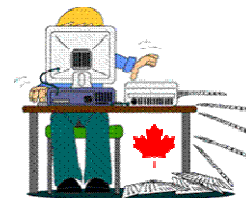


## Media Watch...

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

**Preferred place of death: Scroll down to [Specialist Publications](#) and ‘The “safe death”’: An ethnographic study exploring the perspectives of rural palliative care patients and family caregivers’ (p.14), in *Palliative Medicine*.**

## Canada

### Canadian Institute for Health Information

**Almost all Canadians would benefit from palliative care.  
Only one in seven can actually access it at end-of-life**

*THE GLOBE & MAIL* | Online – 19 September 2018 – 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<sup>1</sup> ... 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. In short, the report confirms what far too many people who have accompanied a loved one in their final days know – that Canada is not a very good place to die. The fundamental problem is lack of timely access, woes that are the result of lack of co-

ordination between different parts of the system. If there is a glimmer of hope in this grim tale, it is that when you get access to PC – which for the most part happens if you are a “young senior” (age 49-74) with cancer – the care is excellent. Canada is known globally as a leader in PC theory, but sadly it fails far too often in practice. <https://goo.gl/mQDk6g>

### Specialist Publications

**‘Access to palliative care in Canada’** (p.10), in *International Journal of Population Data Science*.

1. ‘Access to Palliative Care in Canada,’ Canadian Institute for Health Information, September 2018. **Download/view (scroll down to foot of page and ‘Related Links’) at:** <https://goo.gl/qE2smV>

**N.B.** Additional articles noted in past issues of Media Watch: on the evolution of a national palliative care strategy (#544, pp.18-19); and, on the passage of ‘Framework on Palliative Care in Canada Act’ (#543, pp.1-2). For a listing of nine key studies on end-of-life care in Canada, published between 1995-2014 (#389, p.4). See also ‘Right to Care: Palliative care for all Canadians,’ Canadian Cancer Society (#445, p.1).

## Medically-assisted dying cases need stronger review to safeguard us all

HUFFINGTON POST | Online – 17 September 2018 – Rules to protect “vulnerable persons” are etched into the federal law and professional authorities in each Canadian province and territory have issued practice directives and educational resources on medical assistance in dying (MAiD). A new professional body, the Canadian Association of MAiD Assessors & Providers has emerged and is focusing attention on refinements, such as whether practitioners are adequately compensated, or if MAiD’s bureaucratic requirements need streamlining. But too little is known about how persons who are eligible for MAiD actually experience this new “choice.” And nothing is known about how those of us who care for those persons may have begun to calculate the value of their lives differently. That is why the federal government’s new Regulations for the Monitoring of Medical Assistance in Dying<sup>1</sup> ... fall short of a good faith effort to understand the role that social determinants of health,

such as poverty, insecure housing, isolation or social stigma may play in motivating a request to die. <https://goo.gl/skV7p5>

### Specialist Publications

**‘Morality politics of physician-assisted suicide: Lessons from Canada and the U.S.’** (p.17), in *British Journal of Canadian Studies*.

**‘Euthanasia and suicide’** (p.17), one of several articles on medical assistance in dying in *Canadian Family Physician*.

**‘Medical assistance in dying at a paediatric hospital’** (p.18), in *Journal of Medical Ethics*.

**‘Medical assistance in dying: Challenges for Muslim healthcare professionals’** (p.19), in *Journal of Pastoral Care & Counseling*.

1. ‘Regulations for monitoring medical assistance in dying come into force,’ *Canada Gazette*, 2018, Part II, Vol. 152, No. 16. [Noted in 13 August 2018 issue of Media Watch (#576, p.1)] **Download/view at:** <https://goo.gl/5omKZ1>

## U.S.A.

### Doctors today may be miserable, but are they “burnt out”?

NATIONAL PUBLIC RADIO | Online – 18 September 2018 – Today, the *Journal of the American Medical Association (JAMA)* publishes two major studies on a hot topic: physician burnout. Burnout is a buzzword that’s been in the news, but what is it? How does it affect doctors and their patients? It turns out, nobody really knows. The first study, a systematic review, summarizes the research to date on physician burnout.<sup>1</sup> Study authors found that researchers do not use a consistent definition of burnout, and estimates of how common it is vary widely. The second study followed doctors-in-training over six years and tracked how they felt about their work.<sup>2</sup> They found that women and doctors in certain high-stress specialties were more likely to experience symptoms of burnout, like emotional exhaustion and regret about career choice. There’s a problem with this study and with media reports on doctor burnout, according to Dr. Katherine Gold, coauthor of an editorial accompanying the *JAMA* studies.<sup>3</sup> She says that the main questionnaire used to measure burnout

wasn’t even designed for doctors. Doctors, Gold hypothesizes, may be facing stress related to mounting administrative tasks – a different problem with a different solution. To get a better understanding of what’s going on, we spoke with Gold about her editorial, which calls for more research on exactly what’s afflicting doctors today. <https://goo.gl/ALCvcv>

### Specialist Publications

**‘Burnout, compassion fatigue and psychological capital: Findings from a survey of nurses delivering palliative care’** (p.6), in *Applied Nursing Research*.

**‘Implementing optimal team-based care to reduce clinician burnout’** (p.6), discussion paper posted by the U.S. National Academy of Medicine

Cont.

1. 'Prevalence of burnout among physicians: A systematic review.' **Abstract:** <https://goo.gl/uXW5UH>
2. 'Association of clinical specialty with symptoms of burnout and career choice regret among U.S. resident physicians.' **Abstract:** <https://goo.gl/jiGPKL>
3. 'Physician burnout – a serious symptom, but of what?' **First page view:** <https://goo.gl/pQwZeX>

Noted in Media Watch 13 August 2018 (#576, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 August 2018 – '**Association of perceived futile or potentially inappropriate care with burnout and thoughts of quitting among health-care providers.**' Futile or potentially inappropriate care (futile/PIC) has been suggested as a factor contributing to clinician well-being. Across all clinicians [i.e., survey respondents], 91% reported they either had or had possibly provided futile/PIC to a patient. Overall, 43.4% of clinicians screened positive for burnout syndrome, 7.8% screened positive for depression, and 35.5% reported thoughts of leaving their job as a result of futile/PIC. **Abstract:** <https://goo.gl/Nbt9GY>

Noted in Media Watch 9 April 2018 (#558, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 April 2018 – **“Sacred pause” in the ICU: Evaluation of a ritual and intervention to lower distress and burnout.** “Sacred pause” is a ritual performed at patient’s death to honor the lost life and recognize the efforts of the health-care team. 79% of survey respondents believed the ritual brought closure and helped them overcome the feelings of disappointment, grief, distress and failure after the death of their patient in ICU. 73% percent agreed the ritual has instilled and encouraged a sense of team effort. 82% responded that the ritual makes their efforts feel appreciated. **Abstract:** <https://goo.gl/Lmwyvi>

Noted in Media Watch 12 February 2018 (#550, p.10):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 5 February 2018 – **‘A cross-sectional pilot study of compassion fatigue, burnout, and compassion satisfaction in pediatric palliative care providers in the U.S.’** Compassion fatigue (CF) is secondary traumatic distress experienced by providers from contact with patients’ suffering. Burnout (BO) is job-related distress resulting from uncontrollable workplace factors that manifest in career dissatisfaction. Compassion satisfaction (CS) is emotional fulfillment derived from caring for others. The literature on BO in healthcare providers is extensive, whereas CF and CS have not been comprehensively studied. **Abstract:** <https://goo.gl/Mhb4u6>

### Few teens with chronic health problems have plans to take charge of their own care

REUTERS | Online – 17 September 2018 – Less than one in five teens with chronic health problems have made plans with their pediatrician to take over responsibility for their own care and transition to seeing doctors who treat adults, a U.S. study suggests.<sup>1</sup> Re-searchers examined data from surveys of parents and caregivers of almost 21,000 children ranging in age from 12 to 17, including about 5,900 who were being treated for ongoing medical issues. Just 17% of youngsters with special health needs and 14% of youth without any medical issues appeared prepared to transition from being treated as kids with help from their parents to receiving care as young adults responsible for their own medical issues, the study found. Adolescence is well recognized as a critical period for helping young

people with medical issues transition gradually toward taking more responsibility for their own care and health decisions. But the results highlight how few doctors and parents may be supporting this process, <https://goo.gl/hcvkPs>

#### **Specialist Publications**

**“Will you remember me?”: Talking with adolescents about death and dying** (p.8), in *Child & Adolescent Psychiatric Clinics of North America*.

