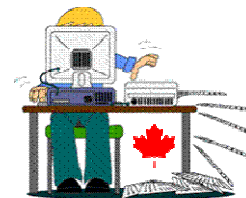


## Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

A paucity of evidence: Scroll down to [Specialist Publications](#) and 'What is the evidence for conducting palliative care family meetings? A systematic review' (p.11), in *Palliative Medicine*.

## Canada

### Few palliative care patients at risk under Ontario's new opioid policy: Study

ONTARIO | *The Globe & Mail* – 2 August 2016 – Only a small number of palliative care (PC) patients in Ontario will be affected by the province's plan to stop paying for high-dose opioid medications under its public drug programs, a new study shows.<sup>1</sup> Ontario will become the first province to cut off publicly funded access to all opioids that exceed the equivalent of 200 milligrams of morphine a day, as part of a measure aimed at combating the widespread abuse of prescription painkillers. Nine out of 10 people in Ontario who were prescribed high-dose opioids paid for by the province's public drug plans were not PC patients, says the study done by the Ontario Drug Policy Research Network based at St. Michael's Hospital. The study ... looked at the 62,605 people in Ontario receiving PC and how physicians were treating their pain. Just over 40% were prescribed opioids paid for by the province in a one-year period. Only 2.7% of those patients received the high-dose formula-

tions. "It is reassuring that the vast majority of PC patients will not be impacted by this policy," said Tara Gomes, a principal researcher at the network. <http://goo.gl/NRkkPU>

#### Extract from *The Globe & Mail* article

Darren Cargill, section chair of palliative medicine at the Ontario Medical Association, said the figures cited in the study for the number of patients in PC highlight the fact that access to PC is poor in the province. "It is odd logic indeed to claim that the number of patients requiring these meds for PC is low when we know the number of patients requiring PC in general is much greater than those currently being served," Dr. Cargill said. The government needs to strike a balance, he said, between addressing the needs of PC patients who require these pain medications to remain comfortable and the widespread abuse of prescription opioids.

1. 'High Strength Opioid Formulations in Ontario: By the Numbers,' Ontario Drug Policy Research Network, St. Michael's Hospital, Toronto, Ontario. August 2016. <http://goo.gl/Spzst9>

Cont.

## Related

- ONTARIO | *The Blackburn News* (Chatham-Kent) – 2 August 2016 – ‘**Local doctor slams province’s new opioid plan.**’ Medical Director of St. Joseph’s, Dr. Glenn Maddison, says there’s very little abuse of these drugs in PC patients and it’s simply not fair to the dying who cannot afford to pay for the pain pills. He says a better scenario would be for the province to allow doctors treating patients in PC to have access to high doses of opioids though the current Palliative Care Facilitated Access program. <https://goo.gl/J02FGz>

Noted in Media Watch, 1 August 2016, #473 (p.2):

- ONTARIO | *The Globe & Mail* – 25 July 2016 – ‘**Palliative care doctors decry Ontario’s new opioid policy.**’ Palliative care doctors are calling on the Ontario government not to cut off access to high-dose opioid medications for their patients, saying those nearing the end of life or suffering from cancer pain “deserve better.” Ontario will become the first province to stop paying for all opioids that exceed the equivalent of 200 milligrams of morphine a day under its public drug plans. Several other provinces are monitoring Ontario’s announcement. The Alberta government says it plans to conduct a formal review of the changes, while Saskatchewan will look at whether it should adopt similar measures. In British Columbia, the government says it is reviewing Ontario’s move, but has no immediate plans to change its coverage of the drugs. <http://goo.gl/CldjNX>

## “Army of unpaid caregivers” should be compensated for senior care: Survey

*THE OTTAWA CITIZEN* | Online – 29 July 2016 – Family and friends should get financial compensation for the hours they put into senior care, says a survey released by the Conference Board of Canada.<sup>1</sup> The EKOS [Research associates] survey of 4,127 Canadians – about two-thirds of respondents were over the age of 55 – found that 60% supported government financial assistance for caregivers who have to change or scale down their work because of care-giving responsibilities. An “army of unpaid caregivers” has been under pressure to provide care for seniors while still working in the paid labour force, says the conference board. According to its research, more than three million Canadians dedicated 1.5 billion hours of home support and community care in 2007, offering 10 unpaid hours of care for every paid hour. As the population ages, some caregivers will be in the position

of being the recipients of care themselves, said Louis Thériault, vice-president of policy at the conference board. [goo.gl/hDr6VP](http://goo.gl/hDr6VP)

### Extract from Conference Board of Canada survey

According to the Canadian Institute for Health Information provincial/territorial health expenditure figures, more money was spent on seniors than on any other age group in 2014.<sup>1</sup> Increased costs in later years are attributable to the high cost of end-of-life care and the higher prevalence of chronic diseases, which require more health resources and are more likely to be prevalent in senior age groups.

