## Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution — to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general — to help keep them abreast of current, emerging and related issues — and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to **Specialist Publications** and 'The art and science of empathy' (p.10), in *European Journal of Palliative Care*.

## U.S.A.

## As they lay dying: Prison inmates find redemption through a hospice program

CALIFORNIA | The New Times (San Luis Obispo) - 13 March 2014 - Roger Brown vividly remembers the first man he helped through death. Brown held vigil over Vernon Burnett, a 42-year-old California Men's Colony [CMC] inmate whom doctors had determined would soon succumb to his pancreatic and liver cancer. Burnett's passing wasn't an easy one. Brown sat up with Burnett the night before he passed away. Brown, himself a California Men's Colony inmate at the time, was a member of Supportive Care Services, a program that teaches inmates to provide hospice care to dying inmates in CMC's hospital. Brown cared for 34 men during his time with the program. In CMC, the program began after an inmate working as a custodian in the prison's hospital overheard the sounds of another inmate dying in one of the hospital rooms. The custodian had been serving his sentence in Vacaville, where the prison offered a hospice program. Tormented by the sound of the dying man, he approached ... Dr. Denise Taylor, and asked if there was anything they could do. <a href="http://www.newtimesslo.com/cover/10697/as-they-lay-dying-prison-inmates-find-redemption-through-a-hospice-program/">http://www.newtimesslo.com/cover/10697/as-they-lay-dying-prison-inmates-find-redemption-through-a-hospice-program/</a>

## **Specialist Publications**

'The grief experience of prison inmate hospice volunteer caregivers' (p.15), in *Journal of Social Work in End-Of-Life & Palliative Care*.

#### The rise of back-to-the-basics funerals

THE NEW YORK TIMES | Online – 11 March 2014 – First there was slow food. Now come slow funerals. On a recent frigid Sunday at the Park Slope Food Coop, Amy Cunningham was giving a PowerPoint talk on green funerals to a graying crowd of about two dozen, many of them note-takers. "I think when the baby boom is of age and we're actively leaving this world, the environmentally friendly approach will be business as usual," she said. "It will not be the odd thing." <a href="http://www.nytimes.com/2014/03/13/fashion/baby-boomers-are-drawn-to-green-and-eco-friendly-funerals.html?hpw&rref=fashion&r=0">http://www.nytimes.com/2014/03/13/fashion/baby-boomers-are-drawn-to-green-and-eco-friendly-funerals.html?hpw&rref=fashion&r=0</a>

# Oklahoma passes protective law to lessen the growing problem of denial of treatment against the wishes of the patient

OKLAHOMA | News Today (National Right to Life) - 10 March 2014 - The Oklahoma House [of Representatives] and Senate, on near unanimous votes, approved the Medical Treatment Laws Information Act ... designed to protect patients from denial of lifepreserving care caused by a health-care provider's lack of awareness of Oklahoma's existing protective laws. Oklahoma has some of the most protective patient laws in the nation. Recently, the state became the first to prevent the involuntary denial of treatment using an anti-discrimination approach drawn from Federal law. Sadly, the involuntary denial of treatment, despite clear advance directives, is a growing problem, not only in Oklahoma, but across all states. There is growing evidence that some in the health-care community ... were not aware of some of the provisions of state law related to provision of life-preserving http://www.nationalrighttolifenews.org/news/ 2014/03/oklahoma-passes-protective-law-tolessen-the-growing-problem-of-denial-oftreatment-against-the-wishes-of-thepatient/#.UyB0Vj9dX8I

### Will your advance directive be followed?<sup>1</sup>

Every state authorizes these legal documents [i.e., advance directives], which allow a person to specify whether and under what circumstances she or he wants life-preserving medical treatment, food or fluids when no longer able to make health care decisions. However, the laws of all but twelve states may allow doctors and hospitals to disregard advance directives when they call for treatment, food, or fluids. Increasingly, healthcare providers who consider a patient's "quality of life" too low are denying life-preserving measures against the will of patients and families - and the laws of most states provide no effective protection against this involuntary denial. In most states, if you want life-saving treatment – or even food and fluids - there is no guarantee your wishes will be honored, even if you make them clear in a valid advance directive.

1. 'Will your advance directive be followed? A Report of The Robert Powell Center for Medical Ethics.' Originally issued in April 2005 and revised in October 2013. <a href="http://www.nrlc.org/uploads/medethics/WillYourAdvance">http://www.nrlc.org/uploads/medethics/WillYourAdvance</a> DirectiveBeFollowed.pdf

Noted in Media Watch, 22 April 2013, #302 (p.3):

OKLAHOMA | Journal Record Legislative Report (Oklahoma City) – Accessed 15 April 2013 – 'Bill prohibiting end-of-life-care discrimination based on patient age, disability or terminal illness approved by Senate committee.' House Bill 1403 – 'Non-discrimination in Treatment Act' – would ban denial of such care on the basis that extending the life of a patient who is elderly, disabled or terminally ill has less value than extending the life of someone who is younger, not disabled or not terminally ill. It also authorizes a legal action against a health care provider who violates the prohibition. <a href="http://jrlr.net/">http://jrlr.net/</a>

N.B. Access to this article requires a subscription.

#### Of related interest:

NEW HAMPSHIRE PUBLIC RADIO | Online – 13 March 2014 – 'New Hampshire Public Radio's Todd Bookman wins journalism award for advance directive series.' Health Reporter Todd Bookman was awarded second place in the 2013 Awards for Excellence in Health Care Journalism by the Association of Health Care Journalists. The organization recognized Todd's series 'Planning for the end: A look at advance directives' in the small market consumer/feature category. In his five-part series, Todd examines efforts to increase the number of people who have advance directives (sometimes called living wills), and the impact for patients who don't have them in place. <a href="http://nhpr.org/post/nhprs-todd-bookman-wins-journalism-award-advance-directive-series">http://nhpr.org/post/nhprs-todd-bookman-wins-journalism-award-advance-directive-series</a>

N.B. Links to the radio series: http://nhpr.org/post/planning-end-look-advance-directives

#### Nursing home standards of care

## One third of skilled nursing patients harmed in treatment

PROPUBLICA | Online - 3 March 2014 -One-in-three patients in skilled nursing facilities [i.e., nursing homes] suffered a medication error, infection or some other type of harm related to their treatment, according to a [recent] government report1 ... that underscores the widespread nature of the country's patient harm problem. Fifty-nine percent of the errors and injuries were preventable. More than half of those harmed had to be readmitted to the hospital at an estimated cost of \$208 million for the month studied about 2% of Medicare's total inpatient spending. Patient safety experts told Pro-Publica they were alarmed because the frequency of people harmed under skilled nursing care exceeds that of hospitals, where medical errors receive the most attention. Doctors working with the inspector general's office reviewed medical records of 653 randomly selected Medicare patients from more than 600 facilities. The doctors found that 22% of patients suffered events that caused lasting harm, and another 11% were temporarily harmed. In 1.5% of cases the patient died because of poor care, the report said.

