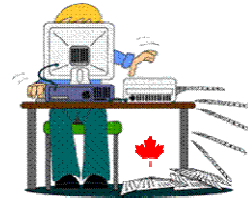


Media Watch...

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

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

Compiled & Annotated by Barry R. Ashpole

Elder care: Scroll down to [Specialist Publications](#) and 'Understanding the experience of living and dying with frailty in old age' (p.13), published in *Social Science & Medicine*.

With this issue of Media Watch, the weekly report begins its 6th year of publication.

Canada

Progress being made in palliative service

ALBERTA | *Lethbridge Herald* – 9 July 2012 – A pilot project for palliative care in Cardston has been called a success and may now lead to further services in other communities across southern Alberta. The original two-bed initiative, provided at the Lee Crest supportive living facility, and operated by the Good Samaritan Society in partnership with Alberta Health Services were opened in January and will now remain in place. The project was designed to determine if supportive living resources could be used to provide palliative care as opposed to hospital beds... <http://www.lethbridgeherald.com/local-news/progress-being-made-in-palliative-services-7912.html>

End-of-life decisions are more complex than do/do-not resuscitate

ONTARIO | *The National* (OpEd) – 3 July 2012 – Like most jurisdictions ... Ontario has established policies meant to honour residents' desire to be resuscitated, or not resuscitated, in the case of medical cataclysm. [A provincial government form], for instance, serves to instruct paramedics and firefighters not to initiate CPR.¹ Resuscitate, or don't resuscitate – those are your two options. In practice, though, end-of-life decisions tend to be more complicated. What about an unconscious person facing end-of-life medical issues who suffers a medical crisis (short of cardiopulmonary collapse) in his home, and faces the prospect of intubation, mechanical ventilation, or transportation to hospital as a means to marginally extend his life? Or what about the question of artificially administered nutrition? These questions form the basis of a form available to residents of Oregon, 'Physician Orders for Life-Sustaining Treatment' [POLST].^{2,3} It is comprised of multiple questions denoted A, B, C, D – leading off with the familiar 'Attempt CPR/Do Not Attempt CPR' issue, but also including further questions about more nuanced situations such as those described above. <http://fullcomment.nationalpost.com/2012/07/03/jonathan-kay-end-of-life-decisions-are-more-complex-than-dodo-not-recussitate/>

Cont.

1. 'Do Not Resuscitate Confirmation Form,' Ministry of Health & Long Term Care, Ontario.
http://www.ofm.gov.on.ca/en/Fire%20Service%20Resources/Forms/DNRCF.asp#Do_Not_Resuscitate_Confirmation_Form
2. 'Physician Orders for Life-Sustaining Treatment,' Center for Ethics in Health Care, Oregon Health & Science University.
<http://www.ohsu.edu/polst/programs/documents/POLST.2011.BWsmample.pdf>
3. 'POLST registry do-not-resuscitate orders and other patient treatment preferences,' *Journal of the American Medical Association*, 2011;307(1):34-35 (noted in Media Watch, 9 January 2012). <http://jama.ama-assn.org/content/307/1/34.2.extract?sid=c0d14c2c-00fa-4759-adc7-9469ac68565d>

Specialist Publications

Of particular interest:

'Framework for Continuous Palliative Sedation Therapy (CPST) in Canada' (p.12), published in the *Journal of Palliative Medicine*.

U.S.A.

Health care reform

Woman's 6-month decline highlights end-of-life care quandary

STATE OF WASHINGTON | *The Spokesman-Review* (Spokane) – 8 July 2012 – As the debate over the Supreme Court's ruling on the national health care overhaul law continues, many experts say that the ethical and financial dynamics of dying should be front and center. Yet few politicians, bureaucrats, insurers and doctors dare even to discuss it. And no one seems to have a clue as to how our society can afford to pay national health costs that approached \$2.6 trillion in 2010 – a tenfold increase since 1980, according to the Centers for Medicaid & Medicare Services. Even two years after their mother's death, [Athlee] Williams' children remain troubled by concerns that all that care did little but prolong her suffering. Be-

yond political and financial pressures, their mother's case lays bare the ethical complexities of the question that so many families must ultimately face.

<http://www.spokesman.com/stories/2012/jul/08/womans-6-month-decline-highlights-end-of-life-care-qu/>

Specialist Publications

Of particular interest:

'Health care costs for patients with cancer at the end of life' (p.11), published in the *Journal of Oncology Practice*.

Of related interest:

- *WALL STREET JOURNAL* | Associated Press report – 2 July 2012 – **'With boomers coming, hospice industry diversifies.'** As they brace for the eventual needs of the aging baby boom generation, hospice providers are working to diversify their services and dispel misconceptions about what they do. According to the National Hospice & Palliative Care Organization, an estimated 1.58 million patients received hospice care from more than 5,000 programs nationwide in 2010...¹
<http://online.wsj.com/article/AP5fa3df6bf53143c6bf221fb53970bbb0.html>

1. National Hospice & Palliative Care Organization, October 2010 – **'Record 1.56 million patients receive hospice care new report shows'** (noted in Media Watch, 11 October 2012). <http://www.prnewswire.com/news-releases/record-156-million-patients-receive-hospice-care-new-report-shows-104338438.html>

