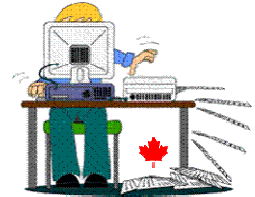


## **Media Watch...**

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.

**2 September 2013 Edition | Issue #321**



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

**Compiled & Annotated by Barry R. Ashpole**

**The use of professional bereavement services: Scroll down to [Specialist Publications](#) and "But I do believe you've got to accept that that's what life's about": Older adults living in New Zealand talk about their experiences of loss and bereavement support' (p.8), in *Health & Social Care in the Community*.**

## **U.S.A.**

### **Exchanging a blanket for a code blue**

*THE ATLANTIC* | Online – 29 August 2013 – When a physician, nurse, or other health professional calls a "code blue," the crash cart is rushed to the patient's room and put to work. Chest compressions can be used to try keep blood circulating, a defibrillator can deliver a shock to restart the heart, and a host of medications and other equipment can be brought to bear in an attempt to save the patient's life. In some cases, a rapid response can make the difference between life and death. But it is also important to know that the vast majority of patients who undergo in-hospital resuscitation do not survive to discharge. In reality, fewer than 20% of such patients leave the hospital alive. When a patient is suffering from a terminal illness, the probability of survival from a resuscitation attempt decreases almost to zero. Knowing they are nearing the end, many patients and families opt for "Allow Natural Death" (formerly "Do Not Resuscitate") status. <http://www.theatlantic.com/health/archive/2013/08/exchanging-a-blanket-for-a-code-blue/279125/>

Noted in Media Watch, 9 July 2012, #261 (p.11):

- *HEC FORUMS* | Online – 1 July 2012 – '**Allow-Natural-Death (AND) orders: Legal, ethical, and practical considerations.**' Conversations with patients and families about the allow-natural-death (AND) order, along with the standard do-not-resuscitate (DNR) order during end-of-life (EOL) decision-making, may create engagement and understanding while promoting care that can be defended using enduring notions of autonomy, beneficence, and professional duty. <http://www.springerlink.com/content/112grh2277342362/>

**N.B.** Footnoted is articles on allow-natural death noted in past issues of Media Watch.

### **Media Watch Online**

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.12.

## New federal regulations affect nursing homes, hospices

PENNSYLVANIA | National Public Radio News – 27 August 2013 – Long-term facilities such as skilled nursing homes or facilities for people with intellectual disabilities often work with hospices. In some cases it goes well. But in other cases, communication can go by the wayside, affecting quality of patient care. New federal regulations from the Centers for Medicare & Medicaid hope to smooth the transition between the facilities as well as give the patient more choice. They went into effect on Monday. "What it translates to for the patients and families that have a loved one residing in a nursing facility is that they cannot be denied access to care by regulation," said Barbara Ivanko ... of Family Hospice & Palliative Care, one of hundreds of hospices in Pennsylvania. "By regulation, the nursing facility has to make sure that they are provided with care by the hospice of their choice even if that facility they themselves cannot provide it." <http://wesa.fm/post/new-federal-regulations-affect-nursing-homes-hospices>

### Patients in long-term care facilities basically now have two options:

**Option 1:** They can arrange for hospice services through an agreement with one or more Medicare-certified hospices.

**Option 2:** They cannot arrange for hospice services at the facility they are at, and the facility has to assist the patient by transferring them to a facility that will arrange for the provision of hospice services when the patient requests that transfer.

### [Specialist Publications](#)

'Geriatric palliative care in long-term care settings with a focus on nursing homes' (p.11), in *Journal of Palliative Medicine*.

'Service use at the end-of-life in Medicare Advantage versus traditional Medicare' (p.11), in *Medical Care*.

## Planning for the end: New Hampshire's advance directive gets an update

NEW HAMPSHIRE | National Public Radio News – 26 August 2013 – New Hampshire's advance directive form is getting an update. Governor Hassan is signing a bill that seeks to streamline and simplify the document. Advance directives ... let people decide who can make medical decisions for them and what invasive treatments should be avoided at the end of life. Many in the healthcare system say they are vital plans that ensure a patient's voice is heard, but only 25% of

Granite Staters have signed advance directives. <http://nhpr.org/post/planning-end-new-hampshires-advance-directive-gets-update>

### [Specialist Publications](#)

'Similarity agreement and assumed similarity in proxy end-of-life decision making' (p.7), in *Families, Systems & Health*.