Though many who died had multiple illnesses, they had been expected to survive. <a href="http://www.propublica.org/article/one-third-of-skilled-nursing-patients-harmed-in-treatment">http://www.propublica.org/article/one-third-of-skilled-nursing-patients-harmed-in-treatment</a>

#### Palliative care perspective

# Extract from U.S. Department of Health & Human Services report

In the case of some resident deaths, physician reviewers found evidence in the medical record that the deaths may have been expected by caregivers, the residents, or family. In one such case, the medical record for the resident's prior hospitalization showed that the hospital physician stopped medical intervention and suggested that the resident seek palliative care at the SNF [skilled nursing facility]. In another case of an elderly resident, the SNF medical record indicated that the resident's family requested palliative care shortly before the resident died of cardiac arrest.

'Adverse Events in Skilled Nursing Facilities: National Incidence Among Medicare Beneficiaries,' Department of Health & Human Services, 2014. <a href="http://oig.hhs.gov/oei/reports/oei-06-11-00370.pdf">http://oig.hhs.gov/oei/reports/oei-06-11-00370.pdf</a>

#### **Specialist Publications**

'Organizational barriers to cultural competence in hospice' (p.7), in American Journal of Hospice & Palliative Medicine.

**'Evaluation of hospice care by family members of Hispanic and non-Hispanic patients'** (p.7), in *American Journal of Hospice & Palliative Medicine.* 

'Assessment of levels of hospice care coverage offered to commercial managed care plan members in California' (p.13), in American Journal of Hospice & Palliative Medicine.

'Integrating care at the end of life: Should Medicare advantage include hospice?' (p.13), in *Journal of the American Medical Association*.

'Resource utilization and end-of-life care in a U.S. hospital following medical emergency team-implemented do not resuscitate orders' (p.16), in *Journal of Hospital Medicine*.

## International

# Latin America has 922 palliative care services, covering only a fraction of the needs in the region

ASOCIACIÓN LATINOAMERICANA DE CUIDADOS PALIATIVOS | Online – 13 March 2014 – Since its start in the eighties, palliative care has developed gradually in Latin America. Currently, there are 922 services in 19 countries or 1.6 services/teams/units per million inhabitants, reflecting the fact that the vast majority of patients with palliative care needs do not have access to treatment. These are some of the data in the Atlas de Cuidados Paliativos en Latinoamerica, developed by the Asociación Latinoamericana de Cuidados Paliativos. This is the first systematic study which presents information on 19 Latin American Countries (Spanish and Portuguese speaking). A cartographic edition of the Atlas was presented during the recent VII Latin American Congress of Palliative Care in Medellin, Colombia. The special edition offers in graphic display and maps the summary of the information compiled for the Atlas. <sup>2</sup>

- 'Atlas de Cuidados Paliativos de Latinoamérica,' Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch, 7 January 2013, #287, (p.8)] Spanish language edition: http://cuidadospaliativos.org/uploads/2012/10/atlas/Atlas%20de%20Cuidados%20Paliativos%20en%20Latinoamerica.pdf; Portuguese language edition: http://cuidadospaliativos.org/uploads/2014/1/Atlas%20Portugues.pdf; English language edition: http://cuidadospaliativos.org/uploads/2013/12/Atlas%20of%20Palliative%20Care%20in%20Latin%20America.pdf
- 'Atlas de Cuidados Paliativos de Latinoamérica: Edición Cartográfica 2013,' Asociación Latinoamericana de Cuidados Paliativos, 2013. [Noted in Media Watch, 2 December 2013, #334 (p.5)] <a href="http://cuidadospaliativos.org/uploads/2014/3/Atlas%20Latinoamerica%20-%20edicion%20cartografica.pdf">http://cuidadospaliativos.org/uploads/2014/3/Atlas%20Latinoamerica%20-%20edicion%20cartografica.pdf</a>

#### **Eco-friendly funerals**

## More sea burials planned to meet rising demand

CHINA | China News Service (Beijing) – 11 March 2014 – The number of people applying to have their loved ones' ashes scattered at sea has been growing by about 3% a year, Gao Jianhua, deputy director of the Funeral Services Center at the Shanghai Civil Affairs Bureau, said. But with just two ferryboats making 20 trips a year, supply has been falling far below demand, he said, adding that applicants often have to wait for up to a year to secure a place. Being made to wait that long can be very upsetting for the families, Gao said. Though sea burials have been around in Shanghai only since 1991, the events are considered solemn affairs that merit proper arrangements and ceremony. The two ferries used by the center carry up to 250 people per trip. Each funeral group can comprise up to six relatives, so the voyages generally involve upward of 40 burials. Once the ashes have been scattered, families return to Binhaiguyuan Cemetery where the names of their late loved ones are carved onto a memorial. The idea of the eco-friendly service was introduced to Shanghai in response to dwindling supplies of land for traditional burials in the city. <a href="http://www.ecns.cn/2014/03-11/104337.shtml">http://www.ecns.cn/2014/03-11/104337.shtml</a>

#### Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

#### End-of-life care in Ireland

## Patients/carers urged to share experiences of palliative care

IRELAND | *The Irish Examiner* (Blackpool, Cork) – 10 March 2014 – The all-Ireland 'Let's Talk About' survey is being conducted by the All-Ireland Institute of Hospice & Palliative Care with support from the Health Service Executive and the Public Health Agency in the North. The qualitative survey asks people with illnesses that may not be cured to share their experiences, both good and bad. People living with conditions such as advanced respiratory disease, cancer, chronic kidney disease, heart failure or dementia can tell their story and help improve policy and services across the island. <a href="http://www.irishexaminer.com/ireland/patientscarers-urged-to-share-experiences-of-palliative-care-261421.html">http://www.irishexaminer.com/ireland/patientscarers-urged-to-share-experiences-of-palliative-care-261421.html</a>

