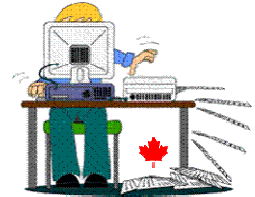


## Media Watch...

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

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to **Specialist Publications** and 'Be a true listener, rather than a good conversationalist' (p.11), in *South Asian Journal of Cancer*.

## Canada

### How we die now

*THE NATIONAL POST* | Online – 25 October 2013 – How each one of us relates to death ... is individual, and always changing – as we mature; as we contemplate life, and death, around us; and, as society changes. *The National Post* presents stories and columns looking at the different ways we see, and prepare for, the Great Equalizer. <http://news.nationalpost.com/2013/10/25/the-full-death-issue-how-we-die-now/>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC TV | The National – 24 October 2013 – '**Last Right: An upcoming series on assisted suicide.**' Monday 28 October 2013, The National begins a series on assisted suicide in Canada. <http://www.cbc.ca/player/News/TV+Shows/The+National/Canada/ID/2414223022/>
- ONTARIO | *The Toronto Sun* – 23 October 2013 – '**Doctors should shape "end of life" discussion: Ontario Medical Association.**' The president of the Ontario Medical Association [OMA] says it's time for the province's doctors to move to the forefront in the debate over "end-of-life care." Dr. Scott Wooder ... said while he ultimately believes Canadians and parliamentarians must make the final decision on physician-assisted suicide, doctors can help shape the debate. But doctors must speak frankly with their patients about "end-of-life care," he said. <http://www.sunnewsnetwork.ca/sunnews/lifestyle/archives/2013/10/20131023-083236.html>
- CANADA | TV 1 News (New Zealand) – 23 October 2013 – '**Assisted suicide opens door to abuse – report.**' Deaths by assisted suicide have increased wherever the practices have been legalised, opening the door to abuse, a report claims.<sup>1</sup> The report ... says legal euthanasia is never just for "exceptional cases" and eligibility rules are highly subjective. It says laws legalising euthanasia/assisted suicide ignore the risks to those who are vulnerable and/or susceptible to coercion as long as they self-define their suffering as unbearable. <http://tvnz.co.nz/national-news/assisted-suicide-opens-door-abuse-report-5658404>

1. *No Second Chances: International Experience Shows Legal Euthanasia is Never Just for "exceptional" Cases*, Institute of Marriage & Family Canada, Ottawa, October 2013. <http://www.imfcanada.org/sites/default/files/Nosecondchances.pdf>

## [U.S.A.](#)

### **Pennsylvania passes "I'm sorry" law to improve physician-patient communication**

PENNSYLVANIA | *MedCity News* – 23 October 2013 – Pennsylvania's House of Representatives unanimously voted to pass benevolent gesture legislation. The bill lets healthcare professionals express compassion to patients and their families without having to worry that those remarks will be used against them in a malpractice suit. It does not protect physicians who admit fault. <http://medcitynews.com/2013/10/pa-passes-im-sorry-law-improve-physician-patient-communication/>

**N.B.** Pennsylvania is the 37<sup>th</sup> state to pass such legislation.

### **Branstad reluctant to hire more hospice inspectors**

IOWA | *The Des Moines Register* – 21 October 2013 – Governor Terry Branstad said he was unaware that Iowa inspects hospice-care providers about once every 20 years, but said he's reluctant to hire new inspectors or take any action that would increase costs for those companies. *The Des Moines Register* reported in April 2011 that Iowa's hospice providers, which provide end-of-life care for terminally ill patients, are inspected by the state once every 20 years – a schedule that is still in place today. Also, the *Register* reported, Iowa exercises no oversight of privately funded home health agencies; cannot impose fines on hospitals or hospital-owned nursing homes; and doesn't require licensing or state inspection of outpatient surgical centers. [http://www.desmoinesregister.com/article/20131022/NEWS09/310220037/Branstad-reluctant-to-hire-more-hospice-inspectors?News&nclick\\_check=1](http://www.desmoinesregister.com/article/20131022/NEWS09/310220037/Branstad-reluctant-to-hire-more-hospice-inspectors?News&nclick_check=1)

Noted in Media Watch, 23 April 2011, #198 (p.2):

- IOWA | *The Des Moines Register* – 24 April 2011 – **'Iowa hospices inspected only once every 20 years.'** Hospice providers that care for hundreds of Iowans in the final stages of a terminal illness are now being inspected by the state on a schedule of one visit every 20 years. Patient advocates say that sort of inspection cycle "doesn't even pass the laugh test." <http://www.desmoinesregister.com/article/20110424/NEWS10/104240335/Iowa-hospices-inspected-only-once-every-20-years?Iowa%20Politics%20Insider>

