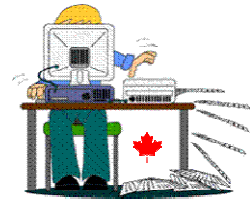


## **Media Watch...**

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, 2014 ©

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

**End-of-life issues: Scroll down to [Specialist Publications](#) and 'General practitioners' perspectives on the avoidability of hospitalizations at the end of life: A mixed-method study' (p.13), in *Palliative Medicine*.**

## **Canada**

### **Pan-Canadian Palliative & End-of-life Care Strategy**

OPENPARLIAMENT.CA | Online – 1 April 2014 – New Democratic Party MP Charles Angus led a discussion in the House of Commons and moved...

*That, in the opinion of the House, the government should establish a Pan-Canadian Palliative & End-of-life Care Strategy by working with provinces and territories on a flexible, integrated model of palliative care that: a) takes into account the geographic, regional, and cultural diversity of urban and rural Canada; b) respects the cultural, spiritual and familial needs of Canada's First Nation, Inuit and Métis people; and, c) has the goal of i) ensuring all Canadians have access to high quality home-based and hospice palliative end-of-life care, ii) providing more support for caregivers, iii) improving the quality and consistency of home and hospice palliative end-of-life care in Canada, iv) encouraging Canadians to discuss and plan for end-of-life care.*

The one-hour allocated to "private member's business" expired without the motion being adopted. A transcript can be accessed at: <http://openparliament.ca/debates/2014/4/1/charlie-angus-11/only/>

**N.B.** Scroll down to 'See context to find out what was said next' for complete transcript. During the discussion, Charles Angus referred to the report *Not to be Forgotten: Care of Vulnerable Canadians*, Ad Hoc (All-Party) Parliamentary Committee on Palliative & Compassionate Care, 17 November 2011. [Noted in Media Watch, 21 November 2011, #228 (p.1)] <http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf>

### **Specialist Publications**

**'Patient-centered care or cultural competence: Negotiating palliative care at home for Chinese Canadian immigrants' (p.6), in *American Journal of Hospice & Palliative Medicine*.**

## Canada's healthcare system needs an unbiased watchdog

*THE TORONTO STAR* (OpEd) | Online – 1 April 2014 – The Health Council of Canada [has] closed its doors for good.<sup>1</sup> The council was established in the 2003 health accord,<sup>2</sup> and the 10 years of its existence have been both progressive and tumultuous... Whether or not you agree with the decision to close the council ... there is a need to assess what will be lost. Trying to critique yet not displease provincial and territorial masters, along with a federal health ministry that footed the bill for the council's operations, required an ongoing balancing act... This problem is not unique to the council. There are many other national health agencies, particularly those governed by multiple masters with varying mandates, whose advice is not always in sync with the government agendas of the day. But unlike other agencies, the council represented a new institutional entity ... established primarily to assess and comment publicly on the performance of the provinces and territories in their largest area of responsibility – healthcare – with a view to holding them to account. The council had the further challenge of monitoring the federal government's performance with respect to its specific obligations... With public and private expenditure on healthcare ... over the next decade almost certain to exceed the close to \$2 trillion spent over the past decade, there is a need for ongoing, consistent, non-partisan and unbiased oversight. [http://www.thestar.com/opinion/commentary/2014/04/01/canadas\\_healthcare\\_system\\_needs\\_an\\_unbiased\\_watchdog.html](http://www.thestar.com/opinion/commentary/2014/04/01/canadas_healthcare_system_needs_an_unbiased_watchdog.html)

1. Health Council of Canada's webpage remains online, at Carlton University Library, for research and reference purposes. [http://www.healthcouncilcanada.ca/results.php?pageNum\\_rsFiles=1](http://www.healthcouncilcanada.ca/results.php?pageNum_rsFiles=1)
2. The health accord was a 10-year agreement between the federal and provincial governments, guaranteeing the latter an annual 6% increase in federal health care funding and also setting targets for improvements to the health care system. The federal government's new formula will see the Canada Health Transfer increase in tandem with the gross domestic product, with a guaranteed floor of 3% per year. The provinces and territories will receive \$36 billion less over the next decade.

### Cross-cultural communications

#### Study identifies language gaps in health care

ONTARIO | *The Toronto Star* – 30 March 2014 – Patients and primary care physicians in Ontario often aren't speaking the same language, says a new study by the Centre for Research on Inner City Health.<sup>1</sup> About 18% of the 20,000 primary-care physicians in the province can "conduct a conversation" in a language other than English or French, and only 3.7% can speak one of the top unofficial languages spoken in Ontario – Chinese, Italian, Punjabi, Portuguese and Spanish. According to the 2006 Census, 2.24% of Ontario's 12 million residents could not speak English or French, including 37,000 Chinese-only speakers, 22,900 Italians, 21,250 Punjabis, 19,360 Portuguese and 13,454 Spanish. In Ontario, researchers identified 488 physicians who can communicate in a Chinese language; 149 in Italian, 98 in Punjabi, 36 in Portuguese and 156 in Spanish. [http://www.thestar.com/news/immigration/2014/03/30/study\\_identifies\\_language\\_gaps\\_in\\_health\\_care.html](http://www.thestar.com/news/immigration/2014/03/30/study_identifies_language_gaps_in_health_care.html)