Patient Protection & Affordable Care Act

Pilot project to assess hospice care

OHIO | *Dayton Daily News* – 5 July 2012 – The Centers for Medicare & Medicaid Services (CMS) is coordinating ... [a] ... pilot project ... [to assess the quality of hospice care]. Under the Patient Protection & Affordable Care Act, hospices will be required to gather and report data on how well they manage patient symptoms, including pain, and other measures, including psycho-social and spiritual support for patients and their families. The data will be publicly available. The project focuses on quality measures endorsed by the National Quality Forum, and aims to assess how burdensome data collection is, as well as how feasible the process is, said Alexis Kirk, a public health analyst with RTI International, an independent, non-profit organization contracted by CMS to oversee the project. <http://www.daytondailynews.com/news/dayton-news/pilot-project-to-assess-hospice-care-1401101.html>

Of related interest:

- KENTUCKY | *Courier-Journal* (Louisville) – 8 July 2012 – **'Hospice care doubles in decade; Louisville part of trend.'** In Louisville and across the nation, more and more dying patients and their families are using the medical and emotional supports provided by hospice, an end-of-life care approach that has moved increasingly into the mainstream since it was introduced in the U.S. just a few decades ago. http://www.courier-journal.com/article/20120707/NEWS01/307070111/Hospice-care-doubles-decade-Louisville-part-trend?nclick_check=1

Talking with teens about death

ILLINOIS | *Chicago Tribune* – 4 July 2012 – End-of-life experts say that children should have the opportunity to discuss death in a developmentally appropriate way with a parent or a knowledgeable adult, though such conversations should not be forced. Many seriously ill children want to have that talk, and that both they and their parents are relieved afterward. But parents often don't know how to begin an end-of-life conversation with their children, said Maureen Lyon, associate research professor in pediatrics at Children's National Medical Center in Washington and principal investigator at its Children's Research Institute. They are often afraid that talking about death will be harmful to the child, Lyon said. And by the time teenagers enter hospice or palliative care programs, which are adept at such conversations, the youths may be too ill to be able to talk or not want to at all. But it can be a crucial conversation, Lyon said. Important decisions may have to be made, like whether to discontinue aggressive medical treatment or whether they would want to die at home or in a hospital. Too often, no one – not even doctors – asks these questions of seriously ill teenagers themselves, she said. Without knowing their children's wishes, families can be torn apart by conflict. And though youths under 18 have no legal standing to direct their medical care, Lyon said, their opinions should be heard. http://articles.chicagotribune.com/2012-07-04/features/ct-x-last-talk-brotman-20120704_1_conversations-about-end-of-life-care-end-of-life-care-ill-children

Of related interest:

- CNN | Online commentary – 6 July 2012 – **'Pediatric palliative care centers growing in the U.S.'** <http://thechart.blogs.cnn.com/2012/07/06/pediatric-palliative-care-centers-growing-in-the-united-states/>

N.B. See Media Watch, 6 June 2011 (p.9) for several articles, etc., on the provision and delivery of end-of-life care for adolescent children and young adults.

International

Postcode lottery that sees thousands of elderly denied vital care services to be abolished

U.K. (England) | *Daily Mail* – 8 July 2012 – Ministers will pledge to end the scandalous postcode lottery in care which sees thousands of vulnerable pensioners denied vital services such as home help. At present, councils are allowed to set their own eligibility thresholds for social care – which has created 152 different systems across England. More than 80% of local authorities have taken the opportunity to limit free care ... to only those whose needs are deemed 'substantial' or greater. <http://www.dailymail.co.uk/news/article-2170667/Postcode-lottery-sees-thousands-elderly-denied-vital-care-services-abolished.html?ito=feeds-newsxml>

Of related interest:

- U.K. | *The Guardian* – 5 July 2012 – **'Shortened care visits putting elderly and vulnerable at risk.'** Councils are putting vulnerable and older people at risk by cutting the times allowed for personal care visits, a survey of providers has found.¹ In England, almost three-quarters (73%) of homecare visits ... are reported as being for periods of 30 minutes or shorter, with one in ten visits commissioned for less than 15 minutes. <http://www.guardian.co.uk/society/2012/jul/05/short-care-visits-elderly-at-risk?newsfeed=true>

1. 'Care is not a commodity,' Commissioning Survey, United Kingdom Homecare Association, July 2012. <http://www.ukhca.co.uk/pdfs/UKHCACommissioningSurvey2012.pdf>

Hospitals 'letting patients die to save money'

U.K. | *Daily Telegraph* – 8 July 2012 – Tens of thousands of patients with terminal illnesses are placed on a "death pathway" to help end their lives every year. However ... six doctors warn that hospitals may be using the controversial scheme to reduce strain on hospital resources.¹ Supporters of the Liverpool Care Pathway, which allows medical staff to withhold fluid and drugs in a patient's final days, claim it is the kindest way of letting them slip away. But the experts say ... natural deaths are often freer of pain and distress. Informed consent is not always being sought by doctors, who fail to ask patients about their wishes while they are still in control of their faculties... <http://www.telegraph.co.uk/health/healthnews/9385674/Hospitals-letting-patients-die-to-save-money.html>

1. 'Deadly one-way street,' *Daily Telegraph*, 8 July 2012.

