# 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.

# 20 August 2012 Edition | Issue #267



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

Compiled & Annotated by Barry R. Ashpole

Caregiver vs. non-caregiver physical morbidities: Scroll down to <u>Specialist Publications</u> and 'The physician's obligation to family caregivers' (p.5), posted on the website of the Chicago Medical Society.

# <u>Canada</u>

### Advance care planning

# 'Health talk' ensures elderly parents' care wishes are respected

BRITISH COLUMBIA | *Vancouver Sun* (Editorial) – 17 August 2012 – It's nice to think that we can talk to our parents, or our adult children, about anything. But when it comes to health, we know that's often not the case. Indeed ... 60% of Canadian adults do not regularly have "the health talk" ... and 30% say they don't know how to start conversations with them about sensitive health topics.<sup>1</sup> These are troubling findings since adult children are often responsible for making health care decisions on behalf of their incapacitated parents. Hence they are placed under considerable stress if they don't know what their parents really want. And parents risk being subjected to treatments they don't wish to receive. That can all be avoided if parents and their children ... speak to each other about their wishes. Beyond that, they can draw up an advance care plan, which may include an advance directive,<sup>2</sup> a legally binding document instructing a health care provider or substitute decision maker about what health care the person wishes to consent to or refuse. http://www.vancouversun.com/Opinion/Editorials/Editorial+Health+talk+ensures+elderly+parents+ care/7108743/story.html

- ONTARIO | Ottawa Citizen 26 July 2012 'Most Canadians have no written plan for end-oflife care, poll finds' (noted in Media Watch, 30 July 2012). http://www.ottawacitizen.com/health/Most+Canadians+have+written+plan+life+care+poll+finds/699 6749/story.html
- 2. In Ontario, advance directives require informed consent ...and, wishes regarding end-of-life care expressed verbally can override previously written wishes.

# <u>U.S.A.</u>

## Parents' religious beliefs can complicate kids' end-of-life care

MISSISSIPPI | WDAM-TV (Hattiesburg) – 14 August 2012 – Despite overwhelming medical evidence supporting the withdrawal of intensive care in extremely ill children who are unlikely to survive, parents who have deeply held religious beliefs may hold out for a miracle, a small study has found.<sup>1</sup> Although religion provides needed support for many families of critically ill patients, the investigators found hopes for divine intervention are increasingly causing children to be subjected to aggressive medical treatment that is not in their best interest. The ethics and legality of these cases should be reevaluated, the study authors suggested. http://www.wdam.com/story/19271992/paren ts-religious-beliefs-can-complicate-kids-endof-life-care

### **Specialist Publications**

Of related interest:

**'Religious red herrings'** (p.7), published in the *Journal of Medical Ethics* 

 'Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?' *Journal of Medical Ethics*, 30 March 2012 (noted in Media Watch, 2 April 2012). <u>http://jme.bmj.com/content/early/2012/03/08/medethics-2011-100104.abstract</u>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

NEW MEXICO | Denver Post (Colorado) – 19 August 2012 – 'Assisted suicide: New Mexico court asked to redefine the term.' The question before the court in New Mexico is absurdly simple and yet impossibly complex. What is the meaning of "assisting suicide"? If a terminally ill patient refuses a ventilator or a feeding tube and the physician yields to that decision, is that assisting suicide? http://www.denverpost.com/opinion/ci 21331135/court-asked-redefine-term-assisted-suicide

# **International**

### Dementia patients given right to say on end-of-life care

U.K. | Daily Telegraph - 16 August 2012 -People in the early stages of dementia are to be given a right to have a say in how and where they want to die under guidelines for medical staff and social workers. New draft quidelines drawn up by the NHS [National Health Service] watchdog NICE [National Institute for Health & Clinical Excellence] will require local authorities and health trusts to give people diagnosed with dementia an opportunity to discuss options for care at the end of their life as early as possible while they still have the capacity. It follows research showing that only a tiny minority of people have communicated their wishes for how they would like to be treated if they were terminally ill. Doctors, campaigners and church leaders have warned that up to

100,000 people a year are denied the chance of dying at home surrounded by friends and family rather than in hospital, often because their wishes were never recorded.<u>http://www.telegraph.co.uk/health/healthnews/9477623/Dementia-patients-given-right-to-say-on-end-of-life-care.html</u>

# Specialist Publications

Of related interest:

'Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers' (p.5), published in *Dementia*.