**N.B.** The survey uses a new way to collect a large volume of information on a nation-wide basis. Survey questionnaire: <a href="http://aiihpc.org/upload/policy/files/1394185350">http://aiihpc.org/upload/policy/files/1394185350</a> lets talk about survey.pdf

Noted in Media Watch, 16 December 2013, #336 (p.7):

■ IRELAND | The Irish Times (Dublin) – 10 December 2013 – 'Our citizens will die better in a culture and setting where we can approach, rather than avoid, our mortality.' There is growing literature that points to the fact that death is not a discrete event, and that good end-of-life care is not something that happens in the last few days or weeks of a person's life. <a href="http://www.irishtimes.com/life-and-style/health-family/a-life-dedicated-to-dying-well-1.1622018">http://www.irishtimes.com/life-and-style/health-family/a-life-dedicated-to-dying-well-1.1622018</a>

#### Elder and home care in Israel

#### Ministry: Lack of internal medicine beds, home care, reduces elderly hospital days

ISRAEL | The Jerusalem Post — 9 March 2014 — Despite the aging and growth of the Israeli population, the number of days that patients were hospitalized in internal medicine units has declined since 2000. The reasons are both positive and negative — more are treated by their health funds in the community and there are too few internal medicine beds in medical centers, forcing medical centers to send some patients home prematurely. This was reported in ... 'Hospitalization in Internal Medicine Departments,' recently issued by the Health Ministry. Internal medicine wards are usually populated by the elderly, as they suffer from more com-

plex chronic conditions and need special care by medical teams with multidisciplinary skills in the malfunction of internal organs. <a href="http://www.jpost.com/Health-and-Science/Ministry-Lack-of-internal-medicine-beds-home-care-reduces-elderly-hospital-days-344776">http://www.jpost.com/Health-and-Science/Ministry-Lack-of-internal-medicine-beds-home-care-reduces-elderly-hospital-days-344776</a>

#### **Specialist Publications**

'Quality of dying and death with cancer in Israel' (p.15), in Supportive Care in Cancer.

**N.B.** Access to the Health Ministry's report was not available at the time this issue of Media Watch was distributed.

#### **Media Watch Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.17.

#### End-of-life care in the U.K.

## Marie Curie Cancer Care plea over home pain relief

U.K. (England) | BBC News – 8 March 2014 – Some terminally ill patients are suffering unnecessarily because of poor access to pain control at home, a leading health charity has warned. A report Marie Curie Cancer Care based on 26 detailed interviews found "terrifying" delays for prescriptions and carers feeling "abandoned." And a U.K.-wide online survey of GPs suggests many are worried about support for terminally ill patients at home. National Health Service England says it is developing a programme of action to improve care. Marie Curie Cancer Care says the voices of terminally ill people and carers are often missing from

discussions about end-of-life care. It high-lights what it says is a lack of round-the-clock help for the terminally ill and calls for more support, especially overnight and at weekends. <a href="http://www.bbc.com/news/health-26484111">http://www.bbc.com/news/health-26484111</a>

## **Specialist Publications**

'Seriously ill patients in U.K. will have access to unlicensed drugs' (p.9), in *British Medical Journal*.

- 'Difficult Conversations with Dying People and their Families,' Marie Curie Policy & Public Affairs, March 2014. <a href="http://blog.mariecurie.org.uk/wp-content/uploads/2014/03/S691-Difficult-Conversations-report.pdf">http://blog.mariecurie.org.uk/wp-content/uploads/2014/03/S691-Difficult-Conversations-report.pdf</a>
- 'Less than half of GPs believe the majority of their patients' pain is relieved all the time,' Marie
  Curie Cancer Care with Doctors.net.uk, March 2014. <a href="http://www.mariecurie.org.uk/en-GB/Media/Press-releases-and-comments/Marie-Curie-calls-for-around-the-clock-care-for-terminally-ill-in-England/">http://www.mariecurie.org.uk/en-GB/Media/Press-releases-and-comments/Marie-Curie-calls-for-around-the-clock-care-for-terminally-ill-in-England/</a>

#### Of related interest:

- U.K. | Care Quality Commission 6 March 2014 'Emerging findings from radical new approach to hospital inspection compassionate care is alive and well in the National Health Service.' The Commission has published findings from its 18 pilot hospital inspections completed last year, the first step in a radical change to its approach.<sup>1</sup> The report concludes that compassionate care is alive and well in the National Health Service. However, inspectors found significant variations in quality between trusts and even between services within trusts. <a href="http://www.cqc.org.uk/media/emerging-findings-radical-new-approach-hospital-inspection-%E2%80%93-compassionate-care-alive-and-well">http://www.cqc.org.uk/media/emerging-findings-radical-new-approach-hospital-inspection-%E2%80%93-compassionate-care-alive-and-well</a>
  - 'Our new approach to the inspection of National Health Service acute hospitals: Initial findings from the Wave 1 pilot inspections,' Care Quality Commission, March 2014. http://www.cqc.org.uk/sites/default/files/media/documents/20140305 acute wave 1 report \_\_ final for publishing 2 formatted.pdf

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ U.K. | The Daily Telegraph – 9 March 2014 – 'Assisted suicide moves closer as Government allows free vote.' The legislation of assisted suicide has moved a significant step closer after the government made it clear that it would not stand in the way of a change in the law. Conservative and Liberal Democratic members of parliament and peers – including Coalition members – will be given a fee vote on a Bill that would enable doctors to help terminally ill patients to dies. The proposed legislation will before parliament in the next few months. <a href="http://www.telegraph.co.uk/news/politics/10685362/Assisted-suicide-moves-closer-as-Government-allows-free-vote.html">http://www.telegraph.co.uk/news/politics/10685362/Assisted-suicide-moves-closer-as-Government-allows-free-vote.html</a>

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

## Shifting our view towards palliative care's life-giving role

& **COMPLEMENTARY** ALTERNATIVE THERAPIES, 2014;20(1):31-33. Too often, palliative care has been linked to the notion that, when there is no life-saving treatments for patients, clinicians should call in the palliative care specialists. Both clinicians and patients need to shift that view to understand that palliative care practitioners are, in fact, not just helping people die, but helping live well and live http://online.liebertpub.com/doi/pdfplus/10.1 089/act.2014.20106