**N.B.** New Hampshire is a state known for its extensive granite formations and quarries.

Of related interest:

- NEW HAMPSHIRE | National Public Radio News – 27 August 2013 – **'Planning for the end: Talking about death often stands in the way.'** A survey from the National Hospice Foundation finds that Americans are more comfortable talking to their kids about sex than they are talking to their elderly parents about death. End-of-life remains simply a taboo subject in many households. <http://nhpr.org/post/planning-end-talking-about-death-often-stands-way>

Noted in Media Watch, 15 July 2013, #314 (p.1):

- NEW HAMPSHIRE | *The Union Leader* (Manchester) – 12 July 2013 – **'Hassan vetoes bill to form end-of-life study committee.'** Governor Maggie Hassan issued her first veto of her term, rejecting as unnecessary legislation that created a committee to study "end-of-life decisions." <http://www.unionleader.com/article/20130712/NEWS06/130719713>

## Huge shortage of caregivers looms for baby boomers, report says

*THE WASHINGTON POST* | Online – 26 August 2013 – Americans should expect an enormous shortage in caregivers for older people in the coming decades, with a dearth of friends and family members available to care for the baby-boom generation as it ages, according to a new report<sup>1</sup> ... [which] ... projects that by 2030 there will be only four potential caregivers available for each person 80 or older, down from a high of more than seven in 2010. By 2050, when boomers are between 86 and 104, the ratio will drop below 3 to 1. Currently, about 14% of potential caregivers ... provide care for someone 80 or older, 9% care for someone 60 to 79, and 7% care for someone 18 to 59. [http://www.washingtonpost.com/national/health-science/huge-shortage-of-caregivers-looms-for-baby-boomers-report-says/2013/08/25/665fb2aa-0ab1-11e3-b87c-476db8ac34cd\\_story.html](http://www.washingtonpost.com/national/health-science/huge-shortage-of-caregivers-looms-for-baby-boomers-report-says/2013/08/25/665fb2aa-0ab1-11e3-b87c-476db8ac34cd_story.html)

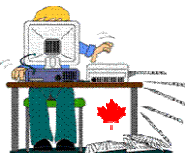
1. 'The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers,' American Association for Retired Persons, August 2013. [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf)

**N.B.** The research quoted in the report was presented in a submission to a recent congressional long-term care commission. [See 'The disappearing family caregiver,' *Forbes*, 26 July 2013, noted in Media Watch, 29 July 2013, #316 (p.1)] <http://www.forbes.com/sites/howardgleckman/2013/07/26/the-disappearing-family-caregiver/>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *FORBES* | OpEd – 26 August 2013 – '**Death with dignity should not be equated with physician assisted suicide.**' I have long contended that in rare circumstances, physician assisted suicide is a compassionate and morally appropriate policy. Nor am I worried about the way the Washington law has worked in practice. Indeed, a ... [recent study] ... demonstrates that patients have chosen assisted suicide sparingly, and without undue coercion from clinicians urging them to "off themselves." My beef is not with the letter of the Washington law, it's with the name. I think it is wrong-headed to equate assisted suicide with the concept of a dignified death. Such a link unduly narrows the concept of dignity, and potentially undermines our ability as clinicians to help patients find other ways of achieving a dignified death. <http://www.forbes.com/sites/peterubel/2013/08/26/death-with-dignity-should-not-be-equated-with-physician-assisted-suicide/>
1. 'Implementing a death with dignity program at a comprehensive cancer center,' *New England Journal of Medicine*, 2013;368(15):1417-1424. As more states consider legislation regarding physician-assisted death, the experience of a comprehensive cancer center may be informative. <http://www.nejm.org/doi/full/10.1056/NEJMsa1213398>