**‘Child mortality in the U.S.: Bridging palliative care and public health perspectives’** (p.15), in *Pediatrics*.

1. 'Transition planning among U.S. youth with and without special health care needs,' *Pediatrics*, published online 17 September 2018. **Abstract:** <https://goo.gl/W9ptrP>

## Stranger in the house

MASSACHUSETTS | *The Boston Globe* – 15 September 2018 – People like Sarah Estrella are the stuff of baby boomers’ nightmares as they increasingly rely on an army of nurse’s aides, personal care attendants, and others to help them remain in their homes deep into old age. The category of personal care aide is projected to add more jobs by 2026 than any other occupation in the country, according to the Bureau of Labor Statistics. Many of these aides enter the home as virtual unknowns, undergoing no background check and receiving little, if any, training. Consumers often know more about what aides cost than whether they can be trusted. And with demand for home aides so high, those seeking care are simply relieved to find someone to take the job. Theirs is an honorable calling, and many home aides feel gratified to help clients in their time of need. Some become dear friends, almost family members. Astonishingly, there is almost no government safety net to protect people seeking home care from these dangerous strangers. Unlike nurses – or even hairdressers or manicurists – home aides don’t need a state license. Anyone can call him or herself a home care worker in Massachusetts and work privately, though state law mandates that home care agencies perform criminal background checks on workers. Agencies typically offer greater accountability and supervision of aides than workers hired privately, but they’re too expensive for many families. <https://goo.gl/EC1ccJ>

Noted in Media Watch 4 September 2017 (#528, p.3):

- *THE NEW YORK TIMES* | Online – 29 August 2017 – ‘**Home health care: Shouldn’t it be worth doing?**’ Do you know who is going to care for you when you are old and frail? By current standards, it’s likely to be a middle-aged immigrant woman, with maybe a high school education and little if any training, making \$20,000 a year. If you live in rural America, you may already have a hard time finding somebody to look after you. Paul Osterman of the Massachusetts Institute of Technology’s Sloan School of Management calculates that if nothing is done to draw more workers into the field, there will be a shortage of at least 350,000 paid care providers by 2040. <https://goo.gl/9zdRe3>

## International

### Project “key” to addressing access to end of life care for marginalised groups

U.K. (Wales) | Wales 24/7 (Cardiff) – 21 September 2018 – Marie Curie has been working with people with dementia, people with learning disabilities and people with different or no religious beliefs over three years as part of ... [the] ‘Including Diverse Communities in End of Life Care’ project.<sup>1</sup> The project has improved understanding of the barriers faced in accessing palliative care services for people with dementia, learning disabilities, and people with different or no religious beliefs. “It has allowed us to work directly with these groups to ensure their voices are considered as we plan, develop and deliver services, and their feedback has enabled us to make changes to both increase access to and to improve the inclusivity and accessibility of our services.” These outcomes and recommendations will continue to influence Marie Curie beyond the project, in line with its current strategic objectives to reach more people affected by terminal illness and to improve the way terminally ill people are cared for in the U.K. <https://goo.gl/G5jwM2>



1. Improving access to palliative care for people with dementia, learning disabilities and people with different or no religious beliefs,’ Marie Curie, August 2018. **Download/view at (scroll down to ‘Read Reports’):** <https://goo.gl/JChbE3>

## End-of-life care in Ireland

### **Ombudsman highlights progress in end-of-life care support**

IRELAND | *The Irish Times* (Dublin) – 20 September 2018 – Hospital staff who broke the news to a woman of her father’s death told her he had been found “pulseless,” she told the Ombudsman in a complaint about the family’s treatment. The case is one of a small number highlighted in the office’s progress report on end-of-life (EoL) care issues.<sup>1</sup> Ombudsman Peter Tyndall said there had been “very considerable progress” since he published ‘A Good Death’ four years ago,<sup>2</sup> but there were still aspects of the service that required “urgent attention.” Mr. Tyndall said that despite “excellent educational initiatives” for staff, complaints about poor communication during EoL continue to come before him. “One complainant said she was left upset and confused about her husband’s prognosis when the doctor told her ‘he did not know when her husband’s demise would be,’” the progress report said. “Another family was told that their father’s condition was ‘incompatible with life.’ The Ombudsman said the conversations had left family members “confused and distressed.” “It is clear, therefore, that ongoing training must be available to support and guide clinical staff when bad news must be shared with patients and their families. In addition, hospitals must ensure that opportunities are available for staff to learn from others trained in this area,” the report added. Since publication of Mr. Tyndall’s report in 2014, the Hospice Friendly Hospitals Programme has been rolled out in most acute hospitals,<sup>3</sup> there has been an increased availability of specialist palliative care services, and the physical facilities for patients and their families have improved. There has also been an increase in the number of EoL co-ordinators. <https://goo.gl/wXi5kV>

1. ‘A Good Death Progress Report: Developments in End-of-Life Care in Irish Hospitals since the publication of the Ombudsman’s report in 2014,’ Office of the Ombudsman, September 2018. **Download/view at:** <https://goo.gl/5Mh9D2>
2. ‘A Good Death: A Reflection on Ombudsman Complaints about End-of-Life Care in Irish Hospitals,’ Office of the Ombudsman, June 2014. [Noted in 30 June 2014 issue of Media Watch (#364, p.6)] **Download/view at:** <https://goo.gl/kkM5Xd>
3. ‘Hospice Friendly Hospitals Publications,’ Irish Hospice Foundation. [Noted in 8 September 2014 issue of Media Watch (#374, p.13)] **Download/view at:** <https://goo.gl/X6fXGy>

**N.B.** Additional articles on end-of-life care in Ireland noted in 18 December 2017 issue of Media Watch (#543, p.8).

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

Representative sample of recent news media coverage:

- U.K. (England) | *The Daily Mail* (London) – 17 September 2018 – **‘National Health Service criticised over TV advertisement which features nurses tending to patients while song ‘about euthanasia’ plays in the background.’** The ‘We are the NHS’ advert, which cost £8 million of public money to create, has been appearing on screens since July in an attempt to lure thousands of nurses to the health service. But the song playing in the background, ‘To Build a Home’ by the British band Cinematic Orchestra, is actually about a man helping to end his partner’s life. The 2007 track video features a man carrying a woman to a remote cottage before crushing up pills and watching her fall asleep. But NHS England insisted the song was not about assisted dying, while the Mullen Lowe Group which produced the ad said the track was selected for its “tone, depth and pacing” rather than lyrics. The advert was launched around the time of the NHS’s 70th anniversary and is a key part of what is its largest-ever recruitment campaign. <https://goo.gl/FpUyxx>



### Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.20.