### **Should caregivers be listed in patient medical records?**

STATE OF WASHINGTON | *Senior Homes* (Seattle) – 21 October 2013 – Caregiving advocates are pursuing a push to get healthcare providers to make an official place in medical records to document the roles of caregivers. Providers currently don't have a standard way of knowing whether patients have caregivers, let alone who the primary caregivers are, and public and private organizations have no reliable way to even count caregivers. When health professionals don't have the caregiver on record, important medical information can be easily missed. <http://www.seniorhomes.com/w/should-caregivers-be-listed-in-patient-medical-records/>

#### [Specialist Publications](#)

**'OPTIMISTIC study aims to reduce avoidable hospitalizations, increase access to palliative care'** (p.9), in *News Medical*.

*Links Updated 28 October 2013*

#### [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.13.

## International

### End-of-life care in Australia

#### **Palliative care demand set to soar**

AUSTRALIA (AUSTRALIAN CAPITAL TERRITORY) | *The Canberra Times* – 28 October 2013 – The ACT government predicts a surge in demand for palliative care services in the territory within the next 10 years. The government will publish ... a plan to cope with the rising number of Canberrans who will require end-of-life care by the year 2022. It predicts demand for palliative care services at Canberra and Calvary hospitals will rise by nearly 3.5% a year ... [and] ... the growth in demand for hospital-based care will be coupled with a surge in requests for community-based services for the growing number of people who want to die at home. The plan says the health workforce and the availability of community services must be increased to improve the options

available to Canberrans at the end of their lives. The report reiterates the need for Canberrans to have a sensible conversation about death with their families and friends to ensure that decisions about their care are made in accordance with their wishes. <http://www.canberratimes.com.au/act-news/palliative-care-demand-set-to-soar-20131027-2wa36.html>

#### Specialist Publications

'National consultation informing development of guidelines for a palliative approach for aged care in the community setting' (p.8), in *Australasian Journal on Ageing*.

### Elder and end-of-life care in the U.K.

#### **Cancer group anger on home care issue**

U.K. (ENGLAND) | *The Nottingham Post* – 25 October 2013 – Hundreds of people in Nottingham are dying in hospital beds when they would prefer to pass away at home. Macmillan Cancer Support has unearthed figures which suggest 770 people who died of cancer in a hospital bed would have preferred to be at home. A recent national survey of bereaved relatives and carers found care for cancer patients in hospital was not as good as at home.<sup>1</sup> Of those who died at home, 63% rated the overall quality of care received as excellent or outstanding, compared to only 37% of those who died in hospitals. Macmillan Cancer Support has launched a report, 'Time to Choose,' which sets new recommendations for improving choice at end-of-life for cancer patients. It calls on the Government to make social care free for everyone in the last weeks of life before the end of this Parliament in 2015. <http://www.nottinghampost.com/Cancer-group-anger-home-care-issue/story-19987691-detail/story.html>

1. 'National Bereavement Survey, 2011,' Office for National Statistics, July 2012. [Noted in Media Watch, 9 July 2012, #261 (p.4)] [http://www.ons.gov.uk/ons/dcp171778\\_269914.pdf](http://www.ons.gov.uk/ons/dcp171778_269914.pdf)

Noted in Media Watch, 12 August 2013, #318 (p.5):

- U.K. (ENGLAND) | *The Daily Express* – 9 August 2013 – **'Cancer patients "denied care and dignity by National Health Service."** Tens of thousands of cancer patients a year are being denied basic care and dignity in hospital, a report reveals. A survey found that of the 170,000 cancer victims admitted to hospitals in England each year, around 18,000 – or 11% – said their files were lost by a doctor or nurse. Some 15% felt they were belittled by nurses while 14% were forced to wait at least 30 minutes after asking for help to go to the toilet – one per cent waited for at least two hours. <http://www.express.co.uk/news/health/420729/Cancer-patients-denied-care-and-dignity-by-NHS>

Cont.