1. 'Potential for patient-physician language discordance in Ontario,' *BMC Health Services Research*, 28 December 2013. <http://www.biomedcentral.com/content/pdf/1472-6963-13-535.pdf>

### 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.11.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | *The Winnipeg Free Press* – 6 April 2014 – **'63% support assisted suicide.'** Most Manitobans believe people with terminal illnesses or severe disabilities ought to have access to euthanasia, and most Manitobans want the provincial government to allow doctors to help. A new poll by Probe Research ... suggests 63% of Manitobans support the right of terminally ill people to end their own lives. An even bigger majority wants the provincial government to introduce legislation allowing for physician-assisted suicide. Those figures mirror a national poll last fall that suggested 68% of Canadians support the legalization of assisted suicide. Despite significant public support, the NDP government says it will not follow Quebec's lead and introduce legislation. <http://www.winnipegfreepress.com/local/63-support-assisted-suicide-254004521.html>

### Corrections & Clarifications

Manitoba Conservative MP Stephen Fletcher introduced two private members bills in Parliament that would decriminalize assisted suicide [see 'Conservative MP Fletcher backs bill to allow assisted suicide,' *The Hamilton Spectator*, 26 March 2014, noted in Media Watch, 31 March 2014, #351 (p.2)]. Downloads: 'An Act to Amend the Criminal Code: Physician Assisted Death': <http://www.parl.gc.ca/HousePublications/Publications.aspx?Language=E&Mode=1&DocId=6487876> and, 'An Act to Amend the Criminal Code: Canadian Commission on Physician Assisted Death': <http://www.parl.gc.ca/HousePublications/Publications.aspx?Language=E&Mode=1&DocId=6487912>

## U.S.A.

### End-of-life medical care bill gets committee nod

LOUISIANA | *The Advocate* (Baton Rouge) – 3 April 2014 – Health insurance companies could not deny health care based on an insured's life expectancy or terminal medical condition under a proposal adopted Wednesday by a Louisiana House panel. According to proponents, House Bill 336, was prompted by a policy adopted in Oregon, where care is rationed by eliminating medications, radiation, chemotherapy and other treatment for the terminally ill. The health plans would provide hospice care instead. Under HB336 ... no health care plan could deny coverage for medically necessary treatment prescribed by a physician and agreed to by "a fully informed insured" or person with legal authority to make decisions for them based only on the person's life expectancy or the fact the insured is diagnosed with a terminal condition. The pro-

hibition would cover any hospital, health or medical insurance policy, hospital or medical service contract, employee welfare benefit plan, contract or agreement with a health maintenance organization or a preferred provider organization, or any other contract of the type, including the state Office of Group Benefits programs. The legislation would apply to the state's private insurance based health plans for Medicaid recipients. <http://theadvocate.com/home/8799758-125/end-of-life-medical-care-bill-gets>

### Specialist Publications

'Advance directive completion by elderly Americans: A decade of change' (p.9), in *Journal of the American Geriatrics Society*.

## Allocation of scarce medical interventions

### Ezekiel Emmanuel's reaper curve

*AMERICAN THINKER* | Online – 1 April 2014 – True [healthcare] reform, Emanuel argues, must include redefining doctors' ethical obligations. In the 18 June 2008 issue of *JAMA* [*Journal of the American Medical Association*], Emanuel blames the Hippocratic Oath for the "overuse" of medical care: "Medical school education and post graduate education emphasize thoroughness," he writes. "This culture is further reinforced by a unique understanding of professional obligations, specifically the Hippocratic Oath's admonition to 'use my power to help the sick to the best of my ability and judgment' as an imperative to do everything for the patient regardless of cost or effect on others."<sup>1</sup> In numerous writings, Emanuel chastises physicians for thinking only about their own patient's needs. He describes it as an intractable problem: "Patients were to receive whatever services they needed, regardless of its cost. Reasoning based on cost has been strenuously resisted; it vio-

lated the Hippocratic Oath, was associated with rationing, and derided as putting a price on life... Indeed, many physicians were willing to lie to get patients what they needed from insurance companies that were trying to hold down costs" (*JAMA*, 16 May 2007).<sup>2</sup> Of course, patients hope their doctors will have that single-minded devotion. Emanuel believes doctors should serve two masters, the patient and society, and that medical students should be trained "to provide socially sustainable, cost-effective care." [http://www.americanthinker.com/2014/04/ezekiel\\_emmanuels\\_reaper\\_curve.html](http://www.americanthinker.com/2014/04/ezekiel_emmanuels_reaper_curve.html)

#### Extract from *American Thinker* article

One sign of progress he sees: "the progression in end-of-life care mentality from 'do everything' to more palliative care shows that change in physician norms and practices is possible."

