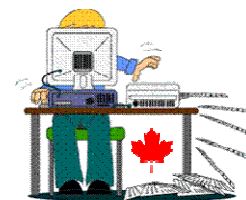


## Media Watch...

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 body of the dying person becomes an arena for conflicting (sub)-cultures of providers, policy makers, and relatives.”**

‘Why global health must talk about death’ (p.10), in *The Lancet*.

## Canada

### Joint statement regarding palliative care and medical assistance in dying

CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION (CHPCA) & CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS (CSPCP) | Online – 27 November 2019 – Due to ongoing confusion amongst the general public, the CHPCA and the CSPCP seek to clarify the relationship of hospice palliative care (HPC) and medical assistance in dying (MAiD). Healthcare articles and the general media continue to conflate and thus misrepresent these two fundamentally different practices. MAiD is not part of HPC; it is not an “extension” of PC nor is it one of the tools “in the palliative care basket.”; National and international HPC organizations are unified in the position that MAiD is not part of the practice of hospice. HPC and MAiD substantially differ in multiple areas including in philosophy, intention and approach: 1) HPC focuses on improving quality of life and symptom management through holistic person-centered care for those living with life threatening conditions; 2) HPC sees dying as a normal part of life and helps people to live and die well. 3) HPC does not seek to hasten death or intentionally end life; and, 4) In MAiD, however, the intention is to ad-

dress suffering by ending life through the administration of a lethal dose of drugs at an eligible person’s request. Less than 30% of Canadians have access to high quality HPC, yet more than 90% of all deaths in Canada would benefit from it. Despite this startling discrepancy, access to HPC is not considered a fundamental healthcare right for Canadians. In contrast, MAiD has been deemed a right through the Canada Health Act, even though deaths from MAiD account for less than 1.5% of all deaths in Canada. The two organizations call on the federal and provincial governments to prioritize funding and improve access to HPC in Canada, and to support the implementation and action plan of the National Framework for Palliative Care in Canada. **Download/view at:** <http://bit.ly/33mmlad>

**‘Perceptions and experiences of medical assistance in dying among illicit substance users and people living in poverty’** (p.16), in *Omega – Journal of Death & Dying*.

Cont.

Noted in Media Watch 4 November 2019 (#638, p.1):

- CANADIAN HEALTHCARE NETWORK | Online – 23 October 2019 – ‘**A (lack-of) action plan for palliative care in Canada.**’ In August 2019, the federal government released its “action plan” for palliative care (PC) in Canada.<sup>1</sup> In ... ‘Framework on Palliative Care in Canada,’ the government admits that while 75% of Canadians would rather die at home, only 15% have access to the necessary community-based services.<sup>2</sup> This is generalizable to Ontario, where ... only 50% of Ontarians receive PC services, with the majority of that care taking place in a hospital.<sup>3</sup> A report from the Canadian Society of Palliative Care Physicians shows that inpatient PC services can save approximately \$7,000 to \$8,000 per hospitalization and reduce hospital costs by 24%.<sup>4</sup> <http://bit.ly/2Pp0JMs>

1. ‘Action Plan on Palliative Care,’ Health Canada, August 2019. **Download/view at:** <http://bit.ly/2Jno3Xa>
2. ‘Framework on Palliative Care in Canada,’ Health Canada, December 2018. [Noted in 10 December 2018 issue of Media Watch (#593, p.1)] **Download/view at:** <http://bit.ly/2AVEghF>
3. ‘Palliative care delivery across health sectors: A population-level observational study,’ *Palliative Medicine*, published online 16 June 2016. [Noted in 20 June 2016 issue of Media Watch (#467, p.15)] **Full text:** <http://bit.ly/31NizQ8>
4. ‘How to improve palliative care in Canada: A call to action for federal, provincial, territorial, regional and local decision makers,’ Canadian Society of Palliative Care Physicians, November 2016. [Noted in 7 November 2016 issue of Media Watch (#486, p.2)] **Download/view at:** <http://bit.ly/2NjQvKy>

Noted in Media Watch 24 September 2018 (#582, p.1):

- *THE GLOBE & MAIL* | Online – 19 September 2018 – ‘**Almost all Canadians would benefit from palliative care. Only one in seven can actually access it at end-of-life.**’ An estimated 89% of Canadians could benefit from palliative care (PC) in the last year of life. But only 15% are actually getting it. That’s a pretty damning commentary on the state of end-of-life care in this country, and it only tells part of the story. The new data, published by the Canadian Institute for Health Information (CIHI), reveals that even those who get PC tend to get it late, and that far too many dying patients are shuffled around mercilessly between home, hospitals and nursing homes in their final days.<sup>1</sup> In short ... Canada is not a very good place to die. <https://tgam.ca/2kpgzTv>

1. ‘Access to Palliative Care in Canada,’ Canadian Institute for Health Information, September 2018. **Download/view at:** <http://bit.ly/2MqmCYO>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CBC News (Quebec City) – 29 November 2019 – ‘**Quebec to expand law on medically assisted dying, look at advance consent.**’ The Quebec government wants to allow those diagnosed with diseases like Alzheimer’s to provide advance consent for medical assistance in dying (MAiD)... Danielle McCann presented the recommendations of a report<sup>1</sup> ... after a panel of experts spent 18 months examining the issue around a patient’s ability to consent to the procedure. McCann also announced the government will be holding public consultations as part of an effort including all four major parties to expand the criteria to access MAiD. Quebec’s law stipulates that a person seeking MAiD must be able to consent at the time of their request, as well as at the moment it is administered. In the case of patients suffering from Alzheimer’s, they may be able to consent after their diagnosis. But in order to receive MAiD in Quebec, a person also has to be at the “end of life.” <http://bit.ly/2L7kXHD>

1. ‘L’aide médicale à mourir pour les personnes en situation d’inaptitude : le juste équilibre entre le droit à l’autodétermination, la compassion et la prudence,’ Santé et des Services sociaux, November 2019. **Download/view French language report at:** <http://bit.ly/2Y015LL>

## U.S.A.

### **A cancer care approach tailored to the elderly may have better results**

NATIONAL PUBLIC RADIO (WJCT, Jacksonville, Florida) | Online – 23 November 2019 – Geriatric assessment is an approach that clinicians use to evaluate their elderly patients' overall health status and to help them choose treatment appropriate to their age and condition. The assessment includes questionnaires and tests to gauge the patients' physical, mental and functional capacity, taking into account their social lives, daily activities and goals. The tool can play an important role in cancer care, according to clinicians who work with the elderly. It can be tricky to predict who will be cured, who will relapse and who will die from cancer treatment. Geriatric assessments can help physicians better estimate who will likely develop chemotherapy toxicities and other serious potential complications of cancer treatment, including death. Geriatric assessment includes an evaluation by a physical therapist, a psychological assessment, a cognitive exam and a complete physical and medical history. The doctor takes all these factors into account and tallies a score for their patient to help guide their decision-making about the patient's treatment. <http://bit.ly/33k0y8C>