1. ‘National Health Expenditure Trends, 1975 to 2014,’ Canadian Institute for Health Information, October 2014. [Noted in Media Watch, 10 November 2014, #383 (p.2)] <http://goo.gl/fplcZl>

1. ‘Feeling at Home: A Survey of Canadians on Senior Care,’ The Conference Board of Canada, 28 July 2016. <http://goo.gl/yil78l>

Noted in Media Watch, 11 April 2016, #457 (p.2):

- ONTARIO | *The Toronto Star* – 5 April 2016 – ‘**Caregivers are needed more than ever, but burning out.**’ Distress among unpaid caregivers who bear the heavy burden of looking after ill, elderly or disabled relatives has doubled in four years, according to Health Quality Ontario, the provincial adviser on quality of health care.<sup>1</sup> <http://goo.gl/XXwdwe>

1. ‘The Reality of Caring: Distress Among the Caregivers of Home Care Patients,’ Health Quality Ontario, April 2016. <http://goo.gl/xkSYRP>

**N.B.** No mention is made in the report of home care for people living with a terminal illness.

Cont.

Noted in Media Watch, 6 October 2014, #378 (p.3):

- *THE GLOBE & MAIL* | Online – 2 October 2014 – ‘**Why Canada’s reliance on unpaid care is not sustainable.**’ More than two million individuals ... received homecare in 2012.<sup>1</sup> Most consider that over a one-year period they received all the services they required to help with their daily activities. Only a minority, approximately 15%, said they had unmet homecare needs. <http://goo.gl/qWHeDZ>

1. ‘Canadians with Unmet Home Care Needs,’ Statistics Canada, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.3)] <http://goo.gl/oBNrck>

**N.B.** See also ‘Family Caregiving: What are the consequences?’ Statistics Canada, December 2013. <http://goo.gl/Qf796g>

### Specialist Publications

‘**Finding a balance: Canada’s law on medical assistance in dying**’ (p.13), in *The Lancet*.

‘**Unresolved issues in Canada’s law on physician-assisted dying**’ (p.13), in *The Lancet*.

## U.S.A.

### **Difference between palliative care and hospice**

*FORBES* | Online – 2 August 2016 – Our medical system is very adept at treating serious illness such as cancer or progressive heart or lung disease. Sometimes a health provider’s focus on treating disease takes away from actually caring for the patient’s symptoms. Illness causes discomfort, and sometimes the treatment of illness adds to that discomfort. What can be done about this? Fortunately, the specialty of palliative care (PC) focuses on keeping a patient well while their disease is being treated. PC doctors treat all the “discomforts” of diseases and treatments such as pain, nausea, and decreased appetite. This focus on improving quality of life throughout your illness results in more enjoyable time with family, better strength to deal with treatment, and improved focus to take care of important logistics of regular life. What is the difference between PC and hospice? Both provide essentially the same type of care by the same doctors, but there are important distinctions: PC can be started and stopped at any time for any serious

illness and does not require you to stop potentially curative treatment of your disease. Hospice is started once it is determined you are terminally ill and have less than a six month life expectancy. Most hospice care requires that you stop any potentially curative treatments and that you accept you are terminally ill and will die of your disease. <http://goo.gl/mc5hIG>

### Specialist Publications

‘**At your defense: [California’s] Aid-in-dying law creates pitfalls for emergency physicians**’ (p.12), in *Emergency Medicine News*.

‘**Palliative care: A partnership across the continuum of care**’ (p.9), in *Health Care Manager*.

‘**Associations between end-of-life cancer care patterns and Medicare expenditures**’ (p.9), in *Journal of National Comprehensive Cancer Network*.

### 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.14.

## **U.S. News & World Report announces the 2016-2017 best hospitals**

U.S. NEWS & WORLD REPORT | Online – 2 August 2016 – U.S. News compared nearly 5,000 medical centers nationwide in 25 specialties, procedures and conditions. This year the Mayo Clinic in Rochester, Minnesota, is No. 1 on the Honor Roll, which has been expanded to highlight 20 hospitals delivering exceptional treatment across multiple areas of care. The Cleveland Clinic is No. 2, followed by Massachusetts General Hospital at No. 3. U.S. News also recognized 504 Best Regional Hospitals in states and metro areas. In the specialty rankings, University of Texas MD Anderson Cancer Center is No. 1 in cancer, the Cleveland Clinic is No. 1 in cardiology & heart surgery, and the Hospital for Special Surgery is No. 1 in orthopedics. <http://goo.gl/0uNJne>

### **How palliative care programs were rated**

In Cancer, hospitals received up to 8 points for palliative care (PC). Hospitals received 1 point for offering a qualified PC program onsite. The program must include at least one physician providing direct PC as well as a nurse coordinator and either a social worker, certified child life specialist or pastoral counselor, and all staff must have training in PC. Hospitals could receive up to 4 points for offering the following pain control programs: patient-controlled analgesia, nurse-controlled analgesia, pediatric pain service consults and pediatric outpatient pain management services. Hospitals received 1 point for having at least 1 physician board-certified in hospice and palliative medicine.