#### Palliative care in Nepal

#### Palliative care, care beyond cure

NEPAL | *Himalayan Times* (Kathmandu) – 15 August 2012 – In Nepal, there is widespread undersupply of specialist palliative care. We have no reliable statistics, but it is a fair guess that more than 80% of cancer cases would be detected late, and would be incurable at the time of diagnosis. They all need palliative care; but very few ... have access to palliative care now. <u>http://www.thehimalayantimes.com/fullNews.php?headline=Palliative+care++Care+beyond+cure &NewsID=343616</u>

Of related interest:

- SWAZILAND | Weekend Observer (Mbabane) 18 August 2012 'The role of family in palliative care.' <a href="http://www.observer.org.sz/index.php?news=42112">http://www.observer.org.sz/index.php?news=42112</a>
- BORNEO POST (Sarawak) | Published online 16 August 2012 'Terminally ill patients shun palliative care.' <u>http://www.theborneopost.com/2012/08/16/terminally-ill-patients-shun-palliativecare/</u>

#### More people able to die at home due to community specialist palliative care

U.K. | National Council for Palliative Care and the National End of Life Care Intelligence Network – 15 August 2012 – Specialist palliative care community services are leading to more people being able to die at home, according to a major new report. Latest figures from the new 2010/2011 Minimum Data Set for Specialist Palliative Care Services (MDS) report show that a third of those receiving specialist palliative care in 2010/11 died at home, compared with just one in five nationally. This is the third successive year that the proportion of deaths at home has increased for people using community specialist palliative care services. The MDS report also finds that nearly half (45%) of the people referred to a specialist palliative care in-patient service are discharged (42%) to their home, dispelling the myth that people only go into a hospice to die. Continued progress has also been made in opening up specialist palliative care services to non-cancer patients, although there remains a long way to go. <u>http://www.ncpc.org.uk/news/more-people-able-diehome-due-community-specialist-palliative-care</u>

### Judge rules boy's life support can be switched off despite parents' hope of miracle

U.K. | *Daily Telegraph* – 13 August 2012 – A judge has ordered that doctors can switch off a young boy's life-support system even though his devout Christian parents pleaded for him to be kept alive in case of a miracle. Mr. Justice Ryder said there was no hope of the eight-year-old recovering from lung failure after a "tragic decline in health" and it would be wrong to keep him alive and possibly in pain on a machine. The judge said that ... he had to agree to the hospital's request to withdraw life-sustaining treatment as doctors and nurses agreed that all further interventions would be futile. Mr. Justice Ryder agreed the continued presence of his family would provide him with comfort and would be in keeping with the tenets of their faith. However he said the child was at risk of further complications and infection as well as already being seriously ill. <a href="http://www.telegraph.co.uk/health/children\_shealth/9470501/Judge-rules-boys-life-support-canbe-switched-off-despite-parents-hope-of-miracle.html">http://www.telegraph.co.uk/health/children\_shealth/9470501/Judge-rules-boys-life-support-canbe-switched-off-despite-parents-hope-of-miracle.html</a>

Noted in Media Watch, 2 April 2012:

 JOURNAL OF MEDICAL ETHICS, 30 March 2012. 'Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?' <a href="http://jme.bmj.com/content/early/2012/03/08/medethics-2011-100104.abstract">http://jme.bmj.com/content/early/2012/03/08/medethics-2011-100104.abstract</a>

**N.B.** Scroll down to <u>Specialist Publications</u> and 'Religious red herrings' (p.5), for links to reader responses to this journal article.

Cont.