#### **Extract from NPR report**

A study published ... in November found that in 197 cancer patients 70 years and older, 27% of the treatment recommendations patients received from the tumor board were different from those received after completing a geriatric assessment.<sup>1</sup>

1. 'How to incorporate geriatric assessment in clinical decision making for older patients with cancer. An implementation study,' *Journal of Geriatric Oncology*, 2019; 10(6):951-959. **Abstract:** <http://bit.ly/2L88DXV>

#### **Specialist Publications**

**'Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S.'** (p.9), in *Journal of Pain & Symptom Management*.

**'Growing number of Catholic-run hospitals raises concerns'** (p.16), in *American Journal of Nursing*.

Noted in Media Watch 9 October 2017 (#533, p.16):

- *CURRENT ONCOLOGY REPORTS* | Online – 2 October 2017 – **'Using geriatric assessment strategies to lead end-of-life discussions.'** End-of-life (EoL) discussions with geriatric oncology patients are a vital part of the comprehensive care of the senior adult patient. Patients and caregivers may have expectations that are not concordant with what is reasonably achievable if the patient is frail. Measuring baseline cognition, nutritional status, and physical function and discussing goals of care are all essential pieces of information that can be obtained through a comprehensive geriatric assessment ... crucial in developing EoL care plans that reflect both the patient's health status and personal values. **Abstract (w. list of references):** <http://bit.ly/34jS173>

Noted in Media Watch 17 April 2017 (#508, p.7):

- *CLINICS IN GERIATRIC MEDICINE* | Online – 6 April 2017 – **'Integrating quality palliative and end-of-life care into the geriatric assessment.'** The comprehensive geriatric assessment is greatly enhanced by integration of ongoing palliative and end-of-life (EoL) care assessments. Discussions about advanced illness management and dying can improve outcomes. Common disease trajectories are evident that indicate a limited life expectancy and the need for palliative care. Common physiology and physical changes are evident, which can be used to improve palliative and EoL symptom management. Anticipation and management of the common physical, psychosocial and spiritual symptoms experienced at the EoL are vital to a quality death for older adults. **First page view:** <http://bit.ly/2Oh4SRH>



Would these articles be of interest to a colleague?

## Registered nurses did not always visit Medicare beneficiaries' homes at least once every 14 days to assess the quality of care and services provided by hospice aides

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES | Online – 18 November 2019 – Registered nurses did not always: 1) Visit hospice beneficiaries' homes at least once every 14 days to assess the quality of care and services provided by hospice aides; or, 2) Document the visits in accordance with Federal requirements. Of the approximately 189,000 high-risk date-pairs, we identified: 1) An estimated 99,000 instances in which the registered nurses did not make the required supervisory visits at least once every 14 days; and, 2) An estimated 5,000 instances in which supervisory visits were not documented in accordance with Federal requirements. These deficiencies occurred because of hospices' lack of oversight, scheduling errors, employee turnover, and the registered nurses not being aware of the 14-day supervisory visit requirement. As a result, there was no assurance that beneficiaries admitted to those hospices received the appropriate care while in hospice care. <http://bit.ly/2QOQVMB>

## International

### Japan health ministry withdraws end-of-life-care poster campaign after online backlash

JAPAN | *The Mainichi* (Tokyo) – 27 November 2019 – “Distressing,” “Like a poster for a consultation on how to die,” wrote patient groups and others online in reaction to the Ministry of Health, Labor & Welfare’s new poster campaign to raise awareness of its advance care planning (ACP) service, which aims to get more people prepared for the final stages of their lives. ACP, also known informally as “the life meeting,” is a ministry effort that seeks to get people and their families to speak to doctors and others repeatedly about what kind of care they should receive at the end of their life. But a promotional campaign, which included posters and video on the ministry website, was suspended after being subject to widespread criticism. As a result, physical posters will no longer be dispatched to municipal governments across Japan, and a related video will not be posted on the ministry website. <http://bit.ly/35DzYZx>

Noted in Media Watch 7 October 2019 (#634, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 September 2019 – ‘**Attitudes and other factors influencing end-of-life discussion by physicians, nurses, and care staff: A nationwide survey in Japan.**’ The authors analyzed responses from 1,012 physicians, 1,824 nurses, and 749 care staff. The number of responders who considered they had adequate end-for-life (EoL) discussion with patients near death was 281 (27.8%), 324 (17.8%), and 139 (18.6%), respectively. Participation in a nationwide education program and caring for at least one dying patient per month were factors that showed a significant association with adequate EoL discussion and identification of the proxy decision maker. **Abstract:** <http://bit.ly/2n6LnjU>

### Specialist Publications

‘**How timely is access to palliative care medicines in the community? A mixed-methods study in a U.K. city**’ (p.7), in *BMJ Open*.

‘**Compassionate communities – a modern form of organising palliative care**’ (p.11), in *Medycyna Palliatywna*.

‘**Consensus document and recommendations on palliative care in heart failure of the Heart Failure & Geriatric Cardiology Working Groups of the Spanish Society of Cardiology**’ (p.14), in *Revista Española de Cardiología*.

‘**Passing on wisdom: Exploring the end-of-life wishes of Aboriginal people from the Midwest of Western Australia**’ (p.15), in *Rural & Remote Health*.

## U.K. charity for seriously ill children launches new end-of-life guides for professionals

U.K. | *Charity Today* – 25 November 2019 – Together for Short Lives children's palliative care charity has launched two new end-of-life (EoL) guides... 'Caring for a Child at End of Life for Professionals' is a practical toolkit for all practitioners providing EoL care to babies, children and young people.<sup>1</sup> It sets out key standards and goals for good practice alongside links to useful sources of information, legislation and regulations. It is aimed at supporting all professionals working with children at EoL in hospital, hospices and in the community, providing guidance from care before death to bereavement

support. 'Caring for a Child at End of Life for Families' is a supportive supplementary resource, guiding families through their child's EoL journey, helping them to prepare themselves for what should happen.<sup>2</sup> <http://bit.ly/2pJXYuK>

### Specialist Publications

**'Experience of nurses who work with children with palliative care needs: A mixed-method systematic review'** (p.14), in *Palliative & Supportive Care*.