## Specialist Publications

### “I know I'm going to beat this”: When patients and doctors disagree about prognosis

*AMERICAN JOURNAL OF BIOETHICS* | Online – 20 September 2018 – As palliative care physicians who frequently discuss goals of care with seriously ill patients and their families, we often get called because the patient/family is in “denial.” In a common scenario, we are consulted by a medical team where team members want us to make sure the family “gets it” and then makes the “appropriate” decision for a do not resuscitate order or for hospice care. Too often, from the consulting service perspective, the term “denial” is a substitute for “the patient won’t do what we think they should be doing.” In these cases, our first challenge as clinicians is to understand the patient beliefs that underlie the disagreement, including how the patient obtained them, how those beliefs function in their life and family, and their malleability. **First page review:** <https://goo.gl/zKZ834> **N.B.**

**N.B.** The focus of the current issue of the *American Journal of Bioethics* is on “evaluating statements by patients and when, if ever, these statements should constitute evidence that a patient is, in fact, in denial.” Contents page: <https://goo.gl/11qunh>

### **Burnout, compassion fatigue and psychological capital: Findings from a survey of nurses delivering palliative care**

*APPLIED NURSING RESEARCH*, 2018;43(5):1-9. An online survey was conducted with 256 registered nurses ... recruited through nursing organisations and a large tertiary level hospital. Psychological empowerment and the commitment and challenge components of psychological hardiness significantly predicted lower scores for the burnout while previous palliative care (PC) education and challenge predicted lower scores for the secondary traumatic stress component of compassion fatigue. Significant predictors of compassion satisfaction included previous PC education, psychological empowerment and both the commitment and challenge components of psychological hardiness. Nurses draw upon unique combinations of “psychological capital” to deal with caring for patients with life-limiting illnesses. **Abstract:** <https://goo.gl/r9DRWG>



#### **Related**

- *THE HEALTH CARE MANAGER* | Online – 17 September 2018 – ‘**Case study of nurses’ experiences related to the deaths of their patients.**’ The study utilized a sample of 16 participants at a rural 123-bed community hospital. Nine themes emerged: 1) Family issues; 2) Patient alone at death; 3) Knowing the community; 4) Never-forgotten experiences; 5) First experiences; 6) Time issues; 7) Responses to unexpected deaths; 8) Role of nurses; and, 9) Nurses’ response to death itself. If nurses do not know how to cope with deaths of their patients, it may lead to personal health issues. There is a need for further research to evaluate whether improved end-of-life education and counseling address the needs of the nurses who deal with deaths of their patients. **Abstract:** <https://goo.gl/28e3NK>
- U.S. NATIONAL ACADEMY OF MEDICINE (Discussion Paper) | Online – 17 September 2018 – ‘**Implementing optimal team-based care to reduce clinician burnout.**’ Team-based health care has been linked to improved patient outcomes and may also be a means to improve clinician well-being. The increasingly fragmented and complex health care landscape adds urgency to the need to foster effective team-based care to improve both the patient and team’s experience of care delivery. This paper describes key features of successful health care teams, reviews existing evidence that links high-functioning teams to increased clinician well-being, and recommends strategies to overcome key environmental and organizational barriers to optimal team-based care in order to promote clinician and patient well-being. **Full text:** <https://goo.gl/vCkgLs>

## **Culturally sensitive communication at the end-of-life in the intensive care unit: A systematic review**

*AUSTRALIAN CRITICAL CARE* | Online – 17 September 2018 – There is a growing body of evidence demonstrating the need for culturally sensitive communication (CSC) in health care; however, limited research has been conducted on the use of CSC at the end-of-life in the ICU. This is the first systematic review to comprehensively synthesise research evidence related to the topic area. CSC is not well defined or translated into clinical practice. It is dependent on the values and beliefs of individual clinicians and has multiple contributing factors. There are challenges related to communication and similarities and differences between how nurses and physicians communicate. The findings also emphasise issues related to the knowledge deficit of clinicians in demonstrating CSC and the need for further education. The cultural and personal characteristics of clinicians, patients, and families and how each of these characteristics influences the quality of CSC at the end-of-life (EoL) are also highlighted in this systematic review. The findings suggest that clinicians lack the knowledge to enable effective interaction with culturally diverse patients and families at the EoL. **Full text:** <https://goo.gl/w32qAm>



## **Suffering at the end of life**

*BIOETHICS* | Online – 18 September 2018 – In the end-of-life (EoL) context, alleviation of the suffering of a distressed patient is usually seen as a, if not the, central goal for the medical personnel treating her. Yet it has also been argued that suffering should be seen as a part of good dying. More precisely, it has been maintained that alleviating a dying patient's suffering can make her unable to take care of practical EoL matters, deprive her of an opportunity to ask questions about and find meaning in and for her existence, and detach her from reality. The author argues that the aims referred to either do not support suffering or are better served by alleviating it. When the aims would be equally well served by enduring suffering and relieving it, the latter appears to be the preferable option, given that the distress a patient experiences has no positive intrinsic value. Indeed, as the suffering can be very distressing, it may not be worth bearing even if that was the best way to achieve the aims: the distress can sometimes be bad enough to outbalance the worth of achieving the goals. Having considered an objection to the effect that a patient can have a self-regarding moral duty to endure the distress she faces at the EoL, the author concludes that the burden of proof is on the side of those who maintain that the suffering experienced at the EoL ought to be endured as a part of dying well. **Abstract:** <https://goo.gl/waMjDi>

## **Neonatal palliative care: A practical checklist approach**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 16 September 2018 – Following publication [in the U.K.] of detailed national neonatal palliative care (PC) guidance, practical regional guidance, in the form of multidisciplinary “checklists,” was implemented aiming to improve the quality of neonatal PC.<sup>1</sup> Case note audit was used to examine the quality of locally delivered neonatal PC before and after regional guidance implementation. Twenty-seven patients were allocated to the “before” cohort and 10 to the “after” cohort. Introduction of the checklists was apparently associated with improvements in domains of pain relief and comfort care, monitoring, fluids and nutrition, completion of diagnostics, treatment ceiling decisions, resuscitation status and discussion with parents. Other support for parents was poorly adhered to. Regional guidance improved some aspects of PC delivery though other areas remained sub-optimal. Other strategies, for example, consultation with paediatric PC services, need to be considered to further improve the quality of PC delivered to babies with life-limiting illnesses. **Abstract:** <https://goo.gl/DJvVub>

1. ‘Practical Guidance for the Management of Palliative Care on Neonatal Units,’ Royal College of Paediatrics & Child Health, 2014. **Download/view at:** <https://goo.gl/KVpGmg>

## **Dying alone: An Indigenous man's journey at the end of life**

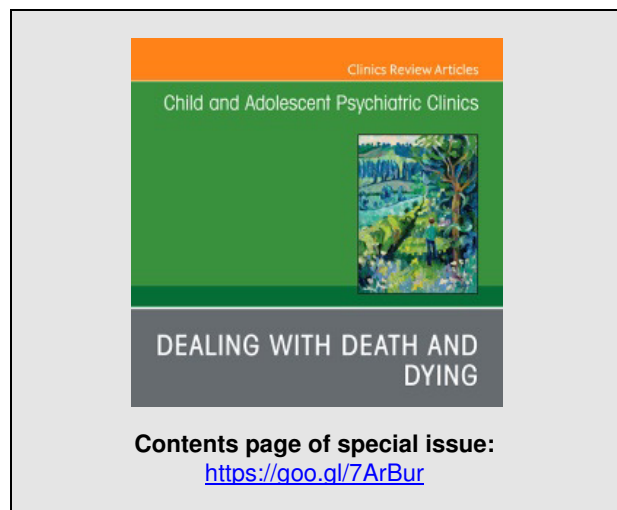
*CANADIAN FAMILY PHYSICIAN*, 2018;64(9):667-668. There has been a recent focus on the disparity of palliative care (PC) resources in underserved areas, including First Nations reserves. This prompted the Canadian Society of Palliative Care Physicians to call for all Canadians to have access to high-quality PC. This case report highlights the inequities faced by an Indigenous patient at the end of life. All health care providers should be aware of the logistic challenges and inequitable access to resources for Indigenous patients from rural and remote communities. In Canada, Indigenous communities have contributed to successful programs that deliver PC to Indigenous peoples. We must continue to work together to provide respectful and appropriate PC for all patients. **Full text:** <https://goo.gl/tuKzbz>

**N.B.** Selected articles on culturally sensitive end-of-life care for Canada's First Nations peoples noted in 3 September 2018 issue of Media Watch (#579, p.12).

## **Ethical issues around pediatric death: Navigating consent, assent, and disagreement regarding life-sustaining medical treatment**

*CHILD & ADOLESCENT PSYCHIATRIC CLINICS OF NORTH AMERICA*, 2018;27(4):539-550. Decisions regarding whether or not to pursue experimental therapies or life-sustaining medical treatment of children with life-limiting illness can be a significant source of distress and conflict for both families and health care providers. This article reviews the concepts of parental permission (consent), assent, and emerging capacity and how they relate to decision-making for minors with serious illness. Decision-making capacity for adolescents is discussed generally and in the context of emotionally charged situations pertaining to the end of life. Strategies for minimizing conflict in situations of disagreement between children and families are provided.