Noted in Media Watch, 25 June 2012.

- U.K. | *Daily Mail* – 19 June 2012 – **'Top doctor's chilling claim...'** NHS [National Health Service] doctors are prematurely ending the lives of thousands of elderly hospital patients because they are difficult to manage or to free up beds, a senior consultant claimed. Professor Patrick Pullicino said doctors had turned the use of a controversial 'death pathway' into the equivalent of euthanasia of the elderly. <http://www.dailymail.co.uk/news/article-2161869/Top-doctors-chilling-claim-The-NHS-kills-130-000-elderly-patients-year.html?ito=feeds-newsxml>

Of related interest:

- U.K. (ENGLAND) | *The Telegraph* – 3 July 2012 – **'Patients dying in hospital in pain and lacking dignity: [National] Survey.'** Patients in hospital are needlessly dying in pain and being stripped of their dignity and privacy, the first national survey of bereaved families has found.¹ It is the first time such a survey has been conducted and responses were received from more than 22,000 families. <http://www.telegraph.co.uk/health/healthnews/9372138/Patients-dying-in-hospital-in-pain-and-lacking-dignity-survey.html>

1. 'National Bereavement Survey, 2011,' Office for National Statistics, July 2012.

Key Findings & Summary: http://www.ons.gov.uk/ons/dcp171778_269914.pdf

Palliative care in Australia

The evidence is now in

AUSTRALIAN AGEING AGENDA | Online report – 5 July 2012 – The Senate Community Affairs Committee has heard evidence of registered nurses ignoring the advance care directives of dying individuals, poor end-of-life pain management and other negative experiences across the whole continuum of care, during its inquiry into palliative care. A series of Senate public hearings held throughout the country as part of the inquiry, which officially ...on 10 July, have brought the palliative care sector's failures, successes and needs to the attention the Australian Parliament's upper house. <http://www.australianageingagenda.com.au/2012/07/05/article/The-evidence-is-now-in/UXVBQMGERJ.html>

Palliative care in China

At life's end, hospices ease pain

CHINA DAILY (Shanghai) | Online report – 5 July 2012 – Earlier this year, Shanghai announced plans to provide hospice care for dying cancer patients. Each of Shanghai's 18 districts and counties will have a community health center providing palliative care. Each community will have a special ward with 10 beds for dying cancer patients. "In China, people's unfamiliarity with hospices prevents them from deciding to stop the treatment for the illness and turn to hospice care," said Huang Weiping, of Shanghai Hand in Hand Life Care Developing Center. "Because of the lack of understanding, hospice care in China lags far behind that in Western countries," he added. A big problem in the [hospice] sector, however, is the shortage of professionals, including social workers, and volunteers who provide the care. According to the Shanghai Municipal Health Bureau, 36,000 people a year die of cancer, and 70% of terminally ill cancer patients need hospice care.

http://www.chinadaily.com.cn/china/2012-07/05/content_15549941.htm

Palliative care in India

Focus on palliative care vital...

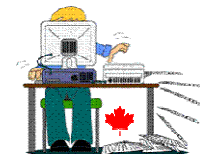
INDIA (KERALA) | *The Hindu* (Thiruvananthapuram) – 5 July 2012 – Palliative care should be made an integral part of patient care and available in all hospitals, at least at the district level, Union Defence Minister A.K. Antony has said. He was inaugurating a function organised by Pallium India to make the formal announcement of its Trivandrum Institute of Palliative Sciences being designated as the WHO Collaborating Centre for Training & Policy on Access to Pain Relief.

<http://www.thehindu.com/news/cities/Thiruvananthapuram/article3604936.ece>

The Quality of Death: Ranking End-of-life-Care Across the World

Australia, China and India were rated 2nd, 37th and 40th, respectively, of the 40 countries surveyed, in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by Economist Intelligence Unit, July 2010 (noted in media watch, 19 July 2012).

http://graphics.eiu.com/upload/QOD_main_final_edition_Jul_12_toprint.pdf



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>

Cont.

Of related interest:

- SRI LANKA (SOUTHERN PROVINCE) | *Asia Tribune* – 5 July 2012 – '**An effort to make their last few days comfortable: Home based palliative care for terminally ill cancer patients.**' <http://www.asiantribune.com/news/2012/07/04/effort-make-their-last-few-days-comfortable-home-based-palliative-care-terminally-il>

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

Professional development

Improving student comfort with death and dying discussions through facilitated family encounters

ACADEMIC PSYCHIATRY, 2012;36(3):188-190. The purpose of this study was to explore the educational potential for a collaboration between palliative medicine and psychiatry designed to improve first-year medical students' knowledge and comfort with end-of-life issues through a facilitated small-group discussion with family members of recently-deceased loved ones. 77% of participants reported increased comfort levels and 85% reported improved knowledge of end-of-life issues. Students reporting benefit were more likely to perceive higher facilitator and family comfort levels with end-of-life discussions, better activity organization, and utility of post-encounter group discussion. <http://journals.psychiatryonline.org/article.aspx?articleid=1209379>