1. 'Caring for a Child at End of Life for Professionals,' Together for Short Lives, November 2019. **Download/view at:** <http://bit.ly/37zH2YV>
2. 'Caring for a Child at End of Life for Families,' Together for Short Lives, November 2019. **Download/view at:** <http://bit.ly/2Dd9hir>

## Behind bars, hospital care is blind to crime

CHINA | *Shanghai Daily* – 24 November 2019 – Doctors working at a unique hospital in Shanghai can rarely hope that a patient who is successfully treated will walk out into the sunshine. Their domain is Shanghai Prison General Hospital, the only one of its kind in the city prison system. Besides ordinary departments, the 450-bed hospital has specialized sections for prisoners suffering from AIDS, tuberculosis, drug addiction and mental diseases. Many young doctors who work in the hospital initially regard the patients as beasts shut in cages, but that impression fades as time passes and they treat what is certainly an unusual population of people suffering from poor health. Inmates with treatable maladies remain in the prison hospital. Those suffering more complicated, severe diseases or needing specialized tests such as magnetic resonance imaging are sent to other hospitals. Pan Cheng, an instructor with the hospital's internal medicine department, who has three decades of experience, said the range of medical problems treated there differs somewhat from that in general hospitals. <http://bit.ly/34iw9bU>

**N.B.** A compilation of selected articles, etc., on end-of-life care in the prison system noted in past issues of Media Watch can be downloaded/viewed from/at the Palliative Care Network website: <http://bit.ly/2RdegnL>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | Politics Home – 19 November 2019 – **'7 in 10 people with advanced or terminal illness support law change on assisted dying.'** New figures ... by YouGov reveal that more than seven in ten (73%) people with an advanced or terminal illness would support a change in the law on assisted dying to allow mentally competent, terminally ill adults with six months or less to live the option of an assisted death in the U.K. The survey also found that around two-thirds (64%) would be pleased to have the option of assisted dying for themselves alongside good end-of-life care, and two-fifths (39%) say they have or would consider travelling abroad for an assisted death. The findings are of the YouGov survey of 502 adults diagnosed with advanced cancer, Parkinson's, motor neurone disease, chronic obstructive pulmonary disease, multiple system atrophy or progressive supranuclear palsy. <http://bit.ly/2rrGofM>



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## Specialist Publications

### **Applying m-Health to palliative care: A systematic review on the use of m-health in monitoring patients with chronic diseases and its transposition in palliative care**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 November 2019 – A systematic review of the English and French literature was conducted. From the 337 selected publications, 8 systematic reviews and 14 original studies were included. The main uses of m-Health apps were biological and clinical monitoring (particularly concerning the symptoms) in 75% of the applications, disease self-management in 64% of the applications, and therapeutic patient education in 50% of the applications, with remote monitoring. The development of an m-Health application could become a complementary monitoring tool during palliative care (PC). However, it seems impor-

tant to question the impact of technique in the professional-patient relationship and avoid the pitfalls of standardizing PC and reducing the patient to a “sick” health technician. A future step would then be to define which healthcare professional would be in charge of this “m-monitoring.” **Abstract:** <http://bit.ly/2DkFZ14>

#### Publishing Matters

**‘Journal editors’ perspectives on the roles and tasks of peer reviewers in biomedical journals: A qualitative study’** (p.16), in *BMJ Open*.

### **Managing opioids, including misuse and addiction, in patients with serious illness in ambulatory palliative care: A qualitative study**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 November 2019 – Pain and opioid management are core ambulatory palliative care (PC) skills. Existing literature on how to manage opioid misuse/use disorder excludes patients found in PC settings, such as individuals with serious illness or those at the end of life. Eighty-three PC clinicians ... participated. Challenges faced when prescribing opioids included clinician differences in approach to care (e.g., transitioning from another clinician with more permissive opioid prescribing), medication access (e.g., inadequate pharmacy supply), resource constraints (e.g., access to mental health and addiction expertise), managing problems outside the typical PC scope (e.g., addiction). Participants also discussed factors that influenced their opioid prescribing decisions, such as opioid-related harms and risks that they need to weigh; they also spoke about the necessity of considering other factors like the patient’s environment, disease, treatment, and prognosis. This study highlights the challenge of opioid management in patients with serious illness, particularly when misuse or substance use disorder is present, and suggests areas for future research focus. Next step will be to establish consensus on approaches to opioid prescribing decision-making and policy in seriously ill patients presenting to ambulatory PC. **Abstract:** <http://bit.ly/2XP8SvK>

**N.B.** Selected articles on PC principles in guiding opioid prescribing noted in 25 November 2019 issue of *Media Watch* (#641, pp.10-11).

### **Matters of life and death: Why do older patients choose conservative management?**

*AMERICAN JOURNAL OF NEPHROLOGY* | Online – 27 November 2019 – Although many older patients with end-stage renal disease and limited prognoses prefer conservative management (CM), it is not widely offered in the U.S. Moreover, there is a dearth of U.S.-based literature reporting clinical experience with shared decision making regarding CM of advanced chronic kidney disease (CKD). In this study at the University of Rochester Medical Center’s CKD clinic, the mean age of the patients studied was 81.8 years. Their reasons for choosing CM included: poor prognoses; a wish to maintain their quality of life; their desire for a dignified life closure; and the intention to protect family members from having to see them suffer, based on their own memory of having witnessed a relative on dialysis previously. A total of 8 patients died: all received hospice services, 6 died at home, one at a nursing home, and one at a hospital.

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Advance care planning was completed in 100% of the cases. Symptoms were managed in collaboration with primary care physicians. Patients' decisions to choose CM were influenced by their values and previous experience with dialysis, in addition to comorbidities and limited prognoses. Promoting the choice of CM in the United States will require training of clinicians in primary palliative care competencies, including communication and decision-making skills, as well as basic symptom management proficiencies. **Abstract (w. list of references):** <http://bit.ly/33qZy2w>

**N.B.** Additional articles on palliative and end-of-life care for people living with CKD noted in 11 November 2019 issue of Media Watch (#639, p.12).

### **How timely is access to palliative care medicines in the community? A mixed-methods study in a U.K. city**

*BMJ OPEN* | Online – 24 November 2019 – This is the first published study to identify the relative impact of factors contributing to non-timely access to palliative medicines/drugs (PMs). This paper is the first in the U.K. to examine perspectives of different healthcare professionals on factors supporting and hindering access to PMs. The study is also novel in its examination of customer experience of accessing PMs and the survey achieved a high response rate. The study is possibly limited by the low number of sites but adds value to the literature in terms of barriers that need to be considered if more timely access to PMs is to be more widely implemented. **Full text:** <http://bit.ly/2KRxKOR>

### **Do physicians require consent to withhold CPR that they determine to be non-beneficial?**

*CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2019;191(47):E1289-E1290. The Ontario Superior Court of Justice recently determined that, under both Ontario's healthcare consent legislation and common law, physicians do not require consent to withhold cardiopulmonary resuscitation (CPR) that they believe to be medically inappropriate. Physicians in Ontario need to distinguish carefully between a scenario where CPR would be outside the standard of care and should not be offered and a scenario where CPR is within the standard of care but the physician does not feel it is in the patient's best interests; each scenario demands a different response. Physicians still have a professional responsibility to communicate (or make reasonable efforts to communicate) honestly and compassionately about the limitations of CPR and the alternatives to aggressive care. **Full text:** <http://bit.ly/2rrjx3G>

Noted in Media Watch 25 March 2019 (#607, p.10):

