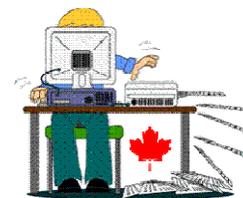


## Media Watch...

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

**'Behind the doors of home hospice patients: A secondary qualitative analysis of hospice nurse communication with patients and families' (p.11), in *Palliative & Supportive Care*.**

## Canada

### Improving advance medical directives: Lessons from Quebec

QUEBEC | Institute for Research on Public Policy (Montreal) – 14 March 2019 – Canadians should be able to meaningfully express their preferences for end-of-life care (EoLC) through advance medical directives (AMDs). More values-based, collaborative approaches to AMDs offer a path forward for Quebec and other provinces... Government efforts to increase the uptake of AMDs, and the legal constraints they impose on health professionals, are bringing greater scrutiny to provincial AMD regimes... Since 2015, Quebecers over the age of 18 have had the option to indicate on a legally binding form their wish to accept or refuse specific medical interventions in cases where they become incapable of giving consent. This process has several shortcomings. It limits individuals' expression of their wishes to a simple checklist, and it relies on people to self-inform. More importantly, it does not provide them with an opportunity to meaningfully discuss their true preferences for EoLC. To be robust, the AMD process should include

informed conversations with healthcare providers, individuals and their families to help people articulate their wishes for EoLC. A regime that requires and supports a deeper discussion of the concerns and constraints that influence a person's choices can ensure they get the consideration they deserve, they conclude. <http://bit.ly/2T67Fwh>

### Specialist Publications

**'Clinical trial implications for study participants accessing medical assistance in dying'** (p.12), in *Current Oncology*.

**'Canadian neurosurgeons' views on medical assistance in dying: A cross-sectional survey of Canadian Neurosurgical Society members'** (p.12), in *Journal of Medical Ethics*.

**'Medical assistance in dying (MAiD): Ten things leaders need to know'** (p.13), in *Nursing Leadership*.



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## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *The Medicine Hat News* – 6 March 2019 – **‘Medically assisted death numbers on the rise in Alberta.’** The number of medical assistance in dying (MAiD) cases in Alberta has now reached 600 ... according to Alberta Health Services data. It works out at 4.6/week averaged over the past 2½ years for the province – 5.9/week in 2018, which had a total of 307. From 6 February to 17 June 2016, medically assisted death was only possible with a court order. During this time there were six assisted deaths in Alberta. Federal legislation kicked in on 17 June 2016 removing the need for a court order. From that point to the end of December that year there were a total of 63 MAiD deaths in Alberta. There were 205 in 2017. Of the 600 cases so far, 379 were carried out in a facility and 221 in the community... A total of 64 patients were transferred from mainly faith-based facilities in order to receive MAiD and 12 were transferred from non-faith-based facilities to a participating facility or to the patient’s home. <http://bit.ly/2uOP6j6>

## U.S.A.

### Deaths from dementia have more than doubled in U.S., report says

CNN | Online – 14 March 2019 – A report ... by the National Center for Health Statistics shows that the rate of Americans who died from dementia has more than doubled from 30.5 deaths per 100,000 people in 2000 to 66.7 in 2017.<sup>1</sup> The term dementia encompasses disease states that impair memory and result in a decline in cognitive function. These conditions seem to be affecting more of the population as it is expected to affect 14 million people age 65 and older by 2060, according to the U.S. Centers for Disease Control & Prevention (CDC).<sup>2</sup> Dr. Ellen Kramarow, lead author of the new report and a health statistician for the Aging & Chronic Disease Statistics Branch for the National Center for Health Statistics, part of the CDC, explained that one cause of the rising number of deaths due to dementia in the U.S. is most likely because of the aging population. Researchers used data from death certificates from all 50 states and the District of Columbia. They examined four types of dementia recognized by the International Classification of Diseases: Alzheimer’s disease, vascular dementia, unspecified dementia and other degenerative diseases of the nervous system. Alzheimer’s disease accounted for 46% of the 261,914 deaths due to dementia in the U.S. in 2017. <https://cnn.it/2W0yWIs>

#### Specialist Publications

**‘Disclosure of religious identity and healthcare practices on Catholic hospital websites’** (p.7), in *Journal of the American Medical Association*.

**‘Early Accountable Care Organization results of end-of-life spending among cancer patients’** (p.5), in *Journal of the National Cancer Institute*.

**‘Planning the transition to end-of-life care in advanced cancer’** (p.5), posted on the website of the National Cancer Institute.

**‘Last days of life’** (p.5), posted on the website of the National Cancer Institute.

**‘Pediatric palliative care’** (p.8), posted on the website of the National Cancer Institute.

**‘Physician aid-in-dying: Updates for geriatric psychiatrists’** (p.12), in *American Journal of Geriatric Psychiatry*.

1. ‘Dementia Mortality in the U.S., 2000-2017,’ National Vital Statistics Report, 2019;68(2), National Center for Health Statistics. **Download/view at:** <http://bit.ly/2O7sWVG>
2. ‘What is the burden of Alzheimer’s disease in the U.S.?’ U.S. Centers for Disease Control & Prevention. **Download/view at:** <http://bit.ly/2XZULDV>

Cont.