- *HOME HEALTHCARE NURSE*, 2012;30(7):420-429. '**Creative forces for retention of home health aides in hospice and palliative care.**' This article explores the history of home health aide services as a backdrop to understanding the creative forces in recruitment and education..., as well as support and team efforts that contribute to successful careers as aides in the home care setting. http://journals.lww.com/homehealthcarenurseonline/Abstract/2012/07000/Creative_Forces_for_Retention_of_Home_Health_Aides.8.aspx
- *PALLIATIVE CARE & MEDICINE*; 2012;2(4). '**Palliative care education: Does it influence future practice.**' The authors' findings suggest that nursing students believe that a discrete course in palliative care should be a core component of an undergraduate nursing program and that they are very receptive to learning that is considered to be relevant to practice, actively engages them in learning and provides them with opportunities to explore topics outside of their prescribed material. <http://omicsgroup.org/journals/2165-7386/2165-7386-2-113.pdf>
- *RESEARCH & THEORY FOR NURSING PRACTICE*, 2012;26(2):95-107. '**Familiarity knowledge in student nurses' clinical studies: Exemplified by student nurses in palliative care.**' Student nurses expertly mentored and tutored while caring for dying patients living at home become, for instance, less apprehensive about facing dying patients than students not so mentored. <http://www.ingentaconnect.com/content/springer/rtnp/2012/00000026/00000002/art00003>
- *YALE JOURNAL OF BIOLOGY & MEDICINE*, 2012;85(2):261-270. '**Benefits of teaching medical students how to communicate with patients having serious illness.**' The authors describe two such educational experiences in the Yale Medical School curriculum for third-year medical students: 1) Communicating Difficult News Workshop; and, 2) Ward-Based End-of-Life Care Assignment. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3375674/>

[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>

A costly separation between withdrawing and withholding treatment in intensive care

BIOETHICS | Online article – 5 July 2012 – Ethical analyses, professional guidelines and legal decisions support the equivalence thesis for life-sustaining treatment: if it is ethical to withhold treatment, it would be ethical to withdraw the same treatment. In this paper the authors explore reasons why the majority of medical professionals disagree with the conclusions of ethical analysis. Resource allocation is considered by clinicians to be a legitimate reason to withhold but not to withdraw intensive care treatment. They analyse five arguments in favour of non-equivalence, and find only relatively weak reasons to restrict rationing to withholding treatment. On the contrary, resource allocation provides a strong argument in favour of equivalence: non-equivalence causes preventable death in critically ill patients. The authors outline two proposals for increasing equivalence in practice: 1) reduction of the mortality threshold for treatment withdrawal; and, 2) time-limited trials of intensive care. These strategies

would help to move practice towards more rational treatment limitation decisions.
<http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2012.01981.x/abstract>

On ethical locations: The good death in Thailand, where ethics sit in places

SOCIAL SCIENCE & MEDICINE, 2012;75(5): 836-844. In Northern Thailand, many feel that it is ethical to withdraw life support in the home, but unethical to withdraw it in the hospital. This is because the place of death is partly responsible for the quality of rebirth. Hospitals, on one hand, are powerful for saving lives; but as places to die, they are amoral, dangerous, devoid of ceremonial history and haunted by spirits. Homes, on the other hand, are optimal for dying because they are imbued with moral power from a history of beneficial ceremony and family living.
<http://www.sciencedirect.com/science/article/pii/S0277953612003383>

A national study of chaplaincy services and end-of-life outcomes

BMC PALLIATIVE CARE | Online article – 2 July 2012 – The present study ... found significantly lower rates of hospital deaths and higher rates of hospice enrollment for patients cared for in hospitals that provided chaplaincy services compared to hospitals that did not. The findings suggest that chaplaincy services may play a role in increasing hospice enrollment. This may be attributable to chaplains' assistance to patients and families in making decisions about care at the end-of-life, perhaps by aligning their values and wishes with actual treatment plans. Additional research is warranted. <http://www.biomedcentral.com/content/pdf/1472-684X-11-10.pdf>

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 4 July 2012 – **'Religious beliefs and practices in end-stage renal disease: Implications for clinicians.'** [The findings of this study] offer insights into chaplains' roles in the end-stage renal disease setting and the issues that they and other palliative care team members can anticipate and address in patient support and decision making. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00166-2/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00166-2/abstract)
- *PSYCHO-ONCOLOGY*, 2012;21(7):714-723. **'Religious coping and behavioral disengagement: Opposing influences on advance care planning and receipt of intensive care near death.'** <http://onlinelibrary.wiley.com/doi/10.1002/pon.1967/abstract>

Noted in Media Watch, 12 December 2011:

- *WALL STREET JOURNAL* | Online article – 6 December 2011 – **'Bigger roles for chaplains...'** http://online.wsj.com/article/SB10001424052970204826704577074462494881428.html?mod=goonews_wsj

Cont.