- *JOURNAL OF CLINICAL ETHICS*, 2019;30(1):67-73. '**Cardiopulmonary resuscitation, informed consent, and rescue: What provides moral justification for the provision of CPR?**' Questions related to end-of-life decision making are common in clinical ethics and may be exceedingly difficult. Chief among these are the provision of cardiopulmonary resuscitation (CPR) and do-not-resuscitate orders (DNRs). To better address such questions, clarity is needed on the values of medical ethics that underlie CPR and the relevant moral framework for making treatment decisions. An informed consent model is insufficient to provide justification for CPR. Instead, ethical justification for CPR rests on the rule of rescue and on substituted interest judgments. **Abstract:** <http://bit.ly/2FpPSLx>

### **Excellence in post-licensure interprofessional palliative care education**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 25 November 2019 – An increasing number of palliative care (PC) educational programs strive to meet the workforce need for PC clinicians. This growth necessitates development of robust quality standards. The steering committee, composed of 6 faculty with experience implementing interprofessional PC educational programs, developed initial characteristics, definitions, and subcategories, which were refined through a series of 3 iterative Delphi surveys and a public presentation at a national PC meeting. More than 50 PC clinicians and educators representing multiple professions were invited to participate in the



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Delphi surveys; 20 completed round 1, 23 completed round 2, and 15 participants completed round 3. The final consensus included 6 characteristics with definitions, and both required and recommended sub-categories for each characteristic. Identified characteristics include competencies, content, educational strategies, interprofessional focus, evaluation, and systems integration. This initial description of quality for post-licensure interprofessional PC education programs may be used by learners to guide program selection, new or existing program faculty for course development or quality improvement, or professional organizations to evaluate program quality in a program certification or quality award initiative. **Abstract:** <http://bit.ly/34CpJ7C>

#### Related

- *JOURNAL OF PALLIATIVE CARE* | Online – 26 November 2019 – ‘**Sowing across a state: Development and delivery of a grassroots pediatric palliative care nursing curriculum.**’ A needs assessment was completed by pediatric nurses caring for children receiving palliative or end-of-life care to inform curricular content (phase 1). A curriculum was designed by an interdisciplinary pediatric palliative care team and piloted with nursing cohorts annually through educational conferences with monthly discussion series for 3 consecutive years (phase 2). Curricular content was then provided for 31 rural hospice team members (phase 3). Grassroots curricular initiatives and ongoing educational mentorship can grow pediatric palliative and hospice services in rural... **Abstract:** <http://bit.ly/2DjE7G0>

**N.B.** Recent articles on professional education and training in the context of end-of-life care noted in 25 November 2019 issue (#641, p.8).

#### “It’s more difficult...”: Clinicians’ experience providing palliative care to adolescents and young adults diagnosed with advanced cancer

*JOURNAL OF ONCOLOGY PRACTICE* | Online – 25 November 2019 – Adolescents and young adults (AYAs) with advanced cancer are a population in whom quality of life is uniquely affected because of their stage of life. However, training focused on palliative care (PC) for AYAs is not routinely provided for healthcare providers (HCPs) in oncology. Semi-structured interviews were conducted with medical and radiation oncologists, PC physicians, psychiatrists, and advanced practice nurses involved in caring for AYAs diagnosed with advanced cancer. Overall, participants perceived the provision of PC for AYAs to be more difficult compared with older adults. Four themes emerged: 1) Challenges helping AYAs/families to engage in and accept PC; 2) Uncertainty regarding how to involve the family; 3) HCPs sense of tragedy; and, 4) HCPs sense of emotional proximity. Findings from this study support the development of dedicated training for HCPs involved in PC. **Abstract:** <http://bit.ly/2DjzHPu>

Noted in Media Watch 4 November 2019 (#638, p.12):

- *JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY* | Online – 29 October 2019 – ‘**End-of-life communication needs for adolescents and young adults with cancer: Recommendations for research and practice.**’ There is little guidance on best-practice care and communication practices with adolescents and young adults (AYAs) as they approach end of life (EoL). The authors highlight best-practice recommendations to guide clinicians around the critical elements of when, who, what, and how EoL conversations may be best facilitated with AYAs. They propose a new model to support clinicians and researchers to better conceptualize how interacting individual, familial, and socio-cultural factors impact EoL communication with AYAs in clinical settings. **Abstract:** <http://bit.ly/2q2Weg8>

Noted in Media Watch 8 July 2019 (#621, p.8):

- *JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY* | Online – 28 June 2019 – “‘**It could have been me**’”: **An interpretive phenomenological analysis of healthcare providers’ experiences caring for adolescents and young adults with terminal cancer.**’ This study revealed: 1) Many unknowns and uncertainties associated with providing care for adolescents and young adults (AYAs) compounded by minimal or no training specifically concerning this population; 2) An intense emotional experience compared with caring for patients with terminal cancer of other ages; 3) Personal identification with patients and their families; and, 4) Attempts to make sense of the circumstance thwarted by feelings of injustice and unfairness. **Abstract:** <http://bit.ly/324p6CZ>



## Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S.

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 November 2019 – Burnout is a major issue facing the palliative care (PC) clinician workforce. Strategies at the discipline-wide and individual levels are needed to sustain the delivery of responsive, available, high quality PC for all patients with serious illness. The authors asked American Academy of Hospice & Palliative Medicine clinician members to complete an electronic survey querying demographic factors, job responsibilities, and the Maslach Burnout Inventory. Overall, the authors observed a burnout rate of 38.7%, with higher rates reported by non-physician clinicians. Most burnout stemmed from emotional exhaustion, with depersonalization comprising a minor portion. Factors associated with higher odds of burnout include non-physician clinical roles, working in smaller organizations, working longer hours, being younger than 50 years of age, and working weekends. Higher rated self-management activities to mitigate burnout include participating in interpersonal relationships and taking vacations. **Abstract (w. link to references):** <http://bit.ly/33jZ8L9>

Noted in Media Watch 2 September 2019 (#629, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 26 August 2019 – ‘**Burnout and resilience after a decade in palliative care: What “survivors” have to teach us. A qualitative study of palliative care clinicians with more than 10 years of experience.**’ Four major themes emerged from this qualitative study: 1) Struggling; 2) Changing mindset; 3) Adapting; and, 4) Resilience. Intervening conditions such as self-awareness, reflection, and evolution were also important factors. The core phenomenon of this study was that of “transformational growth” – a process which PC clinicians have to go through before they achieve resilience. The authors also further classified resilience into both personal and collective resilience. **Abstract (w. link to references):** <http://bit.ly/2HxCJIM>

## Opportunities for palliative care in patients with burn injury: A systematic review

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 November 2019 – The authors’ searches yielded 7,532 unique records which led to 238 manuscripts for full review and 88 studies which met inclusion criteria. Seventy-five studies addressed the domain “physical aspects of care” and merit a separate systematic review; 13 studies were included in the final review. Four of the seven domains – processes of care, psychologic symptoms, social aspects, and end-of-life (EoL) – were addressed, but three domains – spiritual, cultural, or ethics – were unaddressed. Included studies highlight potential benefits from peri-discharge self-care education programs, peer support and group therapy in improving quality-of-life. In patients with severe injuries, EoL decision making protocols were associated with increased utilization of comfort-focused treatments. **Abstract (w. link to references):** <http://bit.ly/2rkuC6T>

### Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 November 2019 – ‘**The role of palliative care in burns: A scoping review.**’ Palliative care is used synonymously with comfort and end-of-life care in burns literature. Comfort care (CC) is mostly initiated when active treatment is withheld (early deaths) or withdrawn (late deaths), limiting its overall benefits to burn patients, their families and health care professionals. Futility decisions are usually complex and challenging, particularly for patients in the late death category and it is unclear if these decisions result in timely commencement of CC measures. Two CC pathways were identified but it remained unclear how these pathways evaluated “good death” or supported the family... **Abstract (w. link to references):** <http://bit.ly/351C0aO>
- *PALLIATIVE MEDICINE* | Online – 12 July 2019 – ‘**Do patients, families, and healthcare teams benefit from the integration of palliative care in burn intensive care units? Results from a systematic review with narrative synthesis.**’ Findings suggest that there may be benefits from integrating palliative care (PC) in burn units, specifically in terms of patients’ comfort, decision-making processes, and family care. Multidisciplinary teams may experience lower levels of burden as result of integrating PC in burn units. This review reflects the challenging setting of burn intensive care units. Evidence from these articles suggests that the integration of palliative care in burn intensive care units improves patients’ comfort, decision-making process, and family care. **Abstract:** <http://bit.ly/35L38Gu>

Cont.

Noted in Media Watch 21 May 2018 (#564, p.10):

- *JOURNAL OF BURN CARE & RESEARCH* | Online – 16 May 2018 – ‘Burn surgeon and palliative care physician attitudes regarding goals of care delineation for burned geriatric patients.’ Palliative physicians [i.e., survey respondents] rated being more familiar with goals of care, were more comfortable having a discussion with laypeople, were more likely to have reported high quality training in performing conversations, believed more palliative specialists were needed in intensive care units, and had more interest in conducting conversations relative to burn surgeons. Burn surgeons favored leading team discussions, whereas palliative specialists preferred jointly led discussions. Both groups agreed that discussions should occur within 72 hours of admission. **Abstract:** <http://bit.ly/2XTyKGU>

### Why global health must talk about death

*THE LANCET* | Online – 23 November 2019 – Global health loves death. We deify mortality. We revel in human oblivion and its causes. We count, estimate, and monitor obsessively the casualties of disease. But there is one quality that global health does not bring to death. We don't value the end of life (EoL). Such indifference is strange. As Shahaduz Zaman (University of Sussex) argued last week, “We all die, so let's talk about it.” He was speaking at our Global Health Lab, held at the London School of Hygiene & Tropical Medicine. Death has a universal incidence. Yet we seem content to allow appalling global disparities in death, dying, and EoL care. We can change this pattern of neglect. Universal health coverage could be a lever to ensure equity. There are two narratives. The standard model is institutionalised specialist palliative care (PC) service delivery. An alternative is a more generalist community approach. Zaman gave examples of neighbourhood networks of PC in India and Bangladesh. Here, EoL care is delivered in the community by PC assistants or volunteers. But the gold standard is held to be western specialist care. The U.K. does well by this measure, topping global indices of Quality of Death. But what a paradox. While the U.K. is regarded by others as an ideal place to die, there is concern and disagreement about how well PC is delivered. The Liverpool Care Pathway was withdrawn in 2014. Most British people do not die in their preferred place (home). And criticism about the over-medicalisation of PC is growing. Zaman argues that it is time to re-evaluate the idea of a good death: “The body of the dying person becomes an arena for conflicting (sub)-cultures of providers, policy makers, and relatives.” Uncritically transposing models of PC from one culture to another is dangerous. Instead, global health should encourage plurality in how we address dying. One should identify “the particular” within “the universal” at the EoL. **Full text:** <http://bit.ly/35yq7nO>

### Exploring the life death divide, questions remain long after the Harvard Criteria

*THE LINACRE QUARTERLY*, 2019;86(4):268-270. Every physician has a memorable story that hinges in one way or another on the issue of brain death (death determined by neurological criteria). For modern medicine, the development of neurological criteria for declaring death is a milestone event. The development of life support systems that could sustain organ function in the face of catastrophic brain injury occasioned both the desire and the need to be able to assess death in different ways than in the past. Questions arose about when and how such support might be discontinued, in large part because traditional ideas about death involved cessation of the very organ function that could now be sustained. The question began to be asked: where is the line between life and death in light of these new technologies? **Full text:** <http://bit.ly/2DmvUB3>

**N.B.** ‘Brain Death: Current Understanding and Questions’ is the focus of the current issue of *The Linacre Quarterly*. **Journal contents page:** <http://bit.ly/34uahe1>

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Closing the Gap Between Knowledge & Technology  
<http://bit.ly/2DANDFB>

Noted in Media Watch 11 June 2018 (#567, p.9):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 7 June 2018 – ‘**The 50-year legacy of the Harvard report on brain death.**’ History is full of ironies, and the 50-year legacy of the Harvard report is no exception.<sup>1</sup> From one perspective, the report laid the foundation for laws that have both saved and improved the lives of hundreds of thousands of patients through organ and tissue donation. Conversely, decades of attempts to find a conceptual justification for linking this diagnosis to the death of the patient remain incomplete. The significance of brain death may diminish in the near future. If new genetic technologies render xenotransplantation safe, there could be a supply of transplantable organs without resorting to human donors... **Abstract:** <http://bit.ly/33xFYBV>

1. ‘A definition of irreversible coma,’ Ad Hoc Committee of the Harvard Medical School, *Journal of the American Medical Association*, 1968;205(6):337-340. **Abstract:** <http://bit.ly/2r0Gllw>

### Experienced physicians more likely to struggle with grief: Poll

*MEDSCAPE* | Online – 29 November 2019 – Asked how often they struggle with grief after a patient dies, 35% of physicians who responded to a *Medscape* poll said they always or often did. The percentages who answered that way differed by gender (42% of female physicians commonly struggle with grief for patients vs 32% of their male colleagues) and generally increased with years in practice. While 27% of physicians who had less than 5 years of practice reported that they always or often struggle with grief for lost patients, 43% of those with more than 30 years of practice said they did. Nurses and advanced practice registered nurses were slightly less likely overall to say they often struggle with grief for patients (31% said they always or often did) and, unlike the trend for physicians, the more experienced nurses were less likely to struggle with grief. While 37% of nurses with

less than 5 years’ experience said they struggle with grief for patients, only 29% of those with more than 30 years in practice said they always or often did. **Full text:** <https://wb.md/2r3bQAS>

#### Extract from *Medscape* report

One poll question asked whether healthcare providers had attended a patient’s funeral. Only a few had done so in their first year. Just 13% of physicians and 17% of nurses and advanced practice registered nurses (APRNs) had done so in the past year; 67% of physicians and 40% of nurses and APRNs responded that they had never attended a patient’s funeral.