**First page view:** <https://goo.gl/ot8Y9S>



## **Supporting children and families at a child's end of life: Pediatric palliative care pearls of anticipatory guidance for families**

*CHILD & ADOLESCENT PSYCHIATRIC CLINICS OF NORTH AMERICA*, 2018;27(4):527-537. Mental health professionals can play a key role in helping pediatric patients and their families prepare for and endure the death of a child. Impactful interventions include assisting a family's transition toward acceptance of a child's pending death, using prognostication as a tool in emotional preparedness, and education on expectant symptoms to optimize management and sense of caregiver efficacy. **First page view:** <https://goo.gl/C4sVuo>

## **"Will you remember me?": Talking with adolescents about death and dying**

*CHILD & ADOLESCENT PSYCHIATRIC CLINICS OF NORTH AMERICA*, 2018;27(4):511-526. This article describes the preparation, rationale and benefits of talking with adolescents who have life-threatening or life-limiting illness about advance care planning (ACP) and end-of-life concerns in a developmentally sensitive manner. The first step is to ensure a health care provider is ready to work with adolescents in ACP by taking a self-inventory, learning communication skills, and understanding individual barriers. The authors outline how to assess patient and family readiness, including developmental, cultural, personal, and psychosocial considerations. Evidence-based techniques for respectfully and productively engaging adolescents in ACP conversations are discussed. **First page review:** <https://goo.gl/cpmEAG>



## **Chronic obstructive pulmonary disease patients in need of palliative care: Identification after hospitalization through the surprise question**

*CHRONIC RESPIRATORY DISEASE* | Online – 16 September 2018 – Currently, few patients suffering from chronic obstructive pulmonary disease (COPD) who might benefit from a palliative care (PC) approach are referred to a PC team. There is need for a simple and easily applicable tool to identify those patients who would benefit from referral to a PC team. The aim of this study was to determine if the surprise question (SQ) “Would I be surprised if this patient dies within 12 months?” in a subset of recently hospitalized COPD patients identifies those subjects. A total of 93 patients were analyzed. The gold standards framework (GSF) prognostic indicator guidance was regarded as the gold standard test and was assessed for each patient. Sensitivity, specificity, and negative and positive predictive values were calculated to determine the accuracy of the SQ plus recent hospitalization compared to the variables of the GSF. In 35 patients (38%), the answer to the SQ was “not surprised.” The “not surprised” group fulfilled significantly more GSF criteria. The SQ after recent hospitalization for COPD has a very high specificity compared to a standardized tool and is therefore a useful tool for the quick identification of patients who are most likely to benefit from PC. However, this method doesn’t identify all patients who are eligible for referral to PC. **Full text:** <https://goo.gl/kg7g9d>

**N.B.** Additional articles: on the “surprise question” noted in 10 September 2018 issue of Media Watch (#580, p.6); and, on palliative care for people living with COPD noted in 3 September 2018 issue of the weekly report (#579, p.8).

## **Palliative care for all? How can Brazil develop a palliative care service founded on principles of equity and access for all?**

*CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 19 September 2018 – Despite the historical international development of palliative care (PC) over the last 50 years, provision of equity of care and access to appropriate medication remains a major problem in many countries across the world. Interest in the public health approach to end-of-life care has grown over the last 20 years. Models of PC, which are affordable and provide equity of care are changing through these new concepts. The authors describe an existing model of practice in a primary care setting in Rio Grande in Brazil, which could act as a template for redesign of PC services. Traditional models of PC have focused on the physical, social, psychological and spiritual domains. Research has proposed a new model, uniting specialist and generalist PC with compassionate communities and the civic component encapsulated in the compassionate city charter. This model is more comprehensive, emphasizing both harm reduction and health and well being promotion, and is currently being rolled out within the Family Health Strategy in Rio Grande in Brazil. An existing model of PC, which includes the public health approach in Rio Grande be used as a basis for more equitable PC in Brazil, to meet a large unmet need. **Abstract:** <https://goo.gl/hNxPF7>

## **End-of-life decisions. Recent jurisprudence of the European Court of Human Rights**

*ERA FORUM* | Online – 19 September 2018 – The European Convention on Human Rights as well as the Biomedicine Convention do not give instructions to States on how to regulate end-of-life (EoL) issues, such as euthanasia and physician assisted dying. The right to life suggests that States should above all protect human life and take steps in case this entitlement is violated. Over the course of the last years, the European Court of Human Rights has acknowledged that individuals also have a right to personal autonomy. Persons who are mentally competent to make informed decisions can, according to the European Court, decide to refuse treatment and, under certain circumstances, decide to shorten their life, depending on the domestic legal framework. States are left a large margin of appreciation to regulate EoL issues. Besides these self-chosen exceptions, doctors may come to the conclusion that further artificial nutrition, hydrating or life sustaining treatment is not justified, provided that such decisions are taken in an utterly careful way and in accordance with domestic legislation. **Full text:** <https://goo.gl/v97um6>

## Professionals need to discuss more effectively the holistic needs of their patients regarding palliative care

*EVIDENCE-BASED NURSING* | Online – 15 September 2018 – Building on existing research, this study uniquely obtains the patients' perspective, highlighting how patients are hesitant to discuss issues of death and dying with medical doctors and how they do not always fully understand the remit of palliative care (PC) and what it may mean for them and their illness. There is a common misperception that doctors' interests are solely focused on the disease, active treatment and cure. When professionals do not use a shared language about PC, offer toned-down language or avoid direct discussion about death and dying, they are not supporting their patients. Instead, they are encouraging misunderstanding and false hope which can be a major barrier to patient well-being and the uptake of supportive services. Successful communication in this context involves baring witness, supporting patients in their distress and discussing ways to optimise the life that they have yet to live. Although we already have checklists, guides and communication training, more engaged therapeutic approaches are needed, mindful of the very delicate space these communicative needs occupy. There is also a broader issue highlighted here, a total focus on disease negates the patients' experience of the illness. Having knowledge of how that illness experience is being lived is helpful for professionals to provide compassionate and patient-centred care. **Full text:** <https://goo.gl/iLjgUW>

## Access to palliative care in Canada

*INTERNATIONAL JOURNAL OF POPULATION DATA SCIENCE* | Online – 6 September 2018 – The authors present the findings of a study on whether Canadian decedents had access to palliative care (PC) in the last year of life. Data from physician billings, drug claims, home care, long-term care and acute care were linked to identify decedents and PC service use. These data were also used to examine how PC may affect, or be affected by other interactions with the health system, including inpatient alternate level care days, admissions from long-term care, emergency department visits and stays in intensive care units. About 70% of decedents were identified using administrative health data, although there were variations across jurisdictions due to differences in data availability and quality (9%-81%). For decedents identified across care settings, few received PC in the community in their last year of life, ranging from 4% in long-term care to 12% in home care. More decedents were identified as palliative in acute care (44%) but only one-third received PC in another setting despite multiple interactions with the health system in the last year of life. Those who had integrated, community-based PC were less likely to have a stay in an intensive care unit, and more likely to die in the community. However, few Canadian decedents had access to this type of care. **Abstract:** <https://goo.gl/BoR7As>

## Effect of *Apoyo con Cariño* ('Support with Caring') trial of a patient navigator Intervention to improve palliative care outcomes for Latino adults with advanced cancer

*JAMA ONCOLOGY* | Online – 20 September 2018 – Strategies to increase access to palliative care (PC), particularly for racial/ethnic minorities, must maximize primary PC and community-based models to meet the ever-growing need in a culturally sensitive and congruent manner. The *Apoyo con Cariño* ('Support with Caring') randomized clinical trial was conducted from July 2012 to March 2016. The setting was clinics across the state of Colorado, including an academic National Cancer Institute-designated cancer center, community cancer clinics (urban and rural), and a safety-net cancer center. In total, 223 Latino adults enrolled and were randomized to control or intervention groups. The intervention had mixed results. The intervention increased advance care planning and improved physical symptoms; however, it had no effect on pain management and hospice use or overall quality of life. Further research is needed to determine the role and scope of lay navigators in PC. **Abstract:** <https://goo.gl/GHDbSo>