Of related interest:

- U.K. (ENGLAND) | EADT 24 (Ipswich) – 22 October 2013 – **'GPs given cash bonuses for filling out controversial "end-of-life" plans.'** Health chiefs defended a pilot programme that saw doctors in Suffolk receive a cash bonus for putting patients on controversial "end-of-life" plans. The £50 bonuses were given out to 41 surgeries in Ipswich and East Suffolk every time they signed a care home patient up to the scheme. Critics claim the project was intended to save money by freeing up costly hospital beds as patients could opt to die at home. [http://www.eadt.co.uk/news/suffolk\\_gps\\_given\\_cash\\_bonuses\\_for\\_filling\\_out\\_controversial\\_end\\_of\\_life\\_plans\\_1\\_2908964](http://www.eadt.co.uk/news/suffolk_gps_given_cash_bonuses_for_filling_out_controversial_end_of_life_plans_1_2908964)
- U.K. | BBC News – 21 October 2013 – **'Hospices: The forgotten pillar of elderly care?'** Elderly care is one of the most pressing issues in the National Health Service [NHS]. Whether it is the quality of hospital care or the affordability of care homes, ministers are busy trying to improve services. But we have heard very little about hospices. Yet, about a fifth of people – 120,000 a year – get help from them before they die. And compared to hospitals and care homes, they are doing much better at making their final days, weeks and months comfortable. According to ... the Office for National Statistics, over 80% of people feel hospices treat patients with dignity and respect compared to just over half in hospitals.<sup>1</sup> A similar picture emerges with the administering of pain relief. But is there more that hospices could do? The sector certainly thinks so. It has set up the Commission into the Future of Hospice Care to put forward its case. In a report ... [the Commission] ... says hospices could be playing more of a role – and in turn relieving the pressure on hospitals and accident and emergency units in particular.<sup>2</sup> But to realise the potential the commission wants both hospices themselves and the NHS to raise their game. <http://www.bbc.co.uk/news/health-24626653>
  1. 'National Bereavement Survey, 2012,' Office for National Statistics, July 2013. [Noted in Media Watch, 15 July 2013, #314 (p.5)] [http://www.ons.gov.uk/ons/dcp171778\\_317495.pdf](http://www.ons.gov.uk/ons/dcp171778_317495.pdf)
  2. *In Future Ambitions for Hospice Care: Our Mission and Our Opportunity*, Help the Hospices Commission, October 2013. <http://www.helpthehospices.org.uk/our-services/commission/>

### **Senegal: Thousands urgently need pain relief**

SENEGAL | Human Rights Watch – 24 October 2013 – Tens of thousands of patients in Senegal suffer from excruciating pain every year without relief [according to a new report].<sup>1</sup> Unnecessarily restrictive government regulations and poor training for healthcare workers impede their effective medical treatment. The report ... found that 70,000 Senegalese each year need what is known as palliative care to control symptoms related to chronic, life-threatening diseases. Morphine is an essential and inexpensive medication for treatment of severe pain, but Senegal only imports about one kilogram of morphine each year – enough to treat about 200 cancer patients. Morphine is unavailable outside of Dakar, Senegal's capital. <http://www.hrw.org/news/2013/10/24/senegal-t-thousands-urgently-need-pain-relief>

### **Specialist Publications**

**'Quality palliative care for cancer and dementia in five European countries: Some common challenges'** (p.7), in *Aging & Mental Health*.

**'Status of palliative care in Latin America: Looking through the Latin America Atlas of Palliative Care'** (p.8), in *Current Opinion in Supportive & Palliative Care*.

**'Communication of the death of a patient in hospices and nursing homes: A qualitative study'** (p.9), in *European Journal of Oncology Nursing*.

**'Community pharmacists' attitudes toward palliative care: An Australian nationwide survey'** (p.8), in *Journal of Palliative Medicine*.

Cont.

1. *Abandoned in Agony: Cancer and the Struggle for Pain Treatment in Senegal*, Human Rights Watch, October 2013. Non-communicable diseases, such as cancer, diabetes and heart disease, are responsible for 30 percent of all deaths in Senegal, and cancer alone kills more Senegalese than malaria, tuberculosis, and HIV/AIDS combined. Moreover, the prevalence of non-communicable illnesses in Senegal, as in Africa as a whole, is projected to increase significantly in the coming decades, due to life-style changes and population aging. [http://www.hrw.org/sites/default/files/reports/senegal1013\\_forinsert\\_ForUpload.pdf](http://www.hrw.org/sites/default/files/reports/senegal1013_forinsert_ForUpload.pdf)