1. 'The perfect storm of overutilization,' *JAMA*. 2008;299(23):2789-2791. <http://jama.jamanetwork.com/article.aspx?articleid=182076&resultClick=3>
2. 'What cannot be said on television about health care,' *JAMA*, 2007;297(19):2131-2133. <http://jama.jamanetwork.com/article.aspx?articleid=207050&resultClick=3>

Of related interest:

- NEBRASKA | *Governing* (Washington, DC) – 31 March 2014 – '**A cost-effective way to care for an aging population.**' The annual cost of nursing-home care in Nebraska averages more than \$75,000 per person. However, nursing-home placement, while necessary for some individuals who require skilled nursing assistance 24-hours a day, seven days a week, is not needed by *everyone* who receives long-term care. The most effective way to save Medicaid costs is to delay or prevent unnecessary nursing-home placement. The key lies in the ability of state policy-makers, working with providers in both the public and private sectors, to delay or prevent unnecessary nursing-home placement through the expansion of more affordable alternatives, specifically home and community based services. <http://www.governing.com/gov-institute/voices/col-aging-population-cost-effective-home-community-based-care.html>

#### 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>



## International

### **A new settlement for health and social care**

U.K. (England) | The King's Fund – 3 April 2014 – This is the interim report from the independent Commission on the Future of Health & Social Care in England. In it, the Commission explains why it believes England needs a single health and social care system, with a ring-fenced, singly commissioned budget, and more closely aligned entitlements. Drawing on accounts from patients and their families, the commission argues that the current system is no longer fit for purpose. At the root of the problem is a lack of alignment in funding, organisation and entitlement. The report analyses the historical divides between the two systems, the effects of our ageing society, and issues of affordability, before exploring options for change in meeting the costs ahead. [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/commission-interim-new-settlement-health-social-care-apr2014.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/commission-interim-new-settlement-health-social-care-apr2014.pdf)

#### **Extract from The King's Fund report**

Care at the end of life is a contentious issue. As we have seen, a large slice of the lifetime cost of health care occurs in the final year or so of life, more or less regardless of the age at which people die. Many people express the wish to die at home but in fact die in hospital, and some relatives feel on occasion that there is excessive intervention. An independent review of palliative care commissioned by the government in 2010 recommended a series of pilots aimed at collecting the data needed to create a tariff for palliative care. Eleven such pilots have been launched. The review's modelling, which the pilots will in part test, suggested that optimised services outside hospital – which will have a cost – could reduce the number of deaths in hospital by 60,000 by 2021, reducing hospital costs by some £180 million per annum.

Recent articles on the integration of health and social services noted in Media Watch:

- *INTERNATIONAL JOURNAL OF INTEGRATED CARE* | Online – 20 March 2014 – '**Integrated end of life care: The role of social services.**' If palliative care must be holistic, then it should include the social nature of the aid. [Noted In Media Watch, 31 March 2014, #351 (pp.7-8)] <http://www.ijic.org/index.php/ijic/article/view/URN%3ANBN%3ANL%3AUI%3A10-1-114777/2376>
- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2014;4(18). '**Benefits of health and social care integration.**' Scotland's health boards and local authorities are moving towards integrated funding and service provision. [Noted in Media Watch, 24 March 2014, #350 (p.8)] <http://spcare.bmj.com/content/4/1/118.1.short>

### **Families fail to seek help while caring for relatives**

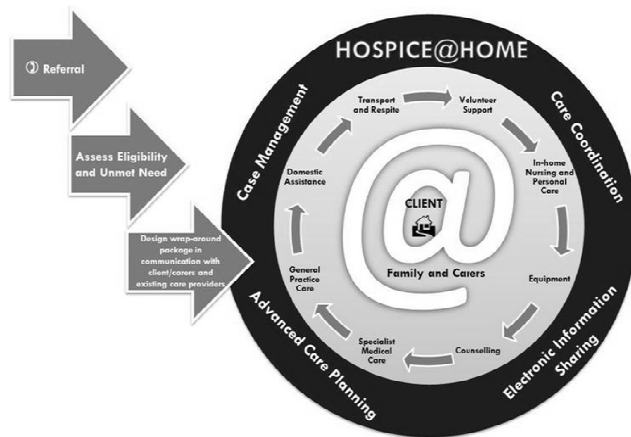
U.K. (Scotland) | *The Herald* (Edinburgh) – 2 April 2014 – Marie Curie Cancer Care has warned those who find themselves looking after a relative often go unidentified and unsupported by the National Health Service, following the release of a new report.<sup>1</sup> The charity commissioned researchers at Edinburgh University to investigate the experiences of carers... Professor Scott Murray, of Edinburgh University Primary Palliative Care Research Group, said: "Carers often prefer to think of themselves as a wife or a son rather than a 'carer,' and so fail to ask for help until they are struggling to cope. We must encourage people to seek help to look after their relatives, and GPs and nurses should be alert to asking their patients if they have any relative with a serious illness." Around 10% of the Scottish population are regarded as unpaid carers with many providing end of life care. <http://www.heraldscotland.com/news/health/families-fail-to-seek-help-while-caring-for-relatives.23851608>

