

## 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

**The illness experience: Scroll down to [Specialist Publications](#) and “I just need to know they are going to do what they say they’re going to do with my mom.” Understanding hospice expectations from the patient, caregiver and admission nurse perspective’ (p.14) in *Patient Education & Counselling*.**

## Canada

### LGBTQ seniors fear renewed discrimination in long-term care

*THE GLOBE & MAIL* | Online – 7 August 2018 – Improving the quality of life for queer seniors nearing the end of life is the next frontier for LGBTQ activists. In some long-term care facilities, staff are trained and vigilant in protecting the rights of sexual minorities. In others, ignorance can lead to discrimination. If you are in your mid-60s or older, you remember when it was a crime to be gay in Canada. You remember when being openly gay could keep you from getting a job. Holding hands or kissing in public? You would never think of such a thing. Now, as an increasing number of LGBTQ seniors require long-term care, some discover that the old days are back. Staff in nursing homes lack training for special needs. Some residents may harbour intolerances from earlier times. Circumstance may place a lesbian in the same room as a funda-

mentalist Christian. And for some, dementia may unleash prejudices that had long been suppressed. The situation is hardly unique to Canada. <https://goo.gl/L2knfW>

### Specialist Publications

**‘Social science and humanities evidence in Charter litigation: Lessons from *Carter v Canada (Attorney General)*’ (p.16), in *International Journal of Evidence & Proof*.**

**‘Providing medical assistance in dying within a home palliative care program in Toronto, Canada: An observational study of the first year of experience’ (p.16), in *Journal of Palliative Medicine*.**

**N.B.** Selected articles on palliative and end-of-life care for LGBTQ persons noted in the 25 June 2018 issue of Media Watch (#569, pp.13-14).

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CANADA GAZETTE*, 2018, Part II, Vol. 152, No. 16. **‘Regulations for monitoring medical assistance in dying come into force.’** The regulations set out reporting requirements for physicians and nurse practitioners who receive written requests for medical assistance in dying, and for pharmacists who dispense medication for assisted dying. **Download/view at:** <https://goo.gl/5omKZ1>

## U.S.A.

### **New palliative care unit offers dignity, respect to ailing prisoners**

CALIFORNIA / *The Record* (Stockton) – 10 August 2018 – California Health Care Facility in July opened a 30-bed palliative care (PC) unit. The state medical prison now is equipped to provide comprehensive and coordinated care to inmates who have chronic, serious or terminal illnesses. The new unit is a mix of palliative and hospice care. Hospice care is for people who are within six months of dying, Dr. Min Hlaing explained. While PC patients may have a terminal diagnosis, but live longer. The purpose of the unit is to offer relief from pain, both physical and emotional. <https://goo.gl/q8MWe7>

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 May 2018) can be downloaded/viewed at: <https://goo.gl/YLckx6>

### **As Catholic hospitals expand, so do limits on some procedures**

*THE NEW YORK TIMES* | Online – 10 August 2018 – One in six hospital patients in the U.S. is now treated in a Catholic facility, according to the Catholic Health Association (CHA), a membership organization that includes 90% of the Catholic hospitals in the U.S. Most facilities provide little or no information up front about procedures they won't perform. *The New York Times* analyzed 652 websites of Catholic hospitals in the U.S., using a list maintained by the CHA. On nearly two-thirds of them, it took more than three clicks from the home page to determine that the hospital was Catholic. Only 17 individual Catholic hospital websites, fewer than 3%, contained an easily found list of services not offered for religious reasons, and all of them were in Washington State, which requires that such information be published on a hospital's site. In the rest of the country, such lists, if available, were posted only on the corporate parent's site, and they were often difficult to find. Responding to a growing number of mergers and affiliations with secular institutions, the U.S. Conference of Catholic Bishops updated its instructions to Catholic hospitals in June,<sup>1</sup> ordering them to continue to provide care consistent with church teaching when entering into such business arrangements, including prohibiting procedures that are "intrinsically immoral, such as abortion, euthanasia, assisted suicide, and direct sterilization." <https://goo.gl/FzLpS8>

1. 'Ethical and Religious Directives for Catholic Health Care Services,' U.S. Conference of Catholic Bishops, June 2018. [See Part 5: 'Issues in Care for the Seriously Ill and Dying,' beginning on p.20] **Download/view at:** <https://goo.gl/d2qan4>

Noted in Media Watch 21 August 2017 (#526, p.5):

- **THE PEW CHARITABLE TRUSTS** | Online – 14 August 2017 – '**Report explores Catholic perspectives on end-of-life care.**' The Center for Practical Bioethics engaged a group of two dozen Catholic educators and thought leaders from a variety of clinical, religious, and ethical perspectives to explore differences in understanding and applying church teachings regarding palliative care and advance care planning. The report, reflects a robust discussion of church teachings on every individual's value and dignity and the moral considerations of burden and benefit around treatment.<sup>1</sup> <https://goo.gl/suSxd4>

1. 'Pathways to Convergence,' The Pew Charitable Trusts, August 2017. <https://goo.gl/AqwTWB>

### Specialist Publications

**'Physicians' religious characteristics and their perceptions of the psychological impact of patient prayer and beliefs at the end of life: A national survey'** (p.6), in *American Journal of Hospice & Palliative Medicine*.

**'Use of palliative care earlier in the disease course in the context of the opioid epidemic: Educational, research, and policy issues'** (p.10), in *Journal of the American Medical Association*.

**'U.S. Department of Corrections compassionate release policies: A content analysis and call to action'** (p.14), in *Omega – Journal of Dying & Death*.

**'Physician aid-in-dying: Practical considerations'** (p.15), in *American Journal of Psychiatry*.

## American Cancer Society says Wisconsin “falling short”

WISCONSIN | Wisconsin Business News Service – 10 August 2018 – The American Cancer Society’s Cancer Action Network says Wisconsin is “falling short” when it comes to policies and legislation that improve quality of life for cancer patients. [In a new report] the group suggests state lawmakers do more to improve access to palliative care (PC) by creating an advisory council of state experts.<sup>1</sup> It recommends making information more readily available, increasing educational opportunities for those going into medicine, and screening patients routinely for “potential palliative care needs.” Though PC is meant for those with serious illnesses, report authors note that it’s not the same as end-of-life care. The report shows cancer patients getting PC during chemotherapy are more likely to finish treatment, stay in clinical trials, and report a higher quality of life. <https://goo.gl/dZMZmh>

1. “How Do You Measure Up?: A Progress Report on State Legislative Activity to Reduce Cancer Incidence and Mortality,” Cancer Action Network, American Cancer Society. Scroll down to foot of the Wisconsin Business News Service for a link to the report.

