

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.

1 January 2018 Edition | Issue #544



Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

Distributive justice: Scroll down to [Specialist Publications](#) and 'An ethical priority in global palliative care' (p.18), in *Journal of Pain & Symptom Management*.

Canada

How redefining palliative care is bringing end-of-life services to First Nations

ONTARIO | TV Ontario (Toronto) – 20 December 2017 – A six-year research project based in Thunder Bay studying four communities has shown that ailing people can stay on reserve and out of hospital for longer with minimal investments in homecare and medical services in the community. While the project's sample size was small, the model's perceived success and potential flexibility is prompting the province to make investments in on-reserve palliative care (PC) in the near future. When representatives of Lakehead University's Centre for Education & Research on Aging & Health visited Naotkamegwaning to consult with elders on developing PC services in 2011, the room's immediate reaction was shocked silence. The concept of PC ... was culturally offensive in a community where dying is a taboo discussion topic. "White people, they plan, they even pick their own plots. Native people don't do that," [Lulu Belle] Kabestra explains. "It's just not acceptable until it happens. That's when you talk about it – not before." At that 2011 meeting, Kabestra broke the silence to tell the story of her father's passing in the hospital. She reframed the discussion to focus on keeping aging people in the community where they can be on the land, in the cul-

ture, and with family. Elders in other communities echoed the desire to age at home. Lakehead's research in three Ontario communities including Naotkamegwaning, Fort William First Nation, and Six Nations as well as Peguis First Nation in Manitoba found 87% of respondents said they believed their community members would prefer to receive services locally if they were available and appropriate. Many elders were also insistent on setting boundaries for cultural outsiders to be involved with their end-of-life care (EoLC). They were especially concerned that bringing culturally alien palliative services to the First Nation could threaten traditional practices surrounding EoLC, which can involve large immediate and tight-knit extended families. <https://goo.gl/qyfq8P>

Specialist Publications

'A national palliative care strategy for Canada' (p.18), in *Journal of Palliative Medicine*.

'A call for integrated and coordinated palliative care' (p.18), in *Journal of Palliative Medicine*.

N.B. Additional articles on palliative care and end-of-life care for the indigenous peoples of Canada are noted in the 4 December and 6 February 2017 issues of Media Watch (#541, pp.1-2 and #498, pp.1-2, respectively).

Aging inmates: Correctional Service of Canada has strategy in the works

THE CANADIAN PRESS | Online – 19 December 2017 – Canada’s prison population is getting greyer, and the Correctional Service of Canada expects to soon complete a strategy for how to deal with aging inmates. The Office of the Correctional Investigator – the ombudsman for federal prisoners – has been pressing the service to do that for several years.¹ Inmates 50 and older are considered to be in the aging category. That cut-off point might seem young to someone on the outside, but health is generally poorer behind bars, said Ivan Zinger, the correctional investigator. “You can basically add a factor of 10 years on chronological age,” he said. That means more heart problems, diabetes and other ailments in facilities designed with much younger occupants in mind. One in four inmates in Canada is over 50, but in some prisons that age group makes up more than half the population, said Zinger. Zinger’s predecessor had been calling for a strategy since at least 2010, when 18% of federal inmates were over 50. The correctional service said in a statement that it plans to complete its strategy in the 2017-2018 fiscal year. It already has a way to assess older offenders so they can get care for chronic dis-

eases related to aging. The demographic trends means more natural deaths behind bars. The correctional service says it can provide end-of-life care in prisons or in regional hospitals. Inmates with life-threatening, non-curable illnesses can also apply for early compassionate release. <https://goo.gl/x4RAuF>

Specialist Publications

‘Incarcerated patients and equitability: The ethical obligation to treat them differently’ (p.15), in *Journal of Clinical Ethics*.

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 November 2017) can be downloaded/viewed at Palliative Care Network-e: <https://goo.gl/YLckx6>

1. ‘Annual Report of the Office of the Correctional Investigator, 2015-2016,’ Office of the Correctional Investigator, June 2016. [Noted in the 9 October 2017 issue of Media Watch (#533, p.2)] **Download/view at:** <https://goo.gl/tq32qo>

The goal of serious illness management is to create balance between your left and right brains: To weigh medical intervention against leaving well enough alone

POLICY OPTIONS | Online – 19 December 2017 – Lance Shaver ... correctly says, “Palliative care (PC) is misunderstood and often forgotten,” but he fails to differentiate PC from medical care.¹ When PC is lumped together with advanced treatment and end-of-life care, patients often think that doing less than “everything” means doing “nothing.” The goal of serious illness management is to create balance between your left and right brains: to weigh medical intervention against leaving well enough alone. As an emergency physician, I’m charged with balancing quality of care with quality of life (QoL). Are my chronically ill patients better managed in the hospital or at home? Most of these patients recognize that being admitted to the hospital is more dreadful than beneficial. When patients have an incurable illness, can they still feel better? QoL begins at home, and home-based PC can provide the necessary resources to manage chronic illness outside the hospital. As Shaver notes, QoL can include home care and nursing support, management of pain and symp-

The Two Sides to Your Thinking
Medical Care vs. Palliative Care

Left Brain Medical Care	Right Brain Palliative Care
Physical Health	Spiritual Well-Being
Healthcare Professionals	Family Caregivers
Medical Intellect	Parental Instincts
Duty to Save Lives	Empathy to Spare Dignity
Fearful of Death & Dying	Value-Conscious
Fight-or-Flight Reaction	Peaceful, Easy Feeling
Glass Half Empty	Glass Half Full
Deficits-Frustrations-Unfinished	Abundance-Satisfaction-Fulfillment
Oblige Others	Supported by Others
Medicare Entitlement	Palli-Care Enlightenment
Big Business	Personal Service
Buying Into the System	Bucking the System
Chance Living Longer	Prefer Dying at Home



Cont.

toms, and support for families and caregivers. None of these services need the direct involvement of a physician. Hence, PC might be seen as a nursing practice rather than a medical specialty. Training physicians to provide QoL or personal wellness is misguided. <https://goo.gl/n5JfkK>

1. 'Expanding access to palliative care will improve quality of life for people with serious illnesses, while also reducing health care costs,' *Policy Options*, 28 November 2017. <https://goo.gl/swwXpf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SASKATCHEWAN | CBC News (Saskatoon) – 19 December 2017 – **'Province recording medically-assisted deaths as suicides...'** The day Alice Tataryn asked for medical assistance to end her life and avoid a painful death, her daughter Susan Tataryn showed her a letter she had written to the Office of the Chief Coroner in Saskatchewan. Alice was in a Prince Albert hospital dying from terminal lung cancer that had spread into her skull, liver, spine and collarbone. But in the process of pursuing medical assistance in dying (MAiD), the family learned Alice's death would be recorded as a suicide. In Saskatchewan, policy dictates that coroners who fill out the medical certificate of death mark the "manner of death" in MAiD cases as being suicide. The policy is currently being reviewed to determine what regulatory or legislative changes are needed. <https://goo.gl/dj9Qy8>

Specialist Publications

'Are informal caregivers of persons with dementia open to extending medical aid in dying to incompetent patients? Findings from a survey conducted in Quebec, Canada' (p.26), in *Alzheimer Disease & Associated Disorders*.

'Decoding conscientious objection in medical aid in dying: First results from a unique study' (p.27), in *Le Spécialiste*.

U.S.A.

Family decision-makers in medical crises benefit from emotional support

REUTERS HEALTH | Online – 29 December 2017 – Making medical decisions for a hospitalized older relative can be very stressful, but family members may be less traumatized and make better decisions when they receive support from healthcare workers, a study suggests.¹ Nearly half of hospitalized older adults need help communicating and making healthcare decisions, and caregivers often experience stress while helping their loved ones. Family members [i.e., study participants] faced at least one tough decision during the hospital stay about life-sustaining therapy such as ventilator use or resuscitation orders, procedures or surgeries requiring written informed consent, or placement in a nursing home. <https://goo.gl/c9wggj>

Specialist Publications

'Assessing the decision making capacity of terminally ill patients with cancer' (p.7), in *American Journal of Geriatric Psychiatry*.

'Bridging the cultural divide between oncology and palliative care sub-specialties: Clinicians' perceptions on team integration' (p.8), in *American Journal of Hospice & Palliative Medicine*.

'Respecting Choices and related models of advance care planning: A systematic review of published evidence' (p.8), in *American Journal of Hospice & Palliative Medicine*.

'American Society for Pain Management Nursing and Hospice & Palliative Nurses Association position statement: Pain management at the end of life' (p.22), in *Pain Management Nursing*.

1. 'Communication quality predicts psychological well-being and satisfaction in family surrogates of hospitalized older adults: An observational study,' *Journal of General Internal Medicine*, published online 28 November 2017. **Abstract:** <https://goo.gl/P1Wch5>

Many with deadly brain cancer don't opt for hospice care

UNITED PRESS INTERNATIONAL | Online – 28 December 2017 – Many patients with a deadly type of brain tumor don't receive adequate hospice care, a new study finds.¹ Massachusetts General Hospital Cancer Center researchers analyzed data from more than 12,000 patients in the U.S. with malignant gliomas who were treated and died between 2002 and 2012. "We know from prior research that patients with terminal illnesses, including incurable cancers, derive numerous benefits from hospice services," corresponding author Dr. Justin Jordan said. "Even though timely hospice enrollment is an important measure of quality oncology care, we found that 37% of malignant glioma patients received no hospice at all prior to death," said Jordan. Sixty percent of patients did enroll in hospice care, and the average length of stay was 21 days. However, 23% of patients enrolled within a week before their death, and 11% less than three days before their death, which was likely too late to do much good. <https://goo.gl/G2ZH65>

1. 'Hospice utilization in patients with malignant gliomas,' *Neuro-Oncology*, published online 10 October 2017. **Abstract:** <https://goo.gl/ZHP8FM>

Can we get better at treating chronic illness?

Filling the palliative care workforce pipeline

STAT NEWS | Online – 22 December 2017 – Medical systems are increasingly turning to palliative care (PC) specialists, who are experts in complex symptom management. One problem looms, though: there aren't enough of them. By some measures, there are at least 11,000 fewer palliative specialists than are needed to care for the current set of patients, and possibly as many as 20,000. As medical systems look to push PC further "upstream" – into clinics and in patients' homes, before they arrive in hospitals – the shortage will be felt even more keenly. Dr. Diane Meier, co-founder of the Center to Advance Palliative Care, identified three areas where the industry should concentrate in the coming year to build PC capacity. First, she said, increase funding for graduate medical education training slots for palliative clinicians, to bolster the ranks of specialists. Second, require medical and nursing schools to provide palliative training, or risk losing accreditation. Third, encourage more training for mid-career doctors who want to strengthen their PC skills. Will it happen? "All we're doing right now is cutting budgets for everything," she said. "This requires a commitment to spend money on the workforce for the future, which is ... hard to be optimistic about it." One ray of hope: The Palliative Care & Hospice Education & Training Act, which was introduced in March and would require the Department of Health & Human Services to support training and research for these medical specialties, attracted early bipartisan support. "For one reason or another it didn't get hooked into any of the bills that were moving this year," Meier said. "So I hope it will next year." <https://goo.gl/P33DJ4>



Noted in Media Watch 3 October 2016 (#482, p.6):

- *AMERICAN JOURNAL OF MEDICINE* | Online – 29 September 2016 – **'Future of the palliative care workforce: Preview to an impending crisis.'** A growing workforce shortage in palliative care (PC) is increasingly recognized. Current estimates report: 6,600 board-certified physicians in practice; a projected shortage of 18,000 physicians (based on optimal need for specialists); and, less than 250 fellowship-trained physicians entering the field annually. Additionally, there is a cap on the number of Medicare funded graduate medical education slots, which means programs have to rely on philanthropy and development to fund fellows. Similar shortages are evident, though not as well studied, among advanced practice providers, nurses, chaplains, and social workers. The authors project no more than a 1% absolute growth in PC physicians in 20 years. **Full text:** <https://goo.gl/0TkS6L>

N.B. Additional articles on the palliative care workforce in the U.S. are noted in this issue of Media Watch.