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

##### **No room for the dying?**

INDIA | *The Times of India* (Gurgaon, Haryana) – 22 October 2013 – Hundreds of terminally ill patients in the city [of Hyderabad] are being deprived of palliative care as hospices in the city are being shunted out from one place to the other by citizens, who find the presence of a "home for the dead" in residential areas inauspicious. Hospice authorities say that the society's hostility and the government's apathy are responsible for gross scarcity of the much-needed specialised sanatoriums in the city. "First it was people's religious beliefs that forced us to move from one place to another. Now, it is the government which is the bane. The society has become insensitive to the needs of the dying," said Dr. Nagendra Parvataneni of The Hospice Foundation of Hyderabad. The Foundation, which launched its centre in Punjagutta in 2004, has had to shift base six times in the past nine years after neighbours complained of its "inauspicious" presence. They have acquired five-acre land in Patancheru, but with the government refusing to help build an approach road, the hospice has been lying defunct. Hyderabad has only two hospices which are functional. [http://articles.timesofindia.indiatimes.com/2013-10-22/hyderabad/43287176\\_1\\_patients-palliative-care-centre-sparsh](http://articles.timesofindia.indiatimes.com/2013-10-22/hyderabad/43287176_1_patients-palliative-care-centre-sparsh)

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

##### **Lack of hospice beds leaves terminal patients out in the cold**

IRELAND | *The Irish Times* (Dublin) – 22 October 2013 – More than a decade ago a report from the National Advisory Committee on Palliative Care recommended that there should be one hospice bed per 10,000 of the population. However, according to the latest report from the Irish Hospice Foundation,<sup>1</sup> just "just two regions – the midwest and northwest – come close to fulfilling government policy." The report found that a number of regions of the country – including the northeast (comprising Louth, Meath, Cavan, Monaghan) and the southeast (Waterford, Wexford, Kilkenny and Carlow) – as well as Wicklow, Mayo, and Kerry – have no hospice inpatient unit. According to the report, "while 67% of Irish people express a preference to die at home, in reality only 26% of the circa 28,000 deaths that occur in Ireland each year take place in the home, and 43% occur in hospital. In contrast, 40% of all patients cared for by hospice home care teams die at home." The report revealed: "The midwest and northwest have very good access to hospice services and much lower percentages of cancer patients dying in acute hospitals. Patients approaching death in the "resource-poor" regions of the southeast, midlands and northeast suffer significant inequity in access to hospice services, with a consequential higher proportion of cancer deaths in acute hospitals." <http://www.irishtimes.com/life-and-style/health-family/lack-of-hospice-beds-leaves-terminal-patients-out-in-the-cold-1.1568194>



1. *Access to Specialist Palliative Care Services and Place of Death in Ireland: What the data tells us,* Irish Hospice Foundation, Perspectives No. 2, May 2013. <http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf>

Cont.

Of related interest:

- IRELAND | *The Irish Times* (Dublin) – 27 October 2013 – **'Forum calls for strategy to deal with end of life.'** A forum of experts called on the government to produce a national strategy to deal with legal, administrative, and economic matters relating to end of life ... to "fulfil its pledge to bring in legislation to strengthen the patient's voice in healthcare decisions." <http://www.irishtimes.com/news/social-affairs/forum-calls-for-strategy-to-deal-with-end-of-life-1.1573149>

Noted in Media Watch, 13 May 2013, #305 (p.12):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(3):130-133. **'Challenges in increasing regional equity in palliative care service provision in Ireland.'** This article reports on this regional inequity after a decade of funding and policy changes. It arose out of a larger study funded by The Atlantic Philanthropies, whose 'End of Life' programme has contributed significantly to hospice and palliative care in the Republic of Ireland.<sup>1</sup>
  1. *Evaluation: Programme to Support Palliative & Hospice Care in the Republic of Ireland*, The Atlantic Philanthropies, 2013. [Noted in Media Watch, 21 January 2013, #289 (p.4)] [http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation\\_Programme\\_Support\\_Palliative\\_and\\_Hospice\\_Care\\_%20Republic\\_of\\_Ireland.pdf](http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation_Programme_Support_Palliative_and_Hospice_Care_%20Republic_of_Ireland.pdf)

**N.B.** Access to articles in the *European Journal of Palliative Care* requires a subscription. Contents page: [http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?JID=4&Year=2013&Edition=474](http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2013&Edition=474)

#### End-of-life care in Japan

#### **Preparation important in choosing terminal care**

JAPAN | *The Japan News* (Tokyo) – 22 October 2013 – The preparation of "living wills" or "advance directives," documents setting down treatment preferences in case a person is unable to make such judgments in their terminal phase, is believed to be important, given the disparity between the reality at hospitals and the will of patients and their relatives. A recent survey on terminal care by [newspaper] *The Yomiuri Shimbun* has revealed 20 out of 38 hospitals that did not take terminal patients off artificial respirators or stop other life-prolonging treatment in the past year did so because there was "no social consensus" on what to do. But as much as 81% of people surveyed ... said they would not want to receive life-prolonging treatments in their terminal phase. <http://the-japan-news.com/news/article/0000737852>