### **Related**

- KAISER HEALTH NEWS | Online – 27 July 2016 – ‘**Many well-known hospitals fail to score 5 stars in Medicare’s new ratings.**’ The federal government released its first overall hospital quality rating, slapping average or below average scores on many of the nation’s best-known hospitals while awarding top scores to dozens of unheralded ones. <http://goo.gl/CbqIRC>

Noted in Media Watch, 5 October 2015, #430 (p.14):

- JOURNAL OF PALLIATIVE MEDICINE | Online – 29 September 2015 – ‘**The growth of palliative care in U.S. hospitals: A status report.**’ This study demonstrates continued steady growth in the number of hospital palliative care (PC) programs in the U.S.,<sup>1</sup> with almost universal access to services in large U.S. hospitals and academic medical centers. Nevertheless access to PC remains uneven and depends on accidents of geography and hospital ownership. <http://goo.gl/h3RAdY>

1. ‘America’s Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation’s Hospitals,’ Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. <https://reportcard.capc.org/>

## **Long-term care is an immediate problem – for the government**

CALIFORNIA | Kaiser Health News – 1 August 2016 – Experts estimate that about half of all people turning 65 today will need daily help as they age, either at home or in nursing homes. Such long-term care (LTC) will cost an average of about \$91,000 for men and double that for women, because they live longer. In California, and across the U.S., many residents can’t afford that, so they turn to Medicaid, the nation’s public health insurance program for low-income people. As a result, Medicaid has become the safety net for millions of people who find themselves unable to pay for nursing home beds or in-home caregivers. Medicaid, known as Medi-Cal in California, was never intended to cover LTC for everyone. Now it pays for nearly 40% of the nation’s LTC expenses, and the share is growing. As Baby Boomers age, federal Medicaid spending on LTC is widely expected to rise significantly – by nearly 50% by 2026. In California, seniors typically can qualify for Medi-Cal if their yearly incomes are under \$16,395. About 21% of the state’s over-65 population is enrolled in Medi-Cal, according to the state Department of Health Care Services. <http://goo.gl/jBB4G0>

Cont.

Noted in Media Watch, 30 May 2016, #464 (p.4):

- ASSOCIATED PRESS-NORC CENTER FOR PUBLIC AFFAIRS RESEARCH | Online – 22 May 2016 – **‘Long-term care in America: Expectations and preferences for care and caregiving.’** The 2016 Long-Term Care (LTC) trends poll finds many people expect to rely on Medicare and Social Security to pay for their LTC needs as they age, although these programs generally do not cover most LTC services or costs. Additionally, support is high for policies that help Americans save for LTC and for those that defray the costs of caregiving. <http://goo.gl/bxa9U3>

**N.B.** Selected articles on long-term care in the U.S. are noted in Media Watch of 23 May 2016, #463 (pp.5,6).

### **A deep flaw has been discovered in thousands of neuroscience studies**

QUARTZ | Online – 30 July 2016 – Modern neuroscience would be impossible without functional magnetic resonance imaging, or fMRI. The technique is barely 25 years old, but thousands of studies that use it are published each year. When you see headlines such as ‘Vegetative state patients can respond to questions’ ... you can be sure that fMRI was involved. Last week a new map of the brain based on fMRI scans was greeted as a “scientific breakthrough.” However, earlier this month, Anders Eklund, of Sweden’s Linköping University, published the latest in a series of papers showing a deep flaw in how researchers have been using fMRI.<sup>1</sup> This flaw, Eklund and his colleagues believe, could ruin the results of as many as 16,500 neuroscience studies over the last 20 years. <http://goo.gl/0viqHI>

1. ‘Cluster failure: Why fMRI inferences for spatial extent have inflated false-positive rates,’ *Proceedings of the National Academy of Science*, 2016;113(28):7900. <http://goo.gl/rD6Fh2>

Noted in Media Watch, 18 February 2013, #293 (p.5):

- *AMERICAN JOURNAL OF BIOETHICS: NEUROSCIENCE*, 2013;4(1):46-51. **‘Communicating with the minimally conscious: Ethical implications in end-of-life care.’** Recent research from electroencephalography and functional magnetic resonance (fMRI) studies appears to indicate that some patients diagnosed in a vegetative state may have some level of awareness and should instead be understood to be in a minimally conscious state. This article addresses ethical implications of the possibility of communication with minimally conscious patients. <http://goo.gl/s9BBak>

## **International**

### **End-of-life care in New Zealand**

#### **Palliative care set for big budgeted increase**

NEW ZEALAND | Radio New Zealand (Wellington) – 4 August 2016 – The government announced more money for hospices in the May budget which would be used to fund the new positions. There was \$52 million allocated directly to hospices over four years as general funding, with \$24 million to be spent on new services that improve palliative care. It will fund 40 confirmed positions at 15 hospices, with nine hospices still working on proposals expected to see a further 20 positions. <http://goo.gl/uFIW6x>

Noted in Media Watch, 7 March 2016, #452 (p.5):

- NEW ZEALAND | TVNZ News (Auckland) – 3 March 2016 – **‘Extra funding wanted to help Kiwis in care die in comfort.’** Around 10,000 Kiwis die each year in residential care, more than in hospitals, and some say they are struggling without ring-fenced funding for end-of-life care. Most are paid around \$180 a night for palliative patients, the same for rest home hospital patients, but they say that doesn’t cover the complex needs of those dying or those of their families. <https://goo.gl/EEpeQg>