The long goodbye: Coping with sadness and grief before a loved one dies

KAISER HEALTH NEWS | Online – 21 December 2017 – The anguish accompanying aging isn't openly discussed very often, nor is its companion: grief. Instead, these emotions are typically acknowledged only after a loved one's death, when formal rituals recognizing a person's passing – the wake, the funeral, the *shiva* – begin. But frailty and serious illness can involve significant losses over an extended period of time, giving rise to sadness and grief for years. The loss of independence may be marked by the need to use a walker or a wheelchair. The loss of a cherished role may dishearten an older woman who is no longer able to cook dinner for her extended family, gathered at the holidays. The loss of shared memories may be painful for

adult children when their older father is diagnosed with dementia. Looming over everything is the loss of the future that an older adult and his or her family imagined they might have, often accompanied by anxiety and dread. This pileup of complex emotions is known as "anticipatory loss." <https://goo.gl/JriYCG>

[Specialist Publications](#)

'Immigrants coping with transnational deaths and bereavement: The influence of migratory loss and anticipatory grief' (p.12), in *Family Process*.

N.B. Additional articles on anticipatory grief are noted in the 5 September 2016 and the 16 May 2016 issues of *Media Watch* (#478, p.19 and #462, pp.6-7, respectively).

Racial disparities in end-of-life care

FORBES | Online – 19 December 2017 – Many studies have shown racial disparities in health care, from access to treatment to different outcomes for similar illnesses. A new study adds to the range of illnesses demonstrating such disparities. The research from the Icahn School of Medicine at Mount Sinai looked at Medicare beneficiaries enrolled in a national random sample of 577 hospices around the country from 2009-2010. Of 145,000 Medicare beneficiaries in these hospices for end-of-life (EoL) care, 92% were white patients and 8% black patients. Most of the hospice programs were urban; half were for profit. There were striking differences in outcomes. Black hospice patients were significantly more likely than white hospice patients to be admitted to the hospital (14.9% vs 8.7%), to go to the emergency room (19.8% vs. 13.5%), and to disenroll from hospice prior to death (18.1%

vs. 13.0%). The differences "were attributable to racial differences within hospices rather than systemic differences between hospices in these outcomes." This suggests cultural/social differences between hospice patients. Why were there such differences? Are there similar differences in EoL choices for patients of Asian, Pacific Islander, or Native American background? How about for other ethnic groups? Little is known about such how such cultural differences influence health decisions. <https://goo.gl/Cx5V6z>

[Specialist Publications](#)

'Examining racial disparities in the time to withdrawal of life-sustaining treatment in trauma' (p.21), in *Journal of Trauma & Acute Care Surgery*.

1. 'Racial disparities in hospice outcomes: A race or hospice-level effect?' *Journal of the American Geriatric Society*, published online 18 December 2017. **Abstract:** <https://goo.gl/dc452b>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- VERMONT | Association Press (Burlington) – 29 December 2017 – '**29 physician-assisted deaths in Vermont since 2013.**' The Vermont Department of Health recently issued its first biennial report. According to the report, physicians prescribed lethal medication to 52 patients. Twenty-nine patients used the medication. Officials say the other patients died from their terminal illness. The state Health Department recorded cases between 31 May 2013 and 30 June 2017. Officials say the majority of patients had either cancer or ALS. <https://goo.gl/HKq46>

International

End-of-life care in Wales

Annual statement of progress

U.K. (Wales) | National Health Service Wales – 20 December 2017 – More people are accessing appropriate end-of-life care, according to a report published by the Welsh Government.¹ The report details the achievements made against the End-of-Life Care Delivery Plan. Healthcare professionals have received training on guidance to implement the care decisions of patients, and utilising advance care plans to support people to die in their preferred place. This has helped to increase of the number of people registered on the palliative care (PC) register, which has increased by 69% since 2011-2012. As a result, more people are able to die in the place of their choice – either at home, or in a care home, reducing the number of people who have died in hospital from 60% to 55% since 2010. This has resulted in a range of associated benefits to those needing PC, including fewer inappropriate and unwanted medical treatments and hospital admission in the last weeks, days and hours of life, and allowing patients to remain in a familiar environment and be close to family and friends. PC services for children and young people have also improved, with access to care available 24/7 following improvements made to the workforce available. An interim arrangement is now in place, meaning that clinicians across Wales have access to out-of-hours specialist paediatric palliative medicine advice from three specialist consultants. <https://goo.gl/wbSTsQ>

1. 'End-of-life care: Annual statement of progress,' National Health Service Wales, December 2017. **Download/view at:** <https://goo.gl/a8fU3S>

N.B. Additional articles on palliative and end-of-life care in Wales are noted in the 18 December 2017 issue of Media Watch (#543, p.12)



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>

Specialist Publications

'Patient-reported experiences on supportive care strategies following the introduction of the first Swedish national cancer strategy and in accordance with the new patient act' (p.7), in *Acta Oncologica*.

'Palliative care professionals' perceptions of barriers and challenges to accessing children's hospice and palliative care services in South East London: A preliminary study' (p.11), in *Death Studies*.

A holistic view from birth to the end of life: End-of-life doula and new developments in end-of-life care in the West' (p.14), in *International Journal of Palliative Nursing*.

'The distress and benefit to bereaved family members of participating in a post-bereavement survey' (p.14), in *Japanese Journal of Clinical Oncology*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- INDIA | Press Trust of India (New Delhi) – 17 December 2017 – ‘**Jail term, fine for those distorting facts in passive euthanasia.**’ Hospitals have to set up approval committees for considering cases of passive euthanasia, and any distortion of facts before such panels may lead to a maximum of 10 years in jail and a fine of up to Rs 1 crore a redrafted bill states. The panels will decide on applications of “Living will”, a written document that allows patients to explicitly state their desire against life-prolonging measures when recovery is not possible from a terminal condition. The redrafted bill also provides for palliative care to patients even if they have opted for passive euthanasia, which is the withdrawal of medical treatment and life support system of a terminally-ill patient. The ‘Management of Patients with Terminal Illness- Withdrawal of Medical Life Support Bill’ states that all super-speciality hospitals should have approval committees on passive euthanasia which will decide on the applications for the execution of a “living will.” <https://goo.gl/zZ8Uki>

Specialist Publications

Patient-reported experiences on supportive care strategies following the introduction of the first Swedish national cancer strategy and in accordance with the new patient act

ACTA ONCOLOGICA | Online – 25 December 2017 – Several supportive care strategies are described in Swedish legislation and policy documents, such as the National Cancer Strategy and the Patient Act. No previous systematic evaluation from a patient perspective has been performed. The aim of this study was to evaluate how these supportive care strategies are experienced by patients treated for cancer in the Stockholm-Gotland region. Among the supportive care strategies suggested in the legislation and policy documents, just over half of the patients reported that they had access to a contact nurse, while 43% had received an individual written care plan and 16% had been referred to palliative care. Only 29% of the patients reported that they had received information about patient advocacy groups and 8% on medical second opinions from their cancer care team. **Full text:** <https://goo.gl/rt5iPF>

Assessing the decision making capacity of terminally ill patients with cancer

AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY | Online – 27 December 2017 – Despite the clinical, ethical and legal magnitude of end-of-life decision-making, the capacity of terminally ill patients to make the medical decisions they often face is largely unknown. In practice, clinicians are responsible for determining when their patients are no longer competent to make treatment decisions, yet the accuracy of these assessments is unclear. Fifty-five patients with advanced cancer receiving inpatient palliative care and 50 healthy adults were administered the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) to evaluate decision-making capacity with regard to the four most commonly used legal standards: Choice, Understanding, Appreciation and Reasoning. Participants made a hypothetical treatment decision about whether to accept artificial nutrition and hydration for treatment of cachexia. Terminally ill participants were significantly more impaired than healthy adults on all MacCAT-T subscales. Most were able to express a treatment choice (85.7%), but impairment was common on the Understanding (44.2%), Appreciation (49.0%) and Reasoning (85.4%) subscales. Agreement between physician-rated capacity and performance on the MacCAT-T subscales was poor. **Abstract:** <https://goo.gl/TjLDWd>

Journal Watch

‘**How can you spot a predatory journal?**’ (p.27), posted online by the American Council of Science & Health.

‘**Selecting a quality publisher**’ (p.28), posted online by the Royal Society Te Apārangi.

Cont.

Related

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 26 December 2017 – ‘**Protocol for the assessment of patient capacity to make end-of-life treatment decisions.**’ Because of uncertainties about capacity, care providers and administrative agencies often must decide whether to honor, or even to elicit, patients’ wishes. General decision-making capacity has been well studied, but few clear protocols exist for ascertaining capacity at the end of life (EoL). Without clear guidelines about how to assess capacity, medical staff may ignore assessment and operate from invalid assumptions. The authors propose a straightforward protocol for assessing capacity to make decisions about EoL interventions. **Abstract:** <https://goo.gl/gjHkYK>

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

Bridging the cultural divide between oncology and palliative care sub-specialties: Clinicians’ perceptions on team integration

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 19 December 2017 – Oncology professional societies endorse the integration of palliative care (PC) into routine care for patients with advanced cancers. Despite this, cultural differences between medical sub-specialties and the limited number of clinicians trained in PC lower the adoption of integrated care models. The authors assessed oncologists’ and PC clinicians’ perceptions about integrating oncology and PC using a nurse delivering PC to patients newly diagnosed with lung cancer. They identified two main themes: 1) Tensions, differences, and mistrust between services occur in the least integrated teams; and, 2) Open communication, sharing common goals, and promoting oncology “buy in” build trust and foster collaboration between teams. Clinicians described qualities important to possess to promote successful adoption of a nurse-led model of PC. Integration between oncology and PC among the 6 Veterans Affairs medical centers [where this study was undertaken] varies considerably. Nurses delivering PC embedded in oncology teams may facilitate the integration of these subspecialties. **Abstract:** <https://goo.gl/jTtck4>

N.B. Additional articles on the integration of oncology and palliative care are noted in the 25 September 2017 issue of Media Watch (#531, p.2).