Of related interest:

 U.K. | ITV News – 15 August 2012 – 'Court to decide fate of man in vegetative state.' The courts are being asked to rule in a dispute over whether it is in "the best interests" of a man from the Greater Manchester area, who is in a vegetative state, to receive life-saving treatment if his condition deteriorates. <u>http://www.itv.com/news/granada/2012-08-15/court-to-decide-fate-of-man-invegetative-state/</u>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- RUSSIA | Pravda (Moscow) 18 August 2012 'Euthanasia luxury for the wealthy.' The topic of euthanasia does not leave anyone indifferent. Voluntary withdrawal from life due to serious illness for some people is a grievous sin, for others the only escape from suffering. For several years, seriously ill people in two states in the U.S. have been able to count on the help of doctors in ending the suffering. <a href="http://english.pravda.ru/society/anomal/18-08-2012/121910-euthanasia\_rich-0/">http://english.pravda.ru/society/anomal/18-08-2012/121910-euthanasia\_rich-0/</a>
- U.K. | The Guardian (OpEd) 17 August 2012 'Assisted dying: the harm in helping.' This week I was forced to face the truth that my much-loved and aged family dog was unnecessarily suffering as a result of a painful illness. I asked the vet to call at home I thought it was right to end my dog's life, and wanted her to die in familiar surroundings. I reasoned that as a responsible pet owner, it could not be fair to let her go on as she was; moribund and miserable. It is often said, on seeing someone suffer a long and painful illness that we would not let an animal suffer in this way. But as terrible as human suffering can be, there is of course no meaningful comparison to be drawn between the morality of ending the lives of animals and people except perhaps for this: how relatively easy it is for us to convince ourselves that we are doing the right thing. http://www.guardian.co.uk/commentisfree/2012/aug/17/assisted-suicide-causes-harm

Noted in Media Watch, 23 July 2012:

- VETERINARY RECORD | Published online 11 July 2012 'Attitudes to animal euthanasia do not correlate with acceptance of human euthanasia or suicide.' <a href="http://veterinaryrecord.bmj.com/content/early/2012/07/10/vr.100451.abstract">http://veterinaryrecord.bmj.com/content/early/2012/07/10/vr.100451.abstract</a>
- U.K. (ENGLAND & WALES) | BBC News 16 August 2012 'Tony Nicklinson loses High Court right-to-die case.' A man paralysed from the neck down has lost his High Court case to allow doctors to end his life without fear of prosecution. Tony Nicklinson, 58 ... communicates by blinking and has described his life as a "living nightmare" since a stroke in 2005. Mr. Nicklinson said he would appeal against the decision. The case went further than previous challenges to the law in England & Wales on assisted suicide and murder. Another man, known only as Martin, who is 47, also lost his case to end his life with medical help. <a href="http://www.bbc.co.uk/news/health-19249680">http://www.bbc.co.uk/news/health-19249680</a>

# 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

#### 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. <u>http://www.pcn-e.com/community/pg/file/owner/MediaWatch</u>

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

### The physician's obligation to family caregivers

CHICAGO MEDICAL SOCIETY | Published online – Accessed 14 August 2012 – Family caregivers provide an incredible amount of support to patients and serve as an integral part of healthcare delivery. In 2009, more than 42 million Americans served as caregivers. The American Medical Association estimates that family caregivers provide 80% of community care at an economic value of \$200 billion annually. This support, however, is matched by adverse physical, psychological, and spiritual effects characterized as "caregiver burden." Reports of negative psychological effects experienced by caregivers include depression (39%), anxiety (40%), anger, resentment, fatigue, and sleep deprivation. A recent trend towards "familycentered" care for elderly, pediatric, and chronically ill patients alters clinicians' relationships with family member caregivers. As a result, caregiver burden may be considered a factor in treatment approaches. Clinicians' duties must be evaluated when caregiver burden 1) causes physical and psychological harm in the caregiver, or 2) reduces quality of care for patients. Caregivers have higher rates of physical morbidities than their non-caregiver counterparts. Caregiver burden in spouses increases the risk for coronary heart disease and increases the rate of emergency department visits or hospitalization. http://www.cmsdocs.org/news/thephysician2019s-obligation-to-familycaregivers

Living with advanced illness: Longitudinal study of patient, family, and caregiver needs