**N.B.** See ‘The Need for Palliative Care in New Zealand,’ Technical report for the Ministry of Health, June 2016. <http://goo.gl/w9cAjW>. Selected articles on end-of-life care in New Zealand noted in Media Watch, 28 December 2015, #442 (pp.5-6).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MALTA | *The Economist* – 1 August 2016 – ‘**Religious leaders grapple with doctor-assisted dying.**’ Life’s beginning and end are, to most religions, sacred moments. Therefore politicians are accustomed to religious leaders weighing in on matters such as contraception and abortion – and on whether and how doctors should be allowed to intervene to speed a patient’s passing. So as Maltese parliamentarians debate doctor-assisted dying, in response to a plea by a sufferer from motor neurone disease who wants to be able to get a doctor’s help to end his life when he chooses, it is unsurprising that two of the country’s most senior religious figures chose to interject themselves in the discussion. In response to deliberation in the parliamentary committee on family affairs which is expected to continue after the summer recess, Charles Scicluna, the Archbishop of Malta, and Mario Grech, the Bishop of Gozo (the western of Malta’s two islands), published an open letter to parliamentarians. Their message? “Medical assistance given to the patients for the abrupt termination of life could never be in his or her best interest.” <http://goo.gl/xQVFC5>

## Specialist Publications

### **“Pain is what the patient says it is” – Nurse-patient communication, information seeking, and pain management**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 August 2016 – Nurse-patient conversations about pain management are complex. Given recent increases in prescription pain pill abuse such interactions merit scholarly attention. The participants in this study gathered pain information from patients through a variety of means and reported facing challenges and dilemmas when communicating with patients about pain management and medicinal preferences. These results have important implications for nurses, patient outcomes and the broader health-care system, and imply that continued educational and intervention efforts are essential in this complicated communicative context. <http://goo.gl/LvHw3p>

### **When terminal illness is worse than death: A multicenter study of health-care providers’ resuscitation desires**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 3 August 2016 – Doctors and nurses have different end-of-life preferences than other hospital workers. Their desire to undergo CPR may change when facing a terminal illness. A total of 852 surveys [sic] were completed. Among the respondents, 21% were physicians, 36.9% were nurses, 10.5% were medical students, and 265 participants were other staff members of the institutions. Most respondents (58.3%) desired “definitely full code” (physicians 73.2%), only 13.8% of the respondents (physicians 8.33%) desired “definitely no code” or “partial support,” and 20.9% of the respondents (among physicians 18.4%) had never considered their code status. There was an association between current code status and resuscitation preference in case of terminal illness, but this association was overall quite weak. <http://goo.gl/LpW1y3>

**N.B.** Participating centers: Universidad Autónoma de Baja California Tijuana, México, Shaare Zedek Medical Center, Hadassah-Hebrew University, Jerusalem, Israel, and Foundation Surgical Hospital of Houston, Houston, Texas. Selected articles on physicians’ personal preferences in the context of end-of-life care are noted in *Media Watch* of 28 March 2016, #455 (pp.13-14) and 25 May 2015, #411 (p.2).

### [Media Watch: Back Issues](#)

Back issues of *Media Watch* are available on the International Palliative Care Resource Center website at: <http://goo.gl/frPgZ5>

## **Comfort experience in palliative care: A phenomenological study**

*BMC PALLIATIVE CARE* | Online – 2 August 2016 – This study demonstrated that the palliative care unit (PCU) can be perceived as a space of comfort where the patient finds a suitable therapeutic context to their needs, but also as a place of discomfort where the patient is confronted with its vulnerability. It can be a space where there is a process of denial or openness to spirituality. The patient feels comfortable through the symptomatic control, compassionate care, the PCU differentiated environment, hope, interpersonal, transpersonal and intrapersonal relationships. Even if such findings may seem intuitive, documenting them is crucial because it invites the reader to reflect on their beliefs about what it means to be comfortable for these patients, and allows the incorporation of this information in the design of focused interventions to maximize the comfort experience. Unless one offers patients the opportunity to be heard on their experience, their perspective will remain hidden and you could hardly provide comfort to them. <http://goo.gl/FX0Xh9>

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

## **Normalising and planning for death in residential care: Findings from a qualitative focus group study of a specialist palliative care intervention**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 August 2016 – Improving access to palliative care (PC) for older adults living in residential care is recognised internationally as a pressing clinical need. The integration of specialist PC in residential care for older adults, however, is not yet standard practice. The intervention led to: 1) Normalising death and dying in these settings; 2) Timely access to a PC specialist who was able to prescribe anticipatory medications aiding symptom management and unnecessary hospitalisations; and, 3) Better decision-making and planned care for residents, which meant that staff and relatives were better informed about, and prepared for, the resident's likely trajectory. The intervention normalised death and dying and also underlined the important role that specialists play in providing staff education, timely access to medicines, and advance care planning. The findings from this study, and the growing wealth of evidence integrating specialist PC in residential care for older adults, indicate a number of priorities for care providers, academics and policymakers. <http://goo.gl/66QdPV>