Respecting Choices and related models of advance care planning: A systematic review of published evidence

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 18 December 2017 – Eighteen articles from 16 studies were included, of which 9 were randomized controlled trials, 6 were observational, and one was a pre-post test study. Only two specifically included a minority population (African American). Fourteen were conducted in the U.S., primarily in the Wisconsin/Minnesota region. Seven studies examined the RC model, whereas 9 examined derivative models. There was significant heterogeneity of outcomes examined. The authors found that there is a low level of evidence that RC and derivative models increase the incidence and prevalence of advance directive and Physician Orders for Life-Sustaining Treatment completion. There is a high level of evidence that RC and derivative models increase patient-surrogate congruence in Caucasian populations. The evidence is mixed, inconclusive, and too poor in quality to determine whether RC and derivative models change the consistency of treatment with wishes and overall health-care utilization in the end of life. The authors urge further studies be conducted, particularly with minority populations and focused on the outcomes of preference-congruent treatment and health-care utilization. **Abstract:** <https://goo.gl/pnq22k>

Cont. next page

Noted in Media Watch 19 October 2015 (#432, p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – **‘Toward evidence-based end-of-life care.’** More than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment programs despite the absence of compelling evidence that they improve patient outcomes.¹ Even less evidence is available to support such well-intentioned private initiatives as the Institute for Healthcare Improvement Conversation Project, the efforts of the Coalition to Transform Advanced Care, the Gundersen Health System’s Respecting Choices program, the widely used Five Wishes advance directive of the Aging with Dignity organization, and the services provided by for-profit companies such as Vital Decisions and Common Practice. **Full text:** <http://goo.gl/9gFs4X>

1. ‘Use of the Physician Orders for Life-Sustaining Treatment Program in the clinical setting: A systematic review of the literature,’ *Journal of the American Geriatrics Society*, published online 29 January 2015. [Noted in the 2 February 2015 issue of Media Watch (#395, p.9)] **Abstract:** <https://goo.gl/bDZqRF>

Related

- *BMC PALLIATIVE CARE* | Online – 28 December 2017 – **‘Religious leaders’ perceptions of advance care planning: A secondary analysis of interviews with Buddhist, Christian, Hindu, Islamic, Jewish, Sikh and Bahá’í leaders.’** Religious beliefs and values around death and dying could be useful in preparing health professionals for advance care planning (ACP) with patients of different religions. Equally important is the need for health professionals to provide culturally sensitive care without assumptions based on religion or culture. Religious leaders could play a greater role in ACP by clarifying followers’ faith misconceptions, encouraging patients to discuss the implications of their faith with health professionals and also raising awareness of ACP within their communities. **Full text:** <https://goo.gl/jM8zuA>
- *BRITISH JOURNAL OF GENERAL PRACTICE* | Online – 18 December 2017 – **‘GPs’ perceptions of advance care planning with frail and older people: A qualitative study.’** This study highlights the difficulties for GPs of encouraging dialogue and respecting individuals’ wishes within the constraints of the existing health and social care system. National publicity campaigns and encouraging patients to prioritise healthcare outcomes could help GPs raise care preferences without causing a detrimental impact on patients or raising unrealistic expectations. Once patients agree their care preferences, they need to be documented, accessible, and reviewed by all relevant health and social care providers to ensure that their wishes are respected, and plans amended as their circumstances change. **Abstract:** <https://goo.gl/pbShrD>
- *FAMILY PRACTICE* | Online – 20 December 2017 – **‘Do non-terminally ill adults want to discuss the end of life with their family physician? An explorative mixed-method study on patients’ preferences and family physicians’ views in Belgium.’** The majority (69.8%) of patients had thought about the end-of-life and would appreciate it if their family physician (FP) would initiate a conversation about this (75.9%). A number of themes captured the thoughts of people according to both patients and FPs: 1) Becoming care dependent; 2) Physical and mental deterioration; 3) Dying alone; and, 4) Having paperwork in order. However, on the basis of patients’ ideas and FPs’ experiences in practice, a difference was noticed between them when it comes to identifying the themes as triggers for initiating advance care planning discussions. **Abstract:** <https://goo.gl/qMbtbd>
- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2017;23(12):596-604. **‘What do patients with cancer and their families value most at the end of life? A critical analysis of advance care planning.’** Findings from participant interviews were organised into four themes: 1) The threat of death and cancer; 2) Patients seek trust and safety at the end of life (EoL); 3) Doctors are human and the healthcare system has limitations; and, 4) The role of advance care planning (ACP). Participants experienced cancer and death as a “threat,” to self and others and as something “uncontrollable.” ACP was seen to have the potential to enhance EoL care by contributing to decreasing uncertainty, enhancing comfort, helping to achieve “the small things,” and in helping the family “know what to do.” However, participants were ... distrustful of documentation and cognisant of uncertainty around medical outcomes and the legal limitations of their capacity to influence care. **Abstract:** <https://goo.gl/JSBw5o>

Cont.

- *JOURNAL OF APPLIED GERONTOLOGY* | Online – 24 December 2017 – ‘**Making your wishes known: Who completes an advance directive and shares it with their health care team or loved ones?**’ Seventy-three percent of [survey] respondents had advance directives (ADs). However, 28% have not shared their ADs with anyone. The sense of having completed a great deal of preparation for the future and the number of illnesses were found to be relevant to the behavior of sharing ADs. Existing educational training and interventions can be expanded to increase public awareness and encourage people to share their completed ADs with others. Policies mandating physicians to engage in conversations with patients during annual checkups might improve completion and sharing of ADs. **Abstract:** <https://goo.gl/jFRx8c>
- *JOURNAL OF PAEDIATRICS & CHILD HEALTH* | Online – 21 December 2017 – ‘**Paediatric advance care planning: Physician experience and education in initiating difficult discussions.**’ In total, 64% of [survey] respondents felt that advance care planning (ACP) discussions should occur early around the time of diagnosis or during a period of stability; however, 57% observed discussions occurring late in illness after multiple acute, severe deteriorations. In total, 46% felt that multidisciplinary teams were the most appropriate to initiate ACP discussions. Prognostic uncertainty was the most common barrier to ACP initiation. Lack of experience and education were identified as barriers... The majority of respondents regarded exposure to ACP and education during training as inadequate. **Abstract:** <https://goo.gl/6F2eLb>

Advice and care for patients who die by voluntarily stopping eating and drinking is not assisted suicide

BMC MEDICINE | Online – 27 December 2017 – The issue of whether physicians, in offering palliative care (PC) to patients undertaking voluntarily stopping eating and drinking (VSED), are acting ethically and, in particular, legally, is important because many of those who may be called upon to provide PC and help with this option will need to be aware of the legal position. Most authors claim either that VSED is suicide and therefore PC of VSED constitutes assisted suicide or, conversely, that VSED is not suicide and thus PC of VSED is not assisted suicide. The authors take a different approach, arguing that VSED is indeed a form of suicide, but that physician provision of PC for these patients and even advising on the option, do not constitute assisting suicide. Thus, this conduct would not fall within legislation prohibiting assisted suicide. **Full text:** <https://goo.gl/w7mtn1>

N.B. Additional articles on voluntarily stopping eating and drinking are noted in the 23 October 2017 issue of *Media Watch* (#535, pp.13-14).

Exploring the rewards and challenges of paediatric palliative care work: A qualitative study of a multi-disciplinary children’s hospice care team

BMC PALLIATIVE CARE | Online – 16 December 2017 – Participants [in this study] described the work as emotionally intensive and multi-faceted; “getting it right” for children was identified as a strong motivator and reward, but also a potential stressor as staff strived to maintain high standards of personalised and emotional care. Other factors were identified as both a reward and stressor, including team functioning, the allocation of work, meeting parent expectations, and the hospice environment. Many participants identified training needs for different aspects of the role to help them feel more confident and competent. Participants also expressed concerns about work-related stress, both for themselves and for colleagues, but felt unable to discuss this at work. Informal support from colleagues and group clinical reflection were identified as primary resources to reflect on and learn from work and for emotional support. However, opportunities for this were limited. Providing regular, structured, and dedicated clinical reflection provides a mechanism through which children’s hospice staff can come together for support and learning, and demonstrates an organisational commitment to staff wellbeing and development. Being aware of children’s hospice specific rewards and challenges can help to ensure that staff feel supported and competent in their role. Breaking down barriers to discussing work-related stress and enhancing awareness about early signs of burnout is also important. **Full text:** <https://goo.gl/wUBor1>

Cont.

Related

- *CHILDREN*, 2018;5(1). ‘**Enhancing pediatric palliative care for Latino children and their families: A review of the literature and recommendations for research and practice in the U.S.**’ Evidence on how to best provide palliative care (PC) to Latino children is sparse. In the U.S., Latinos face multiple barriers that affect their receipt of PC, including poverty, lack of access to health insurance, language barriers, discrimination, and cultural differences. Pediatric PC research and clinical initiatives that target the needs of Latino families are sparse, underfunded, but essential. Education of providers on Latino cultural values is necessary. Advocacy efforts with a focus on equitable care and policy reform are essential to improving the health of this vulnerable population. **Full text:** <https://goo.gl/yTKWjc>
- *CLINICAL PRACTICE IN PEDIATRIC PSYCHOLOGY*, 2017;5(4):392-403. ‘**Perspectives from bereaved parents on improving end-of-life care in the neonatal intensive care unit.**’ Four themes emerged in this retrospective study, including parents as partners in care, communication with the health-care team, relationships with staff, and bereavement support. Both mothers and fathers generally felt positive about their role in treatment decisions, relationships with staff, and memory-making activities. Parents noted areas for improvement, including team communication, anticipatory guidance, family inclusion at bedside, and bereavement care. This study provides a deeper understanding of parents’ experience with their infants at end of life and highlights opportunities for enhancing care. **Abstract:** <https://goo.gl/VzxWe1>
- *DEATH STUDIES* | Online (Inprint) – Accessed 20 December 2017 – ‘**Palliative care professionals’ perceptions of barriers and challenges to accessing children’s hospice and palliative care services in South East London: A preliminary study.**’ According to the palliative care (PC) professionals interviewed several factors contribute to families’ decisions to not seek PC for their children, these include misconceptions and biases of such care as well as receipt of support from community and religious groups. What also emerged is that families wishing to use PC services, particularly for onsite hospice services, encounter numerous challenges and barriers, these include problems with transportation, limited capacity of PC services which may lead to unreliability of respite care. To summarise, the results suggest two key issues, first, not all families are able to benefit from the services of PC due to factors that influence their initial decision to seek these services. Second there are factors impacting such services capacity for provision of care effectively, creating barriers for families wishing to use their services. **Abstract:** <https://goo.gl/waeYgo>

Death, coronary revascularization choices, and chronic kidney disease

CORONARY ARTERY DISEASE, 2018;29(1):4-5. Medical decision-making is a give and take, an assessment of risks versus benefits of any action. Palliative medicine’s growth is a reflection of the application of this approach at the end of one’s life. Other examples include decisions around chemotherapy in the field of oncology and arguably termination of pregnancy for medical reasons. In each of these examples, the decision-making sits at the level of the individual. It takes into account a whole host of variables that embrace the spiritual, psychological, and physical realms of the individual affected by the decision-making. In contrast to these very personal examples, the medical community embraces guidelines based upon “evidence.” In some ways, this is the other end of the decision-making spectrum. It is an impersonal approach in which the choice among alternative approaches is determined by the average response of average patients in the same situation. Somewhere between these two poles lies a “sweet spot” in which there is a merger of personalized decision-making that is also informed by evidence-based medicine. We have less understanding of how individuals approach this interaction between their personal wishes and the evidence from average patients to make a specific decision. **First page review:** <https://goo.gl/6JfpNL>

N.B. Additional articles on palliative and end-of-life care for people living with chronic kidney disease are noted in the 20 November 2017 issue of *Media Watch* (#539, pp.13-14).



