concept in today's medical oncology, can also be applied to our approach to the incurable stages of cancer. In the end, a tailored approach is made possible through rediscovering the human essence of "being with our patients" as they move toward the end of their lives. <http://jco.ascopubs.org/cgi/content/short/27/1/157?rss=1>

Preparing family caregivers for death and bereavement

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2009;37(1):3-12. Many family caregivers are unprepared for the death of their loved one and may suffer from worse mental health as a result. The authors sought to determine the factors that family caregivers believe are important to preparing for death and bereavement. Life experiences such as the duration of caregiving/illness, advance care planning, previous experiences with caregiving or death, and medical sophistication all impacted preparedness, or the degree to which a caregiver is ready for the death and bereavement. Regardless of life experiences, however, all caregivers reported medical, practical, psychosocial, and religious/spiritual uncertainty. Because uncertainty was multidimensional, caregivers often needed more than prognostic information in order to prepare. Communication was the primary mechanism used to manage uncertainty. Good communication included clear, reliable information, combined with relationship-centered care from health care providers. Finally, preparedness had cognitive, affective, and behavioural dimensions. To prepare, some caregivers needed information tailored to their uncertainty (cognitive), others needed to “mentally” or “emotionally” prepare (affective), and still others had important tasks to complete (behavioural). In order to better prepare family caregivers for the death of a loved one, health care providers must develop a trusting relationship with caregivers, provide them with reliable information tailored to their uncertainty, and allow time for caregivers to process the information and complete important tasks. [http://www.jpmsjournal.com/article/S0885-3924\(08\)00223-6/abstract](http://www.jpmsjournal.com/article/S0885-3924(08)00223-6/abstract)

Of related interest:

- *PSYCHOSOMATICS*, 2008;49(November-December):511-519. **'Family caregivers and guilt in the context of cancer care.'** Certain caregiver demographics (i.e., younger age, adult offspring, employed) and care-related stress factors (i.e., greater impact on schedule, less perceived caregiving competence, poorer overall health of the care-recipient) were significantly related to caregiver guilt. <http://psy.psychiatryonline.org/cgi/content/abstract/49/6/511>

Looking beyond where children die

Determinants and effects of planning a child's location of death

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2009;37(1):33-43. While dying at home may be the choice of many, where people die may be less important than argued. The authors examined factors associated with parental planning of a child's location of death (LOD) and its effects on patterns of care and parent's experience. After adjusting for disease and family characteristics, families whose primary oncologist clearly explained treatment options during the child's end of life and who had home care involved were more likely to plan LOD. Planning LOD was associated with more home deaths. Parents who planned were more likely to feel very prepared for the child's end of life and very comfortable with LOD, and less likely to have preferred a different LOD. Among the 73 non-home deaths, planning was associated with more deaths occurring in the ward than in the intensive care unit or other hospital, and fewer children being intubated. Comprehensive physician communication and home care involvement increase the likelihood of planning a child's LOD. Opportunity to plan LOD is associated with outcomes consistent with high-quality palliative care, even among non-home deaths, and thus may represent a more relevant outcome than actual LOD. [http://www.jpmsjournal.com/article/S0885-3924\(08\)00220-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(08)00220-0/abstract)

Of related interest:

- U.K. | This is Derbyshire – 31 December 2008 – **'Two-year-old must wait for home care release.'** A toddler who spends two nights each week in hospital will have to wait months longer than expected to come home for good. <http://www.thisisderbyshire.co.uk/news/year-old-patient-wait-home-care-release/article-577518-detail/article.html>

Seven year review

Has pain management in cancer patients with bone metastases improved?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2009;37(1):77-84. The primary objective of this study was to determine the prevalence of under dosage of analgesics for pain associated with bone metastases in outpatients referred to the Rapid Response Radiotherapy Program at the Odette Cancer Centre (Sunnybrook Health Sciences Centre, Toronto, Canada) from 1999 to 2006. Patients who experienced moderate or severe pain and were prescribed no pain medication, non-opioids, or weak opioids were considered to be under medicated. No appreciable decline was noted in the proportion of patients with moderate-to-severe pain who received no pain medication, non-opioids, or weak opioids during the study period. Despite the publication of pain management guidelines and the dissemination of data regarding the proportion of patients with bone metastases who are being prescribed inadequate analgesics, the authors' findings suggest that a significant proportion of patients continue to be under medicated.
[http://www.jpmsjournal.com/article/S0885-3924\(08\)00218-2/abstract](http://www.jpmsjournal.com/article/S0885-3924(08)00218-2/abstract)



Undertreated Pain in the Context of Palliative & End of Life Care

Incidence, Prevalence & Legal Liability
(and related clinical issues).