Noted in Media Watch, 24 January 2011:

- *PALLIATIVE MEDICINE*, 2011;25(1):21-25. 'Hope beyond (redundant) hope: How chaplains work with dying patients.' <http://pmj.sagepub.com/content/25/1/21.abstract>

Understanding integrated care pathways in palliative care using realist evaluation: A mixed methods study protocol

BMJ OPEN | Online article – 2 July 2012 – Policy- and evidence-based guidelines highlight the need for improved palliative and end-of-life care. However, there is still evidence of individuals dying undignified deaths with little pain control, therefore inflicting unnecessary suffering. New commissioning powers¹ have enabled a 2-year pilot of an innovative integrated care pathway (ICP) designed to improve arrangements for individuals with life-limiting illnesses requiring palliative care. A feature of the ICP is its focus on palliative care over the last 6 months of life, aiming to intervene early to prepare for and ensure a good death. What is not known is if this pathway works, how it works and who it works for. <http://bmjopen.bmj.com/content/2/4/e001533.abstract>

1. 'Advice from National Institute for Health & Clinical Excellence aims to improve commissioning for end of life care,' National Institute for Health & Clinical Excellence, 2012 (noted in Media Watch, 16 January 2012). <http://www.nice.org.uk/newsroom/pressreleases/EndOfLifeCareCommissioning.jsp>

'Leaders in our own lives': Suggested indications for social work leadership from a study of social work practice in a palliative care setting

BRITISH JOURNAL OF SOCIAL WORK | Online article – 2 July 2012 – In the context of calls for the social work profession to show leadership, this article reports a single site qualitative study in a specialist palliative care setting in England, which explored suggested similarities between social work practice and a recently developed model of 'servant and partner' leadership. The research showed that social workers demonstrated integrity in their dealings with both service users and colleagues, in that they were both respectful and holistic. It indicated that social workers used insights gained by engaging at depth with service users to influence decision making within the multidisciplinary team of which they were members. By drawing on sophisticated and adaptive communication skills and genuinely valuing others' contributions, they enhanced the ability of the team to achieve proportionate responses to sensitive and complex situations. <http://bjsw.oxfordjournals.org/content/early/2012/07/01/bjsw.bcs083.abstract>

Complicated grief in late life

DIALOGUES IN CLINICAL NEUROSCIENCE, 2012;14(2):195-202. Complicated grief (CG) is a syndrome that affects 10% to 20% of griever regardless of age, although proportionally more will face the death of loved ones in late life. CG is characterized by preoccupying and disabling symptoms that can persist for decades such as an inability to accept the death, intense yearning or avoidance, frequent reveries, deep sadness, crying, somatic distress, social withdrawal, and suicidal ideation. This syndrome is distinct from major depression and post-traumatic stress disorder, but CG may be co-morbid with each. This communication will focus on the impact of CG in late life (over age 60) and will include a case vignette for illustrating complicated grief therapy. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3384448/pdf/DialoguesClinNeurosci-14-195.pdf>

N.B. This issue of *Dialogues in Clinical Neuroscience* includes several articles on complicated grief. Journal contents page: <http://www.dialogues-cns.org/>

Of related interest:

- *SOCIAL WORK TODAY*, 2012;12(4):8. 'Complicated grief – does it belong in DSM-5?' Prolonged grieving exists, but some argue that classifying it as a separate disorder in DSM-5 [Diagnostic & Statistical Manual of Mental Disorders] is unwarranted and may inadvertently encourage unnecessary treatment with medication. Others contend it may get people the additional help they need to heal. <http://www.socialworktoday.com/archive/070212p8.shtml>

Communicating with dying people

'Being with' a patient who is distressed

END OF LIFE JOURNAL, 2012;2(2). Clinical skills communicating with dying people means more than just imparting information. It is about being physically and emotionally present with patients. The following communication vignette deals with the issue of 'being with' dying patients, as defined by Dame Cicely Saunders, the founder of the modern hospice movement. Dame Cicely... wrote practitioners should 'learn not only how to free patients from pain and distress, how to understand them and never let them down, but also to be silent, how to listen and how just to be there'... 'Being with,' as defined by Dame Cicely..., means staying with patients as they approach death, providing them with an opportunity to talk openly about their feelings and fears, while actively listening to what they have to say. Such action can help people face the reality of their forthcoming death... 'Being with' can also entail simply sitting with a dying patient, whether or not he/she is able, or wishes, to communicate... <http://endoflifejournal.stchristophers.org.uk/clinical-skills/communication-vignettes-being-with-a-patient-who-is-distressed>

Reasons why physicians do not have discussions about poor prognosis, why it matters, and what can be improved

JOURNAL OF CLINICAL ONCOLOGY | Online article – 2 July 2012 – At a time of controversy about a sick and aging population and fiscal constraint, honest communication about choices and outcomes represents an important solution. Yet evidence consistently shows that doctors are hesitant to divulge prognostic information. The authors have found several underlying misconceptions held by health care professionals. If the major barrier to prognosis communication that holds real credence is the pain physicians experience in these conversations, we should work toward supporting one another as physicians in these difficult tasks.