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.28.

Moral frames for lives worth living: Managing the end of life with dementia

DEATH STUDIES | Online – 27 December 2017 – Narratives that frame the end of life (EoL) with dementia as undignified reveal moral claims on which lives are considered worth living. These claims are deeply rooted in the medicalization of death and its appeal to dignity. Drawing from ethnographic fieldwork in nursing homes for people with dementia in The Netherlands, the author demonstrates how the EoL with dementia is managed through such moral frames. Specifically, she elaborates on the production of lives (not) worth living and explores how family members welcomed the death of a loved one with dementia. The author argues that the welcoming of death is not an act of indifference, but can be seen as a form of care. **Abstract:** <https://goo.gl/YpYPxJ>

N.B. Additional articles on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia are noted in the 18 December 2017 issue of *Media Watch* (#543, p.18).

Immigrants coping with transnational deaths and bereavement: The influence of migratory loss and anticipatory grief

FAMILY PROCESS | Online – 14 December 2017 – Immigrants' geographic distance from family complicated caregiving circumstances and rituals surrounding burial, and impacted the grieving process. At the same time, this distance also served as an emotional barrier and provided protection from prolonged grief. Immigrants' U.S.-based family and work responsibilities served as buffers from prolonged grief. Over time, immigrants became Americanized in their attitudes toward coping with death and favored a fast return to productive activities. Finally, immigrants' experience of migratory loss and anticipatory grief early in immigration, along with their personal growth and resilience developed over time, impacted their bereavement experiences later in life. **Abstract:** <https://goo.gl/qZYzyB>

Noted in *Media Watch* 4 July 2016 (#469, p.16):

- *MORTALITY* | Online – 30 June 2016 – '**Coping with dying and deaths at home: How undocumented migrants in the U.S. experience the process of transnational grieving.**' The author argues that the grieving process is unique for a group like this, where the undocumented status means that the migrants cannot go back home to help the dying, support the ones left behind, or receive consolation. **Abstract:** <http://goo.gl/g7y8n8>

HIV/AIDS epidemic in South Africa

Needs and challenges of lay community health workers in a palliative care environment for orphans and vulnerable children

HEALTH SA GESONDHEID, 2017;22(12):333-341. The escalation of HIV/AIDS infections in the last decade has increased the need for palliative care (PC) community organizations to care for orphans and vulnerable children, who are in dire need of support. Many of these organizations depend on the services of lay community health workers to provide constant care to those in need of it in their local communities. The focus of this study is to explore the role of lay health workers in a community organization located in rural Bronkhorstspuit, Gauteng Province of South Africa that provides PC for orphans and vulnerable children diagnosed with HIV/AIDS. Their roles were analysed critically through a job-demands and job-resources theoretical framework. Through the findings, a framework for enhancing the work experiences of the lay community health workers was developed. The uniqueness of this framework is that the focus is on improving the work lives of the lay community health workers, who have serious skills-resourcing needs. There were specific concrete strategies that the organization could adopt to support the knowledge and skills requirements of the lay community health workers in relation to the needs and



Cont.

challenges that will enhance their efficiency in the PC environment. The findings and framework that emanated from this study could be used to support lay community health workers in their respective organizations to be more effective in the support they provide to orphans and vulnerable children. Because South Africa is afflicted by the HIV/AIDS epidemic, this framework can be used in similar organizations that are working with lay community health workers with skill-resourcing needs not only in the health sector, but also in other sectors, such as in education and agriculture. **Full text:** <https://goo.gl/gJUK2v>

Related

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2017;20(4):226-234. **'Factors associated with willingness to volunteer for end-stage AIDS patients among hospice volunteers.'** With the implementation of the Act on Life Sustaining Treatment, hospice-palliative care will be extended to non-cancer diseases including the acquired immunodeficiency syndrome (AIDS). However, there are concerns about negative perceptions and prejudice toward AIDS patients. The purpose of this study was to investigate factors related with willingness to volunteer for patients with end-stage AIDS among hospice volunteers. **Abstract:** <https://goo.gl/ADS86D>

Informal caregivers' views on the division of responsibilities between themselves and professionals: A scoping review

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 18 December 2017 – In Europe, the normative discourse on informal care has changed. Retreating governments and decreasing residential care increase the need to enhance the collaboration between informal caregivers and professionals. Professionals are assumed to adequately address the needs and wishes of informal caregivers, but little is known about informal caregivers' views on the division of care responsibilities. Based on the opinion of informal caregivers, the authors conclude that professionals do not seem to explicitly take into account the views of informal caregivers about the division of responsibilities during their collaboration with them. Roles of the informal caregivers and professionals are not always discussed and the division of responsibilities sometimes seems unclear. Acknowledging the role and expertise of informal caregivers seems to facilitate good collaboration, as well as attitudes such as professionals being open and honest, proactive and compassionate. Inflexible structures and services hinder good collaboration. Asking informal caregivers what their opinion is about the division of responsibilities could improve clarity about the care that is given by both informal caregivers and professionals and could improve their collaboration. Educational programs in social work, health and allied health professions should put more emphasis on this specific characteristic of collaboration. **Full text:** <https://goo.gl/RrffNC>

Improving the quality of nursing documentation in a palliative care setting: A quality improvement initiative

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2017;23(12):577-585. The World Health Organization definition of palliative care includes impeccable assessment and management of pain and other symptoms. However, existing nursing documentation focuses mainly on the management of physical symptoms, with other aspects of nursing less frequently documented. Supported by a project team and expert panel, cycles of review, action and reflection were used to develop a new palliative nursing documentation. The project was divided into three phases: 1) Audits of existing nursing documentation; 2) Development of a new palliative nursing care document and audit tool; and, 3) Pilot implementation and audit of the new nursing documentation. The new palliative nursing care document demonstrated a higher level of compliance in relation to nursing assessments and a more concise, accurate and comprehensive approach to documenting holistic nursing care and recording of patients' perspective. This project has enabled the consistent documentation of holistic nursing care and patients' perspectives; however, continuous education is necessary in order to sustain positive results and ensure that documentation does not become a 'tick box' exercise. Organisational support is required in order to improve documentation systems. **Abstract:** <https://goo.gl/JuD2vT>

A holistic view from birth to the end of life: End-of-life doulas and new developments in end-of-life care in the West

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2017;23(12):612-619. The relatively newly-developed profession of birth doulas, who accompany perinatal women and their families during the birth process, has been in existence since the 1990s. End-of-life (EoL) doulas are another emerging profession in developed Western countries. Doulas provide non-medical support for both childbearing women and people at the EoL, as well as their families. Although birth and death would appear to be opposites, they share common characteristics and challenges, such as tending to be treated in medicalised care settings, and that they both concern vulnerable parties. Doulas, with a holistic view encompassing birth and death, may be able to contribute to the improvement of the healthcare system in modern societies.

Abstract: <https://goo.gl/gVmXBN>

N.B. Additional articles on “death doulas” or “end-of-life midwives” are noted in the 20 November 2017 issue of Media Watch (#539, p.4).

The distress and benefit to bereaved family members of participating in a post-bereavement survey

JAPANESE JOURNAL OF CLINICAL ONCOLOGY | Online – 13 December 2017 – Few studies have simultaneously collected quantitative data regarding the positive and negative effects of participating in post-bereavement surveys. Of the respondents [to a cross-sectional postal questionnaire survey], 62% reported being distressed by completing the questionnaire. Female participants and those who were mentally ill during the caregiving period reported more distress. Major benefits were: contributing to the development of end-of-life (EoL) care as a family (63%); expressing gratitude to the hospital and medical staff (60%); and, looking back and reflecting on the EoL period (40%). Feeling benefit was not correlated with feeling distressed. **Abstract:** <https://goo.gl/ZZsZsV>

Noted in Media Watch 17 July 2017 (#521, p.15):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 July 2017 – **‘Meaningful communication prior to death, but not presence at the time of death itself, is associated with better outcomes on measures of depression and complicated grief among bereaved family members of cancer patients.’** Many families [i.e., survey respondents] wished to be present at the moment of the patient’s death; however, meaningful communication (saying “goodbye”) between the patient and family members, and not their presence or absence itself, was associated with better outcomes on measures of depression or complicated grief. **Abstract:** <https://goo.gl/uVQUvv>

Noted in Media Watch 9 January 2017 (#494, p.6):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 3 January 2017 – **‘Family caregiver participation in palliative care research: Challenging the myth.’** Despite international guidelines emphasizing consumer directed care and autonomous decisions in research participation, there is a common myth that research can be an additional and unwanted burden on patients and their family members. This study provides quantitative and qualitative evidence challenging the myth. In contrast to health professional concerns, family caregivers appreciated the opportunity to participate and benefited from their involvement in research. **Abstract:** <https://goo.gl/ghZQ0b>

Comparativism and the grounds for person-centered care and shared decision making

JOURNAL OF CLINICAL ETHICS, 2017;28(4): 269-278. This article provides a new argument and a new value-theoretical ground for person-centered care and shared decision making that ascribes to it the role of enabling rational choice in situations involving clinical choice. Rather than referring to good health outcomes and/or ethical grounds such as patient autonomy, it argues that a plausible justification and ground for person-centered care and shared decision making is preservation of rationality in the face of comparative non-determinacy in clinical settings. Often, no alternative treatment will be better than or equal to every other alternative. In the face of such comparative non-determinacy ... we can make rational decisions by invoking reasons that are created through acts of willing. This article transfers this view to clinical decision making and argues that shared decision making provides a solution to non-determinacy problems in clinical settings. This view of the role of shared decision making provides a new understanding of its nature, and it also allows us to better understand when caregivers should engage in shared decision making and when they should not. **Abstract:** <https://goo.gl/3L23AW>

Information about expert decision and post-decision distortion of facts of own decision

SCANDINAVIAN JOURNAL OF PSYCHOLOGY | Online – 15 December 2017 – Participants [in this study] were given vignettes with facts about two terminally ill patients, only one of whom could be given life-saving surgery. In Study 1, contrary to the prediction, the results showed that facts were distorted after a decision both by participants who were responsible for the decisions themselves and when doctors had made the decision. In Study 2 the authors investigated the influence of knowledge about expert decisions on a participant's own decision and post-decisional distortion of facts. Facts were significantly more distorted when the participant's decision agreed with an expert's decision than when the participant and expert decisions disagreed. The findings imply that knowledge about experts' decisions can distort memories of facts and therefore may obstruct rational analyses of earlier decisions. This is particularly important when a decision made by a person, who is assumed to be an expert, makes a decision that is biased or wrong. **Abstract:** <https://goo.gl/QtMdHk>

Related

- *BMC PALLIATIVE CARE* | Online – 28 December 2017 – ‘**Existential decision making in a fatal progressive disease: How much do legal and medical frameworks matter?**’ Healthcare legislation in European countries is similar in many respects. Most importantly, the framework of informed consent determines that physicians have the duty to provide detailed information about available therapeutic options and that patients have the right to refuse measures that contradict their personal values. However, when it comes to end-of-life (EoL) decision making a number of differences exist in the more specific regulations of individual countries. The authors show how the legal and medical frameworks of Germany, Poland and Sweden differ with regard to EoL decisions for patients with a fatal progressive disease. **Full text:** <https://goo.gl/oJswH9>