**N.B.** Selected articles on palliative and end-of-life (EoL) care for people living with Alzheimer’s and other forms of dementia noted in several past issues of Media Watch, for example, 7 January 2019 (#596, pp.9-10); and, 10 and 31 December 2018 (respectively, #593, p.7 and #595, p.16). Articles on advance care planning, advance directives and EoL decision-making for people living with Alzheimer’s disease and other forms of dementia noted in 4 March 2019 issue of Media Watch (#604, p.13).

### **What difference does it really make to talk about dying earlier?**

NATIONAL PUBLIC RADIO | Online – 14 March 2019 – For years now, patients with serious illnesses, their family members and medical staffers have been encouraged to discuss their wishes well before the end of life (EoL) draws near. It makes sense that such conversations can lead to better deaths – but how much of a difference do these EoL talks actually make? They seem to cut anxiety and depression quite a bit, according to a four-year study that followed 278 Dana-Farber Cancer Institute patients with advanced cancer.<sup>1</sup> The study enrolled half its subjects in the Serious Illness Care Program developed by Ariadne Labs, the health-care innovation center founded by famed physician-author Atul Gawande, while half got usual care. Among those in the serious illness program, moderate to severe anxiety was only half as common as among those in the control group, the study found. And that improvement persisted for months. But when it came to affecting medical treatment – reducing unwanted or unhelpful measures – the study found no significant effects... It found no clear improvement on dying more peacefully or getting care tailored to personal goals, and no change in survival time. EoL conversations did tend to happen a couple of months earlier, about five months before death. <https://wbur.fm/2JgnMYI>

1. ‘Effect of the Serious Illness Care Program in outpatient oncology: : A cluster randomized clinical trial,’ *JAMA Internal Medicine*, published online 14 March 2019. **Abstract:** <http://bit.ly/2FfOHje>

## **International**

### **China’s rare public hospices help patients die with dignity**

CHINA | *Sixth Tone* (Shanghai) – 13 March 2019 – Liltng music drifts through the corridors of a four-floor public hospice in a tranquil neighborhood of Shanghai’s Changning District. A caregiver slowly maneuvers a wheelchair-bound elderly woman out of the ward for some fresh air, singing to her as she goes. Although the woman can’t speak, she nonetheless smiles serenely. The tender scene may be familiar to people in Western countries, but in China, it’s rare for people to experience this kind of end-of-life care. Although hospices have existed in China since 1987 and, according to the national health authority, the country had around 2,300 hospice organizations by June 2017, they generally remain in developed cities, inaccessible to most. Compared with the U.S., where nearly half of all deaths in 2011 occurred in hospices, the majority of Chinese people either die at home or in hospitals, many of which lack adequate palliative care (PC) facilities. In addition, deep-seated taboos about death prevent many families from

discussing hospice care with dying relatives, making it even harder for them to pass away in greater comfort. In 2015, the most recent edition of The Economist Intelligence Unit’s quality of death index ... placed the Chinese mainland at 71 out of 80.<sup>1</sup> But Chengjiaqiao Community Health Service Center is trying to restore a measure of peace and dignity to the dying. Founded in 2012, the hospital houses one of Shanghai’s first hospice units covered by the public healthcare system. Today, 76 similar facilities serve thousands of patients across the city... <http://bit.ly/2O1kAij>

#### **Specialist Publications**

**‘Royal Australian College of General Practitioners president raises concerns after palliative care GP targeted in opioid crackdown’** (p.8), in *newsGP*.

1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit (London, U.K.), October 2015. (See ‘Case study: China – growing awareness,’ pp.20-21.) Commissioned by the Lien Foundation of Singapore. [Noted in 12 October 2015 issue of Media Watch (#431, p.6)] Download/view at: <http://bit.ly/2O3c7e9>

## Should offices have bereavement first aiders to help with grief at work?

U.K. | *HuffPost* – 12 March 2019 – Bereavement first aiders should be trained by employers to help people in the workplace who are struggling with grief, according to the Sue Ryder charity.<sup>1</sup> The majority of U.K. adults are not getting any formal support after the loss of a loved one. Around seven in 10 (72%) U.K. adults have been bereaved at least once in the last five years, a survey by the charity found. However only 9% said they had received support, apart from that offered by families and friends. More than half (51%) of respondents fear saying the wrong thing to someone who has recently lost a loved one, the survey of more than 2,000 adults found. Among those aged 18 to 34 years old, 63% said they were worried about what to say. This could be because young people are more comfortable discussing difficult topics online than in person, the charity said. Sue Ryder suggested a number of measures to improve support for the bereaved, including a call for employers to consider training “bereavement first aiders” in the workplace, to give people the skills to help colleagues who want to return to work. <http://bit.ly/2HfOrD6>

1. ‘A Better Grief,’ Sue Ryder, March 2019. **Download/view at:** <http://bit.ly/2Hh9x3G>

## Children [in South Africa] are dying in pain because they cannot get the medicines they need

SOUTH AFRICA | GroundUp (Cape Town) – 11 March 2019 – There are only a few places in South Africa offering proper pain relief, despite the fact that at least a million children are dying from – or living with – incurable conditions. Frustratingly, efforts to remedy this unacceptable situation have ground to a halt. In 2010, the Hospice Palliative Care Association of South Africa initiated an alliance that hospices, professionals working in palliative care (PC), academics and some officials from the Department of Health. A draft policy was created but never implemented. A turning point came in 2014 when South Africa co-sponsored a resolution at the World Health Assembly in Geneva which called on all member countries to integrate PC into the hospitals and community care structures. A section of the resolution highlighted the need for policy-making that was tailored towards the needs of children. We heard nothing from government until July 2016 when the Health Minister ... appointed a 12-member steering committee to develop a PC policy. The policy was approved by the National Health Council in 2017 and by 2018, there was developed an implementation plan. It was quite an ambitious plan, which included: 1) Specialist palliative healthcare teams and beds in all major hospitals and district hospitals; 2) The Essential Drug List to include up-to-date PC drugs and to make them available to all patients who needed them; and, 3) PC training for all healthcare officials, including doctors, nurses, pharmacists, social workers and clergy. However, it seems that the plan is not being implemented because of financial constraints. A budget was created but not approved or allocated. <http://bit.ly/2VWO2bX>