## How we may become detached from our patients and what we can do if this happens

*JOURNAL OF CLINICAL ETHICS*, 2018;29(3):167-178. When clinicians provide clinical care or participate in ethics consultations, they may feel exceptionally painful emotions. When they do, they may distance themselves emotionally from patients and families. This distancing may harm these parties profoundly. It is therefore critical that clinicians avoid this distancing. The author presents an approach that lies outside traditional practice that clinicians may use to try to avoid and even reverse this distancing, if and when they sense that this may be occurring. This approach may also benefit patients and families. It may increase their sense that their clinicians are working with them as allies to achieve their shared medical goals. **Abstract:** <https://goo.gl/GmqfZ1>

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

### Deathbed confession

## When a dying patient confesses to murder: Clinical, ethical, and legal implications

*JOURNAL OF CLINICAL ETHICS*, 2018;29(3):179-84. During an initial palliative care (PC) assessment, a dying man discloses that he had killed several people whilst a young man. The junior doctor, to whom he revealed his story, consulted with senior PC colleagues. It was agreed that legal advice would be sought on the issue of breaching the man's confidentiality. Two legal opinions conflicted with each other. A decision was made by the clinical team not to inform the police. In this article the junior doctor, the palliative medicine specialist, a medical ethicist, and a lawyer consider the case from their various perspectives. **Abstract:** <https://goo.gl/VNfACK>

## Plain Anabaptists and healthcare ethics

*JOURNAL OF CLINICAL ETHICS*, 2018;29(3):201-205. Plain Anabaptists are a small but rapidly growing ethno-religious society with significant concentrations of population in a number of regions in North America. Among the most widely known of the various groups of Plain Anabaptists are the Amish and the Old Order Mennonites. This article provides insight into the culture and values of the Plain Anabaptists so that those who may be called upon to address ethical conflict involving Plain Anabaptists can do so with appropriate knowledge and sensitivity. The authors explore the implications of Plain Anabaptist culture and values for applying the ethical principles of respect for autonomy and beneficence/nonmaleficence. They give a brief description of several elements of Plain Anabaptist culture with attention to the potential they create for ethical conflict in the healthcare setting. **Abstract:** <https://goo.gl/JFpNNj>

Noted in Media Watch 9 March 2015 (#400, p.10):

- *JOURNAL OF RURAL & COMMUNITY DEVELOPMENT*, 2014;9(4)246-258. '**Diversity in rural communities: Palliative care for the Low German Mennonites.**' This article presents research related to understanding death and dying among Low German Mennonites to illustrate the complexity of providing care to a unique religious group in rural Canada. **Abstract:** <https://goo.gl/Bv4JFv>

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

## Supportive and palliative care in people with cirrhosis: International systematic review of the perspective of patients, family members and health professionals

*JOURNAL OF HEPATOLOGY* | Online – 19 September 2018 – People with cirrhosis have unmet needs, which could benefit from a palliative care (PC) approach. Developing effective services needs to be evidence-based from those with personal experience. This review explores patient and family perspectives of perceived needs including communication, health professionals' perspectives on delivery of care, and improving PC between specialities. Nineteen research studies predominately from high income Western

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countries were identified, with a total sample consisting of 1,413 patients, 31 family carers and 733 health professionals. Patient and family members had limited understanding about cirrhosis or its impact. They wanted better information about their disease, its treatment and help with psychological and practical needs. Health professionals had difficulty communicating about these issues to patients and their families. General practitioners left care predominantly to the liver clinicians, who lacked confidence to have discussions about prognosis or future care preferences. The role of PC was recognised as important in caring for this group through earlier integration with liver and community services. Future research should focus on developing communication aides, testing existing tools to identify suitable patients for supportive care and explore robust ways of evaluating supportive care interventions, with more studies needed from middle and low income countries. **Full text:** <https://goo.gl/yhbWct>

### **Clinical phenomenology and characteristics of centenarians in hospice**

*JOURNAL OF PALLIATIVE CARE* | Online – 19 September 2018 – Little is known about the hospice experience of centenarians. As the population of centenarians is projected to increase, understanding their unique end-of-life (EoL) needs will be important to inform delivery of quality EoL care. Our objective was to characterize the hospice experience of centenarians. A retrospective single-institution cohort study of centenarians enrolled in hospice from 1 January 2015 to 31 December 2017 was conducted to collect demographic and clinical information. Seventeen centenarians, who comprised 1.4% of hospice admissions, had an average age of 102 years, were mostly female (71%) and widowed (76%), and all Caucasian. Upon hospice admission, centenarians resided in nursing (8, 47%) and assisted living (4, 24%) residences as well as at home (4, 24%) and in senior independent living (1, 6%). Sixty percent of centenarians died in a nursing home. The most common hospice admission diagnosis was dementia (35%). In this group of centenarians, dementia was the most common condition for hospice enrollment. Slightly less than half resided in nursing homes on admission, although death occurred most frequently in a nursing home. Centenarians were generally able to remain out of the hospital at their time of death. **Abstract:** <https://goo.gl/hsDw8o>

Noted in Media Watch 28 May 2018 (#565, p.10):

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 22 May 2018 – ‘**Centenarians’ end-of-life thoughts and plans: Is their social network on the same page?**’ In nearly half of the cases studied, proxies misjudged whether the centenarian thought about end of life (EoL). Although only few centenarians perceived the EoL as threatening, and approximately one-quarter reported longing for death, proxies overestimated centenarians’ reports on the former and underestimated the latter. **Abstracts:** <https://goo.gl/Hqshg9>

Noted in Media Watch 2 May 2016 (#460, p.6):

- *JOURNAL OF AGING & SOCIAL POLICY* | Online – 25 April 2016 – ‘**Meeting the needs of the growing very old population: Policy implications for a global challenge.**’ The authors outline several approaches to develop evidence-based policies and programs tailored to the needs of very old adults and their families. They focus on three key topics essential to life care: importance of integrated care to meet the complex care needs of the very old; balance between formal and informal care; and, development of suitable places for living. **Abstract (w. link to references):** <http://goo.gl/v2wBsi>



### **Barry R. Ashpole**

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>

## Does advance care planning in addition to usual care reduce hospitalisation for patients with advanced heart failure: A systematic review and narrative synthesis

*PALLIATIVE MEDICINE* | Online – 20 September 2018 – Advance care planning (ACP) can support patient preferences, but studies in people with heart failure have not been assessed. Out of the 1,713 articles, 8 were included representing 14,357 participants from in/outpatient settings from five countries. Two randomised controlled trials and one observational study assessed planning as part of a specialist palliative care intervention; one randomised controlled trial assessed planning in addition to usual cardiology care; one randomised controlled trial and one observational study assessed planning in an integrated cardiology-palliative care model; one observational study assessed evidence of planning (advance directive) as part of usual care and one observational study was a secondary analysis of trial participants coded do not attempt cardiopulmonary resuscitation. ACP: 1) Reduced hospitalisation (5/7 studies); 2) Increased referral/use of palliative services (4/4 studies); and, 3) Supported deaths in the patient-preferred place (2/2 studies). **Abstract:** <https://goo.gl/rebpY7>

### Advance directive documentation among adult day services centers and use among participants, by region and center characteristics: [U.S.] National Study of Long-Term Care Providers, 2016

CENTERS FOR DISEASE CONTROL & PREVENTION (National Health Statistics Reports No. 117) | Online – 12 September 2018 – In 2016, 78.1% of adult day services centers (ADSCs) maintained documentation of advance directives (ADs), with the Northeast having the highest percentage among the U.S. regions. A higher percentage of Medicaid-licensed ADSCs maintained documentation of ADs compared with ADSCs that were not Medicaid licensed. Among ADSCs that maintained documentation, about 38% of participants had an AD in their files. Small ADSCs had a higher percentage of participants with ADs compared with medium and large ADSCs. **Download/view:** <https://goo.gl/3JSbEp>