Incarcerated patients and equitability: The ethical obligation to treat them differently

JOURNAL OF CLINICAL ETHICS, 2017;28(4):308-313. Prisoners are legally categorized as a vulnerable group for the purposes of medical research, but their vulnerability is not limited to the research context. Prisoner-patients may experience lower standards of care, fewer options for treatment, violations of privacy, and the use of inappropriate surrogates as a result of their status. This case study highlights some of the ways in which a prisoner-patient's vulnerable status impacted the care he received. The article argues the following: 1) Prisoner-patients are entitled to the same quality of care as all other patients, and healthcare providers should be vigilant to ensure that the stigma of incarceration does not influence care decisions; 2) Options for treatment should reflect what is most medically appropriate in the hospital or other healthcare setting, even when not all treatments would be available in the correctional setting; 3) The presence of guards at the bedside requires that additional measures be taken to protect the privacy

Cont.

and confidentiality of prisoner-patients; and, 4) When end-of-life decisions must be made for an incapacitated patient, prison physicians are not well placed to act as surrogate decision makers, which heightens the obligations of the healthcare professionals in the hospital to ensure an ethically supportable process and outcome. Therefore, healthcare professionals should provide extra protection for those prisoner-patients who do not have decision-making capacity, by utilizing a robust process for decision making such as those used for incapacitated patients without surrogates, rather than relying solely on prison physicians as surrogates. **Abstract:** <https://goo.gl/XT9nx5>

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 November 2017) can be downloaded/viewed at Palliative Care Network-e: <https://goo.gl/YLckx6>

How do clinicians practice the principles of beneficence when deciding to allow or deny family presence during resuscitation?

JOURNAL OF CLINICAL NURSING | Online – 20 December 2017 – Family presence during resuscitation has important benefits for family and is supported by professional bodies and the public. Yet, many clinicians restrict family access to patients during resuscitation, and rationales for decision-making are unclear. The authors analysed 20 interview transcripts from 15 registered nurses, 2 doctors and 3 paramedics who had experienced family presence during resuscitation in an Australian hospital. Decision-making around family presence during resuscitation occurred in time poor environments and in the absence of local institutional guidelines. Clinicians appeared to be motivated by doing “what’s best” for patients and families when allowing or denying family presence during resuscitation. However, their individual interpretations of “what’s best” was subjective and did not always coincide with family preferences or with current evidence that promotes family presence during resuscitation as beneficial. These findings highlight current deficits in decision-making around family presence during resuscitation and could prompt the introduction of clinical guidelines and policies and in turn promote the equitable provision of safe, effective family-centred care during resuscitation events. **Abstract:** <https://goo.gl/mtNna3>

N.B. Additional articles on family presence during cardiopulmonary resuscitation are noted in the 7 August 2017 issue of Media Watch (#524, p.13).

Quality of dying and death in the ICU: The euroQ2 project

JOURNAL OF CRITICAL CARE | Online – 26 December 2017 – Knowledge of families’ perspective of quality of intensive care unit (ICU) care is important, especially with regard to end-of-life (EoL) care. Adaptation of the U.S. developed ‘Quality of dying and death’ (QoDD) questionnaire to a European setting is lacking. The primary aim of this study is to examine the euroQoDD’s usability and its assessments of EoL care in a cohort of Danish and Dutch family members. 217 family members completed the euroQoDD part of the euroQ2 questionnaire. Overall rating of care was high, a median of 9 in The Netherlands and 10 in Denmark on a 0-10 scale. The Danish were more likely to report adequate pain control all or most of the time. When decisions were made to limit treatment, the majority of family members agreed (93%). Most (92%) reported some participation in the decision-making, with half (50%) making the decision jointly with the doctor. About 18% would have preferred greater involvement. Factor analysis identified a six-indicator unidimensional quality of dying and death construct with between-country measurement invariance. However, in its current form the euroQoDD instrument requires modeling the six items as reflective (or effect) indicators, when they are more accurately conceived as causal indicators. Addition of items that can be accurately treated as effect indicators will improve the instrument’s usefulness in measuring the overall quality of dying and death. **Full text:** <https://goo.gl/4uJqUa>

N.B. The euroQ2 project: <https://goo.gl/dhtqFp>

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

Update in hospital palliative care: Symptom management, communication, caregiver outcomes, and moral distress

JOURNAL OF HOSPITAL MEDICINE | Online – 20 December 2017 – Updated knowledge of the palliative care (PC) literature is needed to maintain competency and best address the PC needs of hospitalized patients. The authors critiqued the recent PC literature with the highest potential to impact hospital practice. Key findings include: 1) Scheduled antipsychotics were inferior to a placebo for non-terminal delirium; 2) A low-dose morphine was superior to a weak opioid for moderate cancer pain; 3) Methadone as a co-analgesic improved high-intensity cancer pain; 4) Many hospitalized patients on comfort care still receive antimicrobials; 5) Video decision aids improved the rates of advance care planning, and hospice use and decreased costs; 6) Standardized, PC-led intervention did not improve psychological outcomes in families of patients with a chronic critical illness; 7) Caregivers of patients surviving a prolonged critical illness experienced high and persistent rates of depression; 8) People with non-normative sexuality or gender faced additional stressors with partner loss; and, 9) Physician trainees experienced significant moral distress with futile treatments. **Full text:** <https://goo.gl/DNEB8D>

Related

- *JOURNAL OF HOSPITAL MEDICINE* | Online – 20 December 2017 – ‘**Improving quality of care for seriously ill patients: Opportunities for hospitalists.**’ Hospitalists are ideally positioned to identify patients who could most benefit from palliative care (PC) approaches and often refer the most complex cases to specialty PC teams. Though hospitalists are frequently called upon to provide PC, most lack formal training in these skills, which have not typically been included in medical education. Additional training in communication, safe and effective symptom management, and other PC knowledge and skills are available in both in-person and online formats. **Full text:** <https://goo.gl/gJSU1s>

The marginalisation of religion in end-of-life care: Signs of micro-aggression?

JOURNAL OF HUMAN RIGHTS IN HEALTHCARE | Online (Inprint) – Accessed 19 December 2017 – Service users very often interpret and respond to their experiences of death, dying and bereavement through a religious or spiritual lens. However, recent trends in religion and belief have influenced how professionals respond to indicators such as faith. Since the post-war years in Britain, and due to the transfer of services from church to state, as well as the change in the religious landscape, language has largely secularized. When people start addressing religion and belief again, they lack the appropriate literacy to do so; this is termed religious literacy... This paper explores how professionals in end-of-life care respond to service users’ religious and spiritual indicators, through the lens of religious literacy. This article draws from an ethnographic study undertaken across hospices in England. Healthcare professionals were observed for one calendar year. Results show that lack of religious literacy on the part of healthcare professionals may lead to subtle and unintentional micro-aggression. Three types of indications of micro-invalidation have been noted: verbal, non-verbal and environmental. **Abstract:** <https://goo.gl/hDSPLA>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 December 2017 – ‘**Developing a healing environment for broken souls of patients with life-threatening illnesses and their caregivers.**’ Patients with life-threatening illnesses can struggle with physical, emotional, and existential and spiritual concerns and the suffering of caregivers. A key goal of supportive and palliative care (PC) teams is to alleviate patient and caregiver suffering. When caring for patients with advanced and terminal illness the spirituality of each member of the PC team becomes a single collective spirituality or soul with common goals, values, and belonging, with a main goal of providing the best care for patients and caregivers in the alleviation of suffering. **Abstract:** <https://goo.gl/53jf2z>

Distributive justice: An ethical priority in global palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 December 2017 – Providing care to cancer patients in resource-poor settings often demands complex trade-offs regarding resource allocation. It is estimated that over 60% of all cancer deaths worldwide occur in low- and middle-income countries (LMICs), where channels to care and appropriate symptom management interventions are overstressed or obsolete. Concepts of distributive justice underlie much of global health policy. As appetites for expanding global palliative care services increase so do questions of fair and culturally appropriate distribution. The ethical principle of distributive justice underpins questions of resource allocation at a fundamental level. One of the most challenging concepts for healthcare workers immersing in cross-cultural contexts is the idea that ethics are somewhat malleable; they shape and are shaped by the unique socio-political, economic, intra-cultural, and power dynamics of a particular setting. Notions of distributive justice vary across cultural, societal and even individual norms, with some definitions allowing for discrimination based on merit or need. Resource allocation in the absence of cultural humility or a genuine willingness to understand decision making priorities in a given culture can contribute to inequity and may have harmful consequences. **Abstract:** <https://goo.gl/3ws9CQ>

A national palliative care strategy for Canada

JOURNAL OF PALLIATIVE MEDICINE, 2018; 21(S1):S63-S75. The objective of this study was to identify barriers to achieving universal access to high quality palliative care (PC) in Canada, review published national strategies and frameworks to promote PC, examine key aspects that have been linked to successful outcomes, and make recommendations for Canada. Rapid review was supplemented by the author's personal files, outreach to colleagues within the international PC community, review of European Association for Palliative Care publications, and a subsequent search of the table of contents of the major PC journals. Frameworks were found for 10 countries ranging from detailed and comprehensive multi-year strategies to more general approaches including laws guaranteeing access to PC services for "dying" patients or recommendations for the development of clinical infrastructure. Minimal comparative data exist regarding the quality of care, access to PC services, timing of access in the disease trajectory, and patient and family satisfaction with care. Factors that appear to be associated with success include: 1) Input and early involvement of

senior policy makers; 2) Comprehensive strategies that address major barriers to universal access and that involve the key constituents; 3) A focus on enhancing the evidence base and developing a national system of quality reporting; and, 4) Substantial and sustained government investment. Comprehensive national strategies appear to improve access to high quality PC for persons with serious illness and their families. Such strategies require sustained government funding and address barriers related to infrastructure, professional and public education, workforce shortages, and an inadequate evidence base. **Abstract:** <https://goo.gl/r7C1HR>

JOURNAL OF **Palliative Medicine**

This special issue focuses primarily on palliative and end-of-life care in Canada. **Journal contacts page:** <https://goo.gl/otSL2R>

Related

- *JOURNAL OF PALLIATIVE MEDICINE*, 2018;21(S1):S27-S29. '**A call for integrated and coordinated palliative care.**' Integrated palliative care (PC) is viewed as having the potential to improve service coordination, efficiency, and quality outcomes for patients and family carers. However, the majority of Canadians do not have access to regional, comprehensive, integrated PC. Work needs to be directed toward planning PC services that is integrated into the healthcare and social care system. To further this goal, it is important to have a conceptual understanding of the meaning of integrated care and its expression in organizational models for the provision of PC. **Abstract:** <https://goo.gl/YRBRZv>

Cont.