## [Specialist Publications](#)

### How to talk about attitudes toward the end of life: A qualitative study

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 March 2019 – To individually plan end-of-life (EoL) care, open communication about a person’s preferences and attitudes toward the EoL can facilitate dignity and quality of life in patients and relatives. To improve communication, structured guiding tools might be used as door openers. However, most tools focus on care preferences and decisions without assessing the person’s underlying attitudes in detail. This study aimed to get insights into specific requirements and conditions for communication about the EoL in various EoL care settings. Having EoL discussions primarily depended on a pleasant atmosphere, trusting bonds between conversation partners, and professional attitudes of staff members. Nursing home staff felt obligated to initiate conversations, but some reported insecurities doing so. Starting “early,” including relatives, and having continuous discussions seemed beneficial for EoL conversations. Implementing conversations into exist-

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ing care structures and using low-threshold impulses to start conversations were helpful. Individualized approaches should be preferred. Each staff member can be a partner in detailed conversations about EoL attitudes, but some felt unprepared doing so. Further skill training concerning EoL discussions is needed. Communication might be facilitated by open-format tools using low-threshold impulses when conditions of the care setting are considered. **Abstract:** <http://bit.ly/2HAPkp0>

#### Related

- *JAMA ONCOLOGY* | Online – 14 March 2019 – ‘**Discussing prognosis, preferences, and end-of-life care in advanced cancer: We need to speak.**’ Conversations about prognosis, priorities, and end-of-life care typically occur in the last month of life. The Serious Illness Care Program (SICP) was developed to help oncologists improve the frequency, timeliness, quality, and documentation of discussions about these difficult issues. The SICP is a complex intervention that includes training, coaching and prompts for oncologists; information for patients and their families/caregivers; tools for identifying suitable patients and prompting conversations with them; and, a mechanism for documenting these discussions in the patient’s electronic medical record. Developing, implementing and testing such a complex intervention is a major undertaking. **Full text:** <http://bit.ly/2T7teMU>
- *JOURNAL OF THE NATIONAL CANCER INSTITUTE* | Online – 11 March 2019 – ‘**Early Accountable Care Organization results of end-of-life spending among cancer patients.**’ Accountable Care Organizations (ACOs) are arguably the most important national experiment to control healthcare spending. The authors ... found that the introduction of ACOs, however, had no meaningful impact on overall end-of-life spending in cancer patients... They found no changes in total patient spending by cancer type examined or by spending categories, including cancer-specific categories, radiation oncology, chemotherapy, and hospice services. Finally, emergency department visits, inpatient hospitalization, intensive care unit admissions, radiation therapy, chemotherapy, and hospice use did not meaningfully differ between ACO and non-ACO patients. **Abstract:** <http://bit.ly/2VNLtZE>
- NATIONAL CANCER INSTITUTE (PDQ Supportive & Palliative Care Editorial Board) | Online – 6 March 2019 – ‘**Planning the transition to end-of-life care in advanced cancer.**’ This summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about planning for end-of-life care in advanced cancer. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making healthcare decisions. This summary is reviewed regularly and updated as necessary by the PDQ Supportive & Palliative Care Editorial Board, which is editorially independent of the National Cancer Institute. This review of the literature and does not represent a policy statement of the National Cancer Institute or the National Institutes of Health. **Full text (via PubMed):** <http://bit.ly/2TIL1hX>
- NATIONAL CANCER INSTITUTE (PDQ Supportive & Palliative Care Editorial Board) | Online – 6 March 2019 – ‘**Last days of life.**’ This summary provides clinicians with information about anticipating the end of life; the common symptoms patients experience as life ends, including in the final hours to days; and, treatment or care considerations. The decisions commonly made by patients, families, and clinicians are also highlighted, with suggested approaches. In this summary, unless otherwise stated, evidence and practice issues as they relate to adults are discussed. The evidence and application to practice related to children may differ significantly from information related to adults. When specific information about the care of children is available, it is summarized under its own heading. **Full text (via PubMed):** <http://bit.ly/2HvuQxQ>

#### [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://bit.ly/2RPy9b>



## **Understanding complexity: The palliative care situation as a complex adaptive system**

*BMC HEALTH SERVICES RESEARCH* | Online – 12 March 2019 – The authors provide a conceptual framework and a comprehensive understanding for complexity in palliative care (PC). On the level of the individual care situation, the systemic view can help to understand and shape situations and dynamics. On a higher hierarchical level, it can support an understanding and a framework for the development of care structures and concepts. The framework and the identified system elements can be used as a basis for the development of a classification of complexity in PC, drawing on a differentiation of patients according to their care needs. Relevant outcome measures mirroring the identified system elements have to be identified and implemented in clinical practice. The consideration of phases of illness as an attractor may constitute a promising starting point for the operationalisation of complexity in research, clinical practice, and health policy planning. Further elaboration of relevant parameters and suitable methodology to adequately model complexity should be pursued in future research and theory-based deliberation among interdisciplinary experts. **Full text:** <http://bit.ly/2XXCmHw>