## San Francisco’s Zen Hospice Guest House closes as donations drop

CALIFORNIA | *The San Francisco Chronicle* – 6 August 2018 – After nearly three decades of helping seriously ill people live out their final days with dignity, the Zen Hospice Project’s guesthouse may be nearing its own demise. The project closed the internationally known guesthouse, at least temporarily, at the end of June while it holds out hope for a deep-pocketed donor – as well as reform in the health insurance industry – to help pay the bills of the beautiful Page Street Victorian, where as many as 100 people a year receive care. “We would rather say suspended than closed,” said George Kellar, executive director of the project. <https://goo.gl/xKmrAR>

## You may have signed a living will, but scary mistakes can happen at the ER

*THE WASHINGTON POST* | Online – 5 August 2018 – “Don’t resuscitate this patient; he has a living will,” the nurse told the doctor, Monica Williams-Murphy, handing her a document. Williams-Murphy looked at the sheet bearing the signature of the unconscious 78-year-old man, who had been rushed from a nursing home to the emergency room. “Do everything possible,” it read, with a check approving cardiopulmonary resuscitation. The nurse’s mistake was based on a misguided belief that living wills automatically include “do not resuscitate” (DNR) orders. Working quickly, Williams-Murphy revived the patient, who had a urinary tract infection and recovered after a few days in the hospital. Unfortunately, misunderstandings involving documents meant to guide end-of-life decision-making are “surprisingly common,” said Williams-Murphy, medical director of advance care planning and end-of-life education for Huntsville Hospital Health System in Alabama. A new report out of Pennsylvania, which has the nation’s most robust system for monitoring patient-safety events, treats mix-ups

involving end-of-life documents as medical errors – a novel approach.<sup>1</sup> It found that in 2016, Pennsylvania health-care facilities reported nearly 100 events relating to patients’ “code status” – their wish to be resuscitated or not, should their hearts stop beating and they stop breathing. In 29 cases, patients were resuscitated against their wishes. In two cases, patients weren’t resuscitated despite making it clear they wanted this to happen. The rest of the cases were “near misses” – problems caught before they had a chance to cause permanent harm. <https://goo.gl/8ztsRu>

### Specialist Publications

‘Differences in code status and end-of-life decision making in patients with limited English proficiency in the intensive care unit’ (p.11), in *Mayo Clinic Proceedings*.

1. ‘Empowering Patients and Agents to Help Prevent Errors with Living Wills, DNRs, and POLSTs,’ Pennsylvania Patient Safety Authority, June 2018. [Noted in the 18 June 2018 issue of Media Watch (#568, p.2)] **Download/view at:** <https://goo.gl/YvkHJi>

## International

### **Portugal: Individual rights in a situation of advanced disease and at the end of life**

PORTUGAL | Mondaq – 10 August 2018 – Portugal's new law grants a set of rights, including the right not to suffer in a continuing, disruptive and disproportionate way. After being informed by health professionals and giving their consent, people who are suffering from an advanced disease or are at the end of their life have the right to information on matters relating to their state of health. This information must include the nature of their illness, the estimated prognosis, and the different clinical scenarios and possibilities for treatment. The patient also has the right to be treated in accordance with their treatment plan, which defines care objectives and which was discussed in advance between the medical team and the patient... When it comes to informed consent, people who are suffering from an advanced disease or are coming to the end of their life have the right to give their consent to the clinical treatments to which they are subject, provided they have been given information and explanations in advance by the doctor responsible for them and by the multidisciplinary team that is providing the treatment. The new law establishes that people who are suffering from an advanced disease and people coming to the end of their lives have the right to receive palliative care (PC) through the National Health Service. This care is provided under the 'Base Law of

Palliative Care' and it includes spiritual and religious support. Under the new law, people whose life expectation prognosis is estimated at weeks, or even days, with symptoms of suffering not controlled by PC, have the right to receive palliative sedation to alleviate their suffering. The new law also lists a series of rights that are non-clinical in nature to help people suffering from advanced disease and or coming towards the end of their life. <https://goo.gl/Lt6DKe>

#### Specialist Publications

**'The future of palliative care: Addressing issues of power through community'** (p.9), in *European Journal of Palliative Care*.

**'Joint position statement Indian Association of Palliative Care and Academy of Family Physicians of India – The way forward for developing community-based palliative care program throughout India: Policy, education, and service delivery considerations'** (p.10), in *Journal of Family Medicine & Primary Care*.

**'End-of-life care for patients hospitalised in internal medicine departments'** (p.7), in *Revista Clínica Española*.

### **What people don't realise is how expensive it is to die**

SOUTH AFRICA | *Times Select* (Johannesburg) – 7 August 2018 – At least 10 hospices have been forced to shut down their in-patient units over the past two years because of a lack of funding. Hospice Palliative Care Association (HPCA) CEO Liz Gwyther told *Times Select* that hospices rely on overseas donations and fundraising initiatives to keep their operations going. Only 10% of their funding comes from the government. There are 140 independently run hospices in South Africa, who operate under the umbrella of the HPCA, which accredits them against a set of standards. Research shows that dying people live longer in hospices when their emotional and physical pain is taken care of, said Gwyther. But there is a "scandalous" lack of funding for South African hospices, said Shaun Thomas, HPCA marketing. "When funding runs out, what happens to the patients?" asked Gwyther, a palliative care doctor. She said doctors are often quoted as saying there is nothing more that can be done for a terminally ill patient. But "there is always something more." Well-trained doctors with experience in pain management can control pain, including pain caused by cancer, she said. <https://goo.gl/2nG76V>



#### **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 beginning on p.17.

## End of life care in Australia

### **Australian Capital Territory ignored advice to put palliative care out to tender**

AUSTRALIA | *The Canberra Times* – 6 August 2018 – While the focus in recent days of the Australian Capital Territory (ACT) Assembly's end-of-life choice inquiry has been on voluntary assisted dying and the ACT's inability to bring in a scheme because of federal restrictions, the inquiry has also heard of shortages in palliative care (PC) staffing in Canberra Hospital, bed block in Clare Holland House and horror stories of people dying unnecessarily traumatic deaths. But the government was handed ... a road map to fix the problems in May 2017. Meanwhile the cost of caring for palliative patients in Canberra's acute hospitals has risen by 500% in the past five years, from \$362,000 in 2013-2014 to \$2.47 million in 2017-2018. That correlates with an increase in PC hospitalisations from 728 patients in 2012-2013, to 1,245 in 2016-2017. However the demand for PC is rising across the whole country, not just Canberra. According to the Australian Institute of Health & Welfare, palliative hospitalisations in Australia increased to 73,900 in 2015-2016, a rise of 28.2% on 2011-2012, compared to a 14.6% increase in broader hospitalisations in the same period.<sup>1</sup> In 2011-2012, the ACT had the third lowest rate of PC hospitalisations in the public health system in Australia, at 19.8 per 100,000. But by 2015-16, that ballooned to 33 per 100,000 – the second highest rate in the nation. <https://goo.gl/kgiptq>