#### **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: <http://www.ipcrc.net/barry-r-ashpole.php>

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

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

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

### **Quality palliative care for cancer and dementia in five European countries: Some common challenges**

*AGING & MENTAL HEALTH* | Online – 17 October 2013 – There is a growing consensus world-wide that palliative care needs to be both more inclusive of conditions other than cancer and to improve. This paper explores common challenges currently faced by professionals providing palliative care for patients with either cancer or dementia across five countries. One focus group and 67 interviews were conducted across five countries: England, Germany, Italy, The Netherlands, and Norway, with professionals from dementia, cancer and palliative care settings. The interviews revealed five common challenges faced across the five countries: communication difficulties (between services; and between professionals, and patients and their families); the variable extent of structural/functional integration of services; the difficulties in funding of palliative care services; problematic processes of care (boundaries, definitions, knowledge, skills and inclusiveness) and, finally, time constraints. These are not problems distinct to palliative care, but they may have different origins and explanations compared to other areas of health care. This paper explores deeper themes hidden behind a discourse about barriers and facilitators to improving care. <http://www.tandfonline.com/doi/full/10.1080/13607863.2013.843157#.UmZ9CHBwrhc>

Noted in Media Watch, 8 July 2013, #313 (p.10):

- *PALLIATIVE MEDICINE* | Online – 4 July 2013 – **'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care.'** The authors provide the first definition of palliative care in dementia ... [and] ... a framework to provide guidance for clinical practice, policy and research. 64 experts from 23 countries evaluated a set of 11 domains and 57 recommendations. <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>

### Pediatric palliative care

#### **Using miniature chairs to facilitate communication**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 October 2013 – Good communication is essential but sometimes challenging in pediatric palliative care. The authors describe three cases whereby miniature chairs made of various materials and colors were used successfully to encourage communication among pediatric patients, family, and health care professionals. This chair-inspired model may serve as a simple tool to facilitate complex discussions and to enable self-expression by children in the pediatric palliative care setting. <http://ajh.sagepub.com/content/early/2013/10/20/1049909113509001.full>

Of related interest:

- *EDUCATION & SOCIETY*, 2013;31(1):37-52. **'An analysis of books for preschool children experiencing bereavement and loss.'** To enhance a child's ability to cope after the loss of a loved one, parents and caregivers may use children's books as one of a variety of available strategies. When using this familiar form of therapy with preschoolers, it is important to choose books that are developmentally appropriate for the child and the situation at hand. <http://www.ingentaconnect.com/content/jnp/es/2013/00000031/00000001/art00004>

Noted in Media Watch, 11 February 2013, #292 (p.8):

- *CHILDREN'S LITERATURE IN EDUCATION*, 2013;44(1):1-14. **'Summer's end and sad goodbyes: Children's picturebooks about death and dying.'** This article explores children's picturebooks about death and grieving by considering both psychological and literary aspects. <http://link.springer.com/article/10.1007/s10583-012-9174-3>

## End-of-life care in Australia

### **National consultation informing development of guidelines for a palliative approach for aged care in the community setting**

*AUSTRALASIAN JOURNAL ON AGEING* | Online – 17 October 2013 – This study aimed to obtain perspectives from key stakeholders to inform the development of Australian national guidelines for a palliative approach to aged care in the community setting. Interviews were conducted across Australia and included 172 participants: health-care providers, consumers, volunteers, and researchers/educators. Themes emerging from the data were: provision of a palliative approach in community aged care; carer support; advance care planning; physical and psychological symptom assessment and management; psychosocial support; spiritual support; issues for Aboriginal or Torres Strait Islander people; older people from diverse cultural and language groups; and, clients with special needs. Findings underpinned development of new guideline documents. <http://onlinelibrary.wiley.com/doi/10.1111/ajag.12083/abstract;jsessionid=AB24CBAE10D0B971A89168288F3A78E1.f01t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 October 2013 – '**Community pharmacists' attitudes toward palliative care: An Australian nationwide survey.**' Pharmacists [i.e., survey respondents] were generally positive about providing services and supports for palliative care patients, yet they also reported negative beliefs and emotions about palliative care. In addition, they had good knowledge of some aspects of palliative care, but misconceptions about other aspects. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0171>

