

## 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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Approaching death: Scroll down to [Specialist Publications](#) and 'Psychological ideas in palliative care: Diagnosis and formulation' (p.11), in *European Journal of Palliative Care*.

With this issue, Media Watch begins its 11<sup>th</sup> year of publication.

## Canada

### Canada ranks third-last in study of health care in 11 rich countries

*THE GLOBE & MAIL* | Online – 14 July 2017 – Canada placed third from the bottom in a major new study of health care in 11 affluent nations... Canada's ninth-place finish is a slight improvement over 2014, when the Commonwealth Fund, a New York-based private research foundation, put Canada in 10th place, ahead of only the U.S. In the group's new report<sup>1</sup> ... Canada pulled ahead of France, but stayed well behind such standouts as the U.K., Australia and The Netherlands, which ranked first, second and third. The Commonwealth Fund is one of the few organizations that tries to systematically grade and compare the health-care systems in high-income countries. Canada spent the equivalent of 10% of its gross domestic product on health care in 2014 – the most recent year for which figures were available – more than higher-ranked U.K., New Zealand, Norway and Australia. <https://goo.gl/tGbr6X>

1. 'Mirror, Mirror 2017,' The Commonwealth Fund, July 2017. <https://goo.gl/ZbvpPa>

**N.B.** There is no mention of hospice or palliative care in The Commonwealth Fund report. Countries are rated, however, on advance care planning, i.e., "a written plan" describing treatment people want at the end of life, among adults age 65 and older. See Appendix 2D, 'Engagement & Patient Preferences.' **BRA**

### Grey matters: Being kept alive by default

*THE NATIONAL POST* | Online – 13 July 2017 – The sign in my high school library read: 'Not to Decide is to Decide.' It's a much-needed reminder for our health-care system, particularly in deciding when a patient can no longer benefit from care or, to put it bluntly, when it's time to pull the plug. As provincial health-care systems lack effective ways to reach such decisions, patients across the country are kept alive by default. Thousands of comatose and minimally conscious patients are kept alive in intensive care units across our country. I'll ignore the financials behind keeping them on respirators in ICUs, because some decisions should not be based on dollars. The other costs are steeper: the backlog of untreated patients waiting for hospital beds taken by patients who won't recover, the strain on doctors, nurses and health-care staff who know their care is futile, the psychiatric symptoms and complicated grief of family

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members, and the unknowable pain and suffering of the patients themselves. This is, of course, a modern problem. We used to fall acutely ill, then die or recover. But life-saving – or at least life-prolonging – technology now keeps individuals alive for months, years or even decades, unable to move, feel, touch, taste or communicate. These patients are often kept on machines at the insistence of family members or others making decisions on their behalf. We don't know how big the problem is. <https://goo.gl/vYLvwS>

### Enhanced home care could better match seniors' needs, report says

CBC NEWS | Online – 11 July 2017 – More than 20% of Canadian seniors who go into residential care might have been able to stay at home with supports, according to a new report.<sup>1</sup> There are currently 2.6 million people in Canada aged 75 or older, about seven per cent of the country's population. These seniors tend to rely heaviest on health-care services, and their ranks are expected to more than double over the next 20 years, from 2.6 million to 5.7 million, the Canadian Institute for Health Information says. The report's authors found that after an initial assessment, about one in five (22%) individuals who enter residential care (also known as long-term care) with round-the-clock nursing supports resemble their peers in the community and might have been able to be supported in home care. After considering seniors who could have delayed or avoided admission to residential care with community-based supports, the ratio increased to about one in three or 30%. <https://goo.gl/tS2xtY>

1. 'Seniors in Transition: Exploring Pathways Across the Care Continuum,' Canadian Institute for Health Information, July 2017. <https://goo.gl/geSAMk>

**N.B.** There is no specific mention in the Institute's report of home palliative care. **BRA**

#### Related

- ALBERTA | CBC News – 12 July 2017 – '**Quality of life in Alberta supportive living facilities varies widely, survey suggests.**' The quality of care provided at supportive living facilities in Alberta ranges widely, according to a set of surveys released by a provincial agency that monitors patient safety and health services in the province.<sup>1</sup> <https://goo.gl/nYnZDa>

1. 'Designated Resident Experience Survey Report,' Health Quality Council of Alberta, July 2017. <https://goo.gl/4oDiNj>

**N.B.** Residents receiving palliative care were excluded from the survey. **BRA**

- *THE GLOBE & MAIL* | Online – 11 July 2017 – '**Learning from the Dutch "neighbourhood care" model.**' In our system, there is such a mania for measurable outcomes that care tends to be task-oriented, and the fact that there is an actual person on the receiving end of care too often seems to be forgotten. <https://goo.gl/4fSYoX>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | *The Winnipeg Free Press* – 11 July 2017 – '**Winnipeg Regional Health Authority withholds info on assisted dying.**' The Winnipeg Regional Health Authority (WRHA) is deliberately trying to keep its assisted-dying policies out of the public eye. The province's largest regional health authority admits the decision is motivated by a bid to shield staff and facilities from controversy surrounding the legal changes that now allow patients to seek the assistance of physicians to end their lives. A recent routine request for records on assisted dying was all but denied. In large part, the WRHA relied on section 24(a) of the Freedom of Information & Protection of Privacy Act, which allows it to withhold any information that "could reasonably be expected to threaten or harm the mental or physical health or the safety of another person." <https://goo.gl/GUoEo3>

#### [Specialist Publications](#)

'College of Physicians & Surgeons of Ontario "effective referral" policy does not adequately respect physicians' conscientious care' (p.17), in *University of Toronto Medical Journal*.

## U.S.A.

### **Doctor shortage in rural Arizona sparks another crisis in “forgotten America”**

ARIZONA | National Public Radio – 14 July 2017 – It has long been hard to recruit new doctors to rural America. They can make a lot more money in metropolitan areas as specialists, and many choose to do that, especially if they’re saddled with mounting debt from student loans. But the shortage, especially of primary care providers, has grown steadily worse in recent years. According to the National Rural Health Association, rural areas could be short 45,000 doctors by 2020. Since 2010, more than 70 rural hospitals have closed. <https://goo.gl/zd6246>

Noted in Media Watch 25 April 2016, #459 (p.3):

- *POLITICAL NEWS* | Online – 18 April 2016 – ‘**Legislation to expand rural hospice care.**’ Bipartisan legislation to improve access to hospice care in rural America has been tabled in the Senate. Only 32% of those eligible in rural areas utilize hospice compared to 48% in urban areas, according to a report from the Medicare Payment Advisory Commission. The Rural Access to Hospice Act of 2016 aims to level the playing field. <http://goo.gl/paarBo>