1. 'Palliative care services in Australia,' Australian Institute of Health & Welfare, Canberra, Australian Capital Territory, May 2017. [Noted in the 29 May 2017 issue of Media Watch (#514, p.6)]  
**Download/view at:** <https://goo.gl/nstjoi>

Noted in Media Watch 9 October 2017 (#533, p.5):

- AUSTRALIA (Australian Capital Territory) | *Australian Ageing Agenda* (Canberra) – 4 October 2017 – '**A new palliative approach for residential aged care.**' The Palliative Care Needs Rounds Checklist is undergoing a second trial in 12 facilities after a pilot at four sites in 2014-2015 showed the benefits of taking a proactive integrated approach to providing specialist palliative care within aged care facilities. Benefits of the tool include improved skills and knowledge of the care team, cost-effectiveness for the acute sector, and an increased possibility for residents to die in their preferred place with pain and suffering well managed, according to the study.<sup>1</sup> <https://goo.gl/F75UPn>

1. 'Improving specialist palliative care in residential care for older people: A checklist to guide practice,' *BMJ Supportive & Palliative Care*, published online 2 August 2017. [Noted in the 7 August 2017 issue of Media Watch (#524, p.8)] **Abstract:** <https://goo.gl/vQ6PXV>

**N.B.** 'Palliative Care Services Plan 2013-2017,' ACT Health. **Download/view at:** <https://goo.gl/sgtJz1>

### **Choice of dying at home slipping away as end looms for Tasmanian hospice program**

AUSTRALIA (Tasmania) | ABC News (Hobart) – 8 August 2018 – The closure of an internationally recognised Tasmanian palliative care (PC) program will leave some families fighting to have loved ones die at home. Hospice@HOME was a federally-funded program set up through the Australian Government's Better Access to Palliative Care package, which aimed to increase Tasmanians' access to community-based PC. The three-year program ... was supposed to end in 2016 but was allowed to continue for another two years due to unspent funding. A spokeswoman for the Federal Department of Health said the provision of PC was the responsibility of the states but the Commonwealth had committed "almost \$80 million over three years from 2017 for activities designed to strengthen the PC system." <https://goo.gl/icq1a8>

### **Specialist Publications**

**'Inpatient palliative care of people dying in New South Wales hospitals or soon after discharge'** (p.12), in *Internal Medicine Journal*.

**'Retrospective chart review to assess domains of quality of death ... of patients dying in the acute hospital under the care of a nephrology service with renal supportive care support over time'** (p.12), in *Nephrology*.

## Specialist Publications

### **Association of perceived futile or potentially inappropriate care with burnout and thoughts of quitting among health-care providers**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 August 2018 – Futile or potentially inappropriate care (futile/PIC) has been suggested as a factor contributing to clinician well-being; however, little is known about this association. Of 1,784 clinicians who received surveys, 349 participated. Across all clinicians, 91% reported that they either had or had possibly provided futile/PIC to a patient. Overall, 43.4% of clinicians screened positive for burnout syndrome, 7.8% screened positive for depression, and 35.5% reported thoughts of leaving their job as a result of futile/PIC. A large majority of clinicians [i.e., survey respondents] report providing futile/PIC, and such care is associated with measures of clinician well-being, including burnout and intention to quit. **Abstract:** <https://goo.gl/Nbt9GY>

#### **Related**

- *ANALES DEL SISTEMA SANITARIO DE NAVARRA* | Online – 27 July 2018 – ‘**Burnout and executive functions in palliative care health professionals: Influence of burnout on decision making.**’ Burnout syndrome was present in 54.5% of palliative care health professionals [i.e., study subjects], 15.6% of them with more than one dimension altered... Higher levels of emotional exhaustion and depersonalization were associated with significantly lower scores in the Iowa Gambling Task for assessing decision-making. These executive functions can be relevant in the clinical setting since they could be related to the cognitive thinking required for correct clinical reasoning by health professionals. **Full text:** <https://goo.gl/tAf1KW>

**N.B.** Spanish language article.

### **Physicians’ religious characteristics and their perceptions of the psychological impact of patient prayer and beliefs at the end of life: A national survey**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 August 2018 – Physicians who are more religious or spiritual may report more positive perceptions regarding the link between religious beliefs/practices and patients’ psychological well-being. The authors conducted a secondary data analysis of a 2010 national survey of U.S. physicians from various specialties. Eighty-five percent believed that patients’ prayer has a positive psychological impact, 51% thought that patients’ belief in divine judgment has a positive psychological impact, and only 17% of physicians thought the same with patients’ expectation of a miraculous healing. Opinions varied based on physicians’ religious and spiritual characteristics. Furthermore, 52% of U.S. physicians appear to feel very comfortable discussing death with patients, although end-of-life (EoL) specialists, Hindu physicians, and spiritual physicians were more likely to report feeling very comfortable discussing death... U.S. physicians [i.e., survey respondents] hold divided perceptions of the psychological impact of patients’ religious beliefs/ practices at the EoL, although they more are likely to believe that frequent prayer has a positive psychological impact for patients. Formal training in spiritual care may significantly improve the number of religion/spirituality conversations with patients at the EoL and help doctors understand and engage patients’ religious practices and beliefs. **Abstract:** <https://goo.gl/4U1fiq>

Noted in Media Watch 6 November 2017 (#537, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 October 2017 – ‘**Physicians’ opinions on engaging patients’ religious and spiritual concerns: A U.S. national survey.**’ The majority of physicians [i.e., survey respondents] believe that it is essential to good practice for physicians to address patients’ spiritual concerns at the end of life. Physicians who were more religious were more likely to believe that spiritual care is essential to good medical practice and believe it is appropriate to always encourage patients to talk to a chaplain. **Abstract:** <https://goo.gl/9Px6DN>

**N.B.** The focus of the July 2018 issue of the *American Medical Association Journal of Medical Ethics* is on religion and spirituality in health care practice. [Noted in the 9 July 2018 issue of Media Watch (#571, p.7)] **Journal contents page:** <https://goo.gl/8BwomN>