### **Related**

- *JOURNAL OF PALLIATIVE CARE* | Online – 14 March 2019 – ‘**The path of Cicely Saunders: The “peculiar beauty” of palliative care.**’ An in-depth analysis had the objective of verifying if “the way” of Cicely Saunders to understand, live and propose palliative care (PC) is still current and “beautiful,” so that we can nowadays refer to her fascinating “original PC.” With “beauty” we mean, on the one hand, a way able to allow a personal path of research of the meaning of the disease and of the care, both for those who care and for those who are cared for. On the other hand, it seems to us that Cicely strongly suggests how this path can not be carried out alone, but is only possible within the context of a network of relationships and support, in a so called “relational autonomy,” for the patient, included in a “care ethics.” **Abstract:** <http://bit.ly/2FcQ8P7>

### **Palliative care in Norway**

#### **Reflections on communication of disease prognosis and life expectancy by patients with colorectal cancer undergoing palliative care: A qualitative study**

*BMJ OPEN* | Online – 7 March 2019 – The main focus of this study was patients’ thoughts about how information about disease status and life expectancy was communicated, from the first time that they were informed about the incurable nature of their disease through to post-surgery palliative treatment. The participants’ experience of being told for the first time that they had an incurable disease was perceived as inadequate, while post-surgery palliative chemotherapy, physicians and nurses offered hope. The participants preferred customised information about their treatment and likely future prospects and physicians and nurses who took a holistic and compassionate approach focusing on their lifeworld. To be a sensitive, holistic and compassionate physician or nurse requires knowledge and confidence. To achieve this requires training and guidance at universities and in hospitals. **Full text:** <http://bit.ly/2TsbCk6>

### **Healthcare expenditure in Switzerland**

#### **Proximity to death and healthcare expenditure increase revisited: A 15-year panel analysis of elderly persons**

*HEALTH ECONOMICS REVIEW* | Online – 11 March 2019 – This analysis points to a major, but not exclusive role of proximity-to-death on healthcare expenditure (HCE) growth among elderly. Falling in line with recent research, this study confirmed that morbidity is a key factor pushing HCE growth with rising age and that enhanced health status indicators will be key to a better understanding of age and “healthy aging” on overall HCE growth. Given the residual age-associated HCE growth observed and the expected demographic shift towards more elderly, further, demography-related HCE growth is likely. Because of the relevance of chronic morbidities in the observed sample and the elderly population at large, potential remedies to dampen the expected HCE increases may include more efficient management of chronic illnesses and potentially earlier and wider application of palliative care. **Full text:** <http://bit.ly/2TOh28c>

## Disclosure of religious identity and healthcare practices on [U.S.] Catholic hospital websites

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2019;321(11):1103-1104. Among U.S. Catholic hospitals, 21% did not explicitly disclose their Catholic identity on their websites, and only 28% specified how religious affiliation might influence patient care. A recent review demonstrated that patients are more likely to encounter reproductive restrictions at Catholic facilities compared with non-Catholic facilities; less is known about end-of-life care (EoLC) restrictions. Many patients do not realize the implications of Catholic affiliation on their healthcare. If patients are unaware of the affiliation and encounter restrictions, refusal of or delay in care due to the need to go elsewhere can result in increased medical risk and contribute to wasted healthcare expenditures. This study was limited to hospitals listed in the Catholic Health Care Directory. Greater transparency about religious affiliation and care restrictions may allow patients to make more informed choices. In the state of Washington, hospitals must provide their reproductive and EoLC policies on publicly available websites. **Full text:** <http://bit.ly/2TAZX2e>

**N.B.** Selected articles on Catholic perspectives on EoLC in the U.S. noted in 13 August 2019 issue of *Media Watch* (#576, p.2) and in 6 November 2017 issue of the weekly report (#537, pp.8-9).

## Clinicians' perceptions of futile or potentially inappropriate care and associations with avoidant behaviors and burnout

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 15 March 2019 – Futile or potentially inappropriate care (futile/PIC) for dying inpatients leads to negative outcomes for patients and clinicians. In the setting of rising end-of-life health care costs and increasing physician burnout, it is important to understand the causes of futile/PIC, how it impacts on care and relates to burnout. Surveys were completed by 349 subjects. A majority of clinicians (91.3%) felt they had provided or “possibly” provided futile/PIC in the past six months. The most frequent reason cited for PIC (61.0%) was the insistence of the patient's family. Both witnessing and providing PIC were statistically significantly associated with compensatory and avoidant behaviors, but more strongly associated with avoidant behaviors. Provision of PIC increased the likelihood of avoiding the patient's loved ones by a factor of 2.40, avoiding the patient by a factor of 1.83, and avoiding colleagues by a factor of 2.56. **Abstract:** <http://bit.ly/2Tf4v9K>