<http://jco.ascopubs.org/content/early/2012/06/27/JCO.2012.42.4564.full.pdf+html>

The barriers to organ and tissue donation in palliative care

END OF LIFE JOURNAL, 2012;2(2). Discussions about organ/tissue donation are now expected to become part of end-of-life care discussions, when appropriate. It is commonly perceived that terminally ill people are not eligible to donate their organs/ tissues. However, that is not the case. Palliative care patients can donate various tissues, including corneal tissue, and in some cases organs. Donation rates from palliative care patients are low as a result of a variety of factors, e.g. the family not knowing the deceased's wishes, negative attitudes to organ/tissue transplantation among relatives and clinicians, fears of disfiguring the body and wanting to protect the deceased person from further harm. Health professionals can be reluctant to broach the topic of tissue donation with patients and/ or their families/next of kin. This article will explore the involvement of palliative care patients in decisions about donating their tissues, why families may be reluctant to consent to donating organs/tissues of deceased loved ones and reasons why nurses are wary of discussing the possibility of donation with patients and/or their next of kin. Recommendations for practice will also be made. <http://endoflifejournal.stchristophers.org.uk/clinical-review/the-barriers-to-organ-and-tissue-donation-in-palliative-care>

Noted in Media Watch, 7 February 2011:

- *MEDICAL LAW REVIEW* | Online article – 31 January 2011 – '**End-of-life treatment of potential organ donors: Paradigm shifts in intensive and emergency care.**' This comments on the critical and historic debate affecting the medical treatment of potential deceased organ donors in the last phase of their lives. <http://medlaw.oxfordjournals.org/content/early/2011/01/30/medlaw.fwq032.full>

Acronyms of dying versus patient autonomy

EUROPEAN JOURNAL OF HEALTH LAW, 2012;19(3):289-303. In medical practice in Germany and several other countries abbreviated orders linked to end-of-life decisions, such as DNR (do not resuscitate), are increasingly used. In order to investigate their legal status, this article gives an overview of the recently passed German law, which regulates the process of end-of-life decision-making and the use of living wills, giving primacy to patient autonomy. Concerning the risk of misinterpretation of acronyms, the article describes the impacts of such orders on patient autonomy and safety and suggests a clear systematic classification of the different DNR orders in order to investigate their legal status under the German law. Their general binding force is to be acknowledged, depending on its origination and the fulfilment of certain requirements.

<http://booksandjournals.brillonline.com/content/10.1163/157180912x639143>

Noted in Media Watch, 6 February 2012:

- *BUNDESGESUNDHEITSBLATT - GESUNDHEITSFORSCHUNG - GESUNDHEITSSCHUTZ*, 2012;55(2):231-237. 'Palliative care in the light of legal and regulatory requirements in Germany.' <http://www.springerlink.com/content/3457017t5130nt1p/>

N.B. This article is published in German.

Media Watch Online

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network:

<http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County):

<http://www.hpcconnection.ca/newsletter/inthenews.html>

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

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

U.S.A.

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

Europe

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

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

Asia

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

International

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

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

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

Allow-Natural-Death (AND) orders: Legal, ethical, and practical considerations

HEC FORUMS | Online article – 1 July 2012 – Conversations with patients and families about the allow-natural-death (AND) order, along with the standard do-not-resuscitate (DNR) order during end-of-life (EOL) decision-making, may create engagement and understanding while promoting care that can be defended using enduring notions of autonomy, beneficence, and professional duty. Ethical, legal, and pragmatic issues surrounding EOL care decision-making seem to suggest discussion of AND orders as one strategy clinicians could consider at the individual practice level and at institutional levels. A discussion of AND orders, along with traditional DNR orders is presented. This is followed by argument and counter-argument focused on ethical, legal, and practical issues germane to EOL care decision-making associated with use of AND orders.
<http://www.springerlink.com/content/112grh2277342362/>

Noted in Media Watch, 6 February 2012:

- *THE OCHSNER JOURNAL*, 2011;11(4):302-306. **'DNR, DNAR, or AND? Is language important?'**
<http://www.ochsnerjournal.org/doi/abs/10.1043/1524-5012-11.4.302>

Noted Media Watch, 3 December 2010:

- U.S. | *New York Times* – 6 December 2010 – **'D.N.R. by another name.'**
<http://newoldage.blogs.nytimes.com/2010/12/06/d-n-r-by-another-name/?partner=rss&emc=rss>

Noted Media Watch, 9 March 2009:

- *USA TODAY* | Online commentary – 2 March 2009 – **"Do not resuscitate' vs. 'allow natural death."** http://www.usatoday.com/news/health/2009-03-02-DNR-natural-death_N.htm

Health care costs for patients with cancer at the end of life

JOURNAL OF ONCOLOGY PRACTICE | Online article – 3 July 2012 – With rising health care costs in the U.S., clearly defined end-of-life (EOL) cancer costs are needed to help health administrators proactively manage this important care. The authors' objective was to examine EOL health care resource costs among oncology patients in a U.S. commercial insurance population. A total of 28,530 patients met inclusion criteria. Mean total cancer-related costs in the last 6 MBD [months before death] were \$74,212 ... comprising IP [inpatient] costs of \$40,702 (55%), OP [out-patient] costs of \$30,254 (41%), and hospice costs of \$3,256 (4%). OP costs decreased from \$6,021 in the sixth MBD to \$2,238 in the last MBD, whereas IP care costs increased from \$1,785 to \$20,559. Hospice utilization increased from 0.7% in the sixth MBD to 35.6% in the last MBD.
<http://jop.ascopubs.org/content/early/2012/07/03/JOP.2011.000469.abstract>

Of related interest:

- *THE LANCET ONCOLOGY*, 2012;13(7):649. **'Are patients counting the cost of the economic downturn?'** [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(12\)70302-9/fulltext#article_upsell](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(12)70302-9/fulltext#article_upsell)