### **Related**

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 4 August 2016 – ‘**Avoiding costly hospitalisation at end of life: Findings from a specialist palliative care pilot in residential care for older adults.**’ Specialist palliative care (SPC) is not a standardised component of service delivery in nursing home care in Australia. This study examined whether the addition of a proactive model of SPC reduced resident transfer to the acute care setting, and achieved a reduction in hospital deaths. <http://goo.gl/W2Qy8r>

## **Frailty: A term with many meanings and a growing priority for community nurses**

*BRITISH JOURNAL OF COMMUNITY NURSING*, 2016; 21(8):385-389. The question of exactly what frailty is and what that may mean for patients is extremely complex. This is a very conceptual problem requiring a broad and long-term solution. It is not a disease or a condition that can be treated in isolation. Frailty is a collection of contributing factors that culminate in an individual being susceptible to poorer outcomes following health-care interventions and minor illness. The solution to such a complex problem lies in engaging and empowering staff to understand and champion frailty. Once better understood, it will be possible to educate and enable this workforce to recognise the signs of frailty, poor prognosis and patients requiring more specialised palliative care. Informing staff working within a health-care economy of this issue must be the first step in a shift towards managing patients with frailty more appropriately, and streaming their care towards the correct care pathways sooner. This article discusses what frailty is, what it may mean for patients, and attempts to expand on why the construct of frailty is a prevalent issue for community nurses. The link between frailty and mortality is discussed and how targeted appropriate advanced care planning may be used to address this demographic challenge. <http://goo.gl/aP7nS9>

Cont.

### Selected articles on frailty in the context of end-of-life care

- *FRAILITY IN AGING: BIOLOGICAL, CLINICAL & SOCIAL IMPLICATIONS*, 2015;41:151-160. ‘**End-of-life care in frailty.**’ The authors review the history of palliative care (PC) and the elements of frailty that require the modification of current models of PC. [Noted in Media Watch, 3 August 2015, #421 (p.8)] <http://goo.gl/zNXY1B>
- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS*, 2013;14(6):392-397. ‘**Frailty consensus: A call to action.**’ A consensus group consisting of delegates from six major international, European and U.S. societies created four major consensus points on a specific form of frailty. [Noted in Media Watch, 24 June 2013, #311 (p.11)] <http://goo.gl/JmWQQp>
- *JOURNAL OF NURSING EDUCATION & PRACTICE*, 2013;3(7):75-91. ‘**When frailty should mean palliative care.**’ The aim of this work is to assist physicians in providing proper care for the frail elderly. [Noted in Media Watch, 21 January 2013, #289 (p.8)] <http://goo.gl/55Gj9e>

### Cancer center advertising: Where hope meets hype

*JAMA INTERNAL MEDICINE*, 2016;176(8):1068-1070. [In the U.S.] Cancer centers advertise to reach patients and their families in a very competitive market. Patients often have dangerous cancers and face toxic treatments and the advertisements offer hope. But the hope can – and often does – morph into hype. After all, this is advertising. Medicine has long been ambivalent about advertising services. The American Medical Association’s original code of ethics banned advertising as “derogatory to the profession” and “reprehensible” until forced to relent by federal courts in 1980. However, as Vater et al show in this issue of *JAMA Internal Medicine*,<sup>1</sup> the marketing of cancer services is growing. An essential question is how to ensure that advertisements do not take advantage of vulnerable patients. <http://goo.gl/qBnh2s>

1. ‘Trends in cancer-center spending on advertising in the U.S., 2005 to 2014,’ *JAMA Internal Medicine*, published online 11 July 2016. [Noted in Media Watch, 18 July 2016, #471 (p.12)] <http://goo.gl/vnJlxA>

### Performing, and emotionally surviving, notifications of death to a patient’s family

*JOURNAL OF EMERGENCY MEDICAL SERVICES* | Online 1 August 2016 – The privilege and satisfaction associated with helping those in need isn’t without its emotional toll. There are moments of joy as well as times of confusion, hurt and distress. Training in death and death notification is woefully lacking among first responders; yet, as little as two hours of training on the topic increases comfort levels and reduces anxiety. Leaders must better prepare their members for delivering death notifications to a grieving family. Finally, support systems need to be in place to assist crew members in appropriately handling stress, pain, and grief so as to maintain emotional wellbeing throughout their careers. <http://goo.gl/xSmLxy>

#### Extract from *Journal of Emergency Medical Services* article

A 2003 survey showed that emergency medical services providers will initiate rescue efforts under conditions where they themselves would not want to be resuscitated 40% of the time. First responders see themselves as “lifesavers” and “defender[s] against death.” Rescue workers recognize the immense responsibility they bear and have admitted to initiating CPR to avoid criticism and continuing CPR simply because family members were present.