## Let's talk with children about life-threatening diseases

*THE LANCET*, 2019;393(10176):1072. One of the hardest things to do for any paediatrician is to talk with children or adolescents who have a potentially fatal illness about their diagnosis, treatment, and prognosis. There are many general guidelines and principles about communication with children. For example, the U.K.'s General Medical Council states that “you should provide information that is easy to understand and appropriate to their age and maturity.” However, there is little evidence-based practical guidance grounded in an understanding of the developmental stage of a child and the need for, and effect of, information about life-threatening conditions. Even less evidence is available on how best to communicate with children when their parents have a life-threatening disease. Two articles in this week's issue of *The Lancet* review the literature and provide communication principles and examples based on an integration of the available research and the authors' own clinical and academic perspective.<sup>1,2</sup> **Full text:** <http://bit.ly/2HoKQIX>

1. 'Communication with children and adolescents about the diagnosis of their own life-threatening condition.' **Summary (w. list of references):** <http://bit.ly/2TOSMCR>
2. 'Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent.' **Summary (w. list of references):** <http://bit.ly/2XZZnd1>

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Closing the Gap Between Knowledge & Technology

<http://bit.ly/2DANDFB>

## Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 March 2019 – ‘**Impact of race and ethnicity on end-of-life experiences for children with cancer.**’ A retrospective cohort study was conducted on 321 children with cancer enrolled on a palliative care service at an urban pediatric cancer... Compared to white patients, black patients were more likely to receive cardiopulmonary resuscitation and underwent 3.136 CPR events for every 1 white patient CPR event. The remainder of variables related to treatment and EoL care were not significantly correlated with race. Hispanic patients were less likely to receive cancer-directed therapy within 28 days prior to death as compared to non-Hispanic patients, yet they were more likely to report a goal of cure over comfort as compared to non-Hispanic patients. **Abstract:** <http://bit.ly/2uahbEt>
- *HEALTH & PLACE* | Online – 7 March 2019 – ‘**Coming “home”:** Place bonding for parents accessing or considering hospice based respite.’ Little literature examines the cognitive journey taken by parents considering/receiving hospice care for their child. A constructivist grounded theory study explored 38 parents’ views of considering/using a children’s hospice. The focus of this paper is identified as coming “home.” This concept depicts the desire and the sense of searching that parents experienced in trying to find a place, other than their actual home, where their child could access a caring environment and their parents received some respite from caregiving. Despite there being a paradox associated with hospice-based respite, once they had crossed the threshold the parents bonded with the place and experienced rootedness and familiarity. **Abstract:** <http://bit.ly/2J6O4fz>
- NATIONAL CANCER INSTITUTE (PDQ Supportive & Palliative Care Editorial Board) | Online – 6 March 2019 – ‘**Pediatric palliative care.**’ This summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about supportive care issues related to treatment in children and adolescents. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making healthcare decisions. This summary is reviewed regularly and updated as necessary by the PDQ Supportive & Palliative Care Editorial Board, which is editorially independent of the National Cancer Institute (NCI). The summary reflects an independent review of the literature and does not represent a policy statement of NCI or the National Institutes of Health. **Full text (via PubMed):** <http://bit.ly/2T07DG9>

## Royal Australian College of General Practitioners president raises concerns after palliative care GP targeted in opioid crackdown

*NEWSGP* | Online – 14 March 2019 – The call comes in response to news that a high-profile GP who works in palliative care (PC) and aged care facilities has been targeted in the controversial crackdown, in which GPs with high rates of opioid prescriptions are sent a warning letter. The GP ... told *newsGP* they were surprised at having their prescribing patterns interrogated in a compliance meeting when there were warranted medical indications for prescribing opioids in palliative and aged care. The GP must now reduce their prescribing within six months or risk potentially career-threatening consequences under a Professional Services Review. The GP had only recently taken on four new patients whose GPs had also received the letter, and were now refusing to see them. “I’m worried that the letter will stop doctors working in the aged care and PC space,” the GP said. “GPs are already reluctant to work in that space, and this is yet another reason why GPs may stop or reduce their commitment to this type of work. At the end of the day it is a vulnerable population who will suffer from reduced access to medical care.” The news led College President Dr. Harry Nespolon to call for a rethink on the controversial letter due to the “collateral damage” to patients, and the risk of scaring GPs away from doing much-needed work in PC and aged care. **Full text:** <http://bit.ly/2VTISOS>

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Noted in Media Watch 17 September 2018 (#581, p.8):

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 10 September 2018 – **‘Ensuring and restoring balance on access to controlled substances for medical and scientific purposes: Joint statement from palliative care organizations.’** The central principle of “balance” represents the dual obligation of governments to establish a system of control that ensures the adequate availability of controlled substances for medical and scientific purposes while simultaneously preventing their non-medical use, diversion, and trafficking, two primary goals of the international control system. This report presents examples of unbalanced systems and a joint statement from global and regional palliative care organizations to promote development of balanced systems for optimal public health outcomes. **Abstract:** <http://bit.ly/2O90DWx>

### **The end of life within social work literature: A conceptual review**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 11 March 2019 – This conceptual review sought to identify and describe how the end of life (EoL) was conceptualized and operationalized in top-ranking, peer-reviewed social work journals considering the highly individualized and multidimensional experience of dying put forth by modern scholars and social work practitioners. An iterative content analysis of included articles revealed six themes within reported definitions and four themes within eligibility criteria. Definitions related to treatment responsiveness, the death process, dying, prognosis, admission to specific services, and old age. Eligibility criteria related to proxy assessment, diagnosis, prognosis, and functional ability assessments. Over one-third of included articles did not define what was meant by the EoL and the majority did not include eligibility criteria. The complex lived experience of dying was not manifest within included articles raising important implications for research (e.g., measurement, meta-analysis) and social work practice (viz. service eligibility). **Abstract:** <http://bit.ly/2UwPykN>