Review of recent or current literature
compiled and annotated
by Barry R. Ashpole.

Updated 5 January 2009

PDF file of review distributed with Media Watch

How I wish to be remembered

The use of an advance care planning document in adolescent and young adult populations

JOURNAL OF PALLIATIVE MEDICINE, 2009;11(10):1309-1313. Discussing end-of-life (EOL) issues is difficult with any population. These conversations are even more challenging with adolescents and young adults due to the poignancy of the situation and the need for developmentally appropriate language. The objective of this study was to explore whether adolescents and young adults living with a life-limiting illness find it acceptable and helpful to have a planning document to share their wishes and thoughts regarding EOL care. If so, to learn about specific concerns adolescents and young adults feel are important to include in such a document. Twenty patients completed the survey. Ninety-five percent of the participants reported that an advance directive like Five Wishes® would be "helpful" or "very helpful" to themselves, 90% stated that the document would be helpful to others, and no patients found talking about the issues in Five Wishes® "stressful" or "very stressful." Participants were more interested in items concerning how they wanted to be treated and remembered than items concerning medical decision-making. <http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2008.0126>

Of related interest:

- American Medical Association | *American Medical News* – 5 January 2009 – **'Defective directives? Struggling with end-of-life care.'** Most patients lack advance care plans, leaving doctors and families struggling to make decisions. Is there a better way? <http://www.ama-assn.org/amednews/2009/01/05/prsa0105.htm>

Communication dynamics in hospice teams

Understanding the role of the chaplain in interdisciplinary team collaboration

JOURNAL OF PALLIATIVE MEDICINE, 2009;11(10): 1330-1335. Hospice chaplains provide a specific expertise to patient and family care, however, individual roles and responsibilities that facilitate the interdisciplinary team environment are less well known. The primary aim of this study was to investigate how hospice chaplains perceive their role in interdisciplinary team meetings and to what extent hospice chaplains share common experiences within the interdisciplinary team approach in hospice. Findings revealed that professional role conflict is experienced, primarily with social workers. Although chaplains foster interdisciplinary collaboration within the hospice team, future research needs to address improvements to the chaplain's role within the interdisciplinary team process. <http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2008.0165>

Sedation for the imminently dying: Neurologist views vary

NEUROLOGY TODAY, 2008;8(10)15:14-15. Neurologists support sedation for the imminently dying more in theory than they do in their day-to-day practice, according to the results of a recent survey. Among the findings, 83% said they would provide sedation for the imminently dying in some circumstances, but only 37% said they had ever actually offered to do so. And while 92% agreed with the idea of sedating a patient with end-stage metastatic cancer with refractory pain and delirium, only 54% supported doing so for a patient with end-stage ALS who maintained decision-making capacity yet refused continued hydration. But the seeming contradiction between theory and practice in the survey results may be more apparent than real. Sedation for the imminently dying is for people who are suffering to such an extent that they cannot be made comfortable by any way other than sedating them to the point of unconsciousness, said James L. Bernat, MD, professor of medicine in the department of neurology at Dartmouth Medical School in New Hampshire, and author of *Ethical Issues in Neurology*, 3rd ed. (Lippincott Williams and Wilkins, 2008). <http://www.neurotodayonline.com/pt/re/neurotoday/fulltext.00132985-200805150-00001.htm;jsessionid=Jh9MMLRT7NpsXDd1nQRTsLmw2W1CpbJH0YK3jyN3XL7LbsBlpfCT!-482373940!181195629!8091!-1>