## How can end-of-life care excellence be normalized in hospitals? Lessons from a qualitative framework study

*BMC PALLIATIVE CARE* | Online – 8 August 2018 – This study provides important empirical evidence from healthcare practitioners working in acute care settings on their experiences of providing end-of-life care (EoLC). It is an example of patient focussed theoretically informed medical education research that extends into clinical practice. The findings and conceptual model could inform and optimise interventions to support practitioners' effective normalisation of EoLC excellence in acute care settings. EoLC excellence requires meaningful collaboration with and specialist support from the palliative care (PC) team combined with effective inter-professional co-working. As the acute care team's coherence, collective action, cognitive participation and reflective monitoring are enhanced, the reliance on specialist PC may be limited to complex cases. To address coherence, acute care staff need support to develop their PC knowledge and skills to recognise dying and the point at which to initiate the pathway whilst developing the ability to hold two approaches to care at the same time during transition. This must also relate to understanding of the importance of integrating care practices and promoting the 'Clinical Guidelines for Dying Patients' as a positive aspect of care rather than a failing.<sup>1</sup> Expert and accessible guidance, e.g. from PC specialist or champions, is required to assist acute care staff

to navigate such situations of clinical uncertainty e.g., case-based interprofessional and interdisciplinary team learning sessions. **Full text:** <https://goo.gl/6XbV9k>

### End-of-life care for patients hospitalised in internal medicine departments

*REVISTA CLÍNICA ESPAÑOLA* | Online – 1 August 2018 – This observational, cross-sectional, retrospective multicentre, clinical audit study included 1,447 patients with a median age of 84 years. Of these, 1,065 (74.3%) were polypathological, 751 (51.9%) were terminal and 248 (17.1%) had cancer. For the terminal patients, do-not-resuscitate orders were established for 539 (73.3%), and palliative sedation was performed for 422 (57.4%). There was no record as to whether psychological, religious or grief care was provided in 32%, 64.8% and 44.1% of the terminal patients, respectively. The patients with cancer were more often competent to make decisions, knew their prognosis, received psychological care, died in an individual room, and were accompanied. Their relatives also more frequently received grief care. There is insufficient recording in the medical history as to the end-of-life care. There are differences in the care provided to patients with cancer and to those without cancer. **Abstract:** <https://goo.gl/hr1qT6>

**N.B.** Spanish language article.

1. 'Clinical Guidelines,' Queensland Health. Download/view at: <https://goo.gl/Rin78H>

## Perceptions of trained laypersons in end-of-life or advance care planning conversations: A qualitative meta-synthesis

*BMC PALLIATIVE CARE* | Online – 6 August 2018 – The findings from layperson perspectives on communication with peers experiencing serious illness or related to advance care planning (ACP) have practical implications. Since volunteers are more likely to commit to an activity that is personally satisfying, volunteer laypersons may constitute a reliable and cost-effective way to enhance ACP efforts and support individuals with palliative care (PC) needs, especially in community-based settings. Training, and even paying, laypersons could be a viable alternative to training existing healthcare providers in specific ACP communication skills, especially in resource-limited settings. Moreover, because laypersons may have more time or common life factors on which to establish rapport, laypersons are uniquely positioned to engage in end-of-life (EoL) conversations with peers experiencing serious illnesses. The he studies described the involvement of laypersons in meaningful conversations with their peers and outlined interpersonal interactions, personal impact, contributions, and training that laypersons experienced. Laypersons may complement and potentially enhance the work of healthcare providers in meeting the educational and psychosocial needs of individuals and their family caregivers in PC settings. Programs that involve laypersons should include training specifically for layperson-to-peer conversations related to the EoL period, as well as a mechanism for providing ongoing support to maximize and sustain the impact of the layperson's role. **Full text:** <https://goo.gl/QiyCqb>

Cont.

## Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 9 August 2018 – ‘**Unintended harm? Race differences in the relationship between advance care planning and psychological distress at the end-of-life.**’ Advance care planning (ACP) may not work the same way for black and white individuals [i.e., the patient population studied]. End-of-life (EoL) discussions and naming a healthcare proxy are potentially harmful to dying black patients’ mental health. This finding suggests a need for additional research to understand why caregivers report unmanaged sadness/anxiety for dying black patients who engaged in ACP, and increased attention to these patients’ mental health at the EoL. **Abstract (w. link to references):** <https://goo.gl/dzAVeW>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 August 2018 – ‘**A framework to guide economic analysis of advance care planning.**’ This economic framework considers the costs and benefits of advance care planning that accrue to or are borne by six actors: the patient, the patient’s family and caregivers, healthcare providers, acute care settings, sub-acute and home care settings, and payers. Program implementation costs and non-healthcare costs, such as time costs borne by patients and caregivers, are included. Findings suggest that out-of-pocket costs for patients and families will likely change if sub-acute or home care is substituted for acute care, and sub-acute care utilization is likely to increase while primary healthcare providers and acute care settings may experience heterogeneous effects. **Abstract:** <https://goo.gl/MUKQvS>

### “It is completely ok to give up a little sometimes”: Metaphors and normality in Swedish cancer talk

*CRITICAL APPROACHES TO DISCOURSE ANALYSIS ACROSS DISCIPLINES*, 2018;10(1):1-16. The clichéd conceptualization of cancer illness as a battle, which the patient can either win or lose, can be problematic. For patients referred to palliative care it can cause feelings of guilt and failure. This framing of cancer, referred to as “the battle script,” has been questioned in previous research, and there seems to be awareness among health practitioners that battle metaphors should be avoided. The aim of this article is to shed light on this battle script by examining the discursive dynamics of metaphor use in a large corpus of Swedish blogs written by terminally ill patients. This study focuses on two common linguistic metaphors, *kämpa* [fight/struggle] and *ge upp* [give up]. These expressions have the potential to actualize the battle script, but do not necessarily do so, due to their ambiguous meanings. By analyzing the contextualized meaning of these two metaphors, we illustrate the normality of the battle script as well as the problem to handle the perceived normativity of the script. The authors also discuss discursive strategies used by the bloggers to handle the negative implications of the battle script. **Abstract:** <https://goo.gl/yn1EaZ>

**N.B.** English language article. Click on pdf icon to access full text. Selected articles on the use of metaphors in relation to life-limiting or life-threatening illness noted in the 21 May and 29 January 2018 issues of Media Watch (#564, p.5 and #548, p.15, respectively).