Noted in Media Watch 18 December 2017 (#543, p.1):

- CANADA | *The National Observer* – 11 December 2017 – ‘Canadian parliament makes plans for end-of-life care.’ Canada has moved one step closer to creating national guidelines for palliative care (PC) following the Senate’s passage of a private member’s bill [C-277]. The legislation was adopted more than a year after it was first introduced in the House of Commons... ‘An Act providing for the development of a framework on PC in Canada,’ is expected to receive royal assent...¹ The legislation incorporates recommendations made by an all-party committee report...² The legislation requires the government to come up with a PC framework. <https://goo.gl/fuVuDZ>

1. Bill C-277 received Royal Assent 12 December 2017. **Download/view at:** <https://goo.gl/LWW6kT>
2. ‘Not to be Forgotten: Care of Vulnerable Canadians,’ Parliamentary Committee on Palliative & Compassionate Care. [Noted in the 21 November 2011 issue of Media Watch (#228, p.1)] **Download/view at:** <https://goo.gl/hkXmxE>

The impact of public health awareness campaigns on the awareness and quality of palliative care

JOURNAL OF PALLIATIVE MEDICINE, 2018; 21(S1):S30-S36. The right to health includes a right of access to good quality palliative care (PC), but inequalities persist. Raising awareness is a key plank of the public health approach to PC, but involves consideration of subjects most of us prefer not to address. This review addresses the question: “do public health awareness campaigns effectively improve the awareness and quality of PC”? A comprehensive public awareness campaign about PC (including advance care planning and end-of-life decision making) should be based on clear and shared terminology, use well piloted materials, and the full range of mass media to suit different ages, cultures, and religious/spiritual perspectives. Arts and humanities have a role to play in allowing individuals and communities to express experiences of illness, death, and grief and encourage conversation and thoughtful reflection. There is evidence about key factors for success: targeting, networking, and use of specific, measurable, achievable, realistic time-bound objectives; continuous evaluation; and complementary to national and international policy. Campaigns should be located within the framework of public health promotion and the synergy between short national mass media campaigns and longer term local community action initiatives carefully considered. National and local projects to raise awareness should identify and address any barriers at the level of individuals, communities, and systems of care, for example, literacy skills and unequal access to resources. **Abstract:** <https://goo.gl/MfzCmX>

End-of-life care: How do we move forward?

JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS OF EDINBURG, 2017;47(4):369-373. Death and dying are inevitable. High quality and accessible palliative and end-of-life care (EoLC) can help people who are facing progressive life-threatening and life-limiting illness, and those dear to them, by focusing on their quality of life and addressing the problems associated with their situation. This paper draws attention to the scale of the challenge, some of the key areas we could address and the shifts in culture, mindset and leadership approach that are needed. The Ambitions for Palliative & End-of-Life Care Framework explicitly recognises these challenges through its six ambitions, i.e. “each person is seen as an individual, each person has fair access to care, maximising comfort and wellbeing, care is coordinated, staff are prepared to care, and each community is prepared to help.”¹ It acknowledges that achieving this whole-system approach of “what good looks like” in palliative and EoLC requires every individual, organisation and society as a whole to work together, so that the goal of the best possible EoLC can be achieved. **Full text:** <https://goo.gl/RpHXkU>

Six ambitions to bring that vision about

- 01 Each person is seen as an individual
- 02 Each person gets fair access to care
- 03 Maximising comfort and wellbeing
- 04 Care is coordinated
- 05 All staff are prepared to care
- 06 Each community is prepared to help

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk



Acti
Go to

Cont.

1. 'Ambitions for Palliative & End-of-Life Care: A National Framework for Local Action 2015-2020,' National Palliative & End-of-Life Care Partnership, September 2015. [Noted in the 14 September 2015 issue of Media Watch (#427, p.14)] **Download/view at:** <http://goo.gl/1cXKFe>

Related

- *EUROPEAN JOURNAL OF PERSON CENTERED HEALTHCARE* | Online (In print) – 15 December 2017 – '**Ambitions for palliative and end-of-life care: A relentless focus on the person.**' Many countries are grappling with the dilemma of a growing gap between healthcare need and resource available. This gap is compounded by our collective and growing success in finding new treatments and potential interventions, many of them costly. There is no obvious solution for this conundrum. **Abstract:** <https://goo.gl/XjKiXh>
- *MORTALITY* | Online – 28 December 2017 – '**From cradle to grave? Policy responses to death in the U.K.**' While death features widely in various humanities and some social science disciplines, to date it has not been given the attention it deserves in social policy discourse or research. This paper sets out to begin to rectify that omission. Outlining a range of policy areas affected by death, it argues that budget and outcome-driven priorities in the U.K. have resulted in the evolution of disconnected and inconsistent policy responses to death. The paper begins by outlining death rates and characteristics of population ageing before focussing on social divisions in death and associated policies. It considers the death and U.K. social policy agenda before outlining the key characteristics involved in developing a coherent policy response and policy analysis in this field. **Abstract:** <https://goo.gl/gXgRha>

End-of-life preparations among lesbian, gay, bisexual, and transgender people: Integrative review of prevalent behaviors

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 18 December 2017 – Proactively making end-of-life (EoL) preparations is important to ensure high quality EoL care. Critical to preparation is the discussion of preferences with one's primary health care providers. Lesbian, gay, bisexual, and transgender (LGBT) people often experience discrimination from health care providers that will detrimentally affect their ability to communicate their care preferences. Structural barriers, such as those based on sexual orientation and gender identity, may impede timely and quality care when one is most in need. The aim of this study was to examine the prevalence of EoL preparatory behaviors among LGBT people, with particular focus on transgender individuals. Eight survey instruments with 30 prevalence estimates found in the literature were analyzed. EoL discussions between LGBT people and their primary health care providers were rare (10%). Transgender people were found to be even less prepared for EoL; they were 50-70% less likely than their LGB counterparts to have a will, a living will or to have appointed a healthcare proxy. A need exists for future mixed-methods research focused on LGBT populations accompanied by the cultural sensitivity needed to ensure their wishes are honored at the EoL. **Abstract:** <https://goo.gl/N9XTzR>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 December 2017 – '**Current best practices for sexual and gender minorities in hospice and palliative care settings.**' Although several publications document the healthcare disparities experienced by sexual and gender minorities (SGMs), including lesbian, gay, bisexual, and transgender (LGBT) individuals, less is known about the experiences and outcomes for SGM families and individuals in hospice and palliative care (HPC) settings. This article provides a brief overview of issues pertaining to SGMs in HPC settings, highlighting gaps in knowledge and research. Current and best practices for SGM individuals and their families in HPC settings are described, as are recommendations for improving the quality of such care. **Abstract:** <https://goo.gl/P8dsWG>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 22 December 2017 – '**Promoting LGBTQ inclusivity in palliative care.**' When the author first published his research on the perspectives of the lesbian and gay community regarding end-of-life care, advance care planning, and disclosure of sexual orientation a decade and a half ago, there was little awareness of the unique concerns

Cont.

and experiences of this community, or the importance of cultural proficiency in serving these individuals in palliative care (PC) settings.^{1,2} With growing interest in addressing the health needs and disparities among diverse cultural and demographic populations, it has been increasingly common for professional articles, conference presentations, and clinical guidelines to consider whether and how hospice and PC providers serve the LGBTQ community. **Abstract:** <https://goo.gl/3XWNbw>

1. 'Attitudes on end-of-life care and advance care planning in the lesbian and gay community,' *Journal of Palliative Medicine*, 2001;4(2):173-190. **Abstract:** <https://goo.gl/e8hndD>
2. 'Physician-patient relationships among the lesbian and gay community,' *Journal of the Gay & Lesbian Medical Association*, 2001;5(3):87-93. **Abstract:** <https://goo.gl/cMchwD>

N.B. Additional articles on palliative and end-of-life care for LGBTQ communities are noted in the 18 December 2017 issue of *Media Watch* (#543, p.4).

Examining racial disparities in the time to withdrawal of life-sustaining treatment in trauma

JOURNAL OF TRAUMA & ACUTE CARE SURGERY | Online – 20 December 2017 – Racial disparities in end-of-life decision-making practices have not been well described. When time from admission to time to withdrawal of life-sustaining treatment (WLST) increases so does the potential for ineffective care, health-care resource loss, and patient and family suffering. 13,054 patients from 393 centers were included in the authors' analysis. African-American patients and Hispanic patients were more likely to have late WLST as compared to early WLST. These findings might be due to patient preference or medical decision making, but speak to the value in assuring a high standard related to identifying goals of care in a culturally sensitive manner. **Abstract:** <https://goo.gl/3rr2Ud>

N.B. Additional articles on racial disparities in the provision and delivery of hospice and palliative care in the U.S. are noted in the 16 October and 17 April 2017 issues of *Media Watch* (#534, p.3 and #508, p.10, respectively). The focus of the February 2016 issue of the *Journal of Palliative Medicine* is on end-of-life care for African Americans (noted in the 8 February 2016 issue of *Media Watch* (#448, p.15)). **Journal contents page:** <http://goo.gl/6fapNx>

From disability rights to the rights of the dying (and back again)

LAWS | Online – 15 December 2017 – This article argues for civil rights for dying people. The creation of such rights should be understood as complementary to, but distinct from, existing initiatives to provide dying people with social benefits. A basis for rights for terminally ill people can be found in the disability rights movement. Through an ethnographic case study of two dying individuals, the author argues that terminally ill people can be subjected to disability discrimination as it is understood within the dominant theoretical framework of disability rights: the social model of disability. Nevertheless, while disability rights provides a theoretical basis for understanding discrimination against people who are dying, existing U.S. disability rights legislation largely does not recognize, nor address this discrimination. For this reason, it is necessary to develop a separate set of rights of the dying. The author concludes by arguing that such "dying rights" are a logical extension of disability rights, and will bring ancillary benefits to both disabled people and the disability rights movement itself. There is thus a strong foundation for

a legal and political alliance between disability rights advocates and advocates for people who are dying. **Full text:** <https://goo.gl/1Wq2yg>

Why this article is not about physician-assisted suicide

Physician-assisted suicide (PAS) has dominated interaction between disability rights advocates and advocates for dying people... To an extent, this domination is understandable: PAS is an important issue both in general and, specifically, for disabled people, even in a country such as the U.S., where the practice is limited only to the terminally ill. However, it is also unfortunate. Discussions of the relationship between disability rights advocates and advocates for PAS generally center on the conflict between these two groups. There is a substantial conflict ... and it is worth discussing... However, this conflict is not the only way to imagine the relationship between the two constituencies putatively represented by "disability rights" and PAS: the long-term disabled and the terminally ill.

Cont.

N.B. Articles on palliative and end-of-life care for people living with intellectual disabilities are noted in the 4 September and 28 August 2017 issues of Media Watch (#528, p.9 and #527, pp.6,10-11, respectively).

Do we deny death?