THE PERMANENTE JOURNAL, 2012;16(3):28-35. Inpatient palliative care (IPC) consults are associated with improved quality of care and less intensive utilization. However, little is known about how the needs of patients with advanced illness and the needs of their families and caregivers evolve or how effectively those needs are addressed. The objectives of this study were 1) to summarize findings in the literature about the needs of patients with advanced illness and the needs of their families and caregivers; 2) to identify the primary needs of patients, families, and caregivers across the continuum of care from their vantage point; and 3) to learn how IPC teams affect the care experience. http://www.thepermanentejournal.org/files/Summ

http://www.thepermanentejournal.org/files/Summ er2012/PalliativeCare.pdf

Noted in Media Watch ('Worth Repeating'), 14 February 2011:

 CANADIAN JOURNAL OF PSYCHIATRY, 2004;49(6):359-365. 'Palliative care for families: Remembering the hidden patients.' The authors discuss how to define the family, emphasizing a systems approach to family care. They describe the impact of the illness on the family in terms of... https://ww1.cpaapc.org/Publications/Archives /CJP/2004/june/kristjanson.pdf

# Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers

DEMENTIA | Published online – 10 August 2012 – The experience of being a carer of a person with dementia at the end of life is expressed in these 12 accounts. This is a synthesis of the concerns and challenges for carers at the end of life. These accounts are often insightful and provide several views of carers' and professionals' experience. Having a close relationship as a carer gives a unique and poignant view. What emerges from this review is a range of perspec-tives that provide contrasting views of the heterogeneity of carers and professionals. This may be helpful for professionals and policy makers to consider when planning end-of-life care strategies for people with dementia and insights drawn from hearing directly from carers may be powerful learning tools. <a href="http://dem.sagepub.com/content/early/2012/08/08/1471301212450538.abstract">http://dem.sagepub.com/content/early/2012/08/08/1471301212450538.abstract</a>

Of related interest:

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Published online – 16 August 2012 – 'Grief among demented elderly individuals: A pilot study.' Grief behaviors of 17 elderly persons with dementia living at nursing homes were observed. When compared with bereaved with normal cognitive ability, both similarities and differences were found. Similarities seemed to exist for irritability, lost appetite, increased sedative medication, bodily complaints, less physical activity, and less interest in happy events. Differences were found, for example, social activity, as they did not isolate themselves. http://ajh.sagepub.com/content/early/2012/08/10/1049909112457009.abstract

Also on the topic of grief and dementia:

- PROGRESS IN PALLIATIVE CARE | Published online 9 August 2012 'Is the frequent death of residents in aged care facilities a significant cause of grief for residents with mild dementia?' <u>http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000031</u>
- BRITISH JOURNAL OF NURSING, 2012;21(12):723-727. 'A tormented death: End-of-life care for people with dementia.' District nurses are often faced with difficulties when patients with dementia lack the capacity to express how they feel and the family has to make end-of-life decisions for the sufferer. Although 25% of palliative care is concerned with controlling physical symptoms, health professionals are sometimes faced with challenges when one co-morbidity masks another. http://www.internurse.com/cgi-bin/go.pl/library/abstract.html?uid=92656

Noted in Media Watch, 2 April 2012:

 AGING WELL, 2012;5(2):18. 'Integrating palliative medicine with dementia care.' <u>http://www.agingwellmag.com/archive/031912p18.shtml</u>

Noted in Media Watch, 6 February 2012:

 AMERICAN JOURNAL OF ALZHEIMER'S DISEASE & OTHER DEMENTIAS | Published online – 31 January 2012 – 'Palliative care for advanced dementia: A pilot project in two nursing homes.' <u>http://aja.sagepub.com/content/early/2012/01/04/1533317511432732.abstract</u>

# Inpatient palliative care: A nationwide analysis

*HEALTH POLICY* | Published online – 10 August 2012 – Cancer patients treated on a palliative care (PC) inpatient unit where more likely to receive opioids (a surrogate for quality of end-of-life care) but where less likely to die at home and the cost of care for these patients was higher. The results can be interpreted both from 1) a methodological standpoint that assumes confounding due to the fact that the PC patients might have been suffering from more complex symptoms and 2) a health policy view. <u>http://www.sciencedirect.com/science/article/pii/S0168851012001959</u>