### **Supportive and palliative care: A poorly understood science for the perioperative clinician**

*BEST PRACTICE & RESEARCH CLINICAL ANAESTHESIOLOGY* | Online – 17 October 2013 – Patients facing cancer and other life-threatening illnesses develop a variety of debilitating treatment-related and disease-related symptoms which can be quite distressing and detrimental to their quality of life. Palliative care offers a way to deal with such challenging medical complexities that arise in their lives. However, it appears knowledge about this discipline is still limited among a majority of clinicians in diverse fields of medicine and the utilization of its services is minimal. <http://www.sciencedirect.com/science/article/pii/S1521689613000955>

### **Status of palliative care in Latin America: Looking through the Latin America Atlas of Palliative Care**

*CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 21 October 2013 – Several studies have been published reporting the status of palliative care in different countries of Latin America, but no studies have been published on the status of the discipline across the whole region. This article provides a summary of the current situation as reported in the Atlas of Palliative Care recently completed by the Latin American Association for Palliative Care.<sup>1</sup> The aim of this project was to collect information on the degree of palliative care development, help create a network, and influence the progress of palliative care across Latin America. The Atlas provides an overview of the status of palliative care in Latin America according to the World Health Organization public health strategy for palliative care: policies, drug availability, education, and implementation of services. The results indicate that there is significant variation among countries in the region and that strategies to support and develop palliative care require tailored approaches to meet the needs of each. <http://www.ncbi.nlm.nih.gov/pubmed/24145682>

1. 'Atlas de cuidados paliativos de Latinoamérica,' Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch, 7 January 2013, #287, (p.8)] <http://cuidadospaliativos.org/uploads/2012/10/atlas/Atlas%20de%20Cuidados%20Paliativos%20de%20Latinoamerica.pdf>



### **Communication of the death of a patient in hospices and nursing homes: A qualitative study**

*EUROPEAN JOURNAL OF ONCOLOGY NURSING* | Online – 24 October 2013 – Announcing the death of a patient to another in hospices and nursing homes (NH) requires special skills, especially when the recipient is another resident. The aim of this study is to describe how hospice and NH staff deal with the communication regarding a patient's death, if this communication is perceived as a problem, and strategies implemented. Six themes were identified and grouped into two main themes: a) the choice to tell the truth or not, which may be influenced by: the patients' request for confirmation of the fate of the other resident, by patients' fear of death ("I will be next"), the relationships among the guests, and personal and group experiences; and, b) the need to share own feelings and the burden of deciding whether or not to inform the other residents and how to go about this. [http://www.ejoncologynursing.com/article/S1462-3889\(13\)00109-9/abstract](http://www.ejoncologynursing.com/article/S1462-3889(13)00109-9/abstract)

### **Making the decision to withdraw or withhold life support: Thoughts and questions**

*HELLENIC JOURNAL OF SURGERY*, 2013;85(5):296-300. Doctors must have the conscience or the "courage" to stop a treatment which no longer makes sense, provides no further benefit to the patient, causes discomfort or pain, and prolongs the use of limited resources. Doctors are privileged to be able to assist their patients in their final journey through the dying process. As such, they have a duty to ensure that their patients die with dignity. Although doctors may stop active treatment, they must never stop patient care; withdrawal of therapy does not mean withdrawal of care. <http://link.springer.com/article/10.1007/s13126-013-0055-z#>

### **Cancer caregivers advocate a patient- and family-centered approach to advance care planning**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 October 2013 – Findings [of this study] highlight the impact of caregiver hierarchies, adaptive family decision-making styles, and complex cultural influences on decision making. Some caregivers may develop subsidiary care intentions, based on "knowing" or overriding patients' desires. Hindrances on caregivers supporting patients' advance care plans [ACP] include limited information access, patient or caregiver resistance to engage in conversations, and ACPs association in oncology with losing hope. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00474-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(13)00474-0/abstract)