### [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>

## International

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

#### **Experts to examine end-of-life care after axing of Liverpool Care Pathway**

U.K. | *The Guardian* – 29 August 2013 – The government is expected to announce a new coalition on end-of-life care in response to the scrapping of the controversial Liverpool Care Pathway (LCP).<sup>1</sup> The Leadership Alliance for the Care of Dying People will bring together health and social care groups to improve care for people at the end of their lives. It was announced last month that the controversial LCP would be axed. In response, Norman Lamb, care and support minister, ordered National Health Service hospitals to undertake reviews of the care given to dying patients. He also ordered hospital bosses to ensure that in future all

patients had a named senior clinician responsible for their care in their final hours and days of life. Financial incentives to put people on the regime would be scrapped. <http://www.theguardian.com/society/2013/aug/29/experts-life-care-liverpool-care-pathway>

#### Specialist Publications

**'Can the NICE "end-of-life premium" be given a coherent ethical justification?' (p.10), in *Journal of Health Politics, Policy & Law*.**

1. *Independent Report: Review of Liverpool Care Pathway for dying patients*, Department of Health [England], July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

**N.B.** The alliance will provide guidance on what needs to occur in place of the LCP and will work with end-of-life healthcare professionals, patients and families on what good care means. It will also consider how to implement recommendations around the accountability and responsibility of individual clinicians, out-of-hours decisions, nutrition and hydration, and communication with the patient and their relatives or carers. The Care Quality Commission, the Department of Health, the National Institute for Health and Care Excellence and the Nursing and Midwifery Council are among those who have signed up.

Of related interest:

- U.K. | National Health Service (Improving Quality) – 29 August 2013 – **'Sharing successful strategies for implementing "Supporting people to live and die well."** In 2010 the National End of Life Care Programme launched 'Supporting People to Live and Die Well: A framework for social care at the end of life.' The framework provided a focus and stimulus for delivering end of life care improvements across social care. A progress report is now available. <http://www.nhs.uk/resource-search/publications/sharing-successful-strategies-for-implementing-%E2%80%98supporting-people-to-live-and-die-well.aspx>
- U.K. (ENGLAND) | *The Lancashire Telegraph* – 27 August 2013 – **'East Lancashire hospitals have large increase in "palliative" deaths.'** The proportion of palliative deaths at Royal Blackburn and Burnley General hospitals stood at about 2% from 2003-2010, but jumped to around 10% for the past three years. Rineke Schram, medical director, said: "Despite a rise in the number of deaths coded as palliative within our trust, the percentage of patients who die and coded as having had palliative care is quite low compared with the national picture. We only code cases as receiving palliative care when a member of the palliative care team has been involved in the care of the patient, as required by the coding rules." [http://www.lancashiretelegraph.co.uk/news/10635492.East\\_Lancashire\\_hospitals\\_have\\_large\\_increase\\_in\\_palliative\\_deaths/](http://www.lancashiretelegraph.co.uk/news/10635492.East_Lancashire_hospitals_have_large_increase_in_palliative_deaths/)

## Elder care in the U.K.

### **Thousands of care home residents face uncertainty as one third of businesses risk collapse under a mountain of debt**

U.K. | *The Daily Mail* – 26 February 2013 – One in three care home businesses is at risk of going bust due to "off-the-scale" levels of borrowing. An examination of the accounts of nearly 5,000 companies, responsible for 20,000 care homes across the U.K., will ring alarm bells following the collapse of Southern Cross. Formerly the largest operator in the sector, Southern Cross went under in 2011 when it was unable to pay a £250 million rent bill, bringing misery and anxiety to more than 30,000 elderly residents and their families. Under plans unveiled this year, the Care Quality Commission is to start making

checks on the finances of care homes. <http://www.dailymail.co.uk/news/article-2401970/Thousands-care-home-residents-face-uncertainty-1-3-businesses-risk-collapse.html>

#### Specialist Publications

'Death and dying in residential care: A matter of concern' (p.11), in *Quality in Ageing & Older Adults*.

### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- AUSTRALIA | *Retirement & Estate Planning Bulletin* – Accessed 26 August 2013 – '**Assisted suicide where the "assistor" is a beneficiary under the deceased's will and/or attorney under a power of attorney granted by the deceased: What are the potential consequences?**' The recent criminal conviction of a Queensland teacher for aiding the suicide of an elderly acquaintance raises some timely issues, particularly for succession lawyers. [http://lexisweb.lexisnexis.com.au/JournalOverview.aspx?id=201215REP00200002\\_00004](http://lexisweb.lexisnexis.com.au/JournalOverview.aspx?id=201215REP00200002_00004)
- NEW ZEALAND | *Stuff.co.nz* (Auckland) – 26 August 2013 – '**Elderly suicide rate "higher than others."**' Men aged 85 years and older are committing suicide at a higher rate than any other age group, Chief Coroner Judge Neil MacLean said in releasing annual suicide statistics. The line between euthanasia and suicide was grey and there needed to be more research into why and where older people were committing suicide, Judge MacLean said. In the year to June nine men aged 85 or older committed suicide at a rate of 31 per 100,000. <http://www.stuff.co.nz/national/9088438/Elderly-suicide-rate-higher-than-others>

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

### **How and when to refer a child for specialist paediatric palliative care**

*ARCHIVES OF DISEASE IN CHILDHOOD EDUCATION & PRACTICE* | Online – 23 August 2013 – Specialist paediatric palliative care is a relatively new area of paediatrics, and the interface with other disciplines can occasionally pose challenges for referrers due to lack of information about the diverse services available. Although services vary on a regional basis, there are common principles which may be used to guide and support referrals. Children may be referred to palliative care services via a number of routes from community-based primary care to regional tertiary centres. Identifying those most likely to benefit from the finite resources available can be a challenge, and healthcare professional's negative attitudes to palliative care have been further identified as a potentially modifiable barrier. This article aims to clarify the role of specialist paediatric palliative care, identify who should be eligible for such care, describe the services available (including those from children's hospices) and provide a tool for assessing some of the most challenging referrals. <http://ep.bmj.com/content/early/2013/08/23/archdischild-2012-303325.abstract>

Cont.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 22 August 2013 – **'A comparison of pediatric critical care and oncology providers.'** Critical care physicians [i.e., survey respondents] were more likely to incorporate palliative care for psychosocial support; oncologists for symptom control. Those with palliative care education were more likely to involve in palliative care, did so earlier and for reasons other than end-of-life planning. <http://ajh.sagepub.com/content/early/2013/08/19/1049909113500844.abstract>
- *JAMA PEDIATRICS* | Online – 26 August 2013 – **'Clinician perspectives regarding the do-not-resuscitate order.'** While data exist regarding the frequency and timing of the do-not-resuscitate (DNR) order in children, little is known about clinician attitudes and behaviors regarding this order. There was substantial variability [in this study] in the interpretation of the DNR order. <http://archpedi.jamanetwork.com/article.aspx?articleid=1730533>
- *JOURNAL OF SUPPORTIVE ONCOLOGY*, 2013;11(3):114-125. **'Best practices for pediatric palliative cancer care: A primer for clinical providers.'** This review focuses on the principles of best practice in the provision of palliative care for children and adolescents with cancer. Topics unique to pediatric palliative care that are addressed include: providing pain and symptom management in the broad pediatric range from neonate to adolescent; caring for and interacting with developmentally distinct groups; engaging in shared decision making with parents and adolescents; providing accommodations for prognoses that are often more uncertain than in adult patients; and delivering concurrent disease-directed therapy with palliative care. [http://www.oncologypractice.com/fileadmin/content\\_images/jso/PDF/vol11-no3\\_Ped\\_Pall\\_Canc\\_Care.pdf](http://www.oncologypractice.com/fileadmin/content_images/jso/PDF/vol11-no3_Ped_Pall_Canc_Care.pdf)
- *OMEGA – JOURNAL OF DEATH & DYING*, 2013;67(3):291-303. **'Complicated grief in children: The perspectives of experienced professionals.'** Analyses showed the professionals struggled with defining complicated grief in children, although they agreed the major defining aspects were intensity, duration, and longevity of reactions. They identified traumatic and delayed or inhibited grief as major types and also agreed adult criteria were inappropriate for children. [http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue\\_3,5;journal,1,265;linkingpublicationresults,1:300329,1](http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue_3,5;journal,1,265;linkingpublicationresults,1:300329,1)

#### **End-of-life care in Canada**

#### **A qualitative study examining the sustainability of shared care in the delivery of palliative care services in the community**