Of related interest:

 POLITICAL & MILITARY SOCIOLOGY | Published online – Accessed 15 August 2012 – 'Spillovers of veteran's hospice care: The economic and social impact of palliative care.' http://works.bepress.com/bruce\_mcdonald/9/

# Association between physicians' beliefs and the option of comfort care for critically ill patients

INTENSIVE CARE MEDICINE | Published online – 11 August 2012 – This study assessed how comfort care is presented to surrogates and whether physicians' beliefs are associated with whether comfort care is presented as an option. Using a broad definition of comfort-oriented treatment, this option was presented in 56% of conferences. The only independent predictor of offering comfort care as an option was the strength of the physician's belief that life support should be foregone. <u>http://www.springerlink.com/content/6153r0352128m709/</u>

# Factors that facilitate or constrain the use of continuous sedation at the end of life by physicians and nurses in Belgium: Results from a focus group study

JOURNAL OF MEDICAL ETHICS | Published online – 14 August 2012 – The authors conducted a study to find out which factors may facilitate or constrain the use of continuous sedation [CS] by physicians and nurses. Participants often had clear ideas on what could affect the likelihood that sedation would be used. The physicians and nurses in the focus groups testified that the use of continuous sedation was facilitated in cases where a patient has a very limited life expectancy, suffers intensely, makes an explicit request and has family members who can cope with the stress that accompanies sedation. However, this 'paradigm case' was considered to occur only rarely. Furthermore, deviations from the paradigm case were said to be sometimes due to physicians initiating the discussion on CS too late or not initiating it at all for fear of inducing the patient. <a href="http://jme.bmj.com/content/early/2012/08/13/medethics-2012-100571.abstract">http://jme.bmj.com/content/early/2012/08/13/medethics-2012-100571.abstract</a>

Noted in Media Watch, 15 March 2012:

ARCHIVES OF INTERNAL MEDICINE, 2010;170(5):490-493. 'Continuous deep sedation until death in Belgium: A nationwide survey.' In recent years much debate has focused on the practice of continuous deep sedation until death and its acceptability on an ethical level. While many view its performance as part of normal medical practice ... it is also believed to be a covert form of euthanasia in some cases and thus morally equivalent to euthanasia. <u>http://archinte.ama-assn.org/cgi/content/extract/170/5/490</u>

### Withdrawing and withholding treatment in children

# **Religious red herrings**

JOURNAL OF MEDICAL ETHICS | Published online – 13 August 2012 – Brierley *et al* take big polarised political debates deep into the context of paediatric intensive care.<sup>1</sup> They are concerned that "deeply held belief in religion leads to children being potentially subjected to burdensome care." However, it can be argued that they make a mistake in categorising this as a problem derived from religion, religious belief or the depth of religious conviction. Religion here is a red herring. http://jme.bmj.com/content/early/2012/07/13/medethics-2012-100676.abstract

 'Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?' *Journal of Medical Ethics*, 30 March 2012 (noted in Media Watch, 2 April 2012). <u>http://jme.bmj.com/content/early/2012/03/08/medethics-</u> <u>2011-100104.abstract</u>

Additional comments on the Brierley *et al* article:

- 'Just dying: The futility of futility.' <u>http://jme.bmj.com/content/early/2012/07/13/medethics-2012-100683.abstract</u>
- 'If you ask the wrong question, you'll get the wrong answer.' <a href="http://jme.bmj.com/content/early/2012/07/13/medethics-2012-100682.extract">http://jme.bmj.com/content/early/2012/07/13/medethics-2012-100682.extract</a>
- 'When they believe in miracles.' <u>http://jme.bmj.com/conhttp://jme.bmj.com/content/early/2012/07/13/medethics-2012-100677.abstract</u>

#### Religion and end-of-life treatment preferences: Assessing the effects of religious denomination and beliefs

SOCIAL FORCES | Published online - 10 August 2012 -The authors found no statistically significant differences when comparing traditionally defined religious denominational groups. However, when they considered the intersection of broad denominational group and adherence to Christian fundamentalist beliefs. the authors found that fundamentalist Catholics and fundamentalist Protestants were significantly more likely than their non-fundamentalist counterparts to desire lifeextending treatments in both scenarios. These effects were explained by beliefs about quality of life and religious control over medical decisions.http://sf.oxfordjournals.o rg/content/early/2012/08/09/sf .sos061.abstract