#### Of related interest:

IRISH MEDICAL TIMES | Online – 13 March 2014 – 'Palliative care evolves...' As well as increasing our impact on the overall oncological disease burden, palliative care in Ireland and across the globe has been expanding its horizons into palliation of non-malignant disease. http://www.imt.ie/clinical/2014/03/pa lliative-care-evolves-dispelling-themyths.html

## Sir James Reid and the death of Queen Victoria: An early model for end-of-life care

GERONTOLOGIST | Online - 12 March 2014 - It was found that the lack of effective medical interventions, tensions within the Royal Family, the importance of his post to Sir James' professional career, and the political ramifications unavoidably connected with the illness of a head of state, all presented challenges to Reid's efforts to ease the physical and emotional pain of Queen Victoria's dying. Key features of Sir James' approach included reliance on physician-patient and physician-family relationships, emphasis on emotional support for the patient, and the careful selection of interventions for the family. In the first years of the 20th century, an era when the contemporary concepts of palliative care, hospice, and family dynamics did not exist, Sir James' management of the Queen's final illness suggested an early model for end-of-life care. By the end of Queen Victoria's life, Sir James was seen to have preserved his patient's comfort and dignity, at the same time advancing family and societal acceptance of the death of this matriarchal figure. http://gerontologist.oxfordjournals.org/content/earl y/2014/03/11/geront.gnu016.abstract

#### Organizational barriers to cultural competence in hospice

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 12 March 2014 – This national study with directors of 207 hospices identified major barriers to cultural competence: 1) lack of funding for additional staff for community outreach or development of culturally competent programs; 2) lack of applications from diverse professionals; and, 3) lack of knowledge about diverse cultures and what cultural groups in the community are not being served. Results indicated elements of an organizational culture, which create barriers to access included: 1) failure to prioritize cultural competence; 2) failure to budget for culturally competent services; and, 3) a staff that does not value awareness of cultural differences, is uncomfortable with diversity, and stereotypes diverse individuals. http://ajh.sagepub.com/content/early/2014/03/11/1049909113520614.abstract

### Evaluation of hospice care by family members of Hispanic and non-Hispanic patients

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 12 March 2014 – Caregivers of Hispanic patients were more likely to report that hospice was inconsistent with the patient's wishes, and that they received more attention than desired for emotional issues. Caregivers of Hispanic patients were also more likely to express that emotional/spiritual forms of support were insufficient. Similar levels of satisfaction were reported for caregivers of Hispanics and non-Hispanics regarding dignity/respect, information received, care coordination, and overall satisfaction. http://aih.sagepub.com/content/early/2014/03/11/1049909114526969.abstract

Noted in Media Watch, 7 October 2013, #326 (p.3):

U.S. (California) | New America Media – 2 October 2013 – 'Why are Latinos not using palliative and hospice care?' Without change, aging Latinos are reaching the end of their lives unprepared spiritually or financially. Experts believe that the shift needs to happen from within the community, while others say it is a matter of poor cultural sensitivity from service providers. <a href="http://newamericamedia.org/2013/10/why-are-latinos-not-using-palliative-and-hospice-care.php">http://newamericamedia.org/2013/10/why-are-latinos-not-using-palliative-and-hospice-care.php</a>

Noted in Media Watch, 10 September 2012, #270, (p.11, under 'Worth Repeating'):

PALLIATIVE MEDICINE, 2010;24(4):427-434. 'The worst thing about hospice is that they talk about death': Contrasting hospice decisions and experience among immigrant Central and South American Latinos with U.S.-born White, non-Latino cancer caregivers.' This study identifies a significant dilemma: how to discuss hospice with a patient and family who prefer not to discuss a terminal prognosis. <a href="http://pmj.sagepub.com/content/24/4/427.short">http://pmj.sagepub.com/content/24/4/427.short</a>

### Death talk: Gender differences in talking about one's own impending death

BMC PALLIATIVE CARE | Online – 11 March 2014 – Gender differences in terminal care communication may be radically reduced by using simple evocation methods that are relatively unpretentious, but require considerable clinical training. Men in terminal care are more reluctant than women to enter into discussion regarding their own impending death in clinical settings. Intervention based on non-provocative evocation methods may increase death talk in both genders, the relative increase being higher for men. <a href="http://www.biomedcentral.com/content/pdf/1472-684X-13-8.pdf">http://www.biomedcentral.com/content/pdf/1472-684X-13-8.pdf</a>

#### Of related interest:

■ DEATH STUDIES | Online – 10 March 2014 – 'Remembering the initial realization of one's own mortality.' Research shows many effects of reminding people of their mortality; however, little is known about whether people recall the moment they first realized they will die, or what factors are associated with whether they do. Individuals who recall the moment have slightly lower self-esteem, are more likely to believe in a soul, and are more prone to dissociation than those who do not. http://www.tandfonline.com/doi/abs/10.1080/07481187.2013.837990

Noted in Media Watch, 29 November 2010, #177 (p.5):

■ CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 22 November 2010 – 'Preparing for the inevitable.' The human body is not made to last. Sure, some bodies are heartier than others. Some last for more than a century – not many, but a few. Others are far less fortunate, born with disease or genetic defect, their final breaths occurring not long after their first. Some bodies expire suddenly, victims of fires, head-on collisions, massive heart attacks or any number of other calamities that steal life without warning. But the bodies of those fortunate enough to live lives free of premature catastrophe, be it internal or external, follow a more predictable journey. They start out weak and helpless, grow stronger over the course of three decades or so, and then begin a long, slow decline that accelerates near the end of life and culminates, always, in death. Advances in medicine and health education have extended this journey, but no matter how long the road, the mileposts remain the same. The start of this journey is always cause for celebration. The long middle is filled with work and hobbies and the raising of children. The last part of the journey is something that people, in general, don't like to think about. http://www.cmaj.ca/earlyreleases/22nov10-preparing-for-the-inevitable.dtl

### Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-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, exchange of ideas, information and materials. <a href="http://www.pcn-e.com/community/pg/file/owner/MediaWatch">http://www.pcn-e.com/community/pg/file/owner/MediaWatch</a>