### **The Commonwealth Fund**

#### **What’s actually wrong with the U.S. health system**

*THE ATLANTIC* | Online – 14 July 2017 – Once again, the think tank found the U.S. medical system performed the worst among 11 similar countries, all while spending more.<sup>1</sup> The U.S. fared especially badly on measures of affordability, access, health outcomes, and equality between the rich and poor. America does perform well, comparatively, when it comes to doctor-patient relationships, end-of-life care, and survival rates after major issues like breast cancer or strokes. The U.S. does less well on measures of population health... <https://goo.gl/wZ8rD2>

1. ‘Mirror, Mirror 2017,’ The Commonwealth Fund, July 2017. <https://goo.gl/ZbvpPa>

#### **“Are you saying I’m dying?” Training doctors to speak frankly about death**

STAT | Online – 14 July 2017 – Faced with the uncomfortable task of discussing death, doctors often avoid the topic. Only 17% of Medicare patients surveyed in a 2015 Kaiser Family Foundation study said they had discussed end-of-life care (EoLC) – though most wanted to do so.<sup>1</sup> Since that study, Medicare has begun reimbursing providers for having these conversations. Yet still, just a fraction of Medicare recipients at the end of life have those talks with their doctors.<sup>2</sup> In response, advocates for improving EoLC have launched training sessions for doctors around the country. <https://goo.gl/gTEpYq>

1. ‘Poll finds overwhelming support for Medicare paying for end-of-life talks,’ *Kaiser Health News*, published online 30 September 2015. [Noted in Media Watch 5 October 2015, #430 (p.3)] <https://goo.gl/fQRcDa>
2. ‘Docs bill Medicare for end-of-life advice as “death panel” fears re-emerge,’ *Kaiser Health News*, published online 15 February 2017 [Noted in Media Watch 20 February 2017, #500 (p.2)] <https://goo.gl/SmBEY4>

#### **A chaplain designed a way for ICU patients to request prayers, poetry and a hand to hold**

CNN | Online – 12 July 2017 – “The less straightforward requests [of ICU patients] are the existential questions – emotions, feelings, spiritual pain – that come out when people get new diagnoses or are trying to cope with some nightmare they never wanted to be in, or their batteries are low after a really long course (of treatment),” non-denominational chaplain Joel Nightingale Berning said. “We try to be what they need us to be.” One of the challenges faced by Gene LoCastro, and many other patients in an inten-

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sive care setting, is an inability to effectively communicate wants and needs. ICU patients are often awake and alert but intubated, meaning they have tubes down their throat and can't talk. "My training was mostly about how to have conversations with people about their soul, whether literally or metaphorically," Berning added. "When I started out (in the ICU), I felt very useless and frustrated. I felt like I had something to offer if we could talk ... but if they don't have a physical voice, it was a real stumper." That frustration sparked an idea that transformed LoCastro's hospital stay. Berning had long observed doctors and nurses using communication boards so patients could clearly express their physical needs. Why hasn't anyone developed a board to help patients express their spiritual desires? <https://goo.gl/2j1p4i>

Noted in Media Watch 13 February 2017, #499 (p.10):

- *DIMENSIONS OF CRITICAL CARE NURSING*, 2017;36(2):110-115. 'Creating a sacred space in the intensive care unit at the end of life.' Critically ill patients and their families identify significant unmet spiritual, environmental, and communication needs. Although the Society of Critical Care Medicine recommends that the spiritual needs of critically ill patients be addressed by the health care team and be incorporated in patients' plans of care, spiritual concerns are infrequently addressed during goals-of-care discussions. <https://goo.gl/LRAJ5L>

**N.B.** Selected articles on the role of chaplains in end-of-life care are noted in the 3 July 2017 and 29 May 2017 issues of Media Watch (#519, p.11 & #514, pp.10-11, respectively).

### How to keep long-term care from bankrupting us

*FORBES* | Online – 12 July 2017 – When policymakers, health care analysts and financial journalists talk about the staggering costs of long-term care (LTC), it's often wonky, devoid of humanity. We throw around statistics like this one from the U.S. Department of Health & Human Services: 52% of individuals turning 65 will require long-term care supports and services at some point in their lives. But at a Bipartisan Policy Center webinar ... pegged to its new report on LTC financing solutions,<sup>1</sup> family caregiver MaryAnne Sterling poignantly revealed the financial, physical and mental tolls that long-term care can take. <https://goo.gl/dWmTmY>

1. 'Financing Long-Term Services and Supports: Seeking Bipartisan Solutions in Politically Challenging Times,' Bipartisan Policy Center, July 2017. <https://goo.gl/NjvRmJ>

### The gentler symptoms of dying

*THE NEW YORK TIMES* | Online – 11 July 2017 – While some of the symptoms of dying, like the death rattle, air hunger and terminal agitation, can cause alarm in witnesses, other symptoms are more gentle. The human body's most compassionate gift is the interdependence of its parts. As organs in the torso fail, the brain likewise shuts down. With the exception of the minority of people who suffer sudden death, the vast majority of us experience a slumberous slippage from life. We may be able to sense people at the bedside on a spiritual level, but we are not fully awake in the moments, and often hours, before we die. Every major organ in the body – heart, lungs, liver, kidneys – has the capacity to shut off the brain. It's a biological veto system. When the heart stops pumping, blood pressure drops throughout the body. Like electricity on a city block, service goes out everywhere, including the brain. When the liver or kidneys fail, toxic electrolytes and metabolites build up in the body and cloud awareness. Failing lungs decrease oxygen and increase carbon dioxide in the blood, both of which slow cognitive function. The mysterious exception is "terminal lucidity," a term coined by the biologist Michael Nahm in 2009 to describe the brief state of clarity and energy that sometimes precedes death. <https://goo.gl/Szo5Vf>

Noted in Media Watch 26 June 2017, #518 (p.3):

- *THE NEW YORK TIMES* | Online – 20 June 2017 – 'The symptoms of dying.' Dying has its own biology and symptoms. It's a diagnosis in itself. While the weeks and days leading up to death can vary from person to person, the hours before death are similar across the vast majority of human afflictions. Some symptoms, like the death rattle, air hunger and terminal agitation, appear agonizing, but aren't usually uncomfortable for the dying person. They are well-treated with medications. With hospice availability increasing worldwide, it is rare to die in pain. <https://goo.gl/3gGgth>