1. 'Understanding the barriers to identifying carers of people with advanced illness in primary care: Triangulating three data sources,' *BMC Family Practice*, 2 April 2014, <http://www.biomedcentral.com/content/pdf/1471-2296-15-48.pdf>

## End-of-life care in Australia

### Care of dying to happen at home under new palliative care program

AUSTRALIA (Tasmania) | *The Herald-Sun* (Melbourne) – 1 April 2014 – A new \$35 million palliative care package has been rolled out to allow more Tasmanians to die in their homes. The new Hospice@Home program was launched with Federal Government funding from the Tasmanian Health Assistance Package.<sup>1</sup> Delivered by The District Nurses, it will not only benefit patients and their families but also free up hospital beds. Up to \$35.2 million will be spent over three years delivering 2,000 community-based packages of palliative care... The District Nurses have hired 15 staff so far and will continue to recruit statewide. Assistant Minister for Health Fiona Nash said the program was the first of its type to deliver comprehensive around-the-clock home-based palliative care across a state. <http://www.heraldsun.com.au/news/national/care-of-dying-to-happen-at-home-under-new-palliative-care-program/story-fnj6013-1226870323039>



1. Hospice@Home: [http://www.tasmedicarelocal.com.au/sites/default/files/hospice\\_at\\_home.pdf](http://www.tasmedicarelocal.com.au/sites/default/files/hospice_at_home.pdf)

Noted in Media Watch, 27 May 2013, #307 (p.3):

- AUSTRALIA (Tasmania) | ABC News – 22 May 2013 – **'Big cash injection for palliative care.'** The Federal Government has announced what it says is the biggest ever injection of money into Tasmania's palliative care sector. It will make \$50 million available for palliative care providers over the next four years. The money is part of a \$325 million health package announced by the Commonwealth last year. The Mental Health & Ageing Minister, Mark Butler, says demand for end-of-life care is growing faster in Tasmania than elsewhere and the state's system is a test case for other jurisdictions. Mr. Butler says the funding will help services provide home-based care. <http://www.abc.net.au/news/2013-05-22/big-cash-injection-for-palliative-care/4706108>

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

### **Patient-centered care or cultural competence: Negotiating palliative care at home for Chinese Canadian immigrants**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 April 2014 – The literature about Chinese attitudes toward death and dying contains frequent references to strong taboos against open discussion about death; consequently, there is an assumption that dying at home is not the preferred option. This focused ethnographic study examined the palliative home care experiences of four Chinese immigrants with terminal cancer, their family caregivers, and home care nurses and key informant interviews with 11 health care providers. Three main themes emerged: 1) the many facets of taboo; 2) discursive tensions between patient-centered care and cultural competence; and, 3) rethinking language barriers. Thus, training on cultural competence needs to move away from models that portray cultural beliefs as shared, fixed patterns, and take into account the complicated reality of everyday care provision at end of life in the home. <http://ajh.sagepub.com/content/early/2014/03/26/1049909114527338.abstract>

## Paediatric palliative care – the role of the GP

*AUSTRALIAN FAMILY PHYSICIAN*, 2014;43(4):176-180. This article highlights the important role of the GP in the management of paediatric palliative care (PPC) patients, especially if families want to care for their child at home. The support that specialist PPC teams can offer the GP is also emphasised. The GP has much to offer in conjunction with other local services, being part of a team managing the child with palliative care needs. Specialist PPC services can provide the GP with relevant information, specific education, advice and ongoing support to fulfil their important role for the child and family. <http://www.racgp.org.au/afp/2014/april/paediatric-palliative-care/>

## Reversal of English trend towards hospital death in dementia: A population-based study of place of death and associated individual and regional factors, 2001–2010

*BMC NEUROLOGY* | Online – 26 March 2014 – This study of place of death in dementia in England found that among people with a death certificate mention of dementia, hospital deaths remain amongst the highest in developed countries, with two in five people dying in hospital. However, the trend towards increasing hospital deaths in dementia reversed in 2006, with a subsequent fall in hospital deaths between 2006 and 2010, and a reciprocal increase in care home deaths. Care home bed provision and living in an area of least deprivation were the most important factors associated with care home death. <http://www.biomedcentral.com/1471-2377/14/59>

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

- *AGE & AGEING* | Online – 14 October 2013 – '**Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis.**' There is very limited evidence of patients, family carers and healthcare providers' views on preferred location of death for patients with dementia and the only study included reported that family carers views are more agreed to rather than patients own views regarding place of death. <http://ageing.oxfordjournals.org/content/early/2013/10/14/ageing.aft151.abstract>