### **“So isolation comes in, discrimination and you find many people dying quietly without any family support”: Accessing palliative care for key populations – an in-depth qualitative study**

*PALLIATIVE MEDICINE* | Online – 12 March 2019 – Ensuring palliative care (PC) for all under a new global health policy must include key populations, that is, lesbian, gay, bisexual, transgender and intersex people, and sex workers. Accessibility and quality of care have not been investigated in lower and middle-income countries where civil rights are the weakest. Sixty key population adults and 12 healthcare providers and representatives of PC and key population support organisations were interviewed in four sites (Harare, Bulawayo, Mutare and Masvingo/Beitbridge). Participants described unmet needs and barriers to accessing even basic elements of PC. Discrimination by healthcare providers was common, exacerbated by the politico-legal-economic environment. Two dominant themes emerged: 1) Minimal understanding of and negligible access to PC significantly increased the risk of painful, undignified deaths; and 2) Discriminatory beliefs and practices from healthcare providers, family members and the community negatively affected those living with life-limiting illness, and their wishes at the end of life. Enacted stigma from healthcare providers was a potent obstacle to quality care. Discrimination from healthcare providers and lack of referrals to PC services increase the risk of morbidity, mortality and transmission of infectious diseases. Untreated conditions, exclusion from services, and minimal family and social support create unnecessary suffering. Public health programmes addressing other sexually taboo subjects may provide guidance. **Full text:** <http://bit.ly/2XTIBNV>

### **A systematic review and critical appraisal of quality indicators to assess optimal palliative care for older people with dementia**

*PALLIATIVE MEDICINE* | Online – 11 March 2019 – A major contribution of this study is to have rendered a comprehensive but large list of indicators into a dementia-specific resource, and a framework for future research and implementation of dementia specific end-of-life (EoL) care. There have been recent calls to strengthen the theoretical development underpinning new complex interventions designed to improve EoLC in dementia – such an approach would benefit quality indicators used to assess the effectiveness of

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these types of interventions. Questions remain as to 1) The feasibility of developing a set of quality indicators that could be used across the community settings in which older people are living and dying with dementia (e.g., home settings, long-term care settings with and without on-site nursing); 2) Where along the dementia trajectory quality indicators for EoLC should be introduced; and, 3) Whether quality indicators that are considered important to people with dementia and their families coincide with those habitually used by [National Health Service] commissioners... Overall, a focus on clear and measurable indicators has not so far been able to capture how to apply these over time to reflect what is often an extended dying trajectory involving multiple patient representatives, carers and healthcare professionals at key points. Given the increasing numbers of people who will die with dementia, future work should focus on the development of quality indicators which reflect all aspects of optimal palliative care in dementia, including the use of non-pharmacological interventions, avoidance of overly aggressive, burdensome or futile treatment and skill mix within the healthcare team, potentially building upon indicators developed within person-centred approaches to care aimed at improving comfort and quality of life towards the EoL. **Full text:** <http://bit.ly/2u171WQ>

Noted in Media Watch 28 January 2019 (#598, p.1):

- CANADIAN ACADEMY OF HEALTH SCIENCES | Online – 16 January 2019 – ‘**Improving the quality of life and care of persons living with dementia and their caregivers.**’ Many families and health and social care providers still do not view dementia as a terminal disease. As a result, they fail to implement a palliative approach with comfort as the primary goal of care. In many jurisdictions of Canada, palliative care does not yet embrace persons with dementia. The absence of a palliative approach with clear guidelines, along with divergent opinions amongst families and health and social care professionals, can result in poor management of symptoms towards the end of life, causing considerable distress to both the person with dementia and their caregivers. **Download/view at:** <http://bit.ly/2VLL5KY>

Noted in Media Watch 4 March 2019 (#604, p.13):

- *PALLIATIVE CARE: RESEARCH & TREATMENT:* Online – 27 February 2019 – ‘**Advance care planning in dementia: Recommendations for healthcare professionals.**’ The process of advance care planning in dementia is far from straightforward; as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting decision-making abilities. Family carers find themselves increasingly in a position where they need to inform, or directly make, decisions on behalf of the person with dementia. This article discusses the context and importance of a palliative care approach and recommends rationales and strategies for healthcare professionals to support families affected by dementia to better plan for their future care. **Full text:** <http://bit.ly/2Habdvd>

**N.B.** Additional articles: on palliative and end-of-life (EoL) care for people living with Alzheimer’s and other forms of dementia noted in several past issues of Media Watch, for example, 7 January 2019 (#596, pp.9-10); and, 10 and 31 December 2018 (respectively, #593, p.7 and #595, p.16): and, on advance care planning, advance directives and EoL decision-making for this patient population noted in 18 February 2019 issue of Media Watch (#602, pp.8-9).