## Some hospices want to expand traditional boundaries

FLORIDA | *The Ledger* (Lakeland) – 10 July 2017 – Since the 1990s ... the concept of palliative care (PC) for patients whose illnesses aren't so immediately life threatening has gained momentum. Hospitals, doctors, hospices and others recognize that patients with chronic, severely limiting illnesses often need services beyond traditional hospital and doctor care before their illness is so advanced they meet time guidelines for traditional hospice. Chronic obstructive lung disease or congestive heart failure are examples often cited by supporters of expanded adult PC. Large hospitals, among them Lakeland Regional Health, have created in-hospice PC units. Hospices interested in doing expanded PC, beyond their usual constraints, sometimes partner with hospitals' PC or create their own community-based PC. Compassionate Care Hospice of Central Florida has that type of program... It helps patients with chronic illnesses who are expected to live longer than six months. <https://goo.gl/BMCdYr>

Noted in Media Watch 31 August 2015, #425 (p.5):

- *THE WASHINGTON POST* | Online – 25 August 2015 – **'Medicare reconsiders rule that leaves dying patients facing a stark choice.'** For more than 30 years, Medicare presented dying patients with a stark choice: They could continue treatments that might extend their lives or they could accept the medical and counseling services of hospice care meant to ease their way to death. They could not do both. Now, the federal government is experimenting with a change that would remove that either/or proposition. <https://goo.gl/bq8QeM>

## Why some patients aren't getting palliative care

STATELINE (The Pew Charitable Trusts) | Online – 10 July 2017 – Despite dramatic growth in the number of hospitals providing such care over the last decade, full palliative care (PC) services remain unavailable to many patients. But those who work in the field say they are encouraged by several developments over the last five years. The federal government has used recent demonstration projects to make PC more available to patients ... who have serious illnesses but are not in hospice care or hospitalized. And a small but growing number of Medicare and private health insurance plans now offer PC services to those patients. Several states have enacted laws to require physicians, hospitals and nursing facilities to provide patients with certain serious illnesses with information on PC and where to get it. Some have also adopted consumer protections to assure the

quality of the PC delivered. California has gone the furthest. And, in Congress bipartisan sponsors last month introduced a bill ... that would expand existing pilot projects in Medicare to extend community-based PC services delivered by teams of doctors, nurses, social workers and chaplains to patients who are not in hospice care. <https://goo.gl/u9mBCF>

### [Specialist Publications](#)

**'Delivering end-of-life cancer care: Perspectives of providers'** (p.7), in *American Journal of Hospice & Palliative Medicine*.

**'Understanding the cultural differences among ethnic minorities in palliative and end-of-life care'** (p.8), in *The ASCO Post*.

Noted in Media Watch 6 February 2017, #498 (p.7):

- *HEALTH AFFAIRS* | Online – 30 January 2017 – **'How states can expand access to palliative care.'** Access to palliative care (PC) for people with serious illness has expanded greatly over the last decade due to a rapidly increasing aging population with complex and costly care needs; a growing evidence base demonstrating that PC improves patient and caregiver quality of life and reduces overall cost; and, an accelerated transition to payment models that reward value over volume. <https://goo.gl/lQeUtl>

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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/h3RAy>

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/>

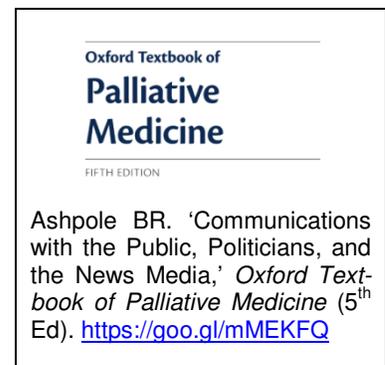
## International

### **Leeds Hospice cements university link in U.K. first**

U.K. (England) | BBC News – 12 July 2017 – A hospice in Leeds has become the first in the U.K. to be officially recognised as a university teaching hospice. St. Gemma’s Hospice has formalised its relationship with the University of Leeds in a move it says will improve care levels, teaching and research. The organisations have been working together for more than 20 years. Through its relationship with the university about 200 medical students are able to develop their skills in palliative care each year. St. Gemma’s said the agreement had been supported by National Health Service Health Education England and the U.K. Medical Schools Council. <https://goo.gl/7e3FcG>

### **Why scientists should speak to journalists about stories like that involving baby Charlie Gard**

U.K. (England) | *Press Gazette* (London) – 12 July 2017 – He’s a little boy with mitochondrial disease who is on life support. His parents want to send him to the U.S. for experimental treatment; the U.K. courts have ruled otherwise, on medical advice that the treatment does not show sufficient promise. At time of writing, the case has been referred back to the High Court for fresh assessment. Medics at Great Ormond Street Hospital think Charlie can’t be helped. His desperate parents claim otherwise, citing the support of seven international doctors and a 350,000 strong petition. It’s a dispute over the most distressing subject imaginable, where we have to choose who has a child’s best interests at heart when doctors and parents can’t agree. At the [*Press Gazette*’s] Science Media Centre almost every call for a week has been about Charlie Gard. Every producer and health reporter is looking for expert reaction to Charlie’s story – his illness, the potential of the treatment, the science of mitochondrial disease, the ethics behind the agonising decision. Getting that reaction from ethicists has been easy, and there has been some intelligent, considered debate over questions of welfare, rights and choice. But overall, medical reaction has been much harder to come by. <https://goo.gl/uwUQjV>



**N.B.** Reports on the Charlie Gard case are noted in the 3 July 2017 issue of Media Watch ( #519, p.5).



Media Watch Online

Updated 07.17.2017

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.18.

## End-of-life care in Australia

### **Nurses and palliative care volunteers**

AUSTRALIA (New South Wales) | Palliative Care New South Wales – Accessed 10 July 2017 – Palliative care (PC) volunteers in inpatient settings typically supplement the emotional support offered by paid staff. Comprising the majority of the workforce in inpatient settings it follows that nurses are the clinicians most likely to be in contact with PC volunteers, and that the support of nurses is a significant predictor of the success of the role of the PC volunteer service. In 2017 Palliative Care New South Wales asked nurses in adult inpatient settings about their experiences with PC volunteers. <https://goo.gl/x7sWJq>

### **Specialist Publications**

**'Rapidly increasing end-of-life care needs: A timely warning'** (p.9), in *BMC Medicine*.

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

Representative sample of recent news media coverage:

- CHINA (Hong Kong) | *South China Morning Post* – 9 July 2017 – **'Hong Kong must first improve its elderly care before euthanasia can be discussed.'** In Hong Kong, people over 65 have the highest suicide rate among all age groups; at 23.5 per 100,000 people, it is double the rate of the general population. Depression is a major factor contributing to a loss of meaning in life and the development of suicidal thoughts among older adults. In 2014, Hong Kong's chief executive initiated a study to identify elderly needs, aimed at achieving "ageing in place," or moving towards community-based care, as opposed to residential homes. Two years later, an Elderly Services Programme Plan was unveiled. The report showed that many elderly people and their family still preferred subsidised residential care services to community care services, as it was not safe for the elderly people to be left home alone. Yet, the current wait for these services in Hong Kong is about one to two years. <https://goo.gl/fJ7xy9>