## Burden for family carers at the end of life: A mixed-method study of the perspectives of family carers and GPs

*BMC PALLIATIVE CARE* | Online – 31 March 2014 – [In this study] the proportion of family carers experiencing a fairly heavy or severe burden increased significantly from 32% (second and third months before death) to 66% (one week before death). Most carers (95%) felt an emotional burden and 29% felt a physical burden in the final week. Three-quarters of carers did not perceive their burden as a problem because caring often felt rewarding. No significant association was found between the characteristics of family caregivers or professional care and the degree of family caregiver burden. <http://www.biomedcentral.com/content/pdf/1472-684X-13-16.pdf>

Noted in Media Watch, 24 March 2014, #350 (p.12):

- *EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 17 March 2014 – '**Burden on family carers and care-related financial strain at the end of life: A cross-national population-based study.**' In all countries studied ... GPs observed a considerable extent of physical/emotional overburden as well as difficulties in covering care-related costs among family carers of people at the end of life. Implications for health- and social care policies are discussed. <http://eurpub.oxfordjournals.org/content/early/2014/03/17/eurpub.cku026.abstract>

Noted in Media Watch, 17 March 2014, #349 (p.12):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2014;311(10):1052-1060. '**Care-giver burden: A clinical review.**' Risk factors for caregiver burden include female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver. <http://jama.jamanetwork.com/article.aspx?articleid=1840211>

### **Acute hospital-based services utilisation during the last year of life in New South Wales, Australia: Methods for a population-based study**

*BMJ OPEN* | Online – 28 March 2014 – The aim of this study is to describe healthcare utilisation in the last year of life for people in Australia, to help inform health services planning. The median age at death was 80 years. Cause of death was available for 95% of decedents and 85% were linked to a hospital admission record. In the greater metropolitan area, where data capture was complete, 83% of decedents were linked to an emergency department presentation. 38% of decedents were linked to a cancer diagnosis in 1994-2007. The most common causes of death were diseases of the circulatory system (34%) and neoplasms (29%). This study is among the first in Australia to give an information-rich census of end-of-life hospital-based experiences. While the administrative datasets have some limitations, these population-wide data can provide a foundation to enable further exploration of needs and barriers in relation to care. They also serve to inform the development of a relatively inexpensive, timely and reliable approach to the ongoing monitoring of acute hospital-based care utilisation near the end of life and inform whether service access and care are optimised. <http://bmjopen.bmj.com/content/4/3/e004455.full>

### **Identifying the key elements of an education package to up-skill multidisciplinary adult specialist palliative care teams caring for young adults with life-limiting conditions: An online Delphi study**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 26 March 2014 – The development of an education programme for specialist palliative care staff in adult services is needed and supported by parents and adult healthcare professionals across the disciplines. A continuous/rolling programme is recommended, tailored in terms of content and mode of delivery to ensure the training is relevant for staff and delivered at the right time. As a direct outcome of the results of this study, a 'Transition Study Day' series has been established in the U.K. This series of six linked study days focuses specifically on the issues around caring for young adults with life-limiting conditions and palliative care needs. <http://spcare.bmj.com/content/early/2014/03/26/bmjspcare-2013-000595.full.pdf>

Of related interest:

- THE LIEN CENTRE FOR PALLIATIVE CARE (Singapore) | Online – 31 March 2014 – '**National education needs survey of healthcare professionals for palliative care.**' There was broad agreement between key interviewees on the palliative care knowledge and skills healthcare professionals should possess. The experts identified many barriers and enablers to palliative care training. These include limited exposure of healthcare professionals to palliative care in basic training, the lack of a standardized curriculum and an aversion to sharing information ("silo mentality"), and difficulties experienced by smaller institutions in developing capacity and ensuring skills learnt are applied in practice. Download 'Report of a National Education Needs Assessment of Healthcare Professionals for Palliative Care in Singapore' at: <http://lcpc.duke-nus.edu.sg/sites/default/files/lcpc/Files/An%20ENA%20Report%20for%20Palliative%20Care%2030%20March%2014.pdf>

### **The emotional labour of caring for patients at the end of life**

*END OF LIFE JOURNAL*, 2014;40(1). Nurses' emotional commitment to their patients contributes to the quality and excellence of nursing care and enhances the nurse-patient relationship. Nurses are expected to manage their emotions in order to present a professional demeanour and maintain professional boundaries, while at the same time provide genuine caring behaviour to their patients. However, if not adequately educated and supported, caring for patients at the end of life can provoke feelings of anxiety, fear and helplessness in nurses. It is only in relatively recent years that the nursing profession has begun to look more closely at the emotional cost to nurses of managing, hiding and suppressing their emotions – what has been termed "emotional labour." <http://endoflifejournal.stchristophers.org.uk/professional-issues/the-emotional-labour-of-caring-for-patients-at-the-end-of-life>