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

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://goo.gl/8JyLmE>



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

### **Associations between end-of-life cancer care patterns and Medicare expenditures**

*JOURNAL OF NATIONAL COMPREHENSIVE CANCER NETWORK*, 2016;14(8):1001-1008. The mean expenditure per cancer decedent in the last month of life was \$10,800, ranging from \$8,300 to \$15,400 in the lowest and highest expenditure quintile areas, respectively. There was considerable variation in the percentage of decedents receiving intensive end-of-life care (EOLC) intervention, with 41.7% of decedents receiving intensive care in the lowest quintile of expenditures versus 57.9% in the highest quintile. Regional patterns of late chemotherapy or late hospice use explained only approximately 1% of the expenditure difference between the highest and lowest quintile areas. In contrast, the proportion of decedents who had ICU admissions within 30 days of death was a major driver of variation, explaining 37.6% of the expenditure difference. <http://goo.gl/qDVopi>

#### **Related**

- *HEALTH CARE MANAGER*, 2016;35(3):189-198. **'Palliative care: A partnership across the continuum of care.'** This study demonstrates that palliative care (PC) programs are more likely in communities with favorable economic factors and higher Medicare populations. Large hospitals with high occupancy rates and a high case mix index use PC programs to better meet patient needs and improve hospital efficiency. <http://goo.gl/ijMSX9>

### **Care in the final month of life among adolescent and young adult cancer patients in Kaiser Permanente Southern California**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 august 2016 – Little is known about the care that adolescent and young adult (AYA) patients with cancer receive at the end of life (EOL). One hundred seven patients (96% of the patient population studied) had documented care preferences in the last month of life. At first documentation, 72% of patients wished for life-prolonging care, 20% wished for care focused on comfort, and 8% were undecided. Forty-seven percent of patients had documented changes in preferences in the last month, with 40% wishing for life-prolonging care when preferences were last noted before death, 56% preferring comfort, and 4% undecided. Seventy-eight percent of patients received at least one form of intensive EOL care, including 75% of those who preferred comfort measures at last documentation. <http://goo.gl/9St71Z>

### **Does the culture of modern day palliative care social work leave room for leadership?**

*JOURNAL OF SOCIAL WORK PRACTICE*, 2016;30(2):203-218. This paper draws on interviews with six high profile leaders at the fore front of end-of-life care sector in the U.K. Its findings, and emerging themes, offer insights about the opportunities for social work leaders in palliative care (PC) in the future and how the profession and PC sector address current barriers to taking advantage of such opportunity. The main focus is leadership related to PC social work. However, it relates to much broader themes including the history, politics and culture of this profession and the requirements for leadership on the part of social work in the broader contexts of health and social care. <http://goo.gl/p76OAW>

#### **Special Issue: Social Work Practice in End-of-Life Care**

### **Journal of Social Work Practice**

Topics: "a good death," advance care planning, psychosocial aspects of end-of-life care, and grief and bereavement. Contents page: <http://goo.gl/zpx0lm>

**N.B.** Selected articles on social work in the context of end-of-life care from the current issue of the *Journal of Social Work in End-of-Life & Palliative Care* were noted in Media Watch, 1 August 2016, #473 (pp. 8,9,14). Contents page: <http://goo.gl/b9bBa4>

## Home and palliative care in England

### **The Guy's and St Thomas's National Health Service Foundation Trust @home service: An overview of a new service**

*LONDON JOURNAL OF PRIMARY CARE* | Online – 29 July 2016 – Hospital in the home is a relatively new concept within the U.K. healthcare system. The Guy's and St Thomas's NHS Foundation Trust (GSTT) @home service 'Bringing hospital care to your home' was commissioned by Lambeth & Southwark Clinical Commissioning Group in 2014 to provide acute care in the patients' place of residence by facilitating rapid discharge from hospital. The service is designed for 260-280 referrals each month from local hospitals, London Ambulance Service, GPs, district nurses and palliative care (PC) services. The GSTT@home provides intensive care for a short episode through multidisciplinary team work with the aim of returning the patient to their prior health status following an acute episode of ill health. The main criteria for referrals are adults, living within Lambeth or Southwark with an acute onset of illness often with acute exacerbations of chronic conditions. Care is delivered using 25 clinical pathways using integrated care teams, including those for respiratory disease, heart failure and PC services. Recently, the service extended to include overnight PC. As care shifts from hospital to the community, it is envisaged that these types of programmes will become an essential component of care provision. This paper describes the service and presents initial service evaluation data. <http://goo.gl/GQKQfE>

Noted in Media Watch, 23 May 2016, #463 (p.8):

- U.K. (England) | *The Northern Echo* (Buckinghamshire) – 19 May 2016 – **'Councils and GP groups overlooking local end-of-life care needs.'** The charity Hospice UK used the Freedom of Information Act to find out how well councils and National Health Service groups assessed the needs of dying people in their communities. The results showed more than a third (34%) of health and wellbeing boards, which are run by councils, do not consider the needs of dying people in their assessments of local needs. <http://goo.gl/1K8sDk>

Noted in Media Watch, 14 March 2016, #453 (p.7):

- U.K. (England) | London Assembly Health Committee – 8 March 2016 – **'Dying well depends on where you live.'** Does good end of life care (EOLC), depend on your age, whether you live alone, your diagnosis or economic status? Does it depend on which London borough you live in? The London Assembly Health Committee has investigated the important issue of EOLC and it has found: only 8 out of 33 London Clinical Commissioning Groups (CCGs) scored above the national average for EOLC quality indicators and fewer than half of local authorities include EOLC within their Health & Wellbeing Strategies. <https://goo.gl/2HIQzo>