## **Specialist Publications**

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

#### **Delivering end-of-life cancer care: Perspectives of providers**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 10 July 2017 – Persistent gaps in end-of-life (EoL) cancer care delivery and growing associated expenditures remain imminent U.S. public health issues. Providers [i.e., study participants] identified three major cancer care delivery challenges including lack of time to educate patients and caregivers due to clinical volume and administrative burdens, ambiguity in determining both prognosis and timing of palliative care at the EoL, and lack of adequate systems to support non-face-to-face communication with patients. To address these challenges, providers endorsed several options for clinical practice redesign in their settings. These included use of a lay health worker to assist in addressing early advance care planning, proactive non-face-to-face communication with patients specifically regarding symptom management, and community and in-home delivery of cancer care services. Specific strategies for cancer care redesign endorsed by health-care providers may be used to create interventions that can more efficiently and effectively address gaps in EoL cancer care. <https://goo.gl/dbdBW6>

## Understanding the cultural differences among ethnic minorities in palliative and end-of-life care

*The ASCO Post* (American Society of Clinical Oncology) | Online – 10 July 2017 – Because cultural origins influence the way patients and health-care providers think about palliative and end-of-life care (P&EoLC), discussions around these issues should take into account how patients' cultural and spiritual beliefs and traditions may impact their health-care decisions not just at the end of life, but from the time of a cancer diagnosis and throughout survivorship as well, according to Emily A. Haozous, Program Director and Associate Professor at the University of New Mexico College of Nursing in Albuquerque. "Culture is the lens through which we experience our lives, so it makes sense a person's cultural heritage will influence how that person hears a cancer diagnosis, how he interacts with the health-care system, and what he expects from the health-care system," said Dr. Haozous. "We know racial and ethnic minorities experience persistent health-care disparities in our medical system, and those disparities extend into P&EoLC as well." To ensure oncologists provide high-quality and effective P&EoLC to minority patients, it is important to understand and practice cultural humility, which acknowledges limited knowledge about another culture, rather than cultural competency, which implies a thorough

knowledge about the mores of another culture, and use culturally congruent approaches in their minority patients' care. <https://goo.gl/iMuX4g>

### Who decides: Me or we? Family involvement in medical decision making in Eastern and Western countries

*MEDICAL DECISION MAKING* | Online – 8 July 2017 – Research suggests that desired family involvement (FI) in medical decision making may depend on cultural values. Unfortunately, the field lacks cross-cultural studies that test this assumption. As a result, providers may be guided by incomplete information or cultural biases rather than patient preferences. The strongest finding across all 7 countries [represented in this survey – Australia, China, Malaysia, India, South Korea, Thailand, and the U.S.] was that those who desired higher self-involvement in medical decision making also wanted lower FI. On the other hand, respondents who valued relational-interdependence tended to want their families involved – a key finding in 5 of 7 countries. In addition, in 4 of 7 countries, respondents who valued social hierarchy desired higher FI. These results suggest that it is important for health providers to avoid East-West cultural stereotypes. <https://goo.gl/3cWbic>

Noted in Media Watch 19 June 2017, #517 (p.13):

- *PALLIATIVE MEDICINE & HOSPICE CARE* | Online – 17 April 2017 – 'Product or process: Cultural competence or cultural humility?' Perhaps nowhere in the health-care delivery system is the emphasis on patient-centered, culturally sensitive care more important than for those addressing life-limiting illness or for frail elders who are coping with the advanced stages of multiple chronic conditions. This editorial ... examines two leading methods for acquiring some degree of cultural sensitivity: cultural competence and cultural humility. <https://goo.gl/jaF3xJ>

### Special issue of Behavioral Sciences

#### Family communication at the end of life

*BEHAVIORAL SCIENCES*, 2017;7(3). People often feel awkward and ill at ease when faced with the opportunity for communication at the end of life (EoL), thus the overall theme for the articles in this special issue is the creation of more awareness and knowledge regarding the depth, breadth, and importance of current research exploring family communication at the EoL. This introductory essay attempts to accomplish the following: 1) Discuss the importance of talk regarding death; 2) Highlight the formative role of family interactions on the death and dying process; and, 3) Outline the articles in this special issue. Scholars contributing to this special issue ... have provided evidence that communication is important between and for terminally ill individuals, family members, and healthcare/palliative care specialists. Overall, research exploring communication at the EoL is especially relevant because every person experiences the death and loss of loved ones, and ultimately faces the reality of their own death. <https://goo.gl/rjT1FN>



**N.B.** The full text of each article can be downloaded. Journal contents page: <https://goo.gl/qzqbaj>

## End-of-life care in Australia

### **Rapidly increasing end-of-life care needs: A timely warning**

*BMC MEDICINE* | Online – 10 July 2017 – Current trends in population ageing show that, in the near future, while more people will live longer, more will also die at any one time. Health systems, as well as individual practitioners, are only just becoming aware of the extent of this problem. Health systems will have to rapidly change practice to manage the number of people dying in the coming years, many with complex multi-morbid conditions. The changes involved should include a personal recognition by all health professionals of their role in caring for the dying, and healthcare education must include end-of-life care (EoLC) management as part of the core curriculum. Further, health systems must improve integration between primary care and specialist clinicians to ensure the burden is shared efficiently across the system. Finally, it should be recognised that EoLC is not terminal care, but should be anticipated months or sometimes years ahead through advance care planning for known future complications by the patient's clinical team, as well as by patients and their main carers, to manage crises as they arise rather than react to them once they arise. <https://goo.gl/AYnAeU>

Noted in Media Watch 22 May 2017, #513 (p.11):

- *BMC MEDICINE* | Online – 18 May 2017 – ‘How many people will need palliative care in 2040? Past trends, future projections and implications for services.’ Current estimates suggest that approximately 75% of people approaching the end-of-life may benefit from palliative care (PC). The growing numbers of older people and increasing prevalence of chronic illness in many countries mean that more people may benefit from PC in the future, but this has not been quantified. <https://goo.gl/7H1Tr9>

### **Better palliative care for people with a dementia: Summary of interdisciplinary workshop highlighting current gaps and recommendations for future research**

*BMC PALLIATIVE CARE* | Online – 14 July 2017 – The care experienced by people with dementia and their families has the potential to be improved through using palliative care (PC) frameworks. However, a solid evidence base is required to inform how to achieve such improvements. As a relatively new field, there are significant methodological and content areas where research is needed. An expert consortium has highlighted priorities for future research. Integrated care may improve outcomes, notably quality-of-life, for people with dementia, hence an interdisciplinary approach to research and priority setting is essential to further actionable knowledge in this area. It is also imperative that there needs to be a unified approach at all levels – nationally, across Europe, and across the world. The authors have highlighted some of the research priorities for PC and neurodegeneration, as discussed by a consortium of multidisciplinary experts.