## Mental disorders and the desire for death in patients receiving palliative care for cancer

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 5 March 2014 – Most [study] participants (69.5%) had no desire for death. Of the remainder, 69 (18.3%) acknowledged occasional transient thoughts, and 46 (12.2%) reported an apparently genuine desire to die. In the latter group, 24 individuals (52.2%) were diagnosed with a mental disorder and 22 (44.8%) were not. Individuals with no serious desire for death and no mental disorder reported the least distress in physical, social, existential, and psychological symptoms and concerns; those with a mental disorder and a significant desire for death reported the most. The subgroup of patients with a serious desire for death but no concurrent mental disorders still reported increased distress due to physical symptoms and social concerns, as well as a higher prevalence of global suffering. The expression of a desire for death by a terminally ill patient should raise a suspicion about mental health problems, but is not in itself clearly indicative of one. Nevertheless, it may serve as a catalyst to review the individual's physical symptom management and interpersonal concerns, and overall sense of suffering. http://spcare.bmj.com/content/early/2014/03/04/bmjspcare-2013-000604.short

## Seriously ill patients in U.K. will have access to unlicensed drugs

BRITISH MEDICAL JOURNAL | Online – 14 March 2014 – Patients in the U.K. are to be given access to some drugs before they have been formally licensed, in an effort to speed up access. The early access scheme, which was first proposed in 2006 and has been under active discussion for the past two years, will apply to life threatening and seriously debilitating conditions. The first step is for the Medicines & Healthcare Products Regulatory Agency to designate a new drug as a "promising innovative medicine." http://www.bmj.com/content/348/bmj.g2161

## Māori perspectives on hospice care

DIVERSITY & EQUALITY IN HEALTH & CARE, 2014;11(1):61-70. A Kaupapa Māori approach to research shaped this study. Thematic analysis identified: 1) that participants perceived hospice as like a hospital, a place where people died; 2) what they appreciated and wanted from hospice, such as family-centred end-of-life care and respect for Māori cultural practices; 3) what they perceived as problems and barriers to receiving hospice care; and, 4) their potential solutions to these problems, such as community information seminars about the breadth of hospice services. http://www.ingentaconnect.com/content/rmp/dehc/2014/00000011/00000001/art00006

Representative sample of articles on Māori perspectives on life, dying and death noted in past issues of Media Watch:

- THE LANCET, 2010;375(9725):1515-1516. 'Hopeful stories of palliative care in southeast Asia.' Working in a country where Māori the tangata whenua or people of the land have given those of us ... an insight into the cyclical nature of life and death, the importance of spirituality in our understanding of health and the significance of family in decision making, I thought I knew something of the way that palliative care could be delivered in different cultures. Despite providing specialist care for people who are dying for more than two decades, it remains clear to me that each encounter is unique and precious and there are as many ways of dying as there are people who do so. [Noted in Media Watch, 3 May 2010, #147 (p.8)] http://download.thelancet.com/pdfs/journals/lancet/PIIS0140673610606435.pdf
- SOCIAL SCIENCE & MEDICINE, 2010;70(11):1756-1764. 'Māori healers' views on well-being: The importance of mind, body, spirit, family and land.' Māori cultural perspectives influence views of the mind, body and spirit. Healers [i.e., study participants] identified additional aspects as significant and fundamental to a person's health, namely whānaul whakapapa [family and genealogy] and whenua [land]. [Noted in Media Watch, 22 February 2010, #137 (p.10)] <a href="https://www.sciencedirect.com/science/article/pii/S0277953610001231">https://www.sciencedirect.com/science/article/pii/S0277953610001231</a>

## Reflections on neurological palliative care

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2014;21(2):57. There has also been an increasing number of studies and publications, with a recent focus on end-of-life care issues in patients with neurological disease. It is essential to build an evidence base, which will make it easier to educate healthcare professionals, particularly in neurology services, about the needs of patients and their families. In that respect, it is crucial to show that, inpatients with neurological disease, the symptom profile and burden may be slightly different than in cancer patients, but the overall needs are very similar – and they often last over a longer period of time. The European Federation of Neurological Societies and the European Association for Palliative Care have been working on a consensus paper on neurological palliative care, which has been submitted for publication. It is hoped that this will be an additional stimulus for research and collaboration. Neurological palliative care has led us to consider new aspects of care, new interventions, different symptoms and challenging issues, setting an example for how palliative care services should deal with non-cancer diagnoses. It will continue to grow, because there is a need for it. The challenge is to ensure there is close collaboration between services for the benefit of all.

**N.B.** Access to this article requires a subscription. Contents page: http://www.haywardpublishing.co.uk/ year search review.aspx?JID=4&Year=2014&Edition=504

#### Of related interest:

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 12 March 2014 – 'Comparison between home and hospital as the place of death for individuals with amyotrophic lateral sclerosis in the last stages of illness.' Providing family education and ensuring the availability of local family physicians are vital to meeting a patient's desire to die at home. <a href="http://ajh.sagepub.com/content/early/2014/03/11/1049909114525259.abstract">http://ajh.sagepub.com/content/early/2014/03/11/1049909114525259.abstract</a>

Noted in Media Watch, 24 February 2014, #346 (p.13):

NEUROLOGY, 2014:18;82(7):640-642. 'Emerging subspecialties in neurology: Palliative care.' Individuals with conditions including stroke, multiple sclerosis, Parkinson disease, muscular dystrophies, amyotrophic lateral sclerosis, and nervous system malignancies share a host of physical, emotional, and existential symptoms that can be difficult to treat. <a href="http://www.neurology.org/content/82/7/640.extract">http://www.neurology.org/content/82/7/640.extract</a>

**N.B.** Noted in this issue of Media Watch is a representative sample of articles on palliative care for people living with a neurology condition or disorder noted in past issues of the weekly report.

## The art and science of empathy

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2014;21(2):69-71. Empathy, with its potential to improve patients' experience and outcomes, should have a central place in palliative care. In palliative care, where cure is not possible, healing can be facilitated by the establishment of a therapeutic relationship in which empathy plays a crucial role, helping to release the innate potential of the sufferer towards reintegration and wholeness. Evidence from neuroscience shows that empathy has a biological basis and is therefore innate; however, this innate capability can be developed through reflective work, reading, writing and so on.