*BMC PALLIATIVE CARE* | Online – 29 August 2013 – This paper focuses on the sustainability of existing palliative care teams that provide home-based care in a shared care model. For the purposes of this study ... sustainability is understood and approached as the ability to continue the program over time. Understanding factors that influence the sustainability of teams and ways to mitigate these factors is paramount to improving the longevity and quality of service delivery models of this kind. Sustainability was conceptualized from two angles: internal and external. An overview of external sustainability was provided and the merging of data from all participant groups showed that the sustainability of teams was largely dependent on actors and organizations at the local (community), regional (Local Health Integration Network or LHIN) and provincial scales. The three scales are not self-contained or singular entities but rather are connected. Integration and collaboration within and between scales is necessary, as community capacity will inevitably reach its threshold without support of the province, which provides funding to the LHIN. While the community continues to advocate for the teams, in the long-term, they will need additional supports from the LHIN and province. The province has the authority and capacity to engrain its support for teams through a formal strategy. The recommendations are presented based on scale and in priority order to better illustrate how actors and organizations could move forward. <http://www.biomedcentral.com/content/pdf/1472-684X-12-32.pdf>

Cont.

Of related interest:

- *RESEARCH & THEORY FOR NURSING PRACTICE*, 2013;27(2):95-114. **'Comfort measures: A concept analysis.'** Comfort measures involve an active, strategic process including elements of "stepping in" and "stepping back," are both simple and complex, move from a physical to a holistic perspective, and are a part of supportive care. Although the concept of comfort measures is often associated with end-of-life care, this analysis suggests that comfort measures are appropriate for nursing care in all settings and should be increasingly considered in the clinical management of patients living with multiple, chronic comorbidities. <http://www.ingentaconnect.com/content/springer/rtnp/2013/00000027/00000002/art00004>

### Defining the practice of "no escalation of care" in the ICU

*CRITICAL CARE MEDICINE* | Online – 28 August 2013 – Withdrawal or withholding of life-sustaining therapies precedes most deaths in the modern ICU. As goals of care for critically ill patients change from curative to palliative, this transition often occurs abruptly, but a slower more staggered approach may also be used. One such approach is "no escalation of care", often the first step in this transition at the end-of-life. [The findings of this study indicate] no escalation of care designation occurs in a significant proportion of ICU decedents shortly before death. Some interventions are more likely to be limited than others using a no escalation of care approach. [http://journals.lww.com/ccmjournal/Abstract/publishahead/Defining\\_the\\_Practice\\_of\\_No\\_Escalation\\_of\\_Care\\_.97745.aspx](http://journals.lww.com/ccmjournal/Abstract/publishahead/Defining_the_Practice_of_No_Escalation_of_Care_.97745.aspx)

### Similarity agreement and assumed similarity in proxy end-of-life decision making

*FAMILIES, SYSTEMS & HEALTH* | Online – 19 August 2013 – Medical decisions near the end of life are often made by proxies who can be inaccurate in their judgments of patient preferences. Given that accuracy in surrogate decision making is an important goal in end-of-life decision making, and in light of that previously seen levels of accuracy reflect substantial disagreement, error, or both, this study examined both relationship and individual factors that potentially affect surrogate accuracy. Specifically, this study examined similarity, agreement, and assumed similarity – a process whereby raters use their own traits and preferences to rate another person – in spousal ratings of end-of-life treatment. This study expands on previous research by examining the potential influence of relationship factors and assumed similarity on end-of-life decision making among a sample of newlyweds. Results indicate a moderate level of similarity on husband and wife self-rated end-of-life treatment preferences and a moderate level of agreement between self and proxy ratings. The largest correlations were seen between self ratings and proxy ratings reflecting strong assumed similarity in proxy ratings. For wives, similarity with husbands on a few attitudinal variables (i.e., spirituality, moral strictness, and conservatism) influenced proxy accuracy. Recognizing the potential impact of personal preferences on proxy ratings, as well as the potential influence of relationship factors, may help improve proxy accuracy and end-of-life care for patients and families. <http://psycnet.apa.org/psycinfo/2013-29664-001/>

Of related interest:

- *JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED*, 2013;24(3):979-986. **'Wishes left unspoken: Engaging underserved populations in end-of-life advance care planning.'** This column highlights barriers to end-of-life advance care planning among medically underserved populations and discusses opportunities for greater engagement. [http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/journal\\_of\\_health\\_care\\_for\\_the\\_poor\\_and\\_underserved/v024/24.3.hilliard.html](http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/journal_of_health_care_for_the_poor_and_underserved/v024/24.3.hilliard.html)
- *LEGAL STUDIES* | Online – 29 August 2013 – **'Advance decision making – rhetoric or reality?'** The paper explores recent [U.K.] case-law and its impact on the effectiveness of advance decisions refusing treatment in practice and compares with advance care planning. <http://onlinelibrary.wiley.com/doi/10.1111/lest.12031/abstract>

**"But I do believe you've got to accept that that's what life's about": Older adults living in New Zealand talk about their experiences of loss and bereavement support**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 28 August 2013 – This paper explores older people's views, experiences and sources of bereavement support following the death of a spouse, family member or other significant individual. Findings indicate that family and friends play a fundamental role supporting older bereaved adults, both emotionally and practically. Existing community-based organisations were identified as an important source of support following bereavement. Despite the emotional, financial and practical challenges associated with bereavement, the majority of participants questioned the role of, need for and value of formal bereavement support services. Instead, study participants cited a combination of being older and previous life experiences as factors that had enabled them to cope with these largely "expected" events. Moreover, they demonstrated considerable resilience in managing the emotional and practical changes associated with

loss and bereavement. The paper highlights the value of adopting a public health-based approach as a way of optimising bereavement support via the use of existing community organisations previously known to older people. This is important in those countries where the provision of bereavement support is limited due to resource constraints. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12069/abstract>

**Extract from *Health & Social Care in the Community* article:**

This study poses a challenge to the argument that the growing secularisation of society has led to an increase in the use of professional bereavement services over more "traditional" forms of support, such as family, friends and community and religious organisations.

**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.



## Spiritual concerns in Hindu cancer patients undergoing palliative care: A qualitative study

*INDIAN JOURNAL OF PALLIATIVE CARE*, 2013;19(2):99-105. The seven most common spiritual concerns reported were benefit of *pooja*, faith in God, concern about the future, concept of rebirth, acceptance of one's situation, belief in *karma*, and the question "Why me?" No participant expressed four of the concerns studied: loneliness, need of seeking forgiveness from others, not being remembered later, and religious struggle. There are spiritual concerns reported by patients receiving palliative care. The qualitative descriptions give a good idea about these experiences, and how patients deal with them. The study indicates the need for adequate attention to spiritual aspects during palliative care. <http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2013;volume=19;issue=2;spage=99;epage=105;aualast=Simha;type=0>

Of related interest:

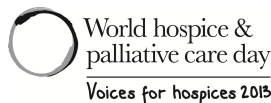
- *ONLINE JOURNAL OF HEALTH & ALLIED SERVICES* | Online – 25 August 2013 – '**Factors related to life satisfaction, meaning of life, religiosity and death anxiety in health care staff and students: A cross-sectional study from India.**' Death is beyond one's personal control, generates great concern and anxiety, among human beings. Studies exploring the association between religious attitudes and death attitudes in adolescents and young adults in postmodern society are scarce. This study examines the relationship between five dimensions of attitude toward death (fear of death, death avoidance, neutral acceptance, approach acceptance, and escape acceptance), death anxiety, life satisfaction and meaning, religiosity and selected personal factors among health care staff and students in three teaching hospitals. <http://www.ojhas.org/issue46/2013-2-7.html>

Noted in Media Watch, 26 November 2012, #281 (p.11):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 22 November 2012 – '**A Hindu perspective on dying and death.**' The authors review the medical, psychiatric, and (to a limited extent) religious literature on the Hindu perspective on death and dying, and provide examples of how physicians can address one aspect of "cultural competency" as it relates to end-of-life care. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8756425&fulltextType=BT&fileId=S1478951512000946>