A genealogy of death denial

MORTALITY | Online – 19 December 2017 – The following is a two-part article on the “death-denial” thesis, namely the assumption that modern Western societies seek to deny and conceal the reality of death. The first part of the article gives a chronological overview of Anglophone and French literature on the thesis, focussing on its development and pervasiveness in the disciplines of history and sociology. In the second part of the article, to be published in a subsequent issue of this journal, the authors summarise the critiques to the said thesis. They also assess its present state in the social sciences and point to new paths for the future of death studies. **Abstract:** <https://goo.gl/Tu7yqZ>

N.B. ‘Critiques of the death-denial thesis.’ **Abstract:** <https://goo.gl/H4rjvy>

American Society for Pain Management Nursing and Hospice & Palliative Nurses Association position statement: Pain management at the end of life

PAIN MANAGEMENT NURSING | Online – 16 December 2017 – Pain at the end of life (EoL) continues to be of great concern as it may be unrecognized or untreated. Although nurses have an ethical obligation to reduce suffering, barriers remain regarding appropriate and adequate pain management at the EoL. This joint position statement ... contains recommendations for nurses, prescribers, and institutions that would improve pain management for this vulnerable population. **Abstract:** <https://goo.gl/9FvLP7>

End-of-life care in Portugal

Risk factors for hospital death in conditions needing palliative care: Nationwide population-based death certificate study

PALLIATIVE MEDICINE | Online – Accessed 19 December 2017 – The findings of this study show that the reality for place of death in Portugal is different to countries where palliative care (PC) is well established: there is a steady upward hospital death trend and dying from cancer, a disease with a more predictable trajectory than others, acts as a risk rather than protective factor for hospital death. This may apply to other aged countries with high-level of need but without integrated PC. While a cultural pattern of extended family support may persist, it seems to co-exist with a reliance on hospitals as providers of the best available care in a hospital-centric health system. This may shape the fact that younger patients and married people are at higher risk of dying in hospital. In this context, hospital beds availability, urbanisation level and deprivation do not seem very influential. The sustainability of this model needs to be assessed in light of the global emerging transition pattern in where people die and taking into account future challenges. As the population ages further and older people are more likely to die out of hospital, the current hospitalisation of dying trend may attenuate but only if the observed patterns of family caregiving persist. This is unlikely as families are becoming smaller and more disperse. Home support must therefore develop so that dying at home is a real option in response to people’s preferences, supported with the best quality care, available in a fair manner to more persons and their families in the future. **Full text:** <https://goo.gl/KQhii8>

Noted in Media Watch 27 June 2016 (#468, pp.13-14):

- *PORTO BIOMEDICAL JOURNAL* | Online – 17 June 2016 – ‘**Palliative care and the Portuguese health system.**’ The present model of palliative care (PC) ceases to respond to the pressing needs. What to do to adapt to the changes brought by demographic change and by innovation? What models should be adopted for better resource optimization in PC? Portugal has a multi-sectoral PC model, in light of what happens in reference countries, however, a better rationalization of resources will be required in order to ensure optimization in the distribution of patients. **Full text:** <http://goo.gl/FF5Fm4>

N.B. English language article.

How using generative learning strategies improved medical student self-competency in end-of-life care

THE PERMANENTE JOURNAL, 2018;22(1):17-64. During a mandatory fourth-year core geriatric medicine rotation at the medical school at the University of North Texas Health Science Center, the authors discovered medical students were struggling with end-of-life (EoL) issues both personally and professionally. They implemented curriculum changes to assist them in developing emotional awareness about death and dying, and to help develop their ability to respond personally and professionally to patients and their families during EoL experiences. In the new curriculum, a seasoned ethicist conducts two educational sessions addressing EoL issues. Students complete self-study content before the first session, in which they have a discussion about their own experience with death and dying. The ethicist facilitates these discussions with a small group (10-14 medical students), allowing the students to explore their own experiences, case studies, and others' experiences in EoL. Before the second session, students prepare a self-reflective narrative essay about an EoL experience. The facilitator, by using a generative learning strategy, has a rich interaction that attempts to connect previous experiences, present training, and how the student physicians may need to adjust behaviors in order to be advocates for their patients in EoL situations in the future. Students complete a pre- and post-self-assessment in the didactic. Results show significant improvement in their perceived competence in EoL issues. In addition, the students' self-reflection essays reveal intriguing themes for future study. **Full text:** <https://goo.gl/msRvbg>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 December 2017 – ‘**Experiences of female and male medical students with death, dying, and palliative care: One size does not fit all.**’ Medical students learn about death, dying, and palliative care (DDPC) through formal curricular offerings and informal clinical experiences; however, the lessons learned in the clinic may be at odds with the formal curriculum. The findings of this study can help clinical faculty engage students more effectively with this challenging topic. **Abstract:** <https://goo.gl/4LXNSH>
- *BMC MEDICAL EDUCATION* | Online – 16 December 2017 – ‘**Palliative care and the arts: Vehicles to introduce medical students to patient-centred decision-making and the art of caring.**’ Palliative care decision-making, augmented by the visual arts, can serve as a vehicle to address several competencies, including those related to being patient-centred, empathic and holistic in the approach to care. These can be incorporated and re-emphasized longitudinally across the whole medical curriculum, from the pre-clinical to the clinical years of medical school, and beyond into specialization programs. **Full text:** <https://goo.gl/xhy3VH>
- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2017;23(12):606-610. ‘**Teaching end-of-life care to baccalaureate nursing students: Lessons learned.**’ End-of-life care (EoLC) is increasingly provided by nurses outside of traditional hospice environments, yet many general nurses have limited education in EoLC. This article describes the development and evolution of an EoLC course in a baccalaureate nursing program, and the resources and strategies the faculty used to facilitate student engagement and learning. The original course was then eliminated and replaced by the inclusion of EoLC education within existing courses. Faculty drew on the experience gained and lessons learned over several years to identify essential content from the course and include it in the new curriculum, to be integrated into existing courses and levels. **Abstract:** <https://goo.gl/uZoaP9>
- *JOURNAL OF CANCER EDUCATION* | Online – 20 December 2017 – ‘**Palliative oncologic care curricula for providers in resource-limited and underserved communities: A systematic review.**’ Fourteen articles were identified and referenced palliative care (PC) education programs in Argentina, Uganda, Kenya, Australia, Germany, the U.S., or multiple countries. The most common teaching strategy was lecture-based, followed by mentorship and experiential learning involving role play and simulation. Education topics included core principles of PC, pain and symptom management, and communication skills. Two programs included additional topics specific to the underserved or American Indian/Alaskan Native community. **Abstract:** <https://goo.gl/RpiRNk>

Family conference in palliative care: Concept analysis

REVISTA BRASILEIRA DE ENFERMAGEM, 2018;71(1):206-213. A family conference (FC), a therapeutic instrument used by the palliative care (PC) team, emerges as a moment of planned dialogue between patient, family and team. Although it is of particular importance, the FC is still less widespread among health professionals. In addition to the scarcity of studies, it can be seen that there is no single definition in the literature about FCs. For some authors, FC is defined as an intervention aimed at sharing information, clarifying doubts about patient and family concerns, and communicating “bad news” in order to allow the family not only to understand the dynamics of the care that is being provided to their loved one in the process of dying, but also establish an affective connection so that it is possible to reach a consensus in the resolution of problems. One study states that the FC reflects a planned intervention with the family with the goal of helping to alleviate suffering. It is an effective means of communication and should be structured to enable nurses and other health professionals to provide information, assess patient and family needs, and create opportunities for shared decision-making for interaction within the family. It is necessary to develop a concept analysis about the FC in the context of PC, aiming at a better understanding and of the concept, and enabling a practical systematization of this therapeutic family instrument. **Full text:** <https://goo.gl/MjQwpi>

N.B. Full text available in both Portuguese and English. Additional articles on family conferences in the context of palliative and end-of-life care are noted in the 28 August 2017 issue of *Media Watch* (#527, p.12).

Related

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 29 December 2017 – ‘**Family care conferences in long-term care: Exploring content and processes in end-of-life communication.**’ Family care conferences (FCCs) were implemented in four long-term care (LTC) sites in Ontario, Canada. Examination of the processes supporting EoL communication found: 1) Advantages to using FCC forms versus electronic charts; and, 2) High levels of multidisciplinary participation overall, but limited participation of personal support workers (PSWs) and physicians. Recommendations for tailoring conferences to optimize communication include use of specific conference forms, increased bereavement discussion, and further engagement of PSWs and physicians. Abstract: <https://goo.gl/CMhM4N>

N.B. Additional articles on family conferences in the context of palliative and end-of-life care are noted in the 28 August 2017 issue of *Media Watch* (#527, p.12).

End -of-life care in the U.K.

Are life-extending treatments for terminal illnesses a special case? Exploring choices and societal viewpoints

SOCIAL SCIENCE & MEDICINE | Online – 16 December 2017 – Criteria used by the National Institute for Health & Care Excellence (NICE) to assess life-extending, end-of-life (EoL) treatments imply that health gains from such treatments are valued more than other health gains. Despite claims that the policy is supported by societal values, evidence from preference elicitation studies is mixed and in-depth research has shown there are different societal viewpoints. Few studies elicit preferences for policies directly or combine different approaches to understand preferences. Survey questions were designed to investigate support for NICE EoL guidance at national and regional levels. These “decision rule” (DC) and “treatment choice” questions were administered to an online sample of 1,496 U.K. respondents... The same respondents answered questions designed to elicit their agreement with three viewpoints (previously identified and described) in relation to provision of EoL treatments for terminally ill patients. The authors report the findings of these choice questions and examine how they relate to each other and respondents’ viewpoints. Overall, this study challenges claims about public support for NICE’s EoL guidance and the focus on life extension at EoL and substantiates existing evidence of plurality in societal values. **Abstract:** <https://goo.gl/Mhm92k>

Exploring Habermas' theory of communicative ethics as an approach to physician communication training: The case of pediatric end-of-life care

SOCIAL THEORY & HEALTH | Online – 13 December 2017 – In pediatric end-of-life (EoL) care, the partnership between physicians and parents is principally centered on communication and the parents' decision-making role about the patient's impending death. And, because parents are charged with EoL decision-making for their children, physicians are morally responsible to ensure that prognoses and treatment options are communicated to parents in a comprehensible way. Poor communication has been posited as a primary reason why the EoL wishes of patients and surrogates are not implemented. This paper is based on findings from a qualitative study that utilized observation in a high-fidelity simulation and semi-structured interviews with physicians to explore narrative influences on pediatric EoL communication. The findings of this study, which revealed an inherent connection between communication, decision-making and ethics, reflect Jürgen Habermas' theory of communicative ethics. Therefore this paper pro-

poses communicative ethics as an important model which, if utilized in physician education and training, could improve physician communication and in particular, physician-parent EoL communication. **Abstract:** <https://goo.gl/npsdRZ>

New ways to cut through ethical Gordian knot

JOURNAL OF CLINICAL ETHICS, 2017;28(4):257-268. Clinicians and ethicists routinely encounter complex ethical dilemmas that seem intractable, which have been described as ethical Gordian knots. How can they best assist patients and surrogate decision makers who are entangled in struggles around the capacity to make life-or-death treatment decisions? The author describes unconventional and unorthodox approaches to help slice through these dilemmas. **Journal contents page (click on 'open access' to access full text):** <https://goo.gl/1UL4yb>

N.B. The "Gordian knot" is a metaphor for an intractable problem

N.B. Profile, philosophy and bibliography of Jürgen Habermas: <https://goo.gl/GA29ou>