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

### **OPTIMISTIC study aims to reduce avoidable hospitalizations, increase access to palliative care**

*NEWS MEDICAL* | Online – 25 October 2013 – The OPTIMISTIC study, developed by researchers from Indiana University and the Regenstrief Institute to improve health care, reduce avoidable hospitalizations and increase access to palliative care, is now underway in 19 nursing facilities throughout Central Indiana. The program is supported by a \$13.4 million 2012 award from the Centers for Medicare & Medicaid Services (CMS). Emergency room visits and hospitalizations are common but extremely stressful to nursing home residents – many of whom are physically frail and/or cognitively impaired – and to their families. Total costs for these potentially avoidable hospitalizations for Medicare-Medicaid enrollees for 2011 have been estimated by CMS to be an estimated \$3 billion. The goal of OPTIMISTIC – Optimizing Patient Transfers, Impacting Medical Quality & Improving Symptoms: Transforming Institutional Care – is to improve care and communication within nursing facilities and between these facilities and acute care institutions so problems can be caught and dealt with before it becomes necessary to transport a resident to the hospital. <http://www.news-medical.net/news/20131025/OPTIMISTIC-study-aims-to-reduce-avoidable-hospitalizations-increase-access-to-palliative-care.aspx>

## **Delivering palliative care to patients and caregivers in inner-city communities: Challenges and opportunities**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 24 October 2013 – Social and economic barriers can hinder access to quality palliative and end-of-life care for patients living in inner-city communities. Using a community-based participatory research (CBPR) approach, the authors investigated the stresses associated with living with a chronic disease and barriers to access and utilization of palliative care resources experienced by low-income patients and caregivers in five inner-city communities. Stresses centered around five themes: lack of family support; communication barriers with healthcare professionals; minority stress; caregiver burden; and, lack of spiritual support. The community stakeholders identified resources and services to improve access to care and the quality of life of underserved, low-income populations living with chronic illnesses.

<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9053731&fulltextType=RA&fileId=S1478951513000230>

## **Improving inpatient hospice environments for older people in England: A documentary analysis**

*PROGRESS IN PALLIATIVE CARE* | Online – 24 October 2013 – Qualitative analysis was undertaken of all grant application forms which resulted in funding and proposed to refurbish or replace inpatient hospice buildings. Themes were identified on the nature and extent of the benefits envisaged for older people, and how older people were involved in the proposed building projects. Of 227 grant applications, 139 (from 111 hospices) met the inclusion criteria. Four categories of building improvement were identified: interior decoration or equipment; public spaces, private spaces, and health and safety. These improvements, while generally beneficial, were rarely targeted at older people. Most ... stated that they had consulted service users, but only 13 specified that they consulted older people. Limited information was supplied about the methods or findings of these consultations. In 15 grant applications, older people were not mentioned at all. Older hospice inpatients, their relatives and advocacy groups should be involved more fully in decisions relating to the physical environment of care. Staff who prepare funding bids should receive training in conducting consultations with service users, and identifying and evaluating other relevant evidence. To ensure a consistently high standard of environmental provision for older people in hospices, evidence-based assessment tools and guidelines should be developed.

[http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney\\_ppc\\_181](http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney_ppc_181)

### **The King's Fund (U.K.)**

## **GP care co-ordination hindered by "intense" workload**

*PULSE* (U.K.) Online – 24 October 2013 – GPs are unable to co-ordinate care for people with long-term conditions due to their "intense workloads" and "insufficient funding," concludes a new report. The ... report<sup>1</sup> ... found that "limited engagement" from GPs reduced the effectiveness of the care co-ordination schemes in place. "Of concern to all programmes was the apparent disengagement of GPs, which sometimes made effective information exchange difficult and prevented them from bringing the GP's general knowledge of the patient/family into discussions about their care. This lack of engagement from GPs represents a curious paradox, as one of their core roles is to provide continuity of care to local people and to act as the patient's advocate through referrals to other services." <http://www.pulsetoday.co.uk/commissioning/commissioning-topics/long-term-conditions/gp-care-co-ordination-hindered-by-intense-workload/20004808.article#.UmkujnBwrhd>

1. *Co-Ordinated Care for People with Complex Chronic Conditions: Key Lessons and Markers for Success*, The King's Fund, October 2013. <http://www.kingsfund.org.uk/publications/co-ordinated-care-people-complex-chronic-conditions>

Cont.

Noted in Media Watch, 21 October 2013, #328 (p.9):

- THE KING'S FUND | Online – Accessed 18 October 2013 – **Delivering Better Services for People with Long-term Conditions: Building the House of Care.** The house of care model is a deliberate simplification of a complex delivery system with primary care as its cornerstone and personalised care planning at its heart, underpinned by the solid foundation of responsive commissioning. <http://ncmn.ca/Resources/Documents/delivering-better-services-for-people-with-long-term-conditions.pdf>