Noted in Media Watch, 20 September 2010, #167 (p.9):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 15 September 2010 – '**Hindu end of life: Death, dying, suffering, and karma.**' With almost 2.3 million Hindus of Indian origin and an additional 1 million practicing American Hindus now in the U.S., healthcare practitioners need to know more about the tenets of Hinduism to provide culturally sensitive care. [http://journals.lww.com/jhpn/Abstract/publishahead/Hindu\\_End\\_of\\_Life\\_Death,\\_Dying,\\_Suffering,\\_and.99999.aspx](http://journals.lww.com/jhpn/Abstract/publishahead/Hindu_End_of_Life_Death,_Dying,_Suffering,_and.99999.aspx)



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

12 October 2013

### [Media Watch posted on Palliative Care Network-e Website](#)

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

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

### **Can the NICE "end-of-life premium" be given a coherent ethical justification?**

*JOURNAL OF HEALTH POLITICS, POLICY & LAW* | Online – 23 August 2013 – In 2009 the U.K. National Institute for Health & Clinical Excellence (NICE) announced that its health technology appraisal committees would henceforth give special additional weight to health gains from life-extending end-of-life treatments. This was a response to mounting concern from NICE's stakeholders that effective new drugs for end-stage cancer often fail NICE's standard test of cost effectiveness. This change of policy may be justifiable on procedural grounds as the result of a democratic political process responding to stakeholder concerns. However, according to the "accountability for reasonableness" framework proposed by the philosopher Norman Daniels and endorsed by NICE, there also needs to be transparency about the substantive ethical grounds for public health care resource allocation decisions. In that spirit, the author analyzes eleven potentially relevant justifications for the NICE "end-of-life premium," drawn from the economics and philosophy literature: 1) rule of rescue; 2) fair chances; 3) ex post willingness to pay; 4) caring externality; 5) financial protection; 6) symbolic value; 7) diminishing marginal value of future life years; 8) concentration of benefits; 9) dread; 10) time to set your affairs in order; and, 11)

severity of illness. He concludes none of them yields a coherent ethical justification for the NICE end-of-life premium. <http://jhpl.dukejournals.org/content/early/2013/08/20/03616878-2373166.abstract>

#### **Royal College of General Practitioners to overhaul GP end-of-life care advice**

*GENERAL PRACTITIONER* | Online – 27 August 2013 – The RCGP [Royal College of General Practitioners] has launched a three-year programme to overhaul end of life care clinical guidelines for GPs. The scheme aims to improve primary care for patients nearing the end of their lives, and will "prioritise advanced care planning, patient choice of place of death, pain management, health inequalities and commissioning issues." Work by the college on clinical priorities including cancer, dementia and care planning will feed into the end of life care programme. The scheme will mark the first time the RCGP's clinical innovation and research centre has worked on a clinical priority across multiple conditions. In addition to developing new guidance for GPs, the end of life programme will build online tools and other support for GPs, promote primary care training and influence CCG policy. <http://www.gponline.com/News/article/1208894/rcgp-overhaul-gp-end-life-care-advice/>

Noted in Media Watch, 16 January 2012, #236 (p.8):

- NATIONAL INSTITUTE FOR HEALTH & CLINICAL EXCELLENCE | Online – 11 January 2012 – **'Advice from National Institute for Health & Clinical Excellence aims to improve commissioning for end of life care.'** The guide aims to support local implementation of the Department of Health End of Life Care Strategy and the NICE Quality Standard for end of life care for adults. The guide includes an end of life care commissioning and benchmarking tool to help users determine the level of service that might be needed locally and to help cost and identify potential savings associated with commissioning end of life care services. <http://www.nice.org.uk/newsroom/pressreleases/EndOfLifeCareCommissioning.jsp>

### **Interprofessional, simulation-based training in end of life care communication: A pilot study**

*JOURNAL OF INTERPROFESSIONAL CARE* | Online – 21 August 2013 – This paper reports on the process and outcomes of a study designed to pilot the use of interprofessional, simulation-based training in end-of-life care communication. results indicated self-perceived improvements in knowledge, skills, confidence and competence when dealing with challenging end of life care communication situations. <http://informahealthcare.com/doi/abs/10.3109/13561820.2013.827163>

## Geriatric palliative care in long-term care settings with a focus on nursing homes

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 August 2013 – Almost 1.7 million older Americans live in nursing homes, representing a large proportion of the frailest, most vulnerable elders needing long-term care. In the future, increasing numbers of older adults are expected to spend time and to die in nursing homes. Thus, understanding and addressing the palliative care needs of this population are critical. The goals of this paper are to describe briefly the current state of knowledge about palliative care needs, processes, and outcomes for nursing home residents; identify gaps in this knowledge; and propose priorities for future research in this area. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.9474>