## End-of-life care in The Netherlands

### **Doctors' reports about palliative systemic treatment: A medical record study**

*PALLIATIVE MEDICINE* | Online – 4 August 2016 – Medical records provide insight into the decision-making process about palliative systemic treatment. The content and detail of doctors' notes, however, widely varies especially concerning their palliative systemic treatment considerations. Registries that aim to measure the quality of (end-of-life) care must be aware of this outcome. About 75% of all notes [of the 147 patients studied] reported doctors' considerations to start/continue palliative systemic treatment, including information about the prognosis (47%), possible survival gain (22%), patients' wish for palliative systemic treatment (33%), impact on quality of life (8%), and patient's age (3%). Co-morbidity (82%), smoking status (78%) and drinking behaviour (63%) were more often documented than patients' performance status (16%). Conversations with the patient/family about palliative systemic treatment were reported in 49% of all notes. Response measurements and dose adaptations were documented in 75% and 71% of patients who received palliative systemic treatment respectively. Future research should further explore how medical records can best assist in evaluating the quality of the decision-making process in the patient's final stage of life. <http://goo.gl/YaVS4k>

## What is the evidence for conducting palliative care family meetings? A systematic review

*PALLIATIVE MEDICINE* | Online – 4 August 2016 – Structured family meeting procedures and guidelines suggest that these forums enhance family-patient-team communication in the palliative care inpatient setting. However, the vulnerability of palliative patients and the resources required to implement family meetings in accordance with recommended guidelines make better understanding about the effectiveness of this type of intervention an important priority. Of the 5,051 articles identified, 13 met the inclusion criteria: 10 quantitative and 3 qualitative studies. There was low-level evidence to support family meetings. Only two quantitative pre- and post-studies used a validated palliative care family outcome measure with both studies reporting significant results post-family meetings. Four other quantitative studies reported significant results using non-validated measures. Despite the existence of consensus-based family meeting guidelines, there is a paucity of evidence to support family meetings in the inpatient palliative care setting. <http://goo.gl/2DMIN3>

### Selected articles on family conferences in the end-of-life care setting

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2016;316(1):51-62. '**Effect of palliative care-led meetings for families of patients with chronic critical illness: A randomized clinical trial.**' Among families of patients with chronic critical illness, the use of palliative care-led informational and emotional support meetings compared with usual care did not reduce anxiety or depression symptoms and may have increased post-traumatic stress disorder symptoms. These findings do not support routine or mandatory palliative care-led discussion of goals of care for all families of patients with chronic critical illness. [Noted in Media Watch, 11 July 2016, #470 (p.15)] <http://goo.gl/YnECmQ>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 July 2015 – '**A systematic review of family meeting tools in palliative and intensive care settings.**' The authors identified 16 articles containing 23 tools in 7 categories: 1) Meeting guide; 2) Meeting planner; 3) Documentation template; 4) Meeting strategies; 5) Decision aid/screener; 6) Family checklist; and, 7) Training module. They found considerable variation across tools in usage and content and a lack of tools supporting family engagement. [Noted in Media Watch, 3 August 2015, #421 (p.7)] <http://goo.gl/JkdiQX>
- *CRITICAL CARE MEDICINE*, 2004;32(7):1484-1488. '**Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction.**' The authors identified family conferences in intensive care units of four Seattle [State of Washington] hospitals during which discussions about withdrawing life support were likely to occur. On average, family members spoke 29% and clinicians spoke 71% of the time. [Noted in Media Watch, 24 March 2014, #350 ('Worth Repeating,' p.16)] <http://goo.gl/VuoPIZ>



### 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.<sup>1</sup> 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://goo.gl/5CHoAG>

1. Ashpole BR. 'Communications with the Public, Politicians, and the News Media,' *Oxford Textbook of Palliative Medicine*, 5<sup>th</sup> Edition (pp.357-359), Oxford University Press, 2015. <https://goo.gl/Vi07RS>.

## **Serious illness and end-of-life care in the homeless: Examining a service system and a call for action for social work**

*SOCIAL WORK & SOCIETY*, 2016;14(1). This study [in a medium sized city in the Midwestern U.S.] suggests very sick homeless patients are often discharged based on the recommendations of social workers to the streets or to a shelter, both of which are inappropriate solutions. In attempting to support the dignity and worth of the patients, social workers should advocate for better discharge practices, and should gain more direct familiarity with the needs of serious and chronically ill homeless individuals. Hospital based social workers need to be educated about the healthcare needs of the homeless, the gaps and barriers to services, and the options for care at the end of life. There needs to be much greater communication and cooperation between agencies as they attempt to serve the homeless population. The lack of such cooperation found in the present study was striking. In a medium sized city, it should be possible to develop a coordinated system of care. Social

workers can play a pivotal role in the development of such a system. As a profession that focuses on case management and referral, social workers could be trained to be leaders in identifying appropriate patients and making those referrals. <http://goo.gl/UiG8EB>

### **Extract from *Social Work & Society* article**

It was striking that these concerned, engaged professionals that witnessed serious illness and death frequently in the homeless population had not really given much thought to the role of hospice care, nor had they made referrals. Even a social worker employed at the major hospice agency in the city had never considered providing hospice care to the homeless. It seemed like the urgency of medical care was such that attention and passion for the delivery of services at end of life was not a priority.