**N.B.** Access to this article requires a subscription. Contents page: <a href="http://www.haywardpublishing.co.uk/">http://www.haywardpublishing.co.uk/</a> <a href="year\_search\_review.aspx?JID=4&Year=2014&Edition=504">year\_search\_review.aspx?JID=4&Year=2014&Edition=504</a>

Noted in Media Watch, 23 December 2013, #337 (p.14):

■ JOURNAL OF PALLIATIVE MEDICINE | Online – 17 December 2013 – "'Yes it's sad, but what should I do?": Moving from empathy to action in discussing goals of care.' The authors discuss: 1) how affect provides a spotlight that illuminates what is important; 2) how empathy affords a way to connect with patients and families that engages deep values; 3) how clinicians can infer deep values through an associative process with patients; and, 4) how clinicians can then design actions with patients and families and nurture their commitment to the actions. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0197

Noted in Media Watch, 30 September 2013, #325 (p.10):

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 September 2013 – ""Isn't there anything more you can do?" When empathic statements work, and when they don't.' The authors discuss four different opening communication strategies – verbalize empathy, exchange information, contain chaos, respect searching – for patients who ask, "Isn't there anything more you can do?" http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0193

## Assessing decision-making capacity at the end-of-life

GENERAL HOSPITAL PSYCHIATRY | Online – 7 March 2014 – This study is the first to examine decisional capacity in patients with terminal illness relative to legal standards of competence. Although not universal, decisional impairment was common. Clinicians working with terminally ill patients should frequently assess capacity as these individuals are called on to make important medical decisions. Comprehensive assessment will aid clinicians in their responsibility to balance a respect for patient autonomy with their responsibility to protect patients from harm resulting from impaired decisional capacity. <a href="http://www.ghpjournal.com/article/S0163-8343(14)00063-2/abstract">http://www.ghpjournal.com/article/S0163-8343(14)00063-2/abstract</a>

Cont. next page

### **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 and research tool.

### **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.

#### Of related interest:

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online 11 March 2014 'Implementation of a quality improvement programme to support advance care planning in five hospitals across a health region.' This report shows that a targeted approach can result in increased uptake in the number of patients who engage in advance care planning. However, systematic identification of potentially eligible patients requires a significant investment of clinical time and resources. http://spcare.bmj.com/content/early/2014/03/11/bmjspcare-2013-000574.abstract
- INTERNAL MEDICINE, 2014;4(1). 'Influence of an educational manual "code status" choice among hospitalized patients.' After reading a study manual focused on end of life issues, 20% of participants indicated they would change their code status choice in a hypothetical advanced-disease scenario. The manual may represent a useful complementary tool to educate patients about end-of-life options and support their choice regarding code status. <a href="http://www.omicsgroup.org/journals/influence-of-an-educational-manual-code-status-choice-among-hospitalized-patients-2165-8048.1000132.pdf">http://www.omicsgroup.org/journals/influence-of-an-educational-manual-code-status-choice-among-hospitalized-patients-2165-8048.1000132.pdf</a>
- JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online 14 March 2014 'A conceptual model of family surrogate end-of-life decision-making process in the nursing home setting: Goals of care as guiding stars.' This article proposes an empirically derived conceptual model of the key factors family surrogate decision-makers consider when establishing or changing goals of care and the iterative process as applied to the nursing home setting. http://www.tandfonline.com/doi/abs/10.1080/15524256.2013.877863

## Widowhood in old age: Viewed in a family context

JOURNAL OF AGING STUDIES, 2014;29(2):98-106. In a study of family bereavement, 24 widows each participated [in this study]. Three inter-related central topics emerged: 1) widows stress the importance of their independence *vis-à-vis* their family as central to their sense of identity; 2) widows perceive that they and their adult children avoid expressing their feelings of sadness and loss with each other; and, 3) widows believe that their children are unable to understand the meaning of the widows' loss because of differences in generations and life situations. Two interwoven underlying themes emerged: 1) protection of self and of other; and, 2) boundaries between widow and children. Just as protection is rooted in a dynamic of separation between widow and child, boundaries are rooted in their deep bond. When researchers and clinicians recognize the dynamics of these two themes they can potentially increase understanding of widowhood within the context of the family. <a href="http://www.sciencedirect.com/science/article/pii/S0890406514000073">http://www.sciencedirect.com/science/article/pii/S0890406514000073</a>

## Caregiver burden: A clinical review

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2014;311(10):1052-1060. Risk factors for caregiver burden include female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver. Practical assessment strategies for caregiver burden exist to evaluate caregivers, their care recipients, and the care recipient's overall caregiving needs. A variety of psychosocial and pharmacological interventions have shown mild to modest efficacy in mitigating caregiver burden and associated manifestations of caregiver distress in high-quality meta-analyses. Psychosocial interventions include support groups or psycho-educational interventions for caregivers of dementia patients. Pharmacologic interventions include use of anticholinergics or antipsychotic medications for dementia or dementia-related behaviors in the care recipient. Many studies showed improvements in caregiver burden—associated symptoms (e.g., mood, coping, self-efficacy) even when caregiver burden itself was minimally improved. http://jama.jamanetwork.com/article.aspx?articleid=1840211

#### Of related interest:

- JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2014;311(10):1060-1061. 'Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers.' Compared with usual care, home palliative care is associated with increased odds of dying at home and fewer symptoms for patients with advanced illness. It is not associated with changes in caregiver grief. Cost-effectiveness is inconclusive. <a href="http://jama.jamanetwork.com/article.aspx?articleid=1840220">http://jama.jamanetwork.com/article.aspx?articleid=1840220</a>
- PALLIATIVE MEDICINE | Online 13 March 2014 'Quality end-of-life care for dementia: What have family carers told us so far? A narrative synthesis.' There was an overarching theme of "a family's belief of death and their choice of treatment." Further themes were identified to explain family carers' beliefs: the relationship with professionals as a core component of care quality; emotional and commitment pressures of caring and, finally, family carers' ability to think about death and dying. It is difficult to define what constitutes high-quality end-of-life care for people with dementia from the perspective of family carers. Their views ... appear to demonstrate more variation of preference of care and treatment and their uncertainty of this. http://pmi.sagepub.com/content/early/2014/03/12/0269216314526766.abstract

## Integrating care at the end of life: Should Medicare advantage include hospice?

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online - 14 March 2014 - Integrating hospice into the Medicare Advantage program has a number of potential advantages and tradeoffs, both of which are discussed... Moreover, should such a change move forward, important safeguards must be in place to ensure optimal end-of-life care for Medicare beneficiaries. Plans currently have a strong incentive to encourage patients with terminal conditions to enroll in hospice, thereby ending the plans' clinical and financial responsibilities for the care of such patients. However, change in the hospice carve-out may not represent optimal end-of-life care. Removing the hospice carve-out would require plans to coordinate care for all enrollees at the end of life, whether or not they elect hospice, and ideally would encourage plans to integrate hospice and other palliative services with the care they deliver to patients with advanced illness. Perhaps more important, by giving plans greater flexibility in their targeting and delivery of services, eliminating the hospice carve-out could reduce the difficult and arbitrary distinctions that Medicare hospice eligibility criteria force clinicians, patients, and families to make about having an expected prognosis of 6 months or less and about forgoing potentially life-prolonging therapies. Reflecting these challenges to timely enrollment, 28% of Medicare hospice decedents enroll in hospice for 3 or fewer days. An integrated hospice benefit also could diminish concerns about longer hospice stays in the context of per diem hospice payments and shift attention to ensuring high-quality end-of-life care. http://jama.jamanetwork.com/article.aspx?articleid=1849362