They have also suggested two models or frameworks that may be useful in mapping out topics to guide research in PC for people with dementia and continue to prompt further questions. <https://goo.gl/RQPkv8>

#### **Dementia is now leading cause of death in women in England**

*BRITISH MEDICAL JOURNAL* | Online – 14 July 2017 – Dementia has become the leading cause of death among women in England, overtaking heart disease, and the second most common cause among men.<sup>1</sup> <https://goo.gl/spgVFw>

1. 'Health Profile for England,' Public Health England, July 2017. <https://goo.gl/NpnJP6>

**N.B.** Selected articles on end-of-life care for people living with dementia are noted in the 10 July 2017 and 19 June 2017 issues of Media Watch (#520, p.6 & #517, p.15, respectively).

## Social workers' involvement in advance care planning: A systematic narrative review

*BMC PALLIATIVE CARE* | Online – 10 July 2017 – On the basis of available evidence, this review provides a whole profile of social workers' attitudes toward, knowledge of, and involvement in advance care planning (ACP) practice, mainly in the U.S. The findings suggest that social workers can be core members of health care teams providing end-of-life care (EoLC), and that they play an important role in promoting and implementing ACP. This review provides useful information or knowledge for implementing ACP through illustrating social workers' perspectives and experiences. It also suggests insufficient knowledge and limited education regarding ACP among social workers, which may be major barriers for social work practice in this field. The results of this review can assist social workers, professionals, educators, and policy makers to develop policies, programs, and practical guidelines for ACP-related education and practice so as to create an appropriate environment for promoting ACP and increase the competency of social workers in EoLC practice. <https://goo.gl/3Kpgqo>

Noted in Media Watch 5 December 2017, #490 (p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 December 2016 – '**Social work involvement in advance care planning: Findings from a large survey of social workers in hospice and palliative care settings.**' Compared with other settings, oncology and inpatient palliative care social workers [i.e., respondents] were less likely to be responsible for ensuring that patients/families are informed of advance care planning (ACP) options and documenting ACP preferences. <https://goo.gl/JZ7wPH>

Noted in Media Watch 1 August 2016, #473 (p.14):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2016;12(3):185-194. '**A time and place: The role of social workers in improving end-of-life care.**' With the release of a second Institute of Medicine report devoted to what it means to die in America in the 21st century,<sup>1</sup> momentum and opportunity for change may increase. If this is to happen, social workers will need to deliver the range of bio-psychosocial care that patients and families so desperately need. <http://goo.gl/2hrcbo>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch 22 September 2014, #376 (p.4)] <http://goo.gl/mm4o6W>

### Editorial

#### Does humanity need palliative care?



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(3):102-103. Although palliative care is becoming a major and respected component of modern healthcare systems, it continues to be difficult to judge when patients should accept the inevitability of their death and shift their focus from trying to find cures to increasing the quality of their lives. This shift sometimes enables them to live longer as well, a welcome side effect. Like a gravely ill patient trying to remain alive, our whole world is struggling to find a silver bullet. Our economic models are not working, our political structures are corrupted, our ability to respond and adapt to our rapidly decaying environment is wanting. We worry about the many threats to our civilization, but seem to be stubbornly confident that we will find a cure. Pundits of all stripes peddle their solutions, their prescriptions. Economists invoke the invisible hand, the devout pin their hopes on the divine and scientists assure us that – given enough funding – they will find the path to salvation. They may all be deluding themselves, and us. Our proposed cures may provoke only more suffering.

THE JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE  
European Journal of  
**Palliative Care** 

Access to articles in the *European Journal of Palliative Care* requires a subscription to the publication. May/June issue contents: <https://goo.gl/qpl4vv>

## Companionship: The shared journey between patient and family caregiver



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(3):104-107. The author believes ultimate companionship is vital for both patients and caregivers. “Ultimate” does not refer to a point in time, but to a process that extends present moments outward into everlasting memories. It affects the quality of life near death. “Companionship” signifies the interdependent patient-caregiver relationship. It engenders intimate connectedness, producing peacefulness for the deceased and the bereaved survivors. Therefore, hospice-related professionals should endeavor to meet the companionship needs of patients and family caregivers in a compassionate, dignified, and humanised manner. This discussion sheds light on two dimensions of companionship. First, while companionship with people near the end of life (EoL) is a humanistic concern in hospice care, the author’s story illustrates the practical underpinnings to the relevant theories and interventions, and it may shed light on hospice programmes such as No One Dies Alone. Although her story includes Chinese and Buddhist concepts, the author’s experience is just one example of what plays out across many cultural and religious backgrounds. Second, the author hopes her story draws more attention to the importance of companionship not only for patients at the EoL but also for their family caregivers.

## Invasive mechanical ventilation: Concerns over terminal extubation



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(3):110-113. Patients with advanced illness at the end of life who are admitted to an intensive care unit are often submitted to aggressive and active life sustaining support therapy, such as dialysis, transfusions, use of vasoactive drugs and invasive mechanical ventilation. Even though these therapeutic resources might sometimes be considered futile, and might prolong the dying process and cause suffering to patients and their families, their use continues to be a major part of the efforts made to save lives. This highlights the need for discussions about ethical decision-making in relation to avoiding the initiation of aggressive life-sustaining therapy (withholding) or discontinuing it (withdrawing).

## Psychological ideas in palliative care: Diagnosis and formulation



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(3):114-118. There is growing recognition in the palliative care (PC) community of the emotional and psychological needs of patients – and their carers – as they reach the end of life. But not every patient needs, wants or has access to formal contact with a psychologist. What’s more, all members of a multidisciplinary team are likely to experience the impact of psychological matters in their daily practice with patients and colleagues, whether or not their role is to explicitly address those. This article, the third in a series, aims to summarise some of the “big ideas” in psychology and translate them into practical advice to promote psychologically informed practice for those providing PC, whether as doctor, nurse, allied health professional or in any other clinical or non-clinical role.

**N.B.** For earlier articles on this series: See ‘**Attachment theory**’ in the 27 February 2017 issue of Media Watch (#501, p.7), and ‘**Emotional regulation**’ in the 3 April 2017 issue of the weekly report (#506, p.11).