**N.B.** Selected articles on the topic of attending patient funerals noted in 16 September 2019 issue of *Media Watch* (#631, p.11).

- *PLOS ONE* | Online 27 November 2019 – ‘**Being there: A scoping review of grief support training in medical education.**’ Grief training was most often a voluntary component of the medical curriculum, despite the fact that many patients rely on physicians to help them with their grief. Nevertheless, this review found evidence that trainees valued being given ample opportunity to reflect on their own attitudes towards death and dying in small group settings. As well, a physician’s awareness of their own and their patients’ grief reactions may allow both to have a higher quality of care. Thus, medical training should include grief training to help physicians prepare for loss and develop competency in dealing the range of losses that will inevitably occur. **Full text:** <http://bit.ly/2OwiKrp>

### Compassionate communities – a modern form of organising palliative care

*MEDYCYNA PALIATYWNA* | Online – 15 November 2019 – This article describes a new approach to creating public policies in health and social care, especially directed to people in severe health crisis. Compassionate communities provide care through an adequately managed network of people and institutions in a specific community. The community mobilises its own resources to ensure the best possible care for its own members. This model can reduce the burden of traditional healthcare providers, who can play a significant role as a coordination centre (not only as care providers). To create a compassionate community, educational institutions are also needed in order to deliver adjusted knowledge management. The compassionate model represents what we call modern palliative care based on interdisciplinary cooperation with a great contribution of social engagement. **Abstract:** <http://bit.ly/2KTdqfs>

**N.B.** Polish language article.

Cont.

Noted in Media Watch 11 March 2019 (#605, p.15):

- *PLOS ONE* | Online – 7 March 2019 – ‘**Matching response to need: What makes social networks fit for providing bereavement support?**’ The research literature emphasizes the many negative consequences of bereavement, with increases in physical and psychological morbidity and mortality, and the disruption of social relationships being a primary determinant of both health and mortality. This puts the impact of bereavement squarely into a public health perspective that pursues health equity. The authors argue for adopting and strengthening a compassionate communities approach, not only for end-of-life care for dying people but also along the continuum of bereavement support. **Full text:** <http://bit.ly/2SQocUX>

Noted in Media Watch 4 February 2019 (#600, p.9):

- *HEALTH PROMOTION INTERNATIONAL* | Online – 27 January 2019 – ‘**Unpacking “the cloud”: A framework for implementing public health approaches to palliative care.**’ The Health Impact Change Model (HICM) was developed to unpack the complexities associated with the implementation and evaluation of a Canadian compassionate communities intervention. The HICM offers utility for citizens, leaders and decision-makers who are engaged in the implementation of population health level strategies or other social approaches to care, such as compassionate cities and age or dementia-friendly communities. The HICM’s concepts can be adapted to address a community’s healthcare context, needs, and goals for change. **Abstract:** <http://bit.ly/2RrPpgd>

### **Predicting attrition among hospice volunteers**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 27 October 2019 – To explore those factors predicting continued involvement among hospice volunteers, this study collected data from questionnaires distributed among 53 individuals who were hospice volunteers, to include personal demographics and measures of locus of control, burnout, hospice self-efficacy, spirituality, and death anxiety. Participants were then contacted between 6 and 8 months later to assess whether they were still actively volunteering for hospice. Those who remained in hospice reported less burnout when adjusting for previous volunteer experience, age, education, and duration of volunteering and a combination of burnout, spirituality, and hospice self-efficacy accurately predicted group membership (completers vs. dropouts) in 82% of the cases. The implications of these exploratory findings for the retention of hospice volunteers are discussed in the context to carefully screening persons before they enter the hospice volunteer role and providing hospice volunteer training for them. **Abstract:** <http://bit.ly/2OWqwtK>

### **Aiding end-of-life medical decision-making: A Cardinal Issue Perspective**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 28 November 2019 – Many challenges exist in bridging communication gaps between clinicians and patients in end-of-life (EoL) decision-making in which there is a continuum of treatment possibilities. The shared decision-making (SDM) approach has demonstrated the potential for improving decisions to achieve better quality of care. However, sharing of EoL decisions in practice happens infrequently due to factors such as time constraints, inadequate communication, clinical situations (e.g., sensitive topics, including EoL discussions), and patient characteristics (e.g., older age and poor condition). Additionally, debate regarding exactly what SDM entails and how it can and should be adopted into practice has likely also hindered its acceptance by medical providers. The authors propose a new approach – using the Cardinal Issue Perspective (CIP) on decision-making as a check list for routinely performing SDM in EoL situations. The CIP has the potential to streamline and address important decision-making considerations that may not be fully attended to in current clinical SDM models and practice. **First page view (w. list of references):** <http://bit.ly/2Y2SMz4>

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## Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 November 2019 – ‘**Exploring quality of life in end-of-life discussions.**’ Researchers conducted a study to identify the differences in quality-of-life (QoL) language found within the advance directives (AD) state statutes from 50 U.S. states and the District of Columbia. Only 3 states specifically addressed QoL. Patients are best served when professionals, regardless of discipline, can share and transform knowledge for patients in times of crisis and loss in ways that are empathetic and precise. Interprofessional collaborative practice comprises multiple health workers from different professional backgrounds working together with patients, families, and communities to deliver the highest quality of care. **Abstract:** <http://bit.ly/2smctWz>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 November 2019 – ‘**Impact of a nurse-led advance care planning intervention on satisfaction, health related quality of life and health care utilization among patients with severe respiratory disease: A randomized patient preference trial.**’ In this multi-center, open-label, patient-preferences, randomized controlled trial, a nurse-facilitated advance care planning (ACP) intervention among patients with severe respiratory disease did not have an impact on satisfaction, health-related quality of life or 12-month mortality rate. Facilitated ACP may be associated with a different type of healthcare utilization during the end-of-life period. **Abstract (w. link to references):** <http://bit.ly/2OWzCXn>
- *MÉDECINE PALLIATIVE* | Online – 26 November 2019 – ‘**Trusted person and advance directives: End-of-life discussion in general practice.**’ Practitioners [i.e., study participants] wanted the end-of-life discussion to be initiated by patients, following a media coverage. Discussion should allow a three-step approach: explain his rights to the patient, guide him in his reasoning, possibly with a specialist colleague or a psychologist, and then help him to transcribe his wills. At the request of the patient, his trusted person could be present during this discussion. A dedicated consultation time should be desirable, but would need a patient’s education to come only for this subject. Some considered several consultations, according to the patient’s needs. **Abstract:** <http://bit.ly/2XNC4n7>

N.B. French language article.