## Applying socio-dramatic methods in teaching transition to palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Published online – 13 August 2012 – The authors introduce the technique of socio-drama, describe its key components, and illustrate how this simulation method was applied in a workshop format to address the challenge of discussing transition to palliative care. They illustrate how the facilitators, using socio-dramatic techniques of doubling and role reversal, helped learners to understand and articulate the hidden feelings of fear and loss behind the family's emotional reactions. By modeling effective communication skills, the facilitators demonstrated how key communication skills, such as empathic responses to anger and blame and using "wish" statements could transform the conversation from one of conflict to one of problem solving with the family. <a href="http://www.jpsmjournal.com/article/S0885-3924(12)00239-4/abstract">http://www.jpsmjournal.com/article/S0885-3924(12)00239-4/abstract</a>

# Hospice and palliative care for terminally ill individuals with serious and persistent mental illness: Widening horizons

JOURNAL OF PSYCHOSOCIAL NURSING & MENTAL HEALTH | Published online – 17 August 2012 – Terminally ill individuals with serious and persistent mental illness (SPMI) are currently underserved by palliative care. However, palliative care nurses can expect to see more patients with SPMI because an estimated 6% of the adult population has chronic mental illness, and mortality and morbidity rates are higher in this group. Reasons for these increased rates are discussed. Literature regarding the provision of palliative care to those with SPMI is sparse, but what literature there is does offer suggestions for improvements in clinical practice. These suggestions for improvement are explored, and conclusions are drawn about the need for future research. <a href="http://www.healio.com/psychiatry/journals/JPN/%7BD0DB264A-B524-4930-9434-7914DF4E3DCC%7D/Hospice-and-Palliative-Care-for-Terminally-III-Individuals-with-Serious-and-Persistent-Mental-Illness-Widening-the-Horizons">http://www.healio.com/psychiatry/journals/JPN/%7BD0DB264A-B524-4930-9434-7914DF4E3DCC%7D/Hospice-and-Palliative-Care-for-Terminally-III-Individuals-with-Serious-and-Persistent-Mental-Illness-Widening-the-Horizons</a>

### The state of development of palliative care in Argentina

PROGRESS IN PALLIATIVE CARE | Published online – 11 August 2012 – Prior to 1960 severe under-treatment of cancer pain was the rule of thumb in Argentina and was described as un-avoidable. Cancer prevention, diagnosis, and treatment were subjects of interest, but symptom control was excluded. The majority of cancer patients was not treated for pain at all, or was treated inadequately. In the period from 1960 to 1980, cancer pain management was the duty of some anesthesiologists that performed different analgesic procedures with erratic results. Around 1980 a growing number of health professionals became aware of the magnitude of cancer symptoms and many of them began to provide adequate control for them. Palliative care was then introduced in the medical scenario and since then the health authority, health professionals, and the community slowly and progressively recognized its importance. Yet despite the progress ... access to palliative care is inconsistent and only a small fraction of patients with cancer pain receive adequate treatment. <a href="http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.000000023">http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.000000023</a>

Noted in Media Watch, 23 January 2012:

THE LANCET, 2012;379(9811):105. 'End-of-life decisions in Argentina.' An overwhelming majority of the Lower House recently passed a bill authorising changes in the current law of patients' rights. <u>http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60042-7/fulltext</u>

Noted in Media Watch, 9 January 2012:

 LATIN AMERICAN ASSOCIATION FOR PALLIATIVE CARE | Posted online – Accessed 3 January 2012 – 'Palliative Care Atlas in Latin America.' The Association has launched 'Palliative Care Atlas in Latin America.' <u>http://www.eapcnet.eu/LinkClick.aspx?fileticket=8YGIFEqJU40%3d</u>

#### Expressions of loss and separation

### The lament of a broken heart: Mourning and grieving in different cultures. How acceptance of difference creates a bridge for healing and hope