### **Spirituality in the continuing education of healthcare professionals: An approach to palliative care**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 13 March 2019 – A major barrier to the adoption of an approach that integrates spirituality into palliative care (PC) is the lack of preparation/education of healthcare professionals on the topic. This study evaluated the effectiveness of a continuing education activity for healthcare professionals addressing spirituality and spiritual care provision to patients and families within PC. Participants completed the Brazilian version of the Spiritual Care Competence Scale before and after attending a four-hour continuing education activity. Significant differences were observed between pre- and post-intervention scores in the following dimensions: assessment and implementation of spiritual care, professionalization and improving the quality of spiritual care, personal support, and patient counseling and referral. These findings provide preliminary evidence of a positive effect of this educational intervention on the development of the competences needed by healthcare professionals to deliver a comprehensive approach centered on the patient/family, which includes attention to spirituality and spiritual care in the decision-making process. **Abstract (w. list of references):** <http://bit.ly/2HgVxHf>

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Noted in Media Watch 11 February 2019 (#601, p.12):

- *MEDICAL SCIENCES* | Online – 7 February 2019 – ‘**Spiritual care in palliative care: A systematic review of the recent European literature.**’ Spiritual care (SC) was seen as attention for spirituality, presence, empowerment and bringing peace. It implied creative, narrative and ritual work. Though several studies reported positive effects of SC, like the easing of discomfort, the evidence for SC is low. Requirements for implementation of SC in palliative care were developing spiritual competency, including self-reflection, and visibility of spirituality and SC, which are required from spiritual counselors that they participated in existing organizational structures. **Abstract:** <http://bit.ly/2GA8jzp>

**N.B.** Click on pdf icon to access full text.

Noted in Media Watch 22 October 2018 (#586, p.5):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 16 October 2018 – ‘**Development of a tool to identify and assess psychosocial and spiritual needs in end-of-life patients...**’ The Psychosocial & Spiritual Needs Evaluation scale was developed through a 7-stage process: 1) Literature review; 2) Expert panel establishment; 3) Discussion and agreement on the most relevant dimensions of psychosocial care; 4) Description of key indicators and consensus-based questions to evaluate such dimensions; 5) Assessment of the scale by palliative care professionals; 6) Evaluation by patients; and, 7) Analysis of scale’s psychometrics properties. **Abstract (w. list of references):** <http://bit.ly/2Ckr8DM>

### **Behind the doors of home hospice patients: A secondary qualitative analysis of hospice nurse communication with patients and families**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 7 March 2019 – Hospice nurses frequently encounter patients and families under tremendous emotional distress, yet the communication techniques they use in emotionally charged situations have rarely been investigated. In this study, researchers sought to examine hospice nurses’ use of validation communication techniques, which have been shown in prior research to be effective in supporting individuals experiencing emotional distress. Researchers performed a directed content analysis of audio recordings of 65 hospice nurses’ home visits by identifying instances when nurses used validation communication techniques and rating the level of complexity of those techniques. All nurses used validation communication techniques at least once during their home visits. Use of lower level (i.e., more basic) techniques was more common than use of higher level (i.e., more complex) techniques. Although hospice nurses appear to use basic validation techniques naturally, benefit may be found in the use of higher level techniques, which have been shown to result in improved clinical outcomes in other settings. **Abstract (w. list of references):** <http://bit.ly/2NWXyZT>

### **Who finds the road to palliative home care support [in Belgium]? A nationwide analysis on the use of supportive measures for palliative home care using linked administrative databases**