Living to the end - palliative care for an ageing population



<http://www.worldday.org/>

October 13 2012

Survey burden for family members surveyed about end-of-life care in the intensive care unit

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 4 July 2012 – Family surveys are an important source of information about quality of end-of-life care in the intensive care unit (ICU). The burden associated with completing such surveys is not well studied. Most families reported no to low burden. Family members who live with their loved one are particularly vulnerable to survey burden and those of older patients report less burden. The association between low quality-of-care ratings and survey burden suggests that the response bias in this type of research is toward overestimating quality of care. [http://www.jpmsjournal.com/article/S0885-3924\(12\)00175-3/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00175-3/abstract)

Dignity in end-of-life care: Results of a national survey of U.S. physicians

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 4 July 2012 – Nine (90%) of 10 physicians [i.e., survey respondents] reported that dignity was relevant to their practice. After controlling for age, gender, region, and specialty, physicians who judged that the case patient had either some dignity or full dignity, and who agreed that dignity is given by a creator, were all positively associated with believing that the patient's life was worth living. Respondents who strongly agreed that "all living humans have the same amount of dignity" were also more likely to believe that the patient's life was worth living. Religious characteristics were also associated with believing that the case patient's life was worth living. [http://www.jpmsjournal.com/article/S0885-3924\(12\)00167-4/abstract](http://www.jpmsjournal.com/article/S0885-3924(12)00167-4/abstract)

Of related interest:

- *HEALTH CARE ANALYSIS* | Online article – 4 July 2012 – **'Autonomy and dignity...'** With dying increasingly becoming a medicalised experience in old age, we are witnessing a shift from concern over death itself to an interest in dying 'well.' Fierce discussions about end-of-life decision making and the permissibility of medical intervention in dying, discursively structured around the notion of a 'good' death, are evidence of this shift. This article focuses on 'autonomy' and 'dignity as key signifiers in these discussions. <http://www.springerlink.com/content/p7525517217562w2/>
- *PALLIATIVE & SUPPORTIVE CARE* | Online article – 6 July 2012 – **'Living with pleasure in daily life at the end of life: Recommended care strategy for cancer patients from the perspective of physicians and nurses.'** One of the most important goals of palliative care is achieving a good death. Most Japanese believe that "having some pleasure in daily life" is necessary at the end of life. The aim of this study was to identify, from the perspective of physicians and nurses, a care strategy that ensures that cancer patients have pleasure in daily life at the end of life. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8632866&fulltextType=RA&fileId=S1478951512000442>

Framework for Continuous Palliative Sedation Therapy (CPST) in Canada

JOURNAL OF PALLIATIVE MEDICINE | Online article – 2 July 2012 – Canada does not have a standardized ethical and practice framework for continuous palliative sedation therapy (CPST). Although a number of institutional and regional guidelines exist, Canadian practice varies. Given the lack of international and national consensus, the Canadian Society for Palliative Care Physicians (CSPCP) formed a special task force to develop a consensus-based framework for CPST. A thorough literature review ... of sedation therapy at the end of life was conducted from which an initial framework was drafted. This document was reviewed by 30 multidisciplinary experts in Canada and internationally, revised several times, and then submitted to CSPCP members for review. Consensus was high on most parts of the framework. The framework for CPST will provide a basis for the development of safe, effective, and ethical use of CPST for patients in palliative care and at the end of life. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0498>

Cont.

Noted in Media Watch, 2 July 2012:

- *BIOETHICS*, 2012;26(6):329-336. **'Continuous deep sedation at the end of life and the 'natural death' hypothesis.'** <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2010.01861.x/abstract>

Pediatric palliative care

Pediatric consent: Case study analysis using a principles approach

NURSING ETHICS, 2012;19(4):581-585. This article will explore pediatric consent through the analysis of a clinical case study using the principles of biomedical ethics approach. Application of ... autonomy, nonmaleficence, beneficence, and justice will be dissected in order to attempt to establish resolution of the ethical dilemma. The main conflict in this case study deals with whether the wishes of an adolescent for end-of-life care should be followed or should the desire of his parents outweigh this request. <http://nej.sagepub.com/content/19/4/581.abstract>

Understanding the experience of living and dying with frailty in old age

SOCIAL SCIENCE & MEDICINE | Online article – 4 July 2012 – Whilst it could be argued developing into death in older age is part of a normal and successful course after a life long-lived, recognition of and support for older people deemed frail is lacking. Frail elders find themselves living in the margin between the Third and Fourth Age with little recognition of or support for the work of living and dying over time. This ... contests dominant cultural and welfare practices and policy frameworks that operate in binary modes: social or health; independent or dependent; living or dying. <http://www.sciencedirect.com/science/article/pii/S027795361200490X?v=s5>

Noted in Media Watch, 26 March 2012:

- CANADA | *Globe & Mail* (Halifax, Nova Scotia) – 18 March 2012 – **'Sometimes, for the frail elderly, the less medical intervention, the better.'** Instead of herding the frail elderly through hospital, one ... program informs them of their risks, after an assessment: among them, cognitive decline and loss of mobility. <http://www.theglobeandmail.com/news/opinions/editorials/sometimes-for-the-frail-elderly-the-less-medical-intervention-the-better/article2373292/>