*PROGRESS IN PALLIATIVE CARE*, 2012;20(3):158-162. Working ... with other cultures in the domain of grief, loss, and bereavement, the challenge for practitioners is to be open to difference and remain conscious of their own cultural beliefs, while being aware of their perceptions and interpretations of another's culture. This paper explores some requirements that need to be in place to develop collaboration and sharing of knowledge, wisdom, and experience when working in palliative care on the interface between individual focussed and community focussed cultures and countries. <a href="http://www.ingentaconnect.com/content/maney/ppc/2012/0000020/0000003/art00003">http://www.ingentaconnect.com/content/maney/ppc/2012/0000020/0000003/art00003</a>

Of related interest:

 INTERNATIONAL JOURNAL OF ART THERAPY | Published online – 7 August 2012 – 'Working with loss: An examination of how language can be used to address the issue of loss in art therapy.' <u>http://www.tandfonline.com/doi/abs/10.1080/17454832.2012.707665</u>

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

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: <u>http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c</u>

#### Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <u>http://centres.sg/</u> (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



Shaping end-of-life care: Behavioral economics and advance directives

SEMINARS IN RESPIRATORY & CRITICAL CARE MEDICINE, 2012;33(4):393-400. This article provides a new framework ... that may explain the current failures of ADs [advance directives] and point to potential solutions. The author discusses how five welldescribed cognitive biases that pervade human decision making (affective forecasting errors, optimism bias, present-biased preferences, focusing effects, and default options) may account for deficiencies in the uptake, efficacy, and patient-centeredness of ADs. <u>https://www.thieme-</u> connect.com/ejournals/abstract/10.1055/s-

connect.com/ejournals/abstract/10.1055/s-0032-1322403

# Participant observation at the end-of-life: Reflecting on tears

HEALTH COMMUNICATIONS | Published online – 8 August 2012 – Hospice is a health care setting where expressions of emotions are assumed and their existence can serve important functions for researchers, health care practitioners, patients, and their loved ones. This essay reflects upon one participant's tears, which ultimately challenge the researcher's assumptions about informed consent, the presence and absence of feelings in the field, and whose emotions are suppressed or privileged in health communications research.

http://www.tandfonline.com/doi/abs/10.1080/1041 0236.2012.699888

Of related interest:

- AMERICAN HEART JOURNAL | Published online 13 August 2012 'Preferences of people with advanced heart failure – a structured narrative literature review to inform decision making in the palliative care setting.' <u>http://www.ahjonline.com/article/S0002-8703(12)00387-</u> <u>0/abstract</u>
- JOURNAL OF HEALTH & SOCIAL BEHAVIOR | Published online 16 August 2012 'People with few assets less likely to plan for end-of-life health care.' http://www.cfah.org/hbns/archives/getDocument.cfm?documentID=22542

### Media Watch: Editorial Practice

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

### **Distribution**

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### Links to Sources

- 1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
- 2. Links often remain active, however, for only a limited period of time.
- 3. Access to a complete article, in some cases, may require a subscription or one-time charge.
- **4.** If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.

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

### Something Missed or Overlooked?

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

# Palliative care for patients with gastrointestinal cancer dying under surgical care: A case for acute palliative care units?

THE SURGEON | Published online – 8 August 2012 – A total of 8019 patients died with gastrointestinal cancer on a surgical ward over 12 years. For 4350 (54%), no operation or endoscopy was performed during the final admission and adverse events were identified in only 86 (2%) of these patients, most commonly due to a complication of an interventional procedures. Specialist palliative care was provided to 57% of patients and was not influenced by cancer site. A substantial proportion of patients die with gastrointestinal cancer on general surgical wards without operative or endoscopic intervention and may receive better end of life care in an acute palliative care setting. <u>http://www.thesurgeon.net/article/S1479-666X(12)00076-5/abstract</u>

# Assisted (or facilitated) death

Representative sample of recent articles, etc:

INDIAN JOURNAL OF PSYCHIATRY, 2012;54(2):177-183. 'Euthanasia: An Indian perspective.' . In our society, the palliative care and quality of life issues in patients with terminal illnesses like advanced cancer and AIDS have become an important concern for clinicians. Parallel to this concern has arisen another controversial issue-euthanasia or "mercy -killing" of terminally ill patients. Proponents of physician-assisted suicide (PAS) feel that an individual's right to autonomy automatically entitles him to choose a painless death. The opponents feel that a physician's role in the death of an individual violates the central tenet of the medical profession. Moreover, undiagnosed depression and possibility of social 'coercion' in people asking for euthanasia put a further question mark on the ethical principles underlying such an act. These concerns have led to strict guidelines for implementing PAS. Assessment of the mental state of the person consenting to PAS becomes mandatory and here, the role of the psychiatrist becomes pivotal. Although considered illegal in our country, PAS has several advocates in the form of voluntary organizations like "death with dignity" foundation. This has got a fillip in the recent Honourable Supreme Court Judgment in the Aruna Shanbaug case. What remains to be seen is how long it takes before this sensitive issue rattles the Indian legislature. http://indianjpsychiatry.org/article.asp?issn=0019-5545:vear=2012:volume=54:issue=2:spage=177:epage=183:aulast=Sinha

Of related interest:

- INDIAN JOURNAL OF PSYCHIATRY, 2012;54(2):108-110. 'Euthanasia: Evolving role of the psychiatrists in India.' <u>http://indianjpsychiatry.org/article.asp?issn=0019-5545;year=2012;volume=54;issue=2;spage=108;epage=110;aulast=Chavan
  </u>
- INTERNATIONAL JOURNAL OF MEDICINE & MEDICAL SCIENCES, 2012;4(6):138-141. 'Physicians' attitude about euthanasia and assisted suicide.' [Study participants] agreed euthanasia and [physician] assisted suicide were never ethically justified and stated that they were influenced by religious believes. <a href="http://academicjournals.org/JJMMS/PDF/pdf2012/Aug/Karami%20et%20al.pdf">http://academicjournals.org/JJMMS/PDF/pdf2012/Aug/Karami%20et%20al.pdf</a>
- INTERNATIONAL MEDICAL JOURNAL MALAYSIA, 2012;11(1):63-68. 'Euthanasia and physician-assisted suicide: A review from Islamic point of view.' Due to globalizing trend of homogenisation of culture, changes in the health care delivery system and market economics infringing on the practice of medicine, there has been a gradual shift in the attitude of the medical community as well as the lay public towards greater acceptance of euthanasia as an option for terminally ill and dying patients. Physicians in developing countries come across situations where such issues are raised with increasing frequency. As the subject has gained worldwide prominence, we want to review this topic from Islamic perspective due to its significance in medical ethics and clinical practice. <a href="http://iiumedic.net/imjm/v1/download/Volume%2011%20No%201/IMJM%20Vol11No1-2012-p63-68.pdf">http://iiumedic.net/imjm/v1/download/Volume%2011%20No%201/IMJM%20Vol11No1-2012-p63-68.pdf</a>

# Worth Repeating

## American Sign Language and end-of-life care: Research in the deaf community

*HEC FORUM*,<sup>1</sup> 2002;14(3):197-208. The authors describe a Community-Based Participatory Research process used to develop a means of discussing end-of-life care needs of deaf seniors. This process identified a variety of communication issues to be addressed in working with this special population. They overview the unique linguistic and cultural characteristics of this community and their implications for working with deaf individuals to provide information for making informed decisions about end-of-life care, including completion of health care directives. The authors research and their work with members of the deaf community show that communication and presentation of information should be in American Sign Language, the language of deaf citizens. https://dada.cs.washington.edu/research/projects/compression2/jjtran/Papers/ASSETS%202010/References/fulltext\_5.pdf

1. HealthCare Ethics Committee Forum

Noted in Media Watch, 13 August 2012:

• JOURNAL OF PALLIATIVE CARE, 2012;28(2):105-112. 'Palliative and end-of-life care in Newfoundland's deaf community.' <u>http://www.ncbi.nlm.nih.gov/pubmed/22860383</u>

Barry R. Ashpole Beamsville, Ontario CANADA 'phone: 905.563.0044 e-mail: <u>barryashpole@bellnet.ca</u>