## Of related interest:

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 March 2014 – 'Assessment of levels of hospice care coverage offered to commercial managed care plan members in California.' The implementation of the Affordable Care Act that provides for the expansion of affordable insurance to uninsured individuals and small businesses, coupled with the provision of mandated hospice coverage, is expected to increase the enrollment of the terminally ill younger population in hospice care. Compared with Medicare and Medicaid, hospice benefits for privately insured patients, particularly those enrolled in managed care plans, varied widely. <a href="http://aiph.sagepub.com/content/early/2014/03/10/1049909114526298.abstract">http://aiph.sagepub.com/content/early/2014/03/10/1049909114526298.abstract</a>

pg. 13

# Hospice providers' awareness of the benefits and availability of single-fraction palliative radiotherapy

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2014;16(2):67-72. Radiotherapy effectively palliates malignant sources of pain. However, once enrolled on hospice, patients are rarely referred for this treatment. To develop educational strategies that can improve access to care, a survey of hospice providers investigated potential misconceptions about its benefits and availability. Ninety-three percent of hospice professionals stated radiotherapy provides pain relief and is appropriate for patients with more than one month of life expectancy. However, less than 1% of their cancer patients had been referred to a radiation oncologist over the past year. <a href="http://journals.lww.com/jhpn/Abstract/2014/04000/Hospice Providers Awareness of the Benefit">http://journals.lww.com/jhpn/Abstract/2014/04000/Hospice Providers Awareness of the Benefit s and 5.aspx</a>

Noted in Media Watch, 6 January 2014, #339 (p.7):

EUROPEAN JOURNAL OF ONCOLOGY NURSING | Online – 21 December 2013 – 'Why a carefully designed, nurse-led intervention failed to meet expectations: The case of the Care Programme for Palliative Radiotherapy.' After a shift from inpatient to outpatient radiotherapy treatment, patients and healthcare professionals perceived shortcomings in the ontological chain of care. http://www.sciencedirect.com/science/article/pii/S1462388913001610

## Integrating palliative care into critical care: A quality improvement study

JOURNAL OF INTENSIVE CARE MEDICINE | Online – 5 March 2014 – Many terminally ill patients experience an increasing intensity of medical care, an escalation frequently not consistent with their preferences. In 2009, formal palliative care consultation (PCC) was integrated into the authors' medical intensive care unit (ICU). They hypothesized that significant differences in clinical and economic outcomes exist between ICU patients who received PCC and those who did not. Patients [i.e., study participants] who received PCC had higher disease acuity, longer ICU lengths of stay, and higher ICU mortality than controls. "Trigger" programs in the ICU may improve utilization of PCC services, improve patient comfort, and reduce invasive, often futile end-of-life care. http://jic.sagepub.com/content/early/2014/03/04/0885066614523923.abstract

Noted in Media Watch, 17 February 2014, #345 (p.13):

■ THE ONCOLOGY TIMES | Online – 12 February 2014 – 'Palliative care shortens ICU, hospital stays, review data show.' Hospital length of stay decreased with palliative care in 8 of 14 studies (57%), in 43% of 5,817 patients. Family satisfaction did not decrease in any studies or families and increased in only 1 of 14 studies (7%) and in 2% of families of 4,927 patients. <a href="http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/palliative-care-shortens-icu-hospital-stays-review-data-show/3c161a3e6d184048e4b91a5e0001394b.html">http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/palliative-care-shortens-icu-hospital-stays-review-data-show/3c161a3e6d184048e4b91a5e0001394b.html</a>

**N.B.** Noted in this issue of Media Watch is a representative sample of articles on palliative care in the ICU noted in past issues of the weekly report.

# Relationship between pain and chronic illness among seriously ill older adults: Expanding role for palliative social work

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 14 March 2014 – Findings [of this study] suggested positive associations between pain and chronic disease, pain and multi-morbidity, as well as an inverse association between pain and education. Policy implications for workforce development and public health are many. Amplification of palliative social work roles to relieve pain and suffering among seriously ill older adults at all stages of the chronic illness trajectory is needed. <a href="http://www.tandfonline.com/doi/abs/10.1080/15524256.2013.877861">http://www.tandfonline.com/doi/abs/10.1080/15524256.2013.877861</a>

## The grief experience of prison inmate hospice volunteer caregivers

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 14 March 2014 – Correctional institutions are obligated to provide end-of-life care to a population with complex medical needs. Prison hospices are increasingly being formed to address this demand. Few studies have examined the impact of caring for dying inmates on the hospice inmate volunteers, who, in several prison health care systems, provide direct care. Experiences of the inmate hospice volunteers with death were investigated to illuminate their grief processes. Understanding the bereavement needs of hospice volunteers and how they navigate grief and remain committed to providing excellent hospice care can inform the grief processes and practices of hospice care professionals. http://www.tandfonline.com/doi/abs/10.1080/15524256.2013.877866

**N.B.** Articles and reports focused on the provision and delivery of end-of-life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.17.