#### Related

- *AUSTRALIAN JOURNAL ON AGEING* | Online – 21 September 2018 – ‘**Changes in resuscitation and end-of-life documentation in older patients’ clinical case notes: A comparison of 2011 and 2017 practice.**’ The Resuscitation Plan 7-Step Pathway has markedly improved the frequency of documented discussion, the rate of recorded Not For CPR status, and clarity of documentation. The proportion of patients with a documented order significantly increased, from 34 to 63%, with a concurrent increased number of patients identified as ‘Not For Cardiopulmonary Resuscitation.’ The standardised documentation has also improved rates of documented discussion, legibility and identification of the involved doctor. **Abstract:** <https://goo.gl/XwSQRF>
- *JOURNAL OF PARAMEDIC PRACTICE* | Online – 18 September 2018 – ‘**Advanced care planning in end-of-life care: The key role of ambulance services.**’ Effective communication and coordination between individual care providers is vitally important to ensure that patients’ wishes are respected throughout their care and when they die, as well as that families and loved ones are supported following the patient’s death. Ambulance services play an increasingly key role in end-of-life care and this is especially true in terms of transfer of the dying patient. This article will explore advanced care planning and, in particular, focuses on do-not-attempt cardiopulmonary resuscitation orders, advanced decisions to refuse treatment and rapid discharge transfers. **Abstract:** <https://goo.gl/GyDevF>



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>



## The “safe death”: An ethnographic study exploring the perspectives of rural palliative care patients and family caregivers

*PALLIATIVE MEDICINE* | Online – 19 September 2018 – In rural settings, relationships between place and self are often stronger than for urban residents, so one may expect that rural people would view dying at home as a major feature of the “good death.” Twelve rural (town and farm) patients with life-limiting illnesses, 18 family caregivers and 6 clinicians, in the Snowy Monaro region of New South Wales, Australia, participated in this study over the course of the deaths of the patients. A “safe death” was central to a “good death” and was described as a death in which one could maintain: 1) A connection with one’s previous identity; 2) Autonomy and control over decisions regarding management of end-of-life care; and, 3) Not being overwhelmed by the physical management of the dying process. For all participants, the preferred place of death was the “safe place,” regardless of its physical location. Safety, in this study, is related to a familiar place for death. A home death is not essential for and does not ensure a “good death.” We all have a responsibility to ensure all places for dying can deliver the “safe death.” Future research could explore the inter-relationships between safety and preference for home or home-like places of death. **Abstract:** <https://goo.gl/c7STf2>



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**N.B.** Additional articles on the provision and delivery of palliative and end-of-life care in rural and remote regions of Australia noted in 27 August 2018 issue of Media Watch (#578, p.15).

## Quality of care for the dying across different levels of palliative care development: A population-based cohort study

*PALLIATIVE MEDICINE* | Online – 19 September 2018 – There is a lack of knowledge about how the provision and availability of specialized palliative care (PC) relates to the quality of dying in hospital and community-based settings. The authors investigated access to PC in Southern Sweden, where one region offers PC in accordance with European Association for Palliative Care guidelines for capacity, and the other region offers less developed PC. Data on approximately 12,000 deaths during 2015 were collected from the Swedish Register of Palliative Care. The quality of care was investigated by region, and was measured in terms of assessment of oral health and of pain, and end-of-life conversation, companionship at death and artificial nutrition/fluid in the last 24 hours. The overall quality of care during last week of life was not consistently better in the region with fully developed PC compared with the less developed region. In fact, for patients dying in hospitals and community-based settings, the quality was statistically significantly better in the less developed region. The small proportion of patients who had access to specialized PC had superior quality of care during the last week of life as compared to patients in other care settings. The capacity of specialized PC does not *per se* influence the quality of care during the last week of life for patients in other settings. **Abstract:** <https://goo.gl/gddQKM>

## Barriers and enablers to deprescribing in people with a life-limiting disease: A systematic review

*PALLIATIVE MEDICINE* | Online – 19 September 2018 – Knowing the barriers/enablers to deprescribing in people with a life-limiting disease is crucial for the development of successful deprescribing interventions. These barriers/enablers have been studied, but the available evidence has not been summarized in a systematic review. A total of 1,026 references were checked. Five studies met the criteria and were included in this review. Three types of barriers/enablers were found: organizational, professional and patient (family)-related barriers/enablers. The most prominent enablers were organizational support (e.g., for standardized medication review), involvement of multidisciplinary teams in medication review and the perception of the importance of coming to a joint decision regarding deprescribing, which highlighted the need for interdisciplinary collaboration and involving the patient and his family in the decision-making process. The most important barriers were shortages in staff and the perceived difficulty or resistance of the nursing home resident’s family – or the resident himself. The scarcity of findings in the literature highlights the importance of filling this gap. Further research should focus on deepening the knowledge on these barriers/enablers in order to develop sustainable multifaceted deprescribing interventions in palliative care. **Abstract:** <https://goo.gl/gptGaF>

## Supporting the bereaved in greatest need: We can do better

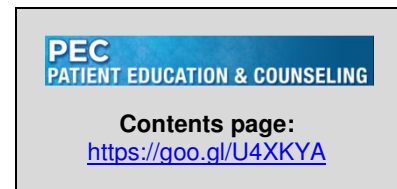
*PALLIATIVE & SUPPORTIVE CARE* | Online – 18 September 2018 – The disturbing truth is that following the loss of someone significant in their lives, those who struggle, those who may benefit from professional support the most, are often the ones who do not end up getting help. This is not unique in the context of bereavement, but given the risk of downstream physical and mental health challenges, that grieving individuals face and the importance of continuity of palliative care through bereavement, the bereaved demand our attention. **Abstract:** <https://goo.gl/SMqZf5>

### Related

- *DEATH STUDIES* | Online – 20 September 2018 – ‘**The role of theory in understanding grief.**’ As the tandem fields of bereavement care and research have evolved, so too has a keener appreciation of the role of theory in advancing both. This article succinctly summarizes the function of theory in directing investigation and intervention in grief and grief therapy and describes “meaning reconstruction” as one exemplar of this bootstrapping process, leading to evidence-based conceptual refinements and creative contributions to clinical practice. **Abstract:** <https://goo.gl/Xe3JvT>

## Shared decision making’s adolescence and transition into adulthood

*PATIENT EDUCATION & COUNSELING*, 2018;101(10):1723-1724. The seven articles comprising the special section in this issue are thematically linked through their interest in how patients and clinicians perceive decisions and shared decision making. Yet they are diverse in many ways including populations, methodologies, and diseases. The articles represent work done in several countries, with qualitative and quantitative methodologies, from small studies on decision making perceptions and desires to large investigations of real-world experience in decision making, an from children and adolescents to older cancer survivors. **Abstract (w. link to references):** <https://goo.gl/Fj2Dzo>



Noted in Media Watch 16 January 2017 (#495, p.7):

- *THE HASTINGS REPORT* | Online – 11 January 2017 – ‘**Conflating capacity and authority: Why we’re asking the wrong question in the adolescent decision-making debate.**’ Are adolescents sufficiently capacitated to make their own medical decisions? Is the mature-minor doctrine, an uncommon legal exception to the rule of parental decision-making authority, something we should expand or eliminate? Bioethicists have dealt with the curious liminality of adolescents – their being neither children nor adults – in a variety of ways. However, recently there has been a trend to rely heavily, and often exclusively, on emerging neuroscientific and psychological data to answer these questions. Two critical mistakes are being made. **Abstract:** <https://goo.gl/ciyAEj>

## Child mortality in the U.S.: Bridging palliative care and public health perspectives

*PEDIATRICS* | Online – 19 September 2018 – Child and adolescent mortality rates in the U.S. have fallen fairly consistently since the 1960s. And yet, infant mortality and deaths in adolescents and young adults are not infrequent. In 2015, 1 out of every 270 infants in the U.S. died before their first birthday, while 1 out of every 1,438 Americans aged 15 to 24 died. Among children and adolescents, non-intentional injuries, suicide, and homicide are leading causes of death. These cause-of-death statistics provide powerful data to inform public health initiatives, preventive medicine programs, and child health advocacy around end-of-life care. Trowbridge *et al* take the novel approach of studying modes of death rather than causes of death.<sup>1</sup> **Introductory paragraph:** <https://goo.gl/gXjKjS>

1. ‘Modes of Death Within a Children’s Hospital,’ *Pediatrics*, published online 18 September 2018. Abstract: <https://goo.gl/26Mzb8>

Cont.