Construction of a parent-derived questionnaire to measure end-of-life care after withdrawal of life-sustaining treatment in the neonatal intensive care unit

PEDIATRICS, 2009;123(1):e87-e95. The authors developed and pre-tested a questionnaire to assess the practice of withdrawal of life-sustaining treatment in the neonatal intensive care unit (NICU) on the basis of the experiences of bereaved parents. The response rate was 48%. Respondents ranked items that pertained to the withdrawal of life-sustaining treatment process highest, indicating that items were done well. Items related to quality of care and bereavement care ranked lowest. Other domains ranked as follows: communication, shared decision-making, and quality of life. Parents' views on important aspects of end-of-life care in the NICU were incorporated into a quality assurance questionnaire. Pre-testing assessed the performance of the instrument and the perceptions of social workers on the effectiveness of end-of-life practices. Respondents identified that parents' practical needs were met during the withdrawal process but were not consistently met in regard to the quality of in-hospital and follow-up bereavement care. <http://pediatrics.aappublications.org/cgi/content/abstract/123/1/e87?rss=1>

Something Missed or Overlooked?

If you come across a media report, journal article, etc., relevant to hospice palliative care or end-of-life issues not mentioned in this edition of Media Watch, please alert this office so that it can be included in a future issue of the weekly report. Thank you.

Wide variation in content of inpatient do-not-resuscitate order forms used at National Cancer Institute-designated cancer centers in the U.S.

SUPPORT CARE CANCER, 2009;17(2):109-15. Available data suggest that clinicians have inconsistent practices when establishing and documenting do-not-resuscitate (DNR) orders. Lack of standardization may contribute to ineffective and unclear discussions regarding resuscitation status (RS). This lack of standardization may reflect the absence of a common understanding of difficult issues, which may contribute to unclear and ineffective communication when addressing RS. <http://www.ncbi.nlm.nih.gov/pubmed/18682989>

Of related interest:

- U.S. | *Tualatin Times* (Oregon) – 1 January 2009 – '**CPR: County pushes chest compression.**' Washington County is taking part in a national study focused on compression-only CPR. http://www.tualatintimes.com/news/story.php?story_id=123076129229727600

Books & Resources

Opioids in Cancer Pain

OXFORD UNIVERSITY PRESS | Publisher's online posting – December 2008 – Opioids have become invaluable in modern medicine, but it is essential that they are prescribed with an understanding of the complex pharmacology behind their effectiveness. Without this, they will frequently fail to achieve their enormous potential of pain relief, minimal side effects, and improved function. In addition, opioids come with problems, including side effects such as constipation, respiratory depression, and sedation, as well as the potential for substance abuse. Clinicians handling the complex pain problems of cancer patients must incorporate the insight of basic scientists and pharmacologists, and this new edition of this comprehensive text brings together a wealth of experience from those involved in all aspects of opioids, with a view to improving both clinician understanding and patient care. **Publication date:** June 2009. <http://www.oup.com/us/catalog/general/subject/Medicine/PainManagement/?view=usa&ci=9780199236640>

Worth Repeating

CANADA | CBC Radio ('White Coat, Black Art') – 29 December 2008 – The last broadcast of 'White Coat, Black Art' in 2008 was a repeat broadcast, a revealing yet sensitive look at death. Host Brian Goldman writes: "Death is one of the last taboos we have in our society. In my work in emergency, I've encountered many otherwise bright people who struggle to understand that life does not go on forever. Perhaps we are too busy to appreciate the passage of time. Perhaps we hope for a final conversation with a loved one that will right the wrongs of disagreements past. A wise person once told me, 'show me a person who is afraid of death, and I'll show you a person who is afraid to live.' Truer words have never been spoken. Though I've tried many times, I know on a deep level that a better conversation or even a better opportunity for a conversation often doesn't come. A wiser course is to live each day and to love each day as if it's your last. If you were dying, would you want to die suddenly in your sleep? Or, would you want to know as close as possible the final moment, so that you could settle your affairs and let as many friends and families as possible know how much you care about them? Death frightens me just much as the next person. But I'd still choose the latter." <http://www.cbc.ca/whitecoat/index.html?copy-podcast>

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