### Critical care nurses’ qualitative reports of experiences with family behaviors as obstacles in end-of-life care

*DIMENSIONS OF CRITICAL CARE NURSING*, 2018;37(5):251-258. Critical care nurses (CCNs) frequently provide end-of-life (EoL) care for critically ill patients. Critical care nurses may face many obstacles while trying to provide quality EoL care. Some research focusing on obstacles CCNs face while trying to provide quality EoL care has been published; however, research focusing on family behavior obstacles is limited. Research focusing on family behavior as an EoL care obstacle may provide additional insight and improvement in care. A random geographically dispersed sample of 2000 members of the American Association of Critical-Care Nurses was surveyed. Sixty-seven EoL obstacle experiences surrounding issues with families’ behavior were analyzed for this study. Experiences were categorized into 8 themes. Top 3 common obstacle experiences included families in denial, families going against patient wishes and advanced directives, and families directing care that negatively impacted patients. In overcoming EoL obstacles, it may be beneficial to have proactive family meetings to align treatment goals and to involve palliative care earlier in the ICU stay. **Abstract:** <https://goo.gl/TqptQK>

## The future of palliative care: Addressing issues of power through community



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2018;25(3): 101. This edition of the journal features some important and

challenging perspectives on the current predicaments in palliative care – raising questions about where we prioritise our efforts, to what end and how – and all within a context shaped by significant political and economic change and shifts in what people facing end of life want and need. There is a recurrent theme around power throughout – either helpful or de-structive at individual, organisation, system and even national levels. An important question is raised regarding how professionals respond to facilitate a high-quality experience for individuals affected. A recent event organised by the innovation foundation Nesta confirmed how the experience of facing a serious or life-threatening diagnosis was vitally shaped by an individual's sense of power or powerlessness in relation to their illness. Power was retained or regained when people had purpose, could continue to make a difference to others, could control engagement with professionals and services, and were enabled to shape the system of available care. Power was lost when information about a condition, opportunities for expression, or choice on issues considered integral to an individual's identity were denied. The experience of powerlessness was shared by some professionals, particularly when

the system denied them the opportunity to make the difference to an individual's life that they believed was important.



The journal has ceased publication. Enquiries about access, editorial or subscription matters should be addressed to the publisher at: <https://goo.gl/WQSxHE>

Articles in the May/June issue include:

'What the social sciences have to offer palliative care'

'U.K. Ambulance services: Collaborating to provide good end-of-life care'

'Psychological ideas in palliative care: Distress, adjustment and coping'

'STOP! Patients receiving CPR despite valid DNACPR documentation'

'The relevance of "total pain" in palliative care practice and policy'

'Using human-centred design in end-of-life care'

**Journal Contents page:** <https://goo.gl/bG3i9U>

**N.B.** See 'European Journal of Palliative Care ceases publication' in the 6 August 2018 issue of Media Watch (#575, p.17). May/June issue contents page: <https://goo.gl/5UYQEs>; Journal's category archives: <https://goo.gl/rwp33C>

## Children's complex care needs: A systematic concept analysis of multidisciplinary language

*EUROPEAN JOURNAL OF PEDIATRICS* | Online – 8 August 2018 – Complex care is a growing phenomenon and population prevalence figures show that there is an increasing number of children with complex care needs (CCNs). However, the concept has not been systematically analyzed before, leaving it generally ill-defined and at times confusing. This is the first time this concept has been systematically analyzed and this analysis provides a much-needed theoretical framework for understanding the multidimensional nature of CCNs in children. Children's CCNs refer to multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. They are individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by family and healthcare structures. It is clear that the very nature of CCNs precludes the possibility that any one profession or discipline can possess the requisite knowledge or scope for high-quality competent care for this population. **Full text:** <https://goo.gl/KpWEor>

**N.B.** Many of the authors' data sources focus on palliative care.

## **Use of palliative care earlier in the disease course in the context of the opioid epidemic: Educational, research, and policy issues**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 9 August 2018 – Historically, the majority of patients seen by palliative care (PC) specialists have been near the end of life, and the field of PC has emphasized the efficacy of opioids for alleviating pain in this context. Likewise, much of hospice and palliative medicine training focuses on the inpatient setting, and clinicians trained in this tradition are often most comfortable treating hospitalized patients with pain due to advanced cancer and other life-limiting illnesses. However, in some settings PC is now recommended earlier in the disease course. For example, recent guidelines from the American Society of Clinical Oncology recommend that patients with advanced cancer receive dedicated PC services within 8 weeks of diagnosis.<sup>1</sup> Modern definitions of PC focus on improving quality of life for patients and their families at any stage of serious illness, and many PC programs are expanding to provide care outside the hospital. A survey of PC in California found that the number of community-based PC programs delivering care in clinics or patient residences doubled from 189 in 2014 to 380 in 2017.<sup>2</sup> Because of this rapid increase, PC clinicians are increasingly treating patients who not only have serious illnesses that are accompanied by moderate or severe pain, but also may have longer life expectancies, ill-defined illness trajectories, and risk factors for opioid misuse, including concomitant mood and substance use disorders. At the same time, the U.S. is in the midst of a national epidemic of opioid use disorder and overdose, driven in some part by an increase in opioid prescribing. Among 42,249 opioid related deaths in the U.S. in 2016, 17,087 involved prescription opioids.<sup>3</sup> The opioid crisis has not spared patients with serious illness. **Full text:** <https://goo.gl/ZS4MVK>

1. 'Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update,' *Journal of Clinical Oncology*, 2017;35(1):96-112. [Noted in the 31 October 2016 issue of Media Watch (#486, p.7)] **Full text:** <https://goo.gl/RGjFMP>
2. 'Palliative Care in California: Narrowing the Gap: Issue brief and interactive maps describe capacity of palliative care programs in 2017,' June 2018. **Download/view at:** <https://goo.gl/sybsDc>
3. 'Changes in synthetic opioid involvement in drug overdose deaths in the U.S., 2010-2016,' *Journal of the American Medical Association*, 2018;319(17):1819-1821. **First page view:** <https://goo.gl/3SS8mM>

## **Joint position statement Indian Association of Palliative Care and Academy of Family Physicians of India – The way forward for developing community-based palliative care program throughout India: Policy, education, and service delivery considerations**

*JOURNAL OF FAMILY MEDICINE & PRIMARY CARE*, 2018;7(2):291-302. A taskforce was formed with Indian and international expertise in palliative care (PC) and family medicine to develop this paper... The taskforce recommends: 1) PC should be integrated into all levels of care including primary care with clear referral pathways, networking between PC specialist centers and family medicine physicians and generalists in community settings, to support education and clinical services; 2) Implement the recommendations of the National Health Policy 2017 to develop services and training programs for upskilling of primary care doctors in public and private sector; 3) Include PC as a mandatory component in the undergraduate and postgraduate curriculum of family physicians; 4) Improve access to necessary medications in urban and rural areas; 5) Provide relevant in-service training and support for PC to all levels of service providers including primary care and community staff; and, 6) Generate public awareness about PC and empower the community to identify those with chronic disease and provide support for those choosing to die at home. **Full text:** <https://goo.gl/W6KUid>