### Be a true listener, rather than a good conversationalist

*SOUTH ASIAN JOURNAL OF CANCER*, 2013;2(4):288-289. Oncology patient care is an ever evolving field both as a science and a clinical art. We evaluate, diagnose, and treat cancer patients daily. We break the bad and the good news to them. We are the hope on which their life and dreams hang on. We ... have to assess each patient as an intelligent observer. We have to devise our strategy to break heartbreaking news to them in a tailored and personalized fashion according to the physical, psychological, emotional, and social status of the patient. The process has to be gentle, perceptive, pragmatic, yet truthful. There needs to be reasonably good observational, listening, comprehending, and delivering potentials ...

sharpened by experience and skills. <http://journal.sajc.org/article.asp?issn=2278-330X;year=2013;volume=2;issue=4;epage=288;epage=289;aulast=Mehdi>

#### Quotable Quotes

*One of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore ... most of us would rather forget our own vulnerability ... Listening is hard but it is also a fundamental moral act.* Arthur Frank, *The Wounded Story Teller: Body, Illness and Ethics* (University of Chicago Press, 1995).

Noted in Media Watch, 27 May 2013, #307 (p.6):

- *JOURNAL OF HOLISTIC NURSING* | Online – 17 May 2013 – **'The journey of discovering compassionate listening.'** This article presents the concept of "compassionate listening" in critical life moments to gain insight into the process of listening with compassion. This insight evolved through a process of layered reflection using a series of texts, particularly stories that captured critical moments in working with people who were facing crisis situations or who were dying. <http://jhn.sagepub.com/content/early/2013/05/17/0898010113489376.abstract>

### Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY* | Online – 18 October 2013 – **'Premises and evidence in the rhetoric of assisted suicide and euthanasia.'** In debates about euthanasia and assisted suicide, it is rare to find an article that begins with an expression of neutral interest and then proceeds to examine the various arguments and data before drawing conclusions based upon the results of a scholarly investigation. Although authors frequently give the impression of being impartial in their introduction, they invariably reach their prior conclusions. Positions tend to be clearly dichotomized: either one believes that the practice of euthanasia or assisted suicide is totally acceptable or completely unacceptable in a just and moral society. Where there is some admission of a gray zone of incertitude, authors attempt to persuade us that their beliefs (preferences) are the only sensible way to resolve outstanding dilemmas. <http://www.sciencedirect.com/science/article/pii/S0160252713000782>

Cont.

- *KENNEDY INSTITUTE OF ETHICS JOURNAL*, 2013;23(3):201-228. '**An undignified side of death with dignity legislation.**' The primary justification for death with dignity legislation has been the principle of respect for autonomy. However, some have objected that if respect for autonomy is the reason for allowing physician-assisted suicide, then why not allow it for people with longer than six months to live? Defenders of the laws have responded that respect for autonomy must be balanced against the state's interest in the lives of its citizens. Persons with less than six months remaining have virtually no life left to protect; persons with more time have a meaningfully long segment of life remaining. The state can therefore overrule their autonomy interests to preserve their lives. This paper argues that this response constitutes an ironic affront to the dignity of people with less than six months to live, for it implies their lives are not worth enough for the state to prevent them from committing physician-assisted suicide. [http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/kennedy\\_institute\\_of\\_ethics\\_journal/v023/23.3.plaisted.html](http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/kennedy_institute_of_ethics_journal/v023/23.3.plaisted.html)

## Worth Repeating

### **Vulnerability, disability, and palliative end-of-life care**

*JOURNAL OF PALLIATIVE CARE*, 2006;22(3):166-174. Palliative care has paid exceedingly little attention to the needs of disabled people nearing the end of life. It is often assumed these individuals, like all patients with little time left to live, arrive at palliative care with various needs and vulnerabilities that by and large, can be understood and accommodated within routine standards of practice. However, people with longstanding disabilities have lived with and continue to experience various forms of prejudice, bias, disenfranchisement and devaluation. Each of these impose heightened vulnerability, requiring an honest, thoughtful, yet difficult revisiting of the standard model of palliative care. A Vulnerability Model of Palliative Care attempts to incorporate the realities of life with disability and how a contextualized understanding of vulnerability can inform how we approach quality, compassionate palliative care for marginalized persons approaching death. <http://europepmc.org/abstract/MED/17058755/reload=0;jsessionid=8v6LkYzNhjoT6DGQkiW5.42>

### 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.

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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.

## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2013/10/media-watch/>

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)

### **Asia**

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

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

### **Australia**

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

### **Canada**

ONTARIO | Central West Palliative Care Network: [http://cwpcn.ca/Health\\_Practitioners/resources.htm?mediawatch=1](http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1)

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/news-events>

### **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>

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