### 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://goo.gl/5CHoAG>

## Palliative care in the intensive care unit



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(3):119-121. At Medway [Maritime Hospital in Kent, England], the hospital palliative care team (HPCT) developed a working relationship with the ICU over many years. A recent, larger study from Sheffield Teaching Hospitals reveals a similar relationship.<sup>1</sup> There, the main reasons for referral were the assessment of symptoms management, place of care, patient and family support and maintaining continuity of care for the patients moved from the ICU onto a general ward. Fewer patients were seen in the ICU Sheffield – 31 patients over six years, one patient every nine weeks on average; at Medway, 24 patients were seen over 30 months, an average of a new patient every five weeks. The Medway ICU has much expertise in the management of symptoms and family care, and this study shows that referral to the HPCT was typically for ethical decision-making issues, when the HPCT would work with the ICU staff to consider the care options and support them in these discussions and decisions. The greater frequency of referral and the focus on ethical decision-making at Medway may reflect the close working relationship between the ICU and HPCT. Other studies have shown that referral is often late. In one study, 6% of patients had died within one week and 51% died within the ICU. In the Medway study 79% of patients died within the ICU, but 21% were transferred to other hospitals for further management or the hospice for end-of-life care.

1. 'Experience of providing palliative care in critical care settings,' *BMJ Supportive & Palliative Care*, 2016;6(1):109-112. <https://goo.gl/xQfchb>

### Related

- *CRITICAL CARE MEDICINE*, 2017;45(4):e372-e378. '**Improving intensive care unit-based palliative care delivery: A multi-center, multidisciplinary survey of critical care clinician attitudes and beliefs.**' Participants generally supported the development of protocolized, collaborative palliative care (PC) systems and were willing to give up substantial autonomy to promote them. Some of the most commonly used PC triggers were among the least acceptable, while many of the most broadly agreeable triggers are currently difficult to automate within electronic health records. <https://goo.gl/ob3LW3>

Noted in Media Watch 13 February 2017, #499 (p.8):

- *DIMENSIONS OF CRITICAL CARE NURSING*, 2017;36(2):106-109. '**Palliative care triggers in the intensive care unit: A pilot success story.**' One suburban health care system adopted triggers unique to their culture and setting in a pilot study and saw an increase in palliative consultations in the ICU. Implementing triggers is often a complex and multifaceted process to adopt. This review shares the steps from concept to implementation of establishing palliative prompts in one ICU within an integrated health care system. <https://goo.gl/GE1R3L>
- *REVISTA BRASILEIRA DE TERAPIA INTENSIVA*, 2017;29(2):222-230. '**New concepts in palliative care in the intensive care unit.**' Mortality in intensive care units remains high, and the health team in intensive care units is constantly faced with complex situations where advanced treatment and advanced life support will not reach the goal of avoiding death, nor respect the patient and family's wishes. Many cases will require palliative care from a support team and advice from the hospital ethics committee. <https://goo.gl/H8a2x7>

**N.B.** Link is to both English and Portuguese language versions of the article.

**Palliative Care Network Community**

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## Information transfer for dying patients moving from home to hospital



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(3):141-143. Key findings from this study include the lack of continuity of care in communicating whether the patient was on a palliative care register, the lack of implementation or communication of advance care planning (ACP), a 100% implementation rate of do not attempt cardiopulmonary resuscitation (DNACPR) orders prior to death and, of nine patients who were eligible for transfer, four experienced a delay in care package delivery. Some solutions that may aid in achieving better results in the future include better transfer of information, better assignment of work roles and earlier identification of possible care needs. Improved transfer of information between care homes, primary care and secondary care could be in the form of physical or electronic means – for example, a single physical paper copy, similar to the community DNACPR form or better integration of electronic systems. Effective assignment of work roles in all care settings could aid in completing ACP; it could, for example, be completed in the comprehensive geriatric assessment *proforma* available in hospital. A more effective prompt could be implemented (in physical or electronic form) as a reminder to complete ACP in suitable patients. While all 28 patients [i.e., study participants] had a DNACPR order in place following hospital admission, only four had one in place on admission. Ideally, completion of DNACPR should now be a prompt to consider ACP.

### End-of-life care in Canada

#### **Priorities and challenges for a palliative approach to care for rural indigenous populations: A scoping review**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 12 July 2017 – The authors' analysis revealed several challenges and priorities relevant to rural indigenous palliative care (PC). Key challenges included: 1) Environmental and contextual issues; 2) Institutional barriers; and, (3) Interpersonal dynamics challenging client/clinician interactions. Priorities included: 1) Family connections throughout the dying process; 2) Building local capacity for PC to provide more relevant and culturally appropriate care; and, 3) Flexibility and multi-sectoral partnerships to address the complexity of day-to-day needs for patients/families. These findings point to several areas for change and action that can improve the relevance, access and comprehensiveness of PC programming for rural indigenous communities in Canada and elsewhere. Taking into account of the diversity and unique strengths of each Indigenous community will be vital in developing sustainable and meaningful change. <https://goo.gl/YKjD6p>

**N.B.** Selected articles on end-of-life care for Canada's indigenous peoples are noted in the 6 February 2017 issue of Media Watch (#498, p.1).

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

#### **Access to specialist palliative care services by people with severe and persistent mental illness: A retrospective cohort study**

*INTERNATIONAL JOURNAL OF MENTAL HEALTH NURSING* | Online – 10 July 2017 – Compared to the general population, people with pre-existing serious and persistent mental illness (SPMI) have higher rates of physical illness and die at an earlier age, raising questions about their palliative and end-of-life care needs when they are diagnosed with an incurable physical illness. In the present study, the authors explored access to specialist palliative care (SPC) services within one New Zealand health district. People with SPMI are 3.5 times less likely to receive SPC services compared to the general population... The present study confirms that those diagnosed with an SPMI are less likely to use SPC services at the end of life. Research using a national dataset is needed to determine whether the study findings are applicable to the national population. <https://goo.gl/eiGX7U>

## End-of-life care in Ireland

### Survey draws concern over coordination of palliative care

*THE IRISH MEDICAL TIMES* | Online – 11 July 2017 – The first ever survey of bereaved relatives by two major acute hospitals in Ireland has highlighted a lack of coordination of end-of-life care (EoLC) between hospital services and GPs. According to the VOICES MaJam report on EoLC by the Mater Misericordiae University and St James's Hospitals in conjunction with the University College Dublin and Trinity College Dublin, while 44% (152) of respondents to a question on coordination of care said that the services worked well together, one-in-10 (33) reported that the hospital services did not work well with GPs or community services. The report included the views of 356 relatives of people who died in the care of the two hospitals between 1 August 2014 and 31 January 2015. It found that the majority of relatives (79%) reported that the person's pain was relieved in the last two days of life and commented on how well pain and other symptoms were managed. However, relatives also suggested the need for access to specialist palliative care (PC) after 5 p.m. and at weekends. Some referred to what they perceived as "unnecessary and burdensome interventions" being continued, which they believed did not improve the dying person's care or comfort. The report made a number of recommendations, including that the availability of on-site specialist PC staff outside core working hours needed to be considered and that the admission of terminally ill patients via the emergency department to acute hospitals in Ireland needed to be reviewed. <https://goo.gl/VkVVEN>

**N.B.** Voices is an acronym for: **V**iews **o**f **I**nformal **C**arers – **E**valuation of **S**ervices. A copy of the VOICES MaJam report can be downloaded at: <https://goo.gl/aFxxvQ>.