## **A needs assessment of palliative care education among the U.S. adult neurology residency programs**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 8 August 2018 – This study had a 35% survey response rate (49 programs). Of the participating programs, 20% offer no palliative care (PC) education to residents. Communication, prognostication, and withdrawing life-prolonging therapies were the domains identified as the most important for resident education; these were also the domains program directors (PDs) and assistant/associate program directors (APDs) were most comfortable providing for their own patients, and the domains their residents are the best trained in currently. Addressing spiritual distress was the domain considered the least important, the domain PDs/APDs were least comfortable providing for their own patients, and the domains residents are currently the least well-trained in. Forty-two percent of programs were dissatisfied with the PC education available at their program. Time for teaching, availability of faculty, and faculty expertise were the most common barriers. **Abstract:** <https://goo.gl/8mZcst>

**N.B.** Selected articles on the palliative care (PC) needs of patients and families living with multiple sclerosis noted in the 30 July issue of *Media Watch* (#574, p.11); with amyotrophic lateral sclerosis noted in the 16 July issue of the weekly report (#572, p.7); and, with Parkinson's disease noted in the 28 May 2018 issue of *Media Watch* (#565, pp.10-11). Additional articles on the role of PC in neurology noted in the 19 February 2018 issue of *Media*

## **Differences in code status and end-of-life decision making in patients with limited English proficiency in the intensive care unit**

*MAYO CLINIC PROCEEDINGS* | Online – 9 August 2018 – Of the 27,523 patients admitted to 7 ICUs in a single tertiary academic medical center from 31 May 2011 through 1 June 2014, 779 (2.8%) had limited English proficiency (LEP). When adjusted for severity of illness, sex, education level, and insurance status, patients with LEP were less likely to change their code status from full code to do not resuscitate during ICU admission and took 3.8 days longer to change to do not resuscitate. Patients with LEP who died in the ICU were less likely to receive a comfort measures order and took 19.1 days longer to transition to comfort measures only. Patients with LEP were less likely to have an advance directive, more likely to receive mechanical ventilation, and more likely to have restraints used. The hospital length of stay was 2.7 days longer for patients with LEP. Additional adjustment for religion, race, and age yielded similar results. **Abstract (w. link to references):** <https://goo.gl/TkQjoS>

Noted in *Media Watch*, 20 June 2016, #467 (p.15):

- *PSYCHO-ONCOLOGY* | Online – 15 June 2016 – ‘**Promoting quality care in patients with cancer with limited English proficiency: Perspectives of medical interpreters.**’ Language barriers and underuse of medical interpreters have been widely identified as obstacles to equitable and quality care; however, the rate of professional interpreter use remains unknown. Further, no known study has explored patients’ reasons for refusing interpreter assistance, rather, existing studies have largely focused on physician and parental barriers. **Full text:** <http://goo.gl/VSe2l8>

**N.B.** Additional articles on patients with limited English proficiency in the context of end-of-life care noted in this issue of *Media Watch*.



### **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>

## Heart failure patients actually live longer in hospice, while using less care

*MEDPAGE TODAY* | Online – 8 August 2018 – Advanced heart failure (HF) patients who received HF-tailored hospice care used less healthcare, lived longer, and were less likely to die in the hospital, according to a propensity score-matched Medicare analysis. Hospice enrollees who had at least two heart failure discharges within 6 months had substantially less healthcare utilization in the next 6 months after second hospital discharge. Compared with propensity-matched HF patients not in hospice, they averaged fewer of the following: 1) Emergency department visits (2.64 versus 2.82); ICU stays (1.25 versus 1.51); and, 3) Hospital days (3.90 versus 4.67) Moreover, hospice patients survived for a median of 80 days, versus 71 days for non-hospice patients... And only 3% of hospice patients died in a hospital setting compared with 56% of non-hospice patients, reported Laura Gelfman, of Icahn School of Medicine at Mount Sinai in New York City, and colleagues...<sup>1</sup> And it's a win-win, commented Craig D. Blinderman, of Columbia University Medical Center in New York City, who was not involved in the study. "While the study was not designed to assess whether hospice and dying at home was concordant with the patients' goals of care, the assumption is that it was, given that most Americans when asked about their preferred place to die would not want to die in the hospital, but prefer to die at home," he told *MedPage Today*. **Full text:** <https://goo.gl/BuhyTo>

1. 'Palliative care in heart failure: Rationale, evidence, and future priorities,' *Journal of the American College of Cardiology*, 2017;70(15):1919-1930. [Noted in the 16 October 2017 issue of *Media Watch* (#534, p.10)] **Abstract:** <https://goo.gl/rqfdL4>

**N.B.** Additional articles on hospice and palliative care in heart failure noted in the 30 July 2018 issue of *Media Watch* (#574, p.7)]

### End-of-life care in Australia

#### **Retrospective chart review to assess domains of quality of death ... of patients dying in the acute hospital under the care of a nephrology service with renal supportive care support over time**

*NEPHROLOGY* | Online – 10 August 2018 – Retrospective chart reviews were undertaken of all deaths in the years 2004, 2009 and 2014 at [New South Wales] St. George Hospital (SGH) and in 2014 at Concord Repatriation General Hospital (CRGH). Domains assessed were recognition of dying, invasive interventions, symptom assessment, anticipatory prescribing, documentation of spiritual needs and bereavement information for families. EoLCP use was also evaluated at SGH. Over 90% of patients were recognised to be dying in all 3 years at SGH. Rates of interventions in the last week of life were low and did not differ across the three years. There was a significant increase in prescription of anti-psychotic, and anti-emetic, and anti-cholinergic medication over the years at SGH. Use of EoLCPs was significantly higher at SGH, and their use improved several quality domains. 68% of all deaths were referred to palliative care at SGH, 33% at CRGH... Cessation of observations and non-essential medications, and documentation of bereavement information given to families was low across both sites in all years, although significantly improved when EoLCPs were used. While acute teams are good at recognising dying, they need support to care for dying patients. The use of end-of-life care plans (EoLCPs) in acute services can facilitate improvements in caring for the dying. Renal supportive care services need time to become embedded in the culture of the acute hospital. **Abstract:** <https://goo.gl/Lft1eY>

**N.B.** Selected articles on palliative and end-of-life care in the field of nephrology noted in the 30 July 2018 issue of *Media Watch* (#574, pp.10-11).