## Barriers to effective end-of-life nursing care out-of-hours

*END OF LIFE JOURNAL*, 2014;40(1). The lack of end-of-life care out-of-hours services can lead to terminally ill and dying patients who want to be cared for at home being admitted unnecessarily to hospital. The number of out-of-hours end-of-life care services has started to increase. However, there are significant variations in terms of service availability and service quality and patients/carers are still experiencing barriers in accessing out-of-hours community care. This article highlights how lack of information about the out-of-hours service, inadequate nursing communication skills and poor inter-professional communication can have a negative impact on care. <http://endoflifejournal.stchristophers.org.uk/personal-reflections/barriers-to-effective-end-of-life-nursing-care-out-of-hours>

Noted in Media Watch, 10 June 2013, #309 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 June 2013 – '**Discontinuity of care at end of life: A qualitative exploration of out-of-hours end of life care.**' Study participants described the importance of being known by the healthcare team, and the perceived positive implications continuity could have for the quality of care they received and the trust they had in their care. <http://spcare.bmj.com/content/early/2013/06/07/bmjspcare-2012-000266.abstract>

## Directives to clarify advanced care protocol

*IRISH MEDICAL TIMES* | Online – 2 April 2014 – In its submission to the Department of Health on the draft General Scheme for Advance Healthcare Directives for incorporation into the Assisted Decision-Making (Capacity) Bill 2013,<sup>1</sup> the Irish Medical Organization (IMO) pointed out that medical professionals increasingly found themselves in a difficult legal and ethical position, in cases where there were diverging views amongst family members on the best treatment and care options for their relatives who no longer have capacity. The IMO considers that patients might make an advance care plan rather than a legally-binding directive. An advance care plan can provide valuable insights into patients' pre-morbid views and wishes at a time of great distress for the patient and their family, the IMO believes. In its submission, the union warned that a situation may arise where a patient-designated healthcare representative contests the decision made in the advanced care document. The capacity of the patient to make that decision at that time may be contested. Equally, it may be argued that the patient changed their decision. <http://www.imt.ie/news/latest-news/2014/04/directives-to-clarify-advanced-care-protocol.html>

1. 'Draft legislation for Bill allowing terminally ill to make "living wills,"' *The Irish Times*, 5 February 2014. The legislation provides that a person may set out their end-of-life care and their desired medical treatment when they have reached a terminal stage of their condition where they no longer have the capacity to make their views known. The draft Bill will now be published and sent out for public consultation. [Noted in Media Watch, 10 February 2014, #344 (p.3)] <http://www.irishtimes.com/news/politics/draft-legislation-for-bill-allowing-terminally-ill-to-make-living-wills-1.1679634>

Of related interest:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 2 April 2014 – '**Advance directive completion by elderly Americans: A decade of change.**' The proportion of decedents [i.e., Health & Retirement Study participants who died between 2000 and 2010 and were aged 60 and older at death] with an advance directives (AD) increased from 47% in 2000 to 72% in 2010. The proportion of decedents with at least one hospitalization in the last 2 years of life increased from 52% to 71%, and the proportion dying in the hospital decreased from 45% to 35%. The trend in declining hospital death over the decade was negligibly associated with the greater use of ADs. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12736/abstract>

### **"This is our last stop": Negotiating end-of-life transitions in assisted living**

*JOURNAL OF AGING STUDIES*, 2014;30):1-13. Assisted living (AL) increasingly is becoming a site of EOL [end-of-life] care and a place where people die. AL residents are moving in older and sicker and with more complex care needs, yet AL remains largely a non-medical care setting that subscribes to a social rather than medical model of care. The authors present a model for how EOL care transitions are negotiated in AL that depicts the range of multilevel intersecting factors that shape EOL processes and events in AL. Facilities developed ... an EOL presence, which varied across and within settings depending on multiple influences, including, notably, the dying trajectories and care arrangements of residents at EOL, the prevalence of death and dying in a facility, and the attitudes and responses of individuals and facilities toward EOL processes and events, including how deaths were communicated and formally acknowledged and the impact of death and dying on the residents and staff. Findings indicate, in the majority of cases, EOL care must be supported by collaborative arrangements of care partners and that hospice care is a critical component. <http://www.sciencedirect.com/science/article/pii/S0890406514000103>

### **Hospice and self-assessed quality of life in the dying: A review**

*JOURNAL OF HUMAN BEHAVIOR IN THE SOCIAL ENVIRONMENT*, 2014;24(3):281-295. This review summarizes the impact of hospice and palliative end-of-life care on the self-assessed quality of life (QoL) in terminally ill persons. Articles were included if researchers utilized at least two observations post-hospice admission and were published in English between January of 2000 and December 2012. Findings from included studies synthesize results of a variety of terminal patients across settings. Only one study utilized a non-treatment control group. The remaining studies compared variations of program inclusions, settings, or QoL scores across carcinoma site. The studies included indicated mixed outcomes related to the effect of hospice on QoL in the dying. <http://www.tandfonline.com/doi/abs/10.1080/10911359.2013.820159#.UzrQfahdX8k>