**N.B.** Selected articles on end-of-life care for the homeless noted in Media Watch 14 March 2016, #453 (pp.14-15). **BRA**

## **Moral ambivalence and informal care for the dying**

*THE SOCIOLOGICAL REVIEW* | Online – 31 July 2016 – Caring for the dying presents perhaps the most challenging site of informal care. Participation in informal caring roles in such contexts has been prone to reification as a virtuous social practice, often without critical reflection as to the implications for caregivers. Here, drawing on interviews with carers who were providing care in the last few weeks or days of life (EOL), the authors develop an understanding of informal care in this setting as a morally ambiguous social practice, framed by social relations of duty, gift and virtue, but in turn encapsulating experiences of failure, shame and suffering. Such a contradictory understanding of caregiving is critical for understanding the tensions within EOL settings and also for countering the concealments produced by the valorization of informal care more broadly in modern societies. The authors present a critical analysis of informal care's contested character at the EOL, challenging normative understandings that are complicit in producing moral ambivalence, shame and suffering for individual carers. <http://goo.gl/V5O86o>

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

Representative sample of recent news media coverage:

- *EMERGENCY MEDICINE NEWS*, 2016;38(8):14. '**At your defense: Aid-in-dying law creates pitfalls for emergency physicians.**' California's End-of-Life Option Act, otherwise known as the Aid-in-Dying law, took effect 9 June, allowing terminal patients to obtain a prescription to self-administer and cause death. Divided opinion among physicians aside, California became the fifth state to allow physician-assisted death, after Oregon, Washington, Vermont, and Montana. California's citizens have spoken, and California physicians now must decide whether they should prescribe a lethal dose of a medication if terminally ill patients ask for it. More importantly for emergency physicians and first responders is what to do when they are called to treat a patient who was prescribed or has just taken an aid-in-dying drug. <http://goo.gl/q5WbdS>

Cont.

- *THE LANCET*, 2016;388(10044):543-545. 'Finding a balance: Canada's law on medical assistance in dying.' 17 June 2016, the Parliament of Canada passed Bill C-14, a new law governing medical assistance in dying. The law permits physicians, and in some cases nurse practitioners, to provide an assisted death for competent adult patients who make a voluntary request, who have been informed of means available to alleviate their suffering, and who have a "grievous and irremediable" condition, as defined in the legislation. Canada's new law must be understood in the context of competing moral and legal claims at play in a highly charged policy debate. <http://goo.gl/qmlsjE>
- *THE LANCET*, 2016;388(10044):545-547. 'Unresolved issues in Canada's law on physician-assisted dying.' On 6 February 2015, a landmark decision by the Supreme Court of Canada declared Criminal Code proscriptions against physicians assisting in the death of patients in violation of the Canadian Charter of Rights and Freedoms. Implementation was suspended for 12 months. With the change of government in late 2015 an extension was granted. After considerable wrangling between the House of Commons and the Senate Bill C-14 was passed 17 June 2016, making medical assistance in dying legal in Canada. The ruling granted the right to assistance in dying to all competent adults with a "grievous and irremediable condition." <http://goo.gl/9i2lga>

## Worth Repeating

### Evaluating a patient's request for life-prolonging treatment: An ethical framework

*JOURNAL OF MEDICAL ETHICS* | Online – 12 June 2012 – Contrary to the widespread concern about over-treatment at the end of life, today, patient preferences for palliative care at the end of life are frequently respected. However, ethically challenging situations in the current health-care climate are, instead, situations in which a competent patient requests active treatment with the goal of life-prolongation while the physician suggests best supportive care only. The argument of futility has often been used to justify unilateral decisions made by physicians to withhold or withdraw life-sustaining treatment. However, the authors argue that neither the concept of futility nor that of patient autonomy alone is apt for resolving situations in which physicians are confronted with patients' requests for active treatment. Instead, they integrate the relevant arguments that have been put forward in the academic discussion about futile treatment into an ethical algorithm with five guiding questions. This algorithm shall facilitate approaching patients' requests for treatments deemed futile by the physician in a systematic way, and respond-

ing to these requests in an ethically appropriate manner. It thereby adds substantive considerations to the current procedural approaches of conflict resolution in order to improve decision making among physicians, patients and families. [Noted in Media Watch, 18 June 2012, #258 (p.13)] <http://goo.gl/UJZoEr>

#### Ethical algorithm

- 1) Is there a chance that medical intervention will be effective in achieving the patient's treatment goal?
- 2) How does the physician evaluate the expected benefit and the potential harm of the treatment?
- 3) Does the patient understand his or her medical situation?
- 4) Does the patient prefer receiving treatment after evaluating the benefit-harm ratio and the costs?
- 5) Does the treatment require many resources?

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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://goo.gl/BZRcqi>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://goo.gl/XrhYCH>

#### **Canada**

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <http://goo.gl/AhlqvD>

#### **Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1I9K>

U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>