### **Related**

- *INTERNAL MEDICINE JOURNAL* | Online – 8 August 2018 – 'Inpatient palliative care of people dying in New South Wales hospitals or soon after discharge.' Of 150,770 decedents, 34.4% received palliative care (PC), a median of 10 days before death. Decedents were more likely to receive PC if they had cancer or were younger. Of the 30.1 days spent in hospital, 8.7 days involved PC. Older age and non-cancer diagnoses were associated with fewer days of inpatient palliation and shorter time between first palliative admission and death. Decedents dying out of hospital started PC 18 days earlier than those dying in hospital. **Abstract:** <https://goo.gl/2G1phB>

## Ethical, palliative, and policy considerations in disorders of consciousness

*NEUROLOGY* | Online – 8 August 2018 – This essay complements the scientific and practice scope of the ‘American Academy of Neurology Guideline on Disorders of Consciousness’ by providing a discussion of the ethical, palliative, and policy aspects of the management of this group of patients.<sup>1</sup> The authors endorse the renaming of “permanent” vegetative state to “chronic” vegetative state given the increased frequency of reports of late improvements, but suggest that further refinement of this class of patients is necessary to distinguish late recoveries from patients who were misdiagnosed or in cognitive-motor dissociation. Additional nosologic clarity and prognostic refinement is necessary to preclude overestimation of low probability events. They argue that the new descriptor “unaware wakefulness syndrome” is no clearer than “vegetative state” in expressing the mismatch between apparent behavioral unawareness when patients have covert consciousness or cognitive motor dissociation. The authors advocate routine universal pain precautions as an important element of neuro-palliative care for these patients given the risk of covert consciousness. In medical decision-making, they endorse the use of advance directives and the importance of clear and understandable communication with surrogates. They show the value of incorporating a learning health care system so as to promote therapeutic innovation. **Abstract:** <https://goo.gl/pBFoJJ>



1. ‘Practice guideline update recommendations summary: Disorders of consciousness,’ *Neurology*, published online 8 August 2018. **Abstract:** <https://goo.gl/11LWKY>

### Related

- *NEUROLOGY* | Online – 8 August 2018 – ‘**Comprehensive systematic review update summary: Disorders of consciousness.**’ The results of this systematic review highlight important gaps in knowledge related to diagnosis, natural history, prognosis, and treatment for patients with prolonged disorders of consciousness. Some consistent weaknesses in study methodology were observed across studies, constraining the strength of the evidence. Small sample size was the most prevalent weakness due to limited study precision and generalizability. **Abstract:** <https://goo.gl/n7bu9b>

**N.B.** Click on pdf icon to access the **full text** of the articles published in *Neurology*.

## Communication apprehension about death, religious group affiliation, and religiosity: Predictors of organ and body donation decisions

*OMEGA – JOURNAL OF DYING & DEATH* | Online – 10 August 2018 – Communication willingness has previously been identified as an important communication factor in influencing individuals’ decisions to become an organ donor. Missing from this conversation is the role of communication apprehension about death and its impact on donation decisions. The purpose of this study was to examine the relationships between communication apprehension about death, religiosity, religious affiliation, and donation decisions. Three hundred and thirty-three individuals participated in an online survey. Findings suggest that communication apprehension about death, especially communication avoidance about death, negatively impact donation decisions. In addition, religiosity and affiliation with a specific religion also negatively impact donation decisions. These variables were also predictors of organ and body donation. The findings show a need for more research on what prevents conversations about donation. In addition, the stark difference between organ donation likelihood and body donation likelihood underscores the need for communication scholars to examine communication about body donation. **Abstract:** <https://goo.gl/eRdv3L>

**N.B.** Articles on organ transplantation in the context of palliative and end-of-life care noted in the 18 December and 9 October 2017 issues of *Media Watch* (#543, p.11 and #533, p.9, respectively).



Media Watch: Behind the Scenes  
<http://goo.gl/XDjHxz>

## **U.S. Department of Corrections compassionate release policies: A content analysis and call to action**

*OMEGA – JOURNAL OF DYING & DEATH* | Online – 6 August 2018 – Large and increasing numbers of inmates with chronic and terminal illnesses are serving time, and dying, in U.S. prisons. The restriction of men and women to die in prisons has many ethical and fiscal concerns, as it deprives incarcerated persons of their autonomy and requires comprehensive and costly health-care services. To ameliorate these concerns, compassionate release policies, which allow inmates the ability to die in their own communities, have been adopted in federal and state prison systems. However, little is known about the content of compassionate release policies within U.S. states' department of corrections, despite recent calls to release incarcerated persons who meet eligibility criteria into the community. This study provides an overview of compassionate release policies in the U.S., which vary widely across the compassionate release process. Specific policy recommendations are made to assure the timely access and utilization of compassionate release among eligible incarcerated individuals. **Abstract:** <https://goo.gl/BKe7Jk>

Noted in Media Watch 2 July 2018 (#570, p.3):

- WASHINGTON DC | Families Against Mandatory Minimums – 27 June 2018 – ‘**Compassionate release for dying prisoners underused: Report.**’ The non-profit advocacy group has released a comprehensive, state-by-state report on the early-release programs available to prisoners struggling with certain extraordinary circumstances, such as a terminal or age-related illness. The report takes a deep dive into the regulations and requirements of these programs in each state, including the varying categories of release, eligibility criteria, and reporting. **Download/view report at:** <https://goo.gl/vsngvp>

## **“I just need to know they are going to do what they say they’re going to do with my mom.” Understanding hospice expectations from the patient, caregiver and admission nurse perspective**

*PATIENT EDUCATION & COUNSELLING* | Online – 6 August 2018 – The objective of this paper is to understand patient, caregiver and hospice admission nurses needs during the hospice admission conversation so patients and their caregivers can make informed decisions about hospice. Four themes were identified: 1) Wide variation in patient knowledge of hospice care prior to the admission conversation;; 2) Competing expectations and objectives for the admission conversation between patients, caregivers and hospice admission team members; 3) Organizational influences around the goals of the admission conversation; and, 4) Importance of integrating the patient and caregiver perspective to improve the quality of admission conversations. Hospice services provided may be inconsistently explained by hospice personnel and, therefore, can be misunderstood by patients and families. With the ubiquitous challenges surrounding hospice admission consults, there is a critical need for complete and accurate information during the admission process. **Abstract: (w. link to references):** <https://goo.gl/c3jy1A>

## **Integrating palliative care into the ICU: From core competency to consultative expertise**

*PEDIATRIC CRITICAL CARE MEDICINE*, 2018;19(8S):S57-S58. All critical care team members should demonstrate and foster their core competencies in caring for patients with complex illness and uncertain prognosis, including at the end of life (EoL). The authors describe these core competencies of the ICU team member as “primary” palliative care (PC) skills. Some ICU team members will have special expertise in EoL care or symptom management and decision-making support and will serve as local experts within the ICU team as a resource to other team members. We call this skill set “secondary” PC. Some patients will benefit from the full range of expertise provided by a separate consulting team, with additional training, focused on caring for patients with PC needs across the full spectrum of patient locations within a health system. We term the skill set provided by such outside consultants “tertiary” PC. Solutions for meeting patients’ PC needs will be unique within each system and individual institution, depending on available resources, history, and structures in place. Providers from multiple professions will usually contribute to meeting patient needs. **Abstract:** <https://goo.gl/o3Pt2P>