#### Selected reports on end-of-life care in Ireland

- 'Finite lives: Dying, death and bereavement.' An independent report examining State services in Ireland by Oireachtas Senator Marie-Louise O'Donnell, May 2017. [Noted in Media Watch 22 May 2017, #513 (p.6)] <https://goo.gl/UA4q9r>
- 'Economic Evaluation of Palliative Care in Ireland.' Commissioned by The Atlantic Philanthropies, August 2015. [Noted in Media Watch 17 August 2015, #423 (pp.7-8)] <https://goo.gl/HxXS6h>
- 'A Good Death: A Reflection on Ombudsman Complaints about End-of-Life Care in Irish Hospitals,' Office of the Ombudsman, June 2014. [Noted in Media Watch 30 June 2014, #364 (p.6)] <https://goo.gl/cvB1hz>
- 'Access to Specialist Palliative Care Services and Place of Death in Ireland: What the data tells us.' Irish Hospice Foundation, May 2013. [Noted in Media Watch 28 October 2013, #329 (p.5)] <https://goo.gl/Omx9gS>

### Palliative care in heart failure

*JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY*, 2017;70(3). The authors investigated whether an interdisciplinary palliative care intervention in addition to evidence-based heart failure care improves certain outcomes. The former showed consistently greater benefits in quality of life, anxiety, depression, and spiritual well-being compared with usual care alone. <https://goo.gl/r5Xdej>

Noted in Media Watch 5 June 2017, #515 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 May 2017 – '**A review of prognostic tools in heart failure.**' Educating stakeholders, including primary care, cardiology, and critical care of the benefits of hospice and palliative medicine for patients with poor prognosis, may increase appropriately timed referrals and improve quality of life for these patients. This article reviews multiple tools useful in prognostication in the setting of advanced heart failure. <https://goo.gl/bEIG4V>

Cont.

Noted in Media Watch 15 May 2017, #512 (p.11):

- *PROGRESS IN CARDIOVASCULAR DISEASES* | Online – 5 May 2017 – ‘**Palliative care in heart failure: What triggers specialist consultation?**’ The use of general palliative care (PC) strategies, as well as expert PC consultation, is limited by a dearth of evidence-based interventions in the heart failure patient population and the knowledge as to when to initiate these interventions, uncertainty regarding patient desires, prognosis and the respective roles of each member of the care team, and a general shortage of specialist PC providers. <https://goo.gl/l0d2Jn>

### **The experiences of staff who support people with intellectual disability on issues about death, dying and bereavement: A metasynthesis**

*JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Online – 12 July 2017 – Historically, people with intellectual disabilities have tended to be excluded from knowing about death, dying and bereavement. Staff in intellectual disability services can play a valuable role in improving understanding of these issues in those they support. This qualitative metasynthesis aimed to understand the experiences of staff supporting adults with intellectual disabilities with issues of death, dying and bereavement. Three themes were developed following a lines-of-argument synthesis: 1) Talking about death is hard: negotiating the uncertainty in death, dying and bereavement; 2) The commitment to promoting a “good death”; and, 3) The grief behind the professional mask. “A cautious silence: The taboo of death” was an overarching theme. <https://goo.gl/CFQ84X>

**N.B.** Additional articles on end-of-life care for people living with intellectual disabilities are noted in the 12 June 2017 and 22 May 2017 issues of Media Watch (#516, pp. 8-9 & #513, p.15, respectively).

### **Pediatric palliative oncology: Bridging silos of care through an embedded model**

*JOURNAL OF CLINICAL ONCOLOGY* | Online – 12 July 2017 – Over the past decade, a growing partnership between the fields of oncology and palliative care (PC) has emerged, giving rise to the nascent discipline of palliative oncology. The relatively recent finding that patients with cancer who receive early integration of PC experience improved survival and quality of life (QoL) has stimulated a wave of research corroborating the beneficial impact of PC integration with adult cancer care paradigms. Within the field of pediatric oncology, similar efforts to study the value of pediatric PC are gaining traction. Integration of pediatric PC into the care of children with cancer has been associated with improved symptom management and QoL, not only for patients, but also for parents through reduction of psychological stress. Further awareness of the value of pediatric palliative oncology has been driven by an expanding body of literature describing and endorsing the field and by the advent of combined training programs in pediatric oncology and palliative medicine. Despite these advances, historical barriers to integration of pediatric PC into the care of children with cancer remain. <https://goo.gl/YN7UB7>

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

### **Meaningful communication prior to death, but not presence at the time of death itself, is associated with better outcomes on measures of depression and complicated grief among bereaved family members of cancer patients**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 July 2017 – Few studies have explored the clinical significance of the family’s presence or absence at the moment of a patient’s death and meaningful communication (saying “goodbye”) in terms of post-bereavement outcomes. Many families [i.e., survey respondents] wished to be present at the moment of the patient’s death; however, meaningful communication (saying “goodbye”) between the patient and family members, and not their presence or absence itself, was associated with better outcomes on measures of depression or complicated grief. Healthcare professionals could consider promoting both mutual communication (relating to preparation for death) between family members and patients before imminent death, as well as the family’s presence at the moment of death. <https://goo.gl/uVQUVv>

## **Palliative sedation: Ethical aspects**

*MINERVA ANESTESIOLOGICA* | Online – 12 July 2017 – Palliative sedation (PS) ... is considered by some commentators to be controversial because of its consequences on residual survival and/or quality of life, and to be inappropriate for treating pure existential suffering. The authors argue that PS must be always proportional, i.e., controlling refractory symptoms while keeping the loss of personal values (communication, affective relationships, care relationship) as low as possible, and that imminence of death is necessary too, from an ethical point of view, if a deep and continuous sedation (DCS) is proposed. Moreover, in case of pure existential suffering DCS should only be considered after repeated trials of respite sedation. The use of progressive consent and advance care planning to share the decision with the patient and to involve the family in the decision process as much as the patient desires is another ethical aspect to be pursued. <https://goo.gl/YiXAgF>