Related

- *ACTA PAEDIATRICA* | Online – Accessed 17 December 2017 – '**Responding to parental requests for life-sustaining treatment: Relational potential revisited.**' One of the most challenging situations for pediatric clinicians is responding to parental requests for life-sustaining medical therapies for a child with profound neuro-developmental disabilities. These therapies ... offer the possibility for the child to live ... for months or years as opposed to experiencing their imminent death. While relatively rare, the tension surrounding these requests can be exceptionally high, as illustrated by the cases of Baby K, Baby Joseph, Jahi McMath, Charlie Gard, and many others... **Abstract:** <https://goo.gl/vMuPP1>
- *CANCER* | Online – 26 December 2017 – '**Intended and unintended consequences: Ethics, communication, and prognostic disclosure in pediatric oncology.**' The authors surveyed 353 parents of children with newly diagnosed cancer at 2 tertiary cancer centers, and each child's oncologist. Prognostic disclosure was not found to be associated with increased parental anxiety, depression, or decreased hope. Among the parents of children with less favorable prognoses, the receipt of high-quality information from the oncologist was associated with greater peace of mind and communication-related hope. High-quality oncologist communication style was associated with greater trust in the physician. **Abstract:** <https://goo.gl/EJrF9W>
- *MEDICAL LAW REVIEW* | Online – 15 December 2017 – '**Who knows best (interests)? The case for Charlie Gard.**' When baby Charlie Gard was diagnosed with a rare mitochondrial disease, his parents located a Professor of Neurology in the U.S. willing to provide nucleoside therapy which offered a theoretical chance of improvement and successfully raised £1.3 million through crowd funding. The decision that unproven therapy was contrary to Charlie Gard's best interests and that life-sustaining treatment should be withdrawn was devastating for his parents and difficult for their supporters to comprehend. **Abstract:** <https://goo.gl/m5eFvN>

N.B. Additional articles/reports on the Charlie Gard case are noted in the 13 November 2017 issue of *Media Watch* (#538, p.8). Also noted in this issue of the weekly report is the November 2017 issue of the *American Journal of Bioethics*, which focuses on the medical decision-making process in pediatrics. **Journal contents page:** <https://goo.gl/vQE2Lk>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ALZHEIMER DISEASE & ASSOCIATED DISORDERS* | Online – 27 December 2017 – ‘**Are informal caregivers of persons with dementia open to extending medical aid in dying to incompetent patients? Findings from a survey conducted in Quebec, Canada.**’ With the objective of contributing scientific data to current societal debates, the authors conducted a survey among 471 informal caregivers of persons with dementia, reached through Alzheimer Societies. They used a series of vignettes featuring a person with Alzheimer disease to investigate respondents’ attitudes towards medical aid in dying (MAiD). Two-thirds [of respondents] found it acceptable to extend MAiD to an incompetent patient at an advanced stage of Alzheimer disease who had made a written request while competent, and 91% found it acceptable at the terminal stage. Self-determination was the most widely endorsed argument in favor of access to MAiD for incompetent patients. **Abstract:** <https://goo.gl/nuS5cA>
- *DEATH STUDIES* | Online – 26 December 2017 – ‘**The paradox of choice and the illusion of autonomy: The construction of ethical subjects in right-to-die activism.**’ The right to die is an issue is predicated on larger cultural understandings of autonomy. Autonomy, in turn, is centered around assumptions of choice, that individuals are able to make health-related decisions based on a rational calculation. In such a way, a medically assisted death is differentiated from suicide. Through an ethnographic study of right to die activists in North America and Australia and how they understand ideals of “good deaths,” this article complicates this view by examining the ethical subject constructed by such activism that reveals autonomy to be a useful guiding fiction that mask larger ethical relationships. **Abstract:** <https://goo.gl/tF4HSW>
- *JOURNAL OF EUROPEAN SOCIAL POLICY* | Online – 22 December 2017 – ‘**The social-political challenges behind the wish to die in older people who consider their lives to be completed and no longer worth living.**’ In The Netherlands, physician-assisted dying has been legalized since 2002. Currently, an increasing number of Dutch citizens are in favour of a more relaxed interpretation of the law. Based on an ethos of self-determination and autonomy, there is a strong political lobby for the legal right to assisted dying when life is considered to be completed and no longer worth living. This article provides a critical ethical reflection upon this social issue. In the first part, the authors discuss the following question: ‘What is the lived experience of older people who consider their lives to be completed and no longer worth living?’ The authors describe the reported loss of a sense of autonomy, dignity and independence in the lives of these older people. In the second part, from an ethics of care stance, they analyse the emerging social and political challenges behind the wish to die. The authors argue that the debate on “completed life in old age” should primarily focus not on the question of whether or not to legitimize a self-directed death but on how to build an inclusive society where people may feel less unneeded, useless and marginalized. **Full text:** <https://goo.gl/BNqz6Y>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 December 2017 – ‘**Family caregivers’ reflections on experiences of assisted suicide in Switzerland: A qualitative interview study.**’ Family members [i.e., study participants] perceived their involvement in assisted suicide as characterized by five phases; 1) Contemplation; 2) Gaining acceptance; 3) Gaining permission; 4) Organization; and, 5) Aftermath. Families can participate in these phases at diverse levels and with varying degrees of involvement. Important triggers for families and patients for transition between phases include patients’ experiences of their life-threatening illnesses and related treatments, their increasing awareness of approaching death, and family member recognition of their loved one’s unbearable suffering. Participating in assisted suicide created further demanding tasks for families in addition to their role of caregivers. Families appeared to be involved in the preparation of assisted suicide along with patients, irrespective of their personal values regarding assisted dying. **Abstract:** <https://goo.gl/KjLT1d>
- *REVUE MEDICALE DE LIEGE*, 2017;72(12):562-563. ‘**Tiredness of life in older adults.**’ Tiredness of life in older adults can lead to a request for the wish to die. This article provides a practical approach for physicians of this problem on the basis of a flow chart. The main causes of tiredness of life should be identified and evaluated for their reversibility and treatment options. The first group are the physical factors which, besides organ pathology, should also take frailty into account as a possible cause. A

Cont.

second important group are the psychological risk factors such as psychiatric disorders, loneliness, dignity, subjective well-being, coping and spiritual power. These factors also determine the complaint and needs of the patient. Here is a multidisciplinary assessment and approach desirable [which] also applies to the socioeconomic risk factors. In addition, the caregiver should examine if the weariness of life indeed gives rise to the suffering of the older person and to what extent this is hopeless and unbearable suffering. Hopelessness is a professional judgment about the remaining treatment and care perspective and is often objectified; unbearable is a matter of the patient and therefore always subjective and personal. The current legislation on euthanasia, the reversibility of the underlying causes and the unbearable suffering will determine whether the request of the patient with tiredness of life can be considered. Some questions will not fit within the proposed framework. For those a multidisciplinary advice of an ethics committee may be desirable. **Abstract:** <https://goo.gl/iHksWQ>

N.B. French language article.

- *LE SPÉCIALISTE*, 2017;19(4):36-40. **'Decoding conscientious objection in medical aid in dying: First results from a unique study.'** Physician participation in medical aid in dying (MAiD) is currently low, which situation, if not addressed, carries the risk of a looming crisis in access to timely MAiD services. The authors' work sheds some light on the motives behind physician objections to MAiD and how doctors view some of their ethical rights and obligations. Using empirical evidence, the authors understand that the term "conscientious objection" is currently used as an opt-out mechanism in the majority of MAiD situations for reasons other than conscientious objection. Physicians object to participating in MAiD most often for reasons other than moral or religious grounds. Major reasons cited include high emotional burden, a perception of incompetence to perform the procedure, and time constraints. This information is important in order to better plan how to support physician concerns without denying access to care for their patients. **Full text:** <https://goo.gl/SM5hpz>



FÉDÉRATION
DES MÉDECINS
SPÉCIALISTES
DU QUÉBEC

N.B. French and English editions of this article are available at the Fédération des médecins spécialistes du Québec website.

Journal Watch

How can you spot a predatory journal?

AMERICAN COUNCIL OF SCIENCE & HEALTH | Online – 13 December 2017 – One of the main reasons for the difficulty lies in a major shift in scientific publishing that has happened in the last decade – the introduction of open access publishing on the Internet. This has brought with it the unfortunate rise of online journals that fall under the category of predatory' journals. These are defined as journals: 1) Actively solicit manuscripts; 2) Charge publications fees; and, 3) Lack robust peer review and editorial services. But, predatory journals are dressed up to look like reputable journals. So, how can one discern if the paper that they are reading is from a predatory journal or not? A group recently set out to find the answer. They chose roughly one hundred journals from each of three different categories and carried out a cross-sectional comparison of characteristics. The categories were potential predatory, legitimate open access, and legitimate subscription-based biomedical journals. The group looked at different factors that defined the journal's characteristics such as website integrity, look and feel, editors and staff, editorial/peer review process, instructions to authors, publication model, copyright and licensing, journal location, and contact. Data were collected, statistics were calculated and 13 characteristics were identified that distinguished predatory journals from presumed legitimate journals. **Full text:** <https://goo.gl/S4gMjN>

Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Selecting a quality publisher

ROYAL SOCIETY TE APĀRANGI | Online – Accessed 21 December 2017 – Getting published is important, but not so important that you should publish in an inappropriate or disreputable journal. This guide provides information to help you navigate the publishing world, with questions to ask of a potential publisher and information on key issues in academic publishing. **Full text:** <https://goo.gl/NaQc9q>



N.B. The Royal Society Te Apārangi is an independent government body in New Zealand providing funding and policy advice in the fields of sciences and the humanities.

Worth Repeating

An Irish perspective

Control and care at the end of life: The “good death” in palliative care

IRISH JOURNAL OF ANTHROPOLOGY, 2016;19(1):100-108. The person who is dying is subject to rule of performativity in relation to the “good death.” They are expected to organise the most disorganised part of life, the stage pre-death. The norms governing this stage of life’s performance are increasingly secularised, technicised and governed by professional (especially medical) logics more so than on compassion and care for the person in palliative care (PC). Moreover, the concept of the “good death” is based on assumptions about end-of-life (EoL) care that disregards the ways in which existing inequalities in economic, political, cultural and affective relations create an “illusion” of choice for many: they have neither the economic resources or affective supports to make particular choices. Nor are certain choices in accord with their cultural values and beliefs. Thus the dominant narrative in Ireland that a good death is one where you “die in your own bed” at home is in need of problematisation not least as it assumes that families have the resources and affective capacity to care for a person at the EoL at home. Finally, choice logic leaves unspoken the highly gendered assumptions as to who will do informal (unpaid) and formal (paid) PC work at home, when dying at home is made a priority “choice.” **Journal contents page** (scroll down to article to access **full text**): <https://goo.gl/n8k5L1>

N.B. See ‘A Good Death: A Reflection on Ombudsman Complaints about End-of-Life Care in Irish Hospitals,’ Office of the Ombudsman, Dublin, Ireland, June 2014. [Noted in 30 June 2014 issue of Media Watch (#364, p.6)] **Download/view at:** <https://goo.gl/cvB1hz>

Media Watch: Online

Updated 12.31.2017

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/m9u1bB>

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

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

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

[Scroll down to ‘Aggregators’ and ‘Media Watch by Barry Ashpole’; see 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’]

Cont.

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>
[Scroll down to 'Are you aware of Media Watch?']

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

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

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

Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/sBTcJS>
[November/December 2017 issue (Scroll down to 'Vulnerable populations: From the homeless to the unbefriended)']

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

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

Media Watch: Editorial Practice

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

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.

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net