## Related

- *PEDIATRICS* | Online – 19 September 2018 – ‘**Modes of death within a children’s hospital.**’ Knowledge about how children die in pediatric hospitals is limited, and this hinders improvement in hospital-based end-of-life care. In this retrospective chart review of all the patients who died in a children’s hospital between July 2011 and June 2014 most deaths occurred in ICUs after the withdrawal of life-sustaining technology. Race and palliative care involvement may influence the manner of a child’s death. **Abstract:** <https://goo.gl/6KBGMr>

## Unlocking the locked-in syndrome: Capacity evaluation and a multidisciplinary approach to care

*PSYCHIATRIC ANNALS*, 2018;48(9):448-451. Locked-in syndrome (LIS) is a state of minimal responsiveness where patients are awake and conscious but are selectively de-efferented (i.e., they are unable to move their limbs or speak). These functional impairments make clinical assessments about patient care challenging. LIS patients may face a high potential for a “disability paradox,” wherein the persistent disability maybe erroneously assumed to be a poor indicator of quality of life. To add to this, some of the fundamental limitations in such a decision-making process are fluctuating levels of alertness, reliance on easily fatigable and inconsistent eye movements for communication, and exhaustive evaluations of cognitive functioning and the patient’s understanding of risks and benefits of the presented information for decision making over the course of days. Hence, establishing an elementary but reliable system of communication between the patient’s family, caregivers, and the patient is essential to optimizing the quality of life. **Introductory paragraphs:** <https://goo.gl/qXUdHD>

Noted in Media Watch 23 June 2014 (#363, p.10):

- *BRAIN INJURY* | Online – 9 June 2014 – ‘**A European survey on attitudes towards pain and end-of-life issues in locked-in syndrome.**’ From the 3,332 respondents to a close-ended survey – 33% physicians, 18% other clinicians, 49% other professions; 47% religious – 90% agreed that patients with locked-in syndrome can feel pain. The majority (75%) disagreed with treatment withdrawal, but 56% did not wish to be kept alive if they imagined themselves in this condition. Religious and southern Europeans opposed to treatment withdrawal more often than non-religious and participants from the North. When the locked-in syndrome was compared to disorders of consciousness, more respondents endorsed that being in a chronic locked-in syndrome was worse than being in a vegetative state or minimally conscious state for patients (59%) than they thought for families. **Abstract (w. link to references):** <https://goo.gl/jgyNx7>

## Rethinking end-of-life care and palliative care: Learning from the illness trajectories and lived experiences of terminally ill patients and their family carers

*QUALITATIVE HEALTH RESEARCH* | Online – 20 September 2018 – Lynn conceptualized end-of-life care (EoLC) for patients with advanced chronic-progressive illnesses as a combination of life-preserving/palliative care (PC), the palliative aspect gradually becoming the main focus as death approaches.<sup>1</sup> The authors checked this concept by exploring the advanced-terminal illness trajectories of 50 patients. Strategies heralding active therapy exhaustion were the catalyst for a participant’s awareness of terminality, but were not a decisive factor in the divergent EoLC pathways detected. The terms life-preserving and palliative do not adequately capture EoLC pathways due to their conceptual ambiguity. Conversely, the concept of EoLC encompassing three PC modalities (life-prolonging palliative therapy, restorative PC, and symptom-oriented [only] PC), each harboring a different blend of life-preserving and symptom-comforting aspects, proved adequate. These modalities could run serially, oscillatorily, or parallelly, explaining the divergent EoLC pathways. The authors suggest an adjustment of the model of Lynn and reconsider the traditional PC concept. **Abstract:** <https://goo.gl/2ZpX94>

1. ‘Measuring quality of care at the end of life. A statement of principles,’ *Journal of the American Geriatrics Society*, 1997;45(4):526-527. **Access options at:** <https://goo.gl/HpAaow>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ACADEMIC EMERGENCY MEDICINE* | Online – 19 September 2018 – ‘**Physician-assisted death: Ethical implications for emergency physicians.**’ In light of changing terminology, laws, public and professional attitudes, and the availability of published data about the practice, the authors review key concepts and terms in the ongoing physician-assisted death (PAD) debate, moral arguments for and against PAD, the current legal status of PAD in the U.S. and in other nations, and data on the reported experience with PAD in those U.S. jurisdictions where it is a legal practice. The authors then identify situations in which emergency physicians (EPs) may encounter patients who request PAD or have attempted to end their lives with physician assistance and consider EP responses in those situations. Based on their analysis, they offer recommendations for emergency medical practice and professional association policy. **Abstract:** <https://goo.gl/mBLXNU>
- *BRITISH JOURNAL OF CANADIAN STUDIES* | Online – Accessed 17 September 2018 – ‘**Morality politics of physician-assisted suicide: Lessons from Canada and the U.S.**’ The authors examine the possible role of public opinion in affecting policy by comparing the life histories of eight parallel issues in Canada and the U.S. Issues selected all involve morality policies and include abortion, capital punishment, gun control, marijuana legalization, physician-assisted suicide, pornography, same-sex relations, and same-sex marriage. Because of the moral content of these issues, they are expected to be highly salient, easy to understand, resistant to compromise, and tied to collective action. When they enter the policy arena, they are typically associated with high levels of conflict. Particular issues are selected because their attributes could be expected to make public opinion about them a significant factor in explaining how they are processed by the political system. The authors’ research aims at answering three questions: 1) To what extent does public opinion involving moral conflicts affect the trajectory of issues, from the time they emerge to their possible resolution? 2) Does the evolution of issues over time affect how and when public opinion reacts? 3) How does the national setting have an impact on the relevance of public opinion? **Abstract (via ResearchGate):** <https://goo.gl/hkoiAQ>
- *CANADIAN FAMILY PHYSICIAN*, 2018;64(9):631. ‘**Euthanasia and suicide.**’ This issue of the journal includes several articles on medical assistance in dying (MAiD). It provides answers to some questions, particularly from the perspectives of patients, their loved ones, and physicians providing MAiD. Nuhn *et al* explore the wishes, fears, and beliefs of 23 Vancouverites who requested MAiD in 2016.<sup>1</sup> The primary reasons given for requesting MAiD were loss of autonomy and control, unacceptable quality of life, loss of independence, loss of physical abilities, incapacity or difficulty communicating, loss of pleasure, and suffering or fear of suffering. Interestingly, the authors mention that pain was very rarely cited as a cause of suffering. In addition, Wiebe *et al* share the results of a retrospective study analyzing the records of patients referred to 1 of the 6 physicians providing MAiD in British Columbia in 2016.<sup>2</sup> Among the 250 who submitted a request, 112 had it granted, 11 died of natural causes, and 127 were not approved; of those in the latter group, most were not ready to receive MAiD or simply wanted to make sure they would eventually be able to access it, while 35 were found ineligible. Those who request MAiD mostly suffer from cancer, multiple organ failure (cardiac or respiratory failure), and neurologic diseases. These results are consistent with those found in other studies conducted on the topic in other countries where MAiD has been legalized. Regarding the experiences of loved ones, the article by Holmes *et al* reveals that most loved ones believed MAiD respected the wishes of the person who had requested it, allowing them to put an end to their suffering, and that the procedure was conducted peacefully.<sup>3</sup> While these studies have provided answers to some questions regarding MAiD, others yet remain. If, as in most of Canada, MAiD consists of voluntary euthanasia and assisted suicide, it would be pertinent to discover the proportion of Canadians opting for one or the other and what led them to that choice. Also, some people afflicted by an incurable disease and pain that cannot be relieved might choose to end their lives by committing suicide alone and without assistance. Another question to consider is whether people suffering from depression request MAiD more than those without depression do. This question is raised in ‘Léopold and his request for medical assistance in dying.’<sup>4</sup> **Full text:** <https://goo.gl/aTtAVu>



1. ‘Experiences and perspectives of people who pursued medical assistance in dying: Qualitative study in Vancouver, British Columbia.’ **Full text:** <https://goo.gl/RhpGHe>