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 26 November 2019 – ‘**Association between palliative care and the rate of advanced care planning: A systematic review.**’ Studies that tested the effects of palliative care (PC) often include the rate of documented advance care planning (ACP) as a secondary end point. Twenty-six trials with 37,924 patients were included in this review. Four were randomized controlled trials, nine cohort studies, and 12 cross-sectional studies. There was a positive correlation between the addition of PC and ACP in 25 studies... Understanding the significant effect of PC on the completion of ACP is an additional emphasis on the importance of this treatment among terminally ill patients. **Abstract (w. list of references):** <http://bit.ly/2On6Uzl>

## Comparing the physical, psychological, social, and spiritual needs of patients with non-cancer and cancer diagnoses in a tertiary palliative care setting

*PALLIATIVE & SUPPORTIVE CARE* | Online – 26 November 2019 – The majority of patients admitted to tertiary palliative care (PC) settings have historically been those with cancer. The tertiary PC needs of patients with non-cancer diagnoses have not been well described... The authors conducted a retrospective chart review of all patients with a non-cancer diagnosis admitted to a tertiary PC unit between ... and compared their needs to those of a matched cohort of patients with cancer diagnoses. The prevalence of needs within the following four main concerns was recorded and the data analyzed using descriptive statistics and content analysis: 1) Physical: pain, dyspnea, fatigue, anorexia, edema, and delirium; 2) Psychological: depression, anxiety, prognosis, and dignity; 3) Social: caregiver burden, isolation, and financial; and, 4) Spiritual: spiritual distress. The prevalence of the four main concerns was similar among patients with non-cancer and cancer diagnoses. The authors description of the PC needs of patients with non-cancer diagnoses will help guide future PC for the increasing population of patients with non-cancer serious illness diagnoses. **Abstract (w. list of references):** <http://bit.ly/35P1a83>

Cont.

## Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 26 November 2019 – ‘**Patient’s spirituality perspectives at the end of life: A qualitative evidence synthesis.**’ Fifty papers (42 unique datasets), incorporating data from 710 patients were included. Studies recruited from a mix of inpatient, outpatient, hospice and community settings across 12 different countries. Three overarching themes were generated: 1) The concept of spirituality; 2) Spiritual needs and distress; and, 3) Spiritual care resources. Relationships were an intrinsic component of spirituality. Meeting patients’ spiritual needs is an integral part of end-of-life (EoL) care. This work emphasises that supporting relationships should be a central focus of spiritual care for patients at the EoL. **Abstract:** <http://bit.ly/35HOUGl>

### **Experience of nurses who work with children with palliative care needs: A mixed-method systematic review**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 26 November 2019 – Finding revealed that working with children with palliative care (PC) needs is an emotionally struggling job for nurses, especially when they try to manage the transition of pediatric patients from curative to PC. Staffing level and time constraints comprise a major obstacle in pediatric PC. Focusing on invasive treatment and technology in spite of the feelings that it will not improve patients’ health status intensifies the feeling of guilt and helplessness for nurses. Finally, nurses asserted the importance of receiving pediatric PC education, especially how to communicate with children with PC needs and their families. Further research is recommended with regard to nurses’ experience in communication with children with PC needs. **Abstract (w. list of references):** <http://bit.ly/2L085TJ>

### **Ambulance Wish: An opportunity for public health palliative care partnerships with paramedics and other community members**

*PROGRESS IN PALLIATIVE CARE* | Online – 25 November 2019 – Paramedicine and, more specifically, the role of paramedics in contexts of community-based palliative and end-of-life care (EoLC) are increasingly discussed in the literature. Within a public health palliative care framework, EoLC is viewed as a shared responsibility for everyone, including the broader community. This brief commentary discusses the international Ambulance Wish movement as an opportunity for innovative partnerships between paramedics, the PC sector, and other community members. **Abstract:** <http://bit.ly/34IDyaw>



**N.B.** Ambulance Wish Queensland website: <http://bit.ly/35GkHap>; History of Ambulance Wish Foundation (first established in The Netherlands): <http://bit.ly/2OOSMOO>. Selected articles on the role of paramedics in palliative and EoLC noted in 18 November 2019 issue of Media Watch (#640, p.7).

### **Consensus document and recommendations on palliative care in heart failure of the Heart Failure & Geriatric Cardiology Working Groups of the Spanish Society of Cardiology**

*REVISTA ESPAÑOLA DE CARDIOLOGÍA* (English Edition) | Online – 21 November 2019 – Heart failure is a complex entity, with high morbidity and mortality. The clinical course and outcome are uncertain and difficult to predict. This document ... addresses various aspects related to palliative care (PC), where most cardiovascular disease will eventually converge. The document also establishes a consensus and a series of recommendations with the aim of recognizing and understanding the need to implement and progressively apply PC throughout the course of the disease, not only in the advanced stages, thus improving the care provided and quality of life. The purpose is to improve and adapt treatment to the needs and wishes of each patient, who must have adequate information and participate in decision-making. **Abstract:** <http://bit.ly/2Ong3Zh>

Cont.

Noted in Media Watch 11 November 2019 (#679, p.8):

- *AMERICAN JOURNAL OF THERAPEUTICS* | Online – 25 October 2019 – ‘**Palliative care in heart failure: A public health emergency.**’ Patients with heart failure (HF) are the largest group eligible for palliative care (PC) services, but only a small percentage of them receive PC. Because of the unpredictability of the disease and difficulty in prognostication, PC should be introduced at the point of diagnosis of HF. Basic education in PC needs to be introduced early in the training of cardiology staff, focused on concept definition, differentiating PC and terminal care, symptom management, communication, and decision-making. Research concerning PC in HF is still scarce and comes predominantly from developed countries. **Abstract:** <http://bit.ly/2WS14Jc>
- *COLLEGIAN* | Online – 2 November 2019 – ‘**Barriers and facilitators to a “good death” in heart failure: An integrative review.**’ Five themes associated with end-of-life care in heart failure (HF) and a good death were generated: 1) Location of death; 2) Preferred care; 3) Palliative care utilisation; 4) Interventions to improve the likelihood of a good death; and, 5) The intersection of individual, family, healthcare providers, and community-level factors. This review identifies modifiable barriers and facilitator of a good death and emphasised the importance of considering the intersection of patient, provider and healthcare system issues in facilitating a good death for patients with HF. **Abstract (w. link to list of references):** <http://bit.ly/34pvipl>

### **Passing on wisdom: Exploring the end-of-life wishes of Aboriginal people from the Midwest of Western Australia**

*RURAL & REMOTE HEALTH* | Online – 30 November 2019 – Indigenous patients with life-limiting conditions have complex needs, experience reduced access to and uptake of treatment, and have lower utilisation of palliative care (PC) services than the general population. Lack of understanding of the role of PC and poor availability of culturally safe specialist PC services impact on Indigenous people’s end-of-life (EoL) decision-making. Aboriginal people were engaged to talk frankly about their wishes and concerns around EoL. The community consultations raised considerable discussion about wills, where to die, burial versus cremation, and the cost of funerals. Possibilities emerging from participants’ reflections on the issue were public celebrations to honour someone’s life, the potential use of sorting cards to help discussions about EoL personal wishes, and interest in making and decorating coffins. Aboriginal people with cancer raised similar issues, and focused on avoiding family disharmony by ensuring their family were aware of their EoL wishes. Within a safe space, Aboriginal people were happy to talk about EoL wishes, although certain aspects of death remain contentious. Sorting cards, ceremonies, education and care roles involving Aboriginal people offer potential means for effectively engaging Aboriginal people in preparing for death and dealing with grief. **Full text:** <http://bit.ly/37RtZ5q>