### **Clinic-based outpatient palliative care before hospice is associated with longer hospice length of service**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 March 2014 – Outpatient non-hospice palliative care has been shown to provide many benefits to patients facing advanced illness, but such services remain uncommon in the U.S. Little is known about the association between clinic-based outpatient palliative care consultation and the timing of hospice enrollment. Using a retrospective study of medical records, a "prior palliative care clinic" group was formed of those hospice patients who had had a non-hospice clinic-based outpatient palliative care consult before hospice admission. For those patients, "control" hospice patients without prior clinic-based palliative care were chosen who were matched by age, gender, median income of their zip code, and diagnostic group. Both groups were restricted to patients who died while enrolled in hospice. LOS [length of service] for these two groups was compared using standard statistical methods of survival analysis. Hospice patients who had clinic-based outpatient palliative consults before hospice enrollment tended, on average, to have a longer LOS in hospice than patients who did not. [http://www.jpsmjournal.com/article/S0885-3924\(14\)00044-X/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00044-X/abstract)

Noted in Media Watch, 4 March 2013, #295 (p.5):

- *BMC PALLIATIVE CARE* | Online – 21 February 2013 – **'International recommendations for outpatient palliative care and pre-hospital palliative emergencies: A prospective questionnaire-based investigation.'** This study detected structurally and nationally differences in outpatient palliative care regarding the treatment of palliative emergencies. Recommended: 1) early integration of "palliative care teams" and basic outpatient palliative care systems; 2) end-of-life discussions; 3) defined emergency medical documents, drug boxes, and "do not attempt resuscitation" orders; and, 4) emergency medical training (physicians and paramedics). <http://www.biomedcentral.com/content/pdf/1472-684X-12-10.pdf>

## Research priorities in spiritual care: An international survey of palliative care researchers and clinicians

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 March 2014 – Spiritual distress, including meaninglessness and hopelessness, is common in advanced disease. Spiritual care is a core component of palliative care, yet often neglected by health care professionals owing to the dearth of robust evidence to guide practice. An online, cross-sectional, mixed-methods survey was conducted. In total, 971 responses, including 293 from palliative care physicians, 112 from nurses, and 111 from chaplains, were received from 87 countries. Fifty-three percent reported their work as "mainly clinical," and less than 2.5% stated that no further research was needed. Integrating quantitative and qualitative data demonstrated three priority areas for research: 1) development and evaluation of conversation models and overcoming barriers to spiritual care in staff attitudes; 2) screening and assessment; and, 3) development and evaluation of spiritual care interventions and determining the effectiveness of spiritual care. In this first international survey exploring researchers' and clinicians' research priorities in spiritual care, the authors found international support for research in this domain. [http://www.jpsmjournal.com/article/S0885-3924\(14\)00047-5/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00047-5/abstract)

### Media Watch Online

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/3/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 | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

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

#### **Europe**

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

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>

## End-of-life care in Africa

### **Qualitative analysis of palliative care and support in medical practices in Democratic Republic of the Congo**

*MÉDECINE ET SANTÉ TROPICALES* | Online – 1 April 2014 – This qualitative study was conducted among 30 doctors and 90 nurses with at least one year of experience in six hospitals in Kinshasa that receive patients at the end of life. The results show that health professionals believe that this care is time-consuming and that the inability to say some things to patients and families generates misunderstandings and concerns likely to prevent the application of palliative care. For them, it is often a futile therapeutic obstinacy, added hygienic care, and neglect of the patient. The obstacles to implementing this care might be linked to the lack of training about this approach and a health system based essentially on curative approaches. The representation of health professionals about palliative care and support are many and varied. They are, however, more structured among physicians than nurses. <http://www.jle.com/en/revues/medecine/mst/docs/00/04/98/50/resume.phtml>

N.B. French language article

### **Patterns of diagnoses among children and young adults with life-limiting conditions: A secondary analysis of a national dataset**

*PALLIATIVE MEDICINE* | Online – 3 April 2014 – Numbers of children and young people with life-limiting conditions are rising, and increasing lifespans require young adults with life-limiting condition to transit to appropriate adult services. Non-malignant diagnoses are common in children and young adults, and services that have historically focussed on oncological care will need to widen their remit to serve this population. The diagnosis determining a patient's life-limiting condition will strongly influence their palliative care service needs. Understanding the diagnostic and demographic breakdown of this population of teenagers and young adults is crucial for planning future service provision. <http://pmj.sagepub.com/content/early/2014/04/03/0269216314528743.abstract>