2. 'Reasons for requesting medical assistance in dying.' Full text: <https://goo.gl/iMpuYG>
3. 'Exploring the experience of supporting a loved one through a medically assisted death in Canada.' Full text: <https://goo.gl/hUF3SH>
4. 'Léopold and his request for medical assistance in dying.' Full text: <https://goo.gl/KoRM7v>

**N.B.** Additional articles/commentaries on MAiD included in the September issue of *Canadian Family Physician*:

'Reflections from a provider of medical assistance in dying.' Full text: <https://goo.gl/UJ1adN>

'Time to clarify Canada's medical assistance in dying law.' Full text: <https://goo.gl/rTPfFZ>

'Providing medical assistance in dying' Full text: <https://goo.gl/PCdizb>

'Exploring family medicine preceptor and resident perceptions of medical assistance in dying and desires for education.' Full text: <https://goo.gl/Vr3kHg>

- *JOURNAL OF DISABILITY & RELIGION* | Online – 20 September 2018 – '**The contradictory expressive functions of the Americans with Disabilities Act and physician-assisted suicide laws.**' Certain laws, such as civil rights laws and criminal laws, are considered to have powerful expressive functions. The expressive functions may be directed at shifting social norms, or at articulating a social consensus about a particularly important norm. The Americans with Disabilities Act (ADA) is such a law, expressing the norm that "society's accumulated myths and fears about persons with disabilities" are as debilitating as actual disabilities. This article analyzes the arguments of disability rights advocates that the expressive effect of laws legalizing physician-assisted suicide directly contradicts the norm of the ADA. Abstract: <https://goo.gl/4wo8G8>
- *JOURNAL OF DISABILITY & RELIGION* | Online – 20 September 2018 – '**Anthropologies of hope and despair: Disability and the assisted-suicide debate.**' The physical criteria that determine who is and who is not eligible for assisted suicide imply that some lives – such as lives with disability – are less "objectively" worthwhile than others. Besides being degrading and discriminatory, this view is self-deceived. Aging makes both the non-disabled and disabled prone over time to experience increasingly serious disabilities, from impaired mobility to hearing loss. Anthropologies that undermine life with disability therefore undermine our humanity as such, risking self-hatred and misanthropy. As an alternative to this anthropology of despair, the author considers hopeful models affirmed by disability rights activists and by Christian theology. Abstract: <https://goo.gl/63vF1Z>
- *JOURNAL OF MEDICAL ETHICS* | Online – 21 September 2018 – '**Medical assistance in dying at a paediatric hospital.**' This article explores the ethical challenges of providing medical assistance in dying (MAiD) in a paediatric setting. More specifically, the authors focus on the theoretical questions that came to light when they were asked to develop a policy for responding to MAiD requests at their tertiary paediatric institution. They illuminate a central point of conceptual confusion about the nature of MAiD that emerges at the level of practice, and explore the various entailments for clinicians and patients that would flow from different understandings. Finally, the authors consider the ethical challenges of building policy on what is still an extremely controversial social practice. While MAiD is currently available to capable patients in Canada who are 18 years or older – a small but important subsection of the population our hospital serve – they write their policy with an eye to the near future when capable young people may gain access to MAiD. The authors propose that an opportunity exists for MAiD-providing institutions to reduce social stigma surrounding this practice, but not without potentially serious consequences for practitioners and institutions themselves. Abstract: <https://goo.gl/VEoqod>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 17 September 2018 – '**Physicians' attitudes towards euthanasia and assisted suicide in Italy.**' In Italy, many cases raised by media recently provided the impetus for a new law regulating the living will. Of concern, it has been recently reported that there is a lack of knowledge among patients about the meaning of end-of-life (EoL) issues. Physician-assisted suicide and euthanasia have been increasingly debated in the public arena, and in some European countries, legislation exists to regulate these EoL issues. Abstract (w. link to references): <https://goo.gl/FqcHPh>

Cont.



- *JOURNAL OF PASTORAL CARE & COUNSELING* | Online – 18 September 2018 – ‘**Medical assistance in dying: Challenges for Muslim healthcare professionals.**’ The discussion of medical assistance in dying (MAiD) among Muslim health caregivers including physicians, social workers, spiritual caregivers, etc., remains insufficient. A thorough analysis of the content of available resources revealed that we need more literature to analyze the attitude of Muslim health caregivers towards MAiD. This article describes the general attitude towards MAiD among non-Muslim. This will allow us to observe the challenges and dilemmas faced by Muslim healthcare professionals around MAiD. **Abstract:** <https://goo.gl/2MsRb5>

## Journal Watch

### PC-FACS

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 17 September 018 – PC-FACS (**F**ast **A**rticle **C**ritical **S**ummaries for Clinicians in Palliative Care) provides hospice and palliative care clinicians with concise summaries of the most important findings from more than 100 medical and scientific journals. **Summary:** <https://goo.gl/i7qsjH>



### “Journalologists” use scientific methods to study academic publishing. Is their work improving science?

*SCIENCE* | Online – 19 September 2018 – A recent Chicago, Illinois, meeting marked the birth of what is now sometimes called “journalology,” a term coined by Stephen Lock, a former editor of the British *Medical Journal*. Its goal: improving the quality of at least a slice of the scientific record, in part by creating an evidence-based protocol for the path from the design of a study to its publication. That medical journals took a leading role isn’t surprising. A sloppy paper on quantum dots has never killed anyone, but a clinical trial on a new cancer drug can mean the difference between life and death. The field has grown steadily and has spurred important changes in publication practices. Today, for example, authors register a clinical trial in advance if they want it considered for publication in a major medical journal, so it doesn’t vanish if the results aren’t as hoped. And authors and journal editors often pledge to include in their papers details important for assessing and replicating a study. But almost 30 years on, plenty of questions remain, says clinical epidemiologist David Moher of The Ottawa Hospital Research Institute, a self-described journalologist. Moher – who once thought his dyslexia explained why he couldn’t understand so much published research – wants to know whether the reporting standards that journals now embrace actually make papers better, for instance, and whether training for peer reviewers and editors is effective. Finding the answers isn’t easy. Journalology still hovers on the edge of respectable science, in part because it’s often competing with medicine for dollars and attention. Journals are also tough to study and sometimes secretive, and old habits die hard. **Full text:** <https://goo.gl/KH4UPy>



**International Congress on Peer Review and Scientific Publication**

**N.B.** ‘Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly work in Medical Journals,’ International Committee of Medical Journal Editors. **Download/view at:** <https://goo.gl/3uPWJg>

Noted in Media Watch 3 September 2018 (#579, p.15):

- *NATURE* | Online – 29 August 2018 – ‘**Publish peer reviews.**’ Less than 3% of scientific journals allow reviews to be published. In a survey, 59% of 3,062 respondents were in favour of open reports.<sup>1</sup> The vast majority of scientists think peer review is essential for vetting research papers. The process gives authors constructive feedback, offers editors insight and assures readers of the trust-worthiness of research. Generally only editors, authors and (sometimes) reviewers see referee reports. That enables several forms of abuse: referees might be superficial, rude or biased; authors might respond inadequately to reasonable criticism; editors might not hold authors or reviewers to account; and, predatory publishers will charge fees without providing quality review. **Full text:** <https://goo.gl/9n8RWL>

1. ‘Survey on open peer review: Attitudes and experience amongst editors, authors and reviewers,’ Plos One, published online 18 December 2017 (#543, p.21). [Noted in 18 December 2017 issue of Media Watch (#543, p.21)] **Full text:** <https://goo.gl/Aoj2yg>

## 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.

## Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

## Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

## 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.

**[Search Back Issues of Media Watch @ http://goo.gl/frPgZ5](http://goo.gl/frPgZ5)**

## Media Watch: Access on Online

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/fJczV6>

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

PALLIATIVE CARE NETWORK: <https://goo.gl/YBP2LZ>

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

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

### **Asia**

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

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

### **Canada**



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

[Scroll down to 'Are you aware of Media Watch?']

Cont.

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

[Scroll down to 'Additional Resources']

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

#### **Europe**

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

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

#### **South America**



Academia Nacional de Cuidados Paliativos (Brazil): <https://goo.gl/b5CV31>

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