**N.B.** The focus of the August 2018 supplement is death and dying the the pediatric intensive care unit.  
**Journal contents page:** <https://goo.gl/KkspZD>

## Personalized approach and precision medicine in supportive and end-of-life care for patients with advanced and end-stage kidney disease

*SEMINARS IN NEPHROLOGY*, 2018;38(4):336-345. Kidney supportive care requires a highly personalized approach to care. Precision medicine holds promise for a deeper understanding of the pathophysiology of symptoms and related syndromes and more precise individualization of prognosis and treatment estimates, therefore providing valuable opportunities for greater personalization of supportive care. However, the major drivers of quality of life are psychosocial, economic, lifestyle, and preference-based, and consideration of these factors and skilled communication are integral to the provision of excellent and personalized kidney supportive care. This article discusses the concepts of personalized and precision medicine in the context of kidney supportive care and highlights some opportunities and limitations within these fields. **Abstract (w. link to references):** <https://goo.gl/yK5yK4>

**N.B.** Additional articles on palliative and end-of-life care for people living with chronic kidney disease noted in the 6 August 2018 issue of Media Watch (#575, p.10).

## Palliative sedation in clinical scenarios: Results of a modified Delphi study

*SUPPORTIVE CARE IN CANCER* | Online – 10 August 2018 – The study failed to reach consensus in continuous palliative sedation and sedation levels for patients with refractory symptoms described in hypothetical clinical scenarios. On hundred nine eligible experts were identified... The study included three vignettes of cancer patients and two non-cancer patients, with an estimated survival of days and severe suffering secondary to refractory complications. Experts were asked about whether they would perform continuous sedation and sedation level... Consensus was considered when 70% or more of the experts agreed on a certain topic. Participants were from the U.S., Canada, Europe, Australia and Asia. 97% and 88% of the respondent agreed use of sedatives, continuously or temporary, in cases of refractory delirium, dyspnea secondary to lung cancer... There were discrepancies for cases of dementia and psycho-existential suffering. **Abstract (w. lists of appendices and references):** <https://goo.gl/Uo9ni1>

### Related

- *THEORETICAL MEDICINE & BIOETHICS* | Online – 4 August 2018 – ‘**Comforting when we cannot heal: The ethics of palliative sedation.**’ The author considers whether palliative sedation (PS) is or is not appropriate medical care. This requires one to consider 1) Whether, in addition to the good of health, relief of suffering is also a proper end of medicine; 2) Whether unconsciousness can ever be a good for a human being; and, 3) how double-effect reasoning can help us think about difficult cases. He concludes that PS may be proper medical care, but only in a limited range of cases. **Abstract (inc. list of references):** <https://goo.gl/zawJqN>

**N.B.** Selected articles on palliative sedation noted in the 6 August 2018 issue of Media Watch (#575, p.4).

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *AMERICAN JOURNAL OF PSYCHIATRY*, 2018;13(8):3-5. ‘**Physician aid-in-dying: Practical considerations.**’ The legalization of physician aid-in-dying (PAiD) in multiple jurisdictions in the U.S. as well as globally has introduced the need to investigate the role of psychiatrists in mental health evaluations and capacity assessments among patients requesting PAiD. In Belgium and the Netherlands, the practice of medically assisted suicide is legal, even among minors (i.e., patients aged ≥12) and individuals with psychiatric disorders. This raises concern that the practice of PAiD might undergo similar expansion worldwide and highlights the need for psychiatry as a field to engage in education on the topic and to become involved in the development of standardized assessment tools. This article provides an overview of the current status of PAiD in the U.S. and worldwide, with discussion of several practical considerations pertaining to legalization and ethics, especially with regard to patients with psychiatric disorders and the effect on the mental health care field. **Full text:** <https://goo.gl/DqJVkP>

Cont.

- *INTERNATIONAL JOURNAL OF EVIDENCE & PROOF* | Online – 2 August 2018 – ‘**Social science and humanities evidence in Charter litigation: Lessons from *Carter v Canada (Attorney General)*.**’ *Carter v Canada (Attorney General)* is a Canadian case that famously struck down the Canadian Criminal Code prohibitions on euthanasia and assisted suicide (now known collectively as medical assistance in dying or MAiD). The most significant issue in the Carter case was that of the status of MAiD. However, this case is also interesting to explore in relation to the issue of the use of expert evidence from social science and humanities researchers. The author offers reflections as an academic trained in philosophy and law, but not expert in the use of social science and humanities evidence in litigation. As someone who was inside the litigation, but outside the generation of the evidence, she seeks to bring a perspective that may be useful to practitioners who might be thinking about working with academics and academics who might be thinking about getting involved in constitutional litigation that relates to their field of study. **Abstract:** <https://goo.gl/mwH2eL>
- *JAMA PSYCHIATRY* | Online – 8 August 2018 – ‘**Suicide and physician-assisted death for persons with psychiatric disorders. How Much Overlap?**’ Physician-assisted death (PAD) of persons in which psychiatric disorders are the basis for the procedure (psychiatric PAD) remains infrequent but rising in number in Belgium and The Netherlands where it is legal, comprising about 1% to 2% of PAD. There were 83 cases in The Netherlands in 2017 (*per capita* U.S. equivalent would be about 1,580 cases). Canada’s euthanasia law generally excludes psychiatric PAD, but there are court challenges to expand the law. **First page view:** <https://goo.gl/v9Atqx>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 August 2018 – ‘**Providing medical assistance in dying within a home palliative care program in Toronto, Canada: An observational study of the first year of experience.**’ Medical Assistance in Dying (MAiD) was legalized in Canada in June 2016. There are no documented experiences of MAiD provision within a home palliative care (PC) program. The majority of PC physicians in Canada object to MAiD. As one of the largest home-based PC providers in Canada, the Temmy Latner Centre for Palliative Care (TLCPC) developed processes to implement MAiD provision within a home PC team with diverse attitudes toward MAiD. Of the 45 patients who were assessed for MAiD, 27 (60%) received MAiD and 18 (40%) did not. The mean age was 74 (range 20-95), 24 (53%) were male, and 33 (73%) had cancer as a primary diagnosis. These 27 patients represent 1.2% of our total patient population during this time period. MAiD was accessed by 1.2% of the patients within a home PC center in the first year of legalization. Patient demographics were consistent with those documented elsewhere. The TLCPC process accommodates the diverse viewpoints of clinicians and emphasizes continuity of PC provision. **Abstract:** <https://goo.gl/XezUJT>

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[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population with poor access to palliative care.')]

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/L7D2hw>

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Barry R. Ashpole  
Guelph, Ontario CANADA

'phone: 519.837.8936  
e-mail: [barryashpole@bell.net](mailto:barryashpole@bell.net)