**Noted in Media Watch 18 February 2019 (#602, p.7):**

#### **Cultural safety strategies for rural Indigenous palliative care: A scoping review**

*BMC PALLIATIVE CARE* | Online – 14 February 2019 – The authors review about Indigenous palliative care (PC) in rural and small-town settings in Canada, the U.S., New Zealand, and Australia revealed various strategies to improve the relevance and cultural appropriateness of PC for Indigenous clients. Culturally competent strategies focused on building opportunities or creating space to accommodate the unique values and traditions of Indigenous patients, families and communities. One strength of these types of approaches is they coach non-Indigenous clinicians to challenge assumptions of universality and consider how cultural difference and historical context may shape care preferences... One key risk ... is that without an awareness of provider privilege and power, institutional norms, or historical oppression, they may enforce simplistic stereotypes, essentialization, and stigma of Indigenous peoples. Given the diverse spiritual and cultural practice between Indigenous communities, cultural competence will only be a value added if it is applied with a great deal of humility and genuine curiosity for the individuality and uniqueness of each client. Partnered approaches to care may enable clinicians to transition towards a culturally safe approach to PC because partnerships may prompt the individual to consider power at the interpersonal level. **Full text:** <http://bit.ly/2EcF6ZO>

**N.B.** Additional articles on palliative and end-of-life care for Australia’s Indigenous peoples noted in 31 December 2018 issue of Media Watch (#595, p.10).

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 26 November 2019 – ‘**Perceptions and experiences of medical assistance in dying among illicit substance users and people living in poverty.**’ Since medical assistance in dying (MAiD) became legal in Canada in 2016, there have been concerns about vulnerable people feeling pressured to end their lives. It is important to understand what people in marginalized communities know and feel about MAiD in order to help prevent any pressure to hasten death and to prevent any barriers to accessing assisted death. This qualitative study explored the perceptions and experiences of MAiD and other end-of-life care (EoLC) options with 46 people who were illicit substance users, living in poverty, or who worked with marginalized people in these communities. Six broad themes were identified: 1) The importance of family, friends, and community; 2) The effects of the opioid crisis; 3) Barriers to accessing EoLC services; 4) Support for MAiD; 5) The difference between suicide and MAiD; and, 6) What constitutes a good death. Findings from this research may be used to help inform future legislation, professional guidelines, and standards of best practice. **Abstract:** <http://bit.ly/2rwZ3Xg>
  - *AMERICAN JOURNAL OF NURSING*, 2019;119(12):15. ‘**Growing number of Catholic-run hospitals raises concerns.**’ A physician in Colorado was fired in August when she joined a terminally ill cancer patient in a lawsuit to allow him to end his life – a right granted by the state’s recently passed aid-in-dying law. However, her employer, Centura Health Corp., a Catholic-run health system, forbade it, citing religious doctrine that describes assisted suicide as “morally unacceptable” ...<sup>1</sup> The Centura case underscores the impact on healthcare services of the growing influence of Catholic hospitals and healthcare systems in the U.S. as a result of healthcare institution mergers. In some mergers between secular and religious-affiliated institutions, the secular institutions are required to follow church policies. In 2016, four of the 10 largest health systems in the nation were Catholic sponsored... And Catholic-owned or Catholic-affiliated hospitals included 548 acute care facilities, reflecting a 22% growth rate between 2001 and 2016. Currently, one out of every seven U.S. hospitals are Catholic owned or affiliated. In 20 states – most of them in the Northwest and Upper Midwest – from 20% to 40% or more of acute care beds (Alaska has the most with 49.2%) are in Catholic hospitals; and 46 communities in the nation are served only by a Catholic hospital. **Full text:** <http://bit.ly/2OSa5P9>
1. ‘Firing doctor, Christian hospital sets off national challenge to aid-in-dying laws.’ *Kaiser Health News*, 30 August 2019. [Noted in 9 September 2019 issue of *Media Watch* (#630, p.4)] <http://bit.ly/2lzNhbF>

## Publishing Matters

### **Journal editors’ perspectives on the roles and tasks of peer reviewers in biomedical journals: A qualitative study**

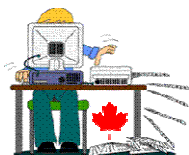
*BMJ OPEN* | Online – 24 November 2019 – This study provides an in-depth, behind-the-scenes account of 56 journal editors’ experiences with, and expectations towards, peer reviewers. The authors found that journal editors’ understanding of the roles and tasks of peer reviewers are profoundly shaped by each journal’s unique context and characteristics, including financial and human resources and journal reputation. Thus, in line with existing literature, the authors found that editorial decision making and expectations towards peer reviewers are unavoidably shaped by social externalities that at times may have little to do with the scientific content of the manuscript. They found that the majority of their interviewees gave considerable importance to the reviewers’ recommendation function, despite concerns regarding the lack of a commonly agreed-upon definition of the available options, frequent disagreement among peer reviewers and existing bias. Given these limitations, journal editors should seriously consider removing the reviewers’ “recommendation function,” where they are expected to provide the editor with their recommendation regarding the article’s suitability for publication. This is in line with existing research on the relationship between external reviewers’ recommendations and the editorial outcome of manuscripts. This would help to realign the role of peer reviewers as “advisors” rather than convey the idea that they are decision makers. **Full text:** <http://bit.ly/2QOxG5H>

Cont.



Noted in Media Watch 25 February 2019 (#603, p.16):

- **MEDSCAPE | Online – 19 February 2019 – ‘To maintain trust in science, lose the peer review.’** “Trust me, I’m a doctor.” In the Internet age, that phrase has never been more fraught. Uncertainty is the rule in medicine and science. In an ideal world, doctors, scientists, and laypeople would independently evaluate the evidence behind any scientific or medical statement. Instead, scientific and medical evidence increasingly comes from small groups of sub-specialists who write in obscure prose for academic publications that few can access. That leaves the media to disseminate findings from thinly read scientific journal articles that are held up as totems of authority. But there’s a hitch. The Internet’s democratization of all voices allows misinformation ... to easily spread. **Full text:** <https://wb.md/2SR2cy8>



### [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/2RPJy9b>

### [Media Watch: Editorial Practice](#)

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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### [Something Missed or Overlooked?](#)

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

## Media Watch: Access on Online

### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/2NgALqN>

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PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU> ]

### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2G2jqko>

[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

### Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <http://bit.ly/2XC24jA>

HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

### South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

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**Barry R. Ashpole, Ontario CANADA**

**e-mail: [barryashpole@bell.net](mailto:barryashpole@bell.net)**