Of related interest:

- *QUALITY IN AGEING & OLDER ADULTS*, 2013;14(3). **'Death and dying in residential care: A matter of concern.'** The focus of this paper is to contrast official policy with everyday practice. Whilst policy documents suggest recognition of the importance of dignity and respect from dying residents, the research literature indicates great variation in the practice of everyday care. <http://www.emeraldinsight.com/journals.htm?articleid=17093463&show=abstract>

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

#### Service use at the end-of-life in Medicare Advantage versus traditional Medicare

*MEDICAL CARE* | Online – 21 August 2013 – Hospice use in the year preceding death was higher among MA [Medicare Advantage] than TM [traditional Medicare] decedents in 2003 (38% vs. 29%), but the gap narrowed over the study period (46% vs. 40% in 2009). Relative to TM, MA decedents had significantly lower rates of inpatient admissions (5%-14% lower), inpatient days (18%-29% lower), and emergency department visits (42%-54% lower). MA decedents initially had lower rates of ambulatory surgery and procedures that converged with TM rates by 2009 and had modestly lower rates of physician visits initially that surpassed TM rates by 2007. Relative to comparable TM decedents in the same local areas, MA-HMO [health maintenance organizations] decedents more frequently enrolled in hospice and used fewer inpatient and emergency department services, demonstrating that MA plans provide less end-of-life care in hospital settings. [http://journals.lww.com/lww-medicalcare/Abstract/publishahead/Service\\_Use\\_at\\_the\\_End\\_of\\_Life\\_in\\_Medicare.99241.aspx](http://journals.lww.com/lww-medicalcare/Abstract/publishahead/Service_Use_at_the_End_of_Life_in_Medicare.99241.aspx)

#### Yes, but how do I know what I don't know? Moving towards conscious competence in end-of-life care

*NURSING IN CRITICAL CARE*, 2013;18(5):217-218. No abstract or link to article available. <http://onlinelibrary.wiley.com/doi/10.1111/nicc.12043/abstract>

Noted in Media Watch, 26 July 2010, #159 (p.11, under 'Worth Repeating'):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2004;291(4):483-491. **""They don't know what they don't know": Supporting family caregivers at the end of life.'** The amorphous relationship between physicians and the families of patients at the end of life presents both challenges and opportunities for which physicians may be unprepared. Families play important roles in the practical and emotional aspects of patient care and in decision making at the end of life. At the same time, family members may carry significant burdens as a result of their work. Through the perspectives of the wife, daughter, and home care nurse of a patient who died from pancreatic cancer, the authors illustrate the range of family caregiver experiences and suggest potentially helpful physician interventions. <http://jama.ama-assn.org/cgi/content/abstract/291/4/483?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=forgiveness+at+the+end+of+life&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT>

**Integrating palliative care in the out-of-hospital setting:  
Four things to jump-start an EMS-palliative care initiative**

*PREHOSPITAL EMERGENCY CARE* | Online – 22 August 2013 – Emergency medical service (EMS) is frequently called to care for a seriously ill patient with a life-threatening or life-limiting illness. The seriously ill include both the acutely injured patients (for example in mass casualty events) and those who suffer from advanced stages of a chronic disease (for example severe malignant pain). EMS therefore plays an important role in delivering realistic, appropriate, and timely care that is consistent with the patient's wishes and in treating distressing symptoms in those who are seriously ill. The purpose of this article is to review four case scenarios that relate to palliative care and may be commonly encountered in the out-of-hospital setting and provide a road map by suggesting four things to do to start an EMS-palliative care initiative in order to optimize out-of-hospital care of the seriously ill and increase preparedness of EMS providers in these difficult situations. <http://informahealthcare.com/doi/abs/10.3109/10903127.2013.811566>

**Media Watch Online**

**Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/](http://APHN.ORG/CATEGORY/MEDIA-WATCH/)

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

**Australia**

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

**Canada**

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

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

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

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

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/?s=ashpole>

**Europe**

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

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

**International**

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

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

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

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