Noted in Media Watch ('Worth Repeating'), 1 August 2011:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY*, 2003;51(4):492-498. **'The last 2 years of life: Functional trajectories of frail older people.'** [The results of this study] suggest end-of-life care systems that are targeted toward patients with functional trajectories clearly suggesting impending death are poorly suited to older people dying with progressive frailty. <http://onlinelibrary.wiley.com/doi/10.1046/j.1532-5415.2003.51157.x/abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *INTERNATIONAL JOURNAL OF AGEING AND LATER LIFE* | Online article – Accessed 8 July 2012 – **'The fight-to-die: Older people and death activism.'** This article explores the activities and convictions of older right-to-die activists who belong to a small but very active interest group based in Scotland, U.K., called Friends at the End (FATE). The analysis presented here is based on knowledge gained through seventeen months of ethnographic research with the organisation. While FATE activists currently campaign for a legal right to a medically assisted death, many are also open to taking matters into their own hands, either by travelling to the Swiss organisation Dignitas or by opting for what is known as "self-deliverance." FATE members' openness to different means of securing a hastened death contrasts sharply with the more limited demands of the UK's main right-to-die organisation, Dignity in Dying, and highlights their specific orientation to freedom, which, it is argued here, results from the organisation's older demographic. <http://www.ep.liu.se/ej/ijal/>

Cont.

- *INTERNATIONAL JOURNAL OF SOCIAL PSYCHIATRY*, 2012;58(4):381-385. **'Social acknowledgement as a predictor of post-traumatic stress and complicated grief after witnessing assisted suicide.'** Family members of patients who use assisted suicide may hesitate to disclose the manner of death, and the community and societal environment may express strong views concerning the end-of-life decision. This can lead to increased levels of post-traumatic stress disorder and complicated grief. <http://isp.sagepub.com/content/58/4/381.abstract>

Noted in Media Watch, 21 February 2011:

- *EUROPEAN PSYCHIATRY* | Online article – 11 February 2011 – **'Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide.'** http://www.psychologie.uzh.ch/fachrichtungen/psypath/ForschungTools/Schwerpunkte/1_Wagner_etal_PTSD_assist_suic_EP2011.pdf
- *THE PERMANENTE JOURNAL*, 2012;16(2):75-76. **'Physician-assisted suicide and euthanasia.'** Re: 'Physician-assisted suicide and euthanasia: Can you even imagine teaching medical students how to end their patients' lives?'¹ Considering physician-assisted suicide and euthanasia is a sensitive and controversial topic, the reductionism and the lack of objectivity of the question asked and of its discussion are intriguing. It is clear the author and advisers wished no answer but their own. It is not usual for scholars to be reluctant to confront their views with others. Surprising ... of those with the most experience in the field, none were consulted, namely from the Netherlands, Belgium, and the State of Oregon. <http://www.thepermanentejournal.org/files/Spring2012/Letters.pdf>
 1. 'Physician-assisted suicide and euthanasia: Can you even imagine teaching medical students how to end their patients' lives?' *The Permanente Journal*, 2012;15(4):79-84 (noted in Media Watch, 16 January 2012). <http://www.thepermanentejournal.org/files/Fall2011/Suicide.pdf>
- *PRACTICAL ETHICS* (Oxford University) | Online article – 5 July 2012 – **'Should minimally conscious patients be allowed to end their lives?'** Doctors distinguish between patients in a vegetative state, who are completely unresponsive and assumed to lack conscious awareness, and patients in a minimally conscious state, who have some degree of responsiveness and are assumed to have some awareness – although it is unclear what their experiences are like and what mental abilities they have. A third category of patients are those in a "locked-in" state. These people are fully aware and awake, but paralysed and unable to communicate except through eye movements. Patients in a persistent vegetative state are highly unlikely to recover from it, and in most countries the law allows, under certain conditions, passive euthanasia for this group, for example by disconnecting a feeding tube that provides life support. But is this policy ethically defensible... <http://blog.practicaethics.ox.ac.uk/2012/07/should-minimally-conscious-patients-be-allowed-to-end-their-lives/>

Worth Repeating

Personal legacy

Ethical capital: 'What's a poor man got to leave?'

SOCIOLOGY OF HEALTH & ILLNESS, 2012;32(6):880-897. For those of little or no means, leaving one's mark through financial assets, social connections, and human investment is difficult. Using secondary analysis of transcripts from face-to-face interviews with 33 terminally-ill patients from an outpatient clinic at a public hospital serving the disadvantaged in the southern U.S., the authors examine the legacy participants wish to leave behind. As part of this process, participants assess life circumstances to try and generate a legacy allowing them to remain personally relevant to loved ones after death. For the low-SES [socio-economic status] terminally ill persons in this study, the desire to leave a material legacy and the means to do so are not congruous. In the absence of economic resources to bequeath loved ones, participants describe their desire to leave loved ones some form of ethical currency to facilitate interactions with others and protect them against social marginalisation. The authors call this concept ethical capital. They then argue ethical capital is a way for disadvantaged people to find dignity and to affirm their lives. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-9566.2010.01246.x/abstract>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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