Representative sample of articles on the transition to adult services for young people living with a terminal illness noted in recent issues of Media Watch:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 December 2013 – **'Palliative care answers the challenges of transitioning serious illness of childhood to adult medicine.'** There is an urgent need to develop approaches that assist with the transition of care from pediatrics to adult medicine. Palliative care, by virtue of its unique skills, is ideally positioned to play a part in this transition. [Noted in Media Watch, 6 January 2014, #339 (p.12)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0263>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 November 2013 – **'Young adult palliative care: Challenges and opportunities.'** From the data, two primary themes emerge 1) ongoing young adult development not only generates unique biologic disease burdens and clinical treatment options, but also requires frequent assessment and promotion; and, 2) binary health care systems often leave young adults without access to developmentally appropriate health care. [Noted in Media Watch, 11 November 2013, #331 (p.6)] <http://ajh.sagepub.com/content/early/2013/11/06/1049909113510394.abstract>
- *PALLIATIVE MEDICINE* | Online – 18 October 2013 – **'Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study.'** Transition to adult services and adulthood is a prospect for young people with life-limiting conditions requiring palliative care. Transition planning [among the study participants] was absent or poorly coordinated; for most families, there were no equivalent adult health/social services. [Noted in Media Watch, 21 October 2013, #328 (p.13)] <http://pmj.sagepub.com/content/early/2013/10/15/0269216313507626.abstract>

## General practitioners' perspectives on the avoidability of hospitalizations at the end of life: A mixed-method study

*PALLIATIVE MEDICINE* | Online – 1 April 2014 – According to 24% of 319 general practitioners [i.e., study participants], the last hospitalization in the final three months of their patient's life could have been avoided. Of all avoidable hospitalizations, 46% could have been avoided by proactive communication with the patient, 36% by more communication between professionals around hospitalization, 28% by additional care and treatment at home, and 10% by patient and family support. <http://pmj.sagepub.com/content/early/2014/04/02/0269216314528742.abstract>

Representative sample of articles on avoidable hospital readmissions of hospice or palliative care patients noted in past issues of Media Watch:

- *PALLIATIVE MEDICINE* | Online – 17 February 2014 – **'What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses.'** There are a number of scenarios study participants considered to justify a hospital admission at the end of life: when the patient prefers a hospital admission, when the caring capacity of the care setting is considered to be inadequate and when one of a number of acute medical situations occurs. [Noted in Media Watch, 24 February 2014, #346 (p.12)] <http://pmj.sagepub.com/content/early/2014/02/14/0269216314522317.abstract>
- *JOURNAL OF HOSPITAL MEDICINE* | Online – 14 February 2014 – **'Risk factors for potentially avoidable readmissions due to end-of-life care issues.'** Patients with these risk factors might benefit from palliative care consultation prior to discharge to improve end-of-life care and possibly reduce unnecessary re-hospitalizations. [Noted in Media Watch, 24 February 2014, #346 (p.12)] <http://onlinelibrary.wiley.com/doi/10.1002/jhm.2173/abstract>
- *PALLIATIVE MEDICINE* | Online – 23 December 2013 – **'Economic impact of hospitalisations among patients in the last year of life: An observational study.'** Of 483 admissions, 35 were classified as potentially avoidable. Avoiding these admissions and caring for the patients in alternative locations would save the two hospitals [involved in the study] £5.9 million per year. Reducing length of stay in all 483 patients by 14% has the potential to save the two hospitals £47.5 million per year... [Noted in Media Watch, 30 December 2013, #338 (p.12)] <http://pmj.sagepub.com/content/early/2013/12/23/0269216313517284.abstract>

## An integrative review of dignity in end-of-life care

*PALLIATIVE MEDICINE* | Online – 31 March 2014 – Dying with dignity is regarded as a goal of quality end-of-life care. However, the meaning of dying with dignity is ambiguous, and no comprehensive synthesis of the existing literature has been published. Themes of dying with dignity are as follows: a human right, autonomy and independence, relieved symptom distress, respect, being human and being self, meaningful relationships, dignified treatment and care, existential satisfaction, privacy, and calm environment. Factors influencing dignity include demographic, illness-related, and treatment-/care-related factors, as well as communication. Models of dignity in end-of-life care and instruments to measure dignity were reported. Interventions to support dignity stressed physical, psychological, and spiritual supports not only to dying patients but also to family members. <http://pmj.sagepub.com/content/early/2014/03/31/0269216314528399.abstract>

Cont. next page.

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

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

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 March 2014 – **'Dying with dignity: Is this a universal concept?'** Dying with dignity is a fundamental human right that should not be denied or withheld. <http://online.liebertpub.com/doi/full/10.1089/jpm.2013.0340>

Noted in Media Watch, 16 September 2013, #323 (p.14):

- *PROGRESS IN PALLIATIVE CARE* | Online – 13 September 2013 – **'Dignity: A unifying concept for palliative care and human rights.'** This article examines the evolution of the meaning of dignity, the nature of intrinsic and extrinsic dignity and its place in palliative care and human rights law (especially as it pertains to the international right to health care). [http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney\\_ppc\\_167](http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney_ppc_167)

### 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.
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### Something Missed or Overlooked?

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

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