*PLOS ONE* | Online – 12 March 2019 – Many countries developed supportive measures for palliative home care (PHC), such as financial incentives or multidisciplinary PHC teams. For policy makers, it is important to evaluate the use of these national PHC supportive measures on a population level. Using routinely-collected data on all deaths in Belgium in 2012, the authors measured the use of four statutory supportive measures, specifically intended for patients who have obtained the legal palliative status, and three non-statutory supportive measures. Of all deaths of adult home-dwelling persons in Belgium, 17.9% used at least one statutory supportive measure and 51.5% used at least one non-statutory supportive measure. In those who died of an illness indicative of palliative care (PC) needs 33.1% used at least one statutory supportive measure and 62.2% used at least one non-statutory supportive measure. Statutory supportive measures for PHC are underused, even in a sub-population of persons with potential PC needs. Policy makers should stimulate an equitable uptake, and reducing the observed inequalities is an important focus for healthcare policy. **Full text:** <http://bit.ly/2J6laLp>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY*, 2019;27(3):S3. **‘Physician aid-in-dying: Updates for geriatric psychiatrists.’** At this time, five states (Oregon, Washington, Vermont, Hawaii, and California) and Washington DC have statutes permitting physician aid-in-dying (PAD) and outlining procedures for this process. One state, Montana, allows PAD under common law. At least thirty-six states have attempted to introduce legislation to legalize PAD. In states with statutes addressing PAD, patients are typically required to make multiple requests, both orally and in writing. They are required to have a terminal illness with a prognosis of six months or less as agreed upon by two physicians. Mental health and/or capacity assessments are typically not mandated unless at least one of the two evaluating physicians suspects a contributory underlying psychiatric illness or incapacitation. All states provide opt-out measures for conscientious objectors or those not wishing to participate. Initial data suggests that patients utilizing PAD are frequently college educated, insured, and engaged in hospice care. Patients requesting PAD are often those with terminal illnesses who are experiencing co-morbid severe pain, discomfort, and deterioration in functional status. Women, African Americans, and those with cognitive impairments may be more likely to oppose PAD, highlighting the need to maintain protections for vulnerable patients where PAD is permitted. In one survey of physicians who have received requests for PAD (including those practicing in states where PAD has not been legalized), physicians reported a significant amount of co-morbid depression in those requesting PAD. Despite this, no legal requirements for psychiatric and/or capacity assessments exist in any state that has legalized PAD, except for Hawaii. In several European countries, chronic mental illness has been accepted as a terminal diagnosis, which may have significant impact in the U.S. as PAD is legalized in more states. Finally, as a federal entity, PAD is not permitted at Veteran Affairs (VA) facilities, even in states where it has been legalized. This may have major implications for patients and providers within the VA health-care system. **Abstract:** <http://bit.ly/2CmX8Hm>
- *CURRENT ONCOLOGY*, 2019;26(1):10-11. **‘Clinical trial implications for study participants accessing medical assistance in dying.’** The legalization of medical assistance in dying (MAiD) in June 2016 expanded options for end-of-life (EoL) care in Canada. That change in the EoL topography created a need to explore the impact of MAiD at multiple levels, including accommodating conscientious objection for healthcare professionals, supporting MAiD assessors and providers, applying a quality improvement lens to the delivery of MAiD, and clarifying the role of palliative care in supporting patients who choose to proceed with MAiD. Empirical research and experience are providing more clarity on those and other emerging issues related to the new option. However, one area that has not been explored in the literature is the potential effect of MAiD on clinical trial data. Given that cancer is the diagnosis leading to MAiD in 64% of cases in Ontario ... MAiD has the potential to affect trial data – specifically, survival outcomes. In this commentary, the authors aim to identify one institution’s nascent observations in that regard and to raise awareness about how MAiD could affect clinical trial results. **Full text:** <http://bit.ly/2JfN09g>
- *JOURNAL OF MEDICAL ETHICS* | Online – 12 March 2019 – **‘Canadian neurosurgeons’ views on medical assistance in dying: A cross-sectional survey of Canadian Neurosurgical Society members.’** The Society recently published a position statement on medical assistance in dying (MAiD).<sup>1</sup> Of the 300 active members of the Society, 89 respondents completed the survey, 71% of whom were attending neurosurgeons and 29% were neurosurgery residents. Most respondents, (74.2%), supported the right of physicians to participate in MAiD with 7.8% opposing. 23.6% had been asked by patients to assist with MAiD, but only 11% would consider personally providing it. 84% of neurosurgeons surveyed supported the physicians’ right to conscientious objection to MAiD, while 21% thought attending surgeons should be removed from the inquiry and decision-making process. 43.8% agreed that the requirement to refer a patient to a MAiD service should be mandatory. Glioblastoma multiforme (65%), quadriplegia/quadriparesis secondary to spinal tumour/trauma (54%) and Parkinson’s disease (24%) were the most common suggested potential indications for MAiD among the neurosurgical population. **Abstract:** <http://bit.ly/2HnP0eb>
  1. ‘Medical Assistance in Dying (MAiD) and the Neurosurgeon: Position Statement of the Canadian Neurosurgical Society (CNSS),’ *Canadian Journal of Neurological Sciences*, 2017;44(6):744-746. [Noted in 28 August 2017 issue of Media Watch (#527, p.15)] **First page view:** <http://bit.ly/2O2HbL4>

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- *LAW LIBRARY JOURNAL*, 2019;111(1):31-69. **'Physician-assisted death: A selected annotated bibliography.'** Physician -assisted death (PAD), which encompasses physician-assisted suicide and physician -administered euthanasia, has long been controversial. However, recent years have seen a trend toward legalizing some form of PAD in the U.S. and abroad. The author provides an annotated bibliography of sources concerning PAD and the many issues raised by its legalization. **Summary:** <http://bit.ly/2EXXx3y>
- *NURSING LEADERSHIP*, 2018;34(4):74-81. **'Medical assistance in dying (MAiD): Ten things leaders need to know.'** The provision of MAiD will be in flux for a few years, as legislative challenges are underway. This article addresses what leaders need to know and do to support nurses today and in the future regarding care of patients choosing MAiD. Drawing on complexity leadership theory and research into nurses' experiences in caring for persons choosing MAiD, the authors share 10 simple yet foundational things a leader must know. Underpinning their key messages are current evidence and familiar nursing concepts such as end-of-life care, death trajectories, conscientious objection, scope of practice, ethics, sense-making and care cultures. These key messages are embedded in a framework of leadership practices where attention to inter-relationships, emergence and innovation are highlighted. They provide nurse leaders with concrete actions to inspire a team dynamic for creating inclusive cultures of quality care. Leadership is needed across healthcare settings where MAiD is being enacted. **Abstract:** <http://bit.ly/2Uv0Nu0>

## [Publishing Matters](#)

### **Predatory science journals pivot to video**

CANADA | *The Ottawa Citizen* – 14 March 2019 – Predatory science publishers, the wolves of the research world, are dressing themselves in a fancier quality of sheep's clothing: Online videos. These fake journals are common academic scams, taking money to publish anything that scientists write without asking questions about accuracy. Publishing in these provides back-alley career advancement for researchers who must publish their work in order to get tenure or promotion, but who are turned down by real journals with strict standards. Now these cash-for-easy-publication journals are adding video, which tends to be of low quality. It represents a new revenue stream for them, with fees ranging from \$1,500 to \$4,200 to post a video, as opposed to a few hundred for a written document. We had to give the new trend a test to show whether such journals will still publish anything for a buck, but in video form. And our ridiculous and unscientific video submission on how evolution sometimes runs backwards, producing defective species such as Florida Man, has been accepted by the *Journal of Clinical & Molecular Medicine*, *American Journal of Biomedical Science & Research*, and *International Journal of Cell Science & Molecular Biology*. (One of these has already posted the video; the others want payment up front.) <http://bit.ly/2W3qQbX>

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