# The ethics of forgoing life-sustaining treatment: Theoretical considerations and clinical decision making

MULTIDISCIPLINARY RESPIRATORY MEDICINE | Online – 11 March 2014 – Withholding or withdrawing a life-sustaining treatment tends to be very challenging for health care providers, patients, and their family members alike. When a patient's life seems to be nearing its end, it is generally felt that the morally best approach is to try a new intervention, continue all treatments, attempt an experimental course of action, in short, do something. In contrast to this common practice, the authors argue that in most instances, the morally safer route is actually to forego life-sustaining treatments, particularly when their likelihood to effectuate a truly beneficial outcome has become small relative to the odds of harming the patient. The ethical analysis proceeds in three stages. First, the difference between neglectful omission and passive acquiescence is explained. Next, the two necessary conditions for any medical treatment, i.e., that it is medically indicated and that consent is obtained, are applied to life-sustaining interventions. Finally, the difference between withholding and withdrawing a life-sustaining treatment is discussed. In the second part of the paper the authors show how these theoretical-ethical considerations can guide clinical-ethical decision making. http://www.mrmjournal.com/content/9/1/14/abstract

#### Of related interest:

ONCOLOGY NURSING FORUM, 2014;41(2):130-140. 'The nature of ethical conflicts and the meaning of moral community in oncology practice.' [In this study] most ethical conflicts pertained to complex end-of-life situations. Three factors were associated with ethical conflicts: 1) delaying or avoiding difficult conversations; 2) feeling torn between competing obligations; and, 3) the silencing of different moral perspectives. Moral communities were characterized by respectful team relationships, timely communication, ethics-minded leadership, readily available ethics resources, and provider awareness and willingness to use ethics resources. Moral disagreements are expected to occur in complex clinical practice. However, when they progress to ethical conflicts, care becomes more complicated and often places seriously ill patients at the epicenter. http://ons.metapress.com/content/1480t1633388247i/

## Quality of dying and death with cancer in Israel

SUPPORTIVE CARE IN CANCER | Online – 4 March 2014 – This retrospective study ... demonstrated that the overall quality of dying and death was regarded as poor by almost half of the caregivers. These findings may reflect the relative lack of specialized palliative care and advance care planning in Israel at the time of this study, which took place between 2006 and 2009. Further research and enhancement of palliative care resources may be needed in Israel and several encouraging recent developments (e.g., staff training and legislation) suggest that such changes are now underway. http://link.springer.com/article/10.1007/s00520-014-2163-x#

## Family presence during resuscitation: Attitudes of Yale-New Haven hospital staff

YALE JOURNAL OF BIOLOGY & MEDICINE, 2014;87(1):63-72. A novel paradigm of patient-and family-centered care has been promoted and adopted by many parties in the U.S. This new attitude emphasizes the role of the family in the care of the patient. One topic that should be affected by the new paradigm is family presence during resuscitation, which continues to be a highly debatable topic with no widespread implementation. Seventy-seven percent of staff members favored allowing the option of family presence during resuscitation. Seventy-six percent of staff members believed that family members would want to be present during their loved one's resuscitation. <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3941452/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3941452/</a>

Noted in Media Watch, 18 March 2014, #297 (p.4):

New England Journal of Medicine | Online – 14 March 2013 – 'Family presence during cardiopulmonary resuscitation.' Relatives [i.e., study participants] who did not witness CPR had symptoms of anxiety and depression more frequently than those who did witness CPR. Family-witnessed CPR did not affect resuscitation characteristics, patient survival, or the level of emotional stress in the medical team, and also did not result in medico-legal claims. http://www.nejm.org/doi/full/10.1056/NEJMoa1203366?query=featured home

#### Of related interest:

- BMC ANESTHESIOLOGY | Online 8 March 2014 'Development, validation, and results of a survey to measure understanding of cardiopulmonary resuscitation choices among ICU patients and their surrogate decision makers.' A substantial proportion of ICU patients and surrogates decision-makers [i.e., survey respondents] have poor knowledge of CPR and basic resuscitation options. <a href="http://www.biomedcentral.com/content/pdf/1471-2253-14-15.pdf">http://www.biomedcentral.com/content/pdf/1471-2253-14-15.pdf</a>
- JOURNAL OF HOSPITAL MEDICINE | Online 6 March 2014 'Resource utilization and end-of-life care in a U.S. hospital following medical emergency team-implemented do not resuscitate orders.' Patients with medical emergency team-implemented DNR orders had relatively low utilization of end-of-life resources, including palliative care consultation, and home hospice services. <a href="http://onlinelibrary.wiley.com/doi/10.1002/jhm.2183/abstract">http://onlinelibrary.wiley.com/doi/10.1002/jhm.2183/abstract</a>

## **Worth Repeating**

Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals

PALLIATIVE MEDICINE, 2006;20(7):703-710. It is not uncommon for patients with advanced incurable disease to express a desire to hasten their death. Health professionals often have difficulty responding to such statements, and find it challenging to ascertain why these statements are made. Health professionals may struggle to determine whether a "desire to die" statement (DTDS) is about a request for hastened death, a sign of psychosocial distress, or merely a passing comment that is not intended to be heard literally as a death wish. Given the lack of guidelines to assist health professionals with this issue, the authors prepared multidisciplinary recommendations for responding to a DTDS, underpinned by key principles of therapeutic communication and a systematic review of empirical literature. Where the relevant literature was lacking, the recommendations were drafted by the authors (clinicians and/or academics from the following disciplines: nursing, medicine, psychiatry, psychology, sociology, aged care and theology), based on their expert opinion. Multiple drafts of the recommendations were circulated to the authors for refinement until consensus was reached. Strategies for advancing the evidence base for the maturation of guidelines in this area are offered. http://pmi.sagepub.com/content/20/7/703.abstract

### **Media Watch Online**

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <a href="http://hospicecare.com/about-iahpc/newsletter/2014/3/media-watch/">http://hospicecare.com/about-iahpc/newsletter/2014/3/media-watch/</a>

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

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

PALLIMED (Hospice & Palliative Medicine Blog): <a href="http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html">http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html</a> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

#### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <a href="http://centres.sg/updates/international-palliative-care-resource-center-media-watch/">http://centres.sg/updates/international-palliative-care-resource-center-media-watch/</a>

#### Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <a href="http://palliativecarewa.asn.au/site/helpful-resources/">http://palliativecarewa.asn.au/site/helpful-resources/</a> [Scroll down to 'International Websites' and <a href="http://www.ipcrc.net/archive-global-palliative-care-news.php">www.ipcrc.net/archive-global-palliative-care-news.php</a> to access the weekly report]

#### Canada

ONTARIO | Central Regional Hospice Palliative Care Program: http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health Practitioners/resources.htm?mediawatch=1

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/inthenews.html

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

ONTARIO | Palliative Care Consultation Program (Oakville): <a href="http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/">http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/</a> [Scroll down to 'Additional Resources']

#### Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <a href="http://www.eapcnet.eu/Themes/Organization/Links.aspx">http://www.eapcnet.eu/Themes/Organization/Links.aspx</a> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <a href="http://www.hospicehaz.hu/en/training/">http://www.hospicehaz.hu/en/training/</a> [Scroll down to 'Media Watch']

U.K. | Omega, the National Association for End-of-Life Care: <a href="http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c">http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c</a>

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