**N.B.** English language article.

### **Selected articles on palliative sedation**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 May 2017 – ‘**A survey of hospice and palliative care clinician’s experiences and attitudes regarding the use of palliative sedation.**’ A variety of terms and attitudes surround palliative sedation (PS) with little research devoted to hospice and palliative care clinicians’ perceptions and experiences with PS. These factors may contribute to the wide variability in the reported prevalence of PS. Nine hundred thirty-six [members of the American Academy of Hospice & Palliative Medicine ] responded to the survey. [Noted in Media Watch 8 May 2017, #511 (p.11)] <https://goo.gl/BrGdEV>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 20 April 2017 – ‘**International variations in clinical practice guidelines for palliative sedation: A systematic review.**’ In this review, the authors identify and compare national/regional clinical practice guidelines on palliative sedation (PS) against the European Association for Palliative Care PS framework and assess the developmental quality of these guidelines using the Appraisal Guideline Research & Evaluation (AGREE II) instrument. There were striking differences in terminologies used and in life expectancy preceding the practice. [Noted in Media Watch 24 April 2017, #509 (p.9)] <https://goo.gl/c8NhbR>
- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 1 July 2016 – ‘**A systematic literature review on the ethics of palliative sedation: An update (2016).**’ In a 2010 review of palliative sedation (PS), the following areas were identified as lacking in consensus: 1) Inconsistent terminology; 2) Its use in non-physical suffering; 3) The ongoing experience of distress; and, 4) Concern that the practice of PS may hasten death. This review looks at the literature over the past 6 years and provides an update on these outstanding concerns. [Noted in Media Watch 11 July 2016, #470 (p.13)] <http://goo.gl/qWxPgk>

### End-of-life care in Belgium

#### **Palliative care service use by older people: Time trends from a mortality follow-back study between 2005 and 2014**

*PALLIATIVE MEDICINE* | Online – 13 July 2017 – Palliative care (PC) service use has increased mostly in care homes, possibly as a result of policy changes, while hospital-based PC services lag behind. Contrary to recommendations, access for non-cancer patients may remain difficult and PC is often initiated late in the disease trajectory. General practitioners [i.e., survey respondents] identified 5,344 deaths. Overall, PC service use increased from 39% in 2005 to 63% in 2014... The use of a reference person for PC in a care home increased from 12% to 26% ... and of a palliative homecare team from 14% to 17.5% ... but hospital-based PC services did not increase. Controlling for socio-demographic characteristics, no differences were obtained over time in the proportion of cancer/non-cancer patients for whom they provided care. The timing of initiation of PC care services remained unchanged at a median of 15 days before death. <https://goo.gl/z2DEGN>

## **Strategies used in improving and assessing the level of reporting of implementation fidelity in randomised controlled trials of palliative care complex interventions: A systematic review**

*PALLIATIVE MEDICINE* | Online – 10 July 2017 – The effectiveness of an intervention can only be determined if there is implementation fidelity (IF) – meaning the extent an intervention is implemented as intended. Current understanding of IF and strategies to improve this have been largely derived from behaviour change interventions, but there has been no analysis of this for palliative care (PC). IF in PC is under-recognised. Strategies used to improve IF in randomised controlled trials of PC can be categorised under the following elements: “treatment design,” “training providers,” “delivery of treatment,” “receipt of treatment” and “enactment of treatment skills.” Over 88 strategies have been identified to improve IF. A table ... representing the elements of fidelity, their sub-components, and showcasing the strategies identified, has been produced. The strategies identified could be used, not just in research but in clinical practice, to guide all phases of the development and evaluation of PC interventions. Substantial administrative burden in the application of the identified strategies suggests that further investigation is required to identify which strategies are more effective in improving, as well as assessing, the level of reporting of IF in PC interventions. <https://goo.gl/UhAXzn>

## **Bereavement support standards and bereavement care pathway for quality palliative care**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 13 July 2017 – Provision of bereavement support is an essential component of palliative care (PC) service delivery. While bereavement support is integral to PC, it is typically insufficiently resourced, under-researched, and not systematically applied. A total of 10 standards were developed along with a pragmatic care pathway to assist PC services with implementation of the standards. The bereavement standards and care pathway constitute a key initiative in the evolution of bereavement support provided by PC services. Future endeavors should refine and examine the impact of these standards. Additional research is required to enhance systematic approaches to quality bereavement care. <https://goo.gl/igZGQT>

**N.B.** A link to the article at the journal's website was not active at the time of compiling this issue of Media Watch.

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

Representative sample of recent journal articles:

- *UNIVERSITY OF TORONTO MEDICAL JOURNAL*, 2017;94(3):29-31. ‘**College of Physicians & Surgeons of Ontario “effective referral” policy does not adequately respect physicians’ conscientious care.**’ The ruling in *Carter v Canada* and the subsequent passage of Bill C-14 by the Canadian Parliament have had a profound impact on what is deemed healthcare in Canada. With the legalization of euthanasia and assisted suicide, codified under the blanket term “medical assistance in dying” (MAiD), participation in the intentional and active hastening of a patient’s death has gone from being a punishable act to one enshrined as an essential component of comprehensive healthcare. Many physicians have expressed discomfort with this redefinition of their profession; a poll conducted shortly after the conclusion of the Carter case found that 63% of surveyed physicians would refuse to provide MAiD if requested. The College’s policy ‘Professional Obligations & Human Rights’ ... sets out the minimum expectations of dissenting physicians with respect to the provision of MAiD. Under this policy, physicians who object to a particular procedure or service are required to provide an “effective referral” to a non-objecting physician who can provide the procedure or service in an efficient manner. With respect to MAiD, the requirement for effective referral means that Ontario physicians have greater constraints upon their freedom of conscience than those in other jurisdictions where euthanasia or assisted-suicide is legal. <https://goo.gl/Dyy1ts>

## Worth Repeating

### **Bereavement and palliative care: A public health perspective**

*PROGRESS IN PALLIATIVE CARE* | Online – 3 December 2013 – In recent years, there has been an increasing emphasis upon public health perspectives that place palliative care (PC) in the context of end-of-life (EoL) services across whole populations. There is little corresponding public health interest in bereavement. Yet, if we have to develop relevant, coherent, and comprehensive EoL care policies and practices, public health approaches to PC need to be accompanied by public health approaches to bereavement care. The authors argue that PC services should match their commitment to providing a good death with a commitment to supporting good grief, and that this means investing their efforts principally in developing community capacity for bereavement care rather than seeking to deliver specialized bereavement services to relatives and friends of those who have received PC services. [Noted in Media Watch 16 February 2013, #336 (p.16)] <https://goo.gl/gT88a2>

### Media Watch: Online

Updated 07.17.2017

#### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/nZMuK7>

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

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

PALLIMED: <http://goo.gl/7mrgMQ>

[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/XO4mD>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

#### **Canada**



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>  
[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>  
[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <https://goo.gl/IOSNC7>

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>  
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

#### **Europe**



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

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1I9K>

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

### 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, research and teaching tool.

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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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