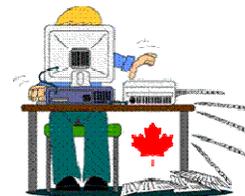


## Media Watch...

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.

5 February 2018 Edition | Issue #549



Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

The role of technology in a pediatric clinical setting: Scroll down to [Specialist Publications](#) and 'A review of apps for calming, relaxation, and mindfulness interventions for pediatric palliative care patients' (p.10), in *Children*.

## Canada

### Palliative-care mentor packs it in as Nova Scotia Health Authority strategy fails miserably

NOVA SCOTIA | *The Chronicle Herald* (Halifax) – 3 February 2018 – A Cape Breton palliative care (PC) doctor is giving up his medical licence next month – in part because the way PC is provided in Richmond County is forcing more and more people to die in hospitals rather than at home. For the past four years, Dr. Bob Martel has been on his own to help patients, because he's not part of the Nova Scotia Health Authority (NSHA) PC program and any patient in Richmond County needing the services of a PC doctor is referred to the physician who visits the area every two weeks. NSHA's reported response is nothing more than rhetoric. Their words bring cold comfort to patients and sounds the death knell to doctors. NSHA is "industrializing" health care. It will be available in measured portions in different parts of the province; depending on where you live, your access to health-care services will be different. So much for what was recognized as universal access to health care in the Canada Health Act. NSHA has found ingenious ways to cut costs, restrict services, ration compassion and gift it to us as the best evidence-based approach to care. When

asked for feedback from family doctors about their province-



wide PC strategy, two issues were flagged for them: 1) PC must be accessible to all Nova Scotians (particular efforts should be made to support local communities in rural and urban locations); and, 2) The PC strategy should also create the economic framework within which the model is expected to work (it should identify areas of investment, which are expected at the start of this initiative, in order to match scaling up with education, development of human resources, e-health tools and outreach to rural/urban centres with unique needs). Reality check: the severe shortage of family doctors in the province must already be affecting PC services. <https://goo.gl/uoeHvW>

### Specialist Publications

'Medicare and the care of First Nations, Métis and Inuit' (p.10), in *Health Economics, Policy & Law*.

Cont.

Noted in Media Watch 29 May 2017 (#514, p.1):

- NOVA SCOTIA | *The Globe & Mail* – 22 May 2017 – **‘Better health care means fixing bureaucratic failings.’** Two years after Nova Scotia “de-regionalized” – merged its nine health regions into a single provincial health authority – an informal, blue-ribbon group has offered up a scorching analysis of the exercise. It concluded that the Nova Scotia Health Authority, which has 23,400 employees and a budget of \$2.1 billion, is a “non-system – disconnected, not communicating, non-agile, non-‘people-centred’ as well as [having] front-line staff and managers who feel helpless and unable to effect the changes they know have to happen.” That is, sadly, a description that applies to many provincial and regional health administrative bodies around the country. <https://goo.gl/hwJX7D>

Noted in Media Watch 11 July 2016 (#470, p.1):

- NOVA SCOTIA | *The Cape Breton Post* (Sydney) – 7 July 2016 – **‘Richmond County palliative care doctor pulls services, blames slow provincial action.’** Dr. Bob Martel will no longer provide palliative care (PC) services for the Strait-Richmond area. Martel said Richmond is one of three counties in the province without PC nursing services on weekday evenings and on weekends. Other than Martel working as a full-time PC doctor, medical PC consultations are only available from out-of-town physicians every three to four weeks. There are other resources lacking such as a full-time social worker, dedicated field-based PC nurses, physicians, and nurse practitioners. Provincial PC co-ordinator Cheryl Tschupruk admitted there are gaps in PC service... <http://goo.gl/hFjuiC>

### Doctors concerned at-home palliative care could die in Scarborough

ONTARIO | *Inside Toronto* – 2 February 2018 – What makes it possible for James McDonald and other patients to spend final weeks or months at home is a small physician team supervising their palliative care (PC). Scarborough, however, had teams bringing PC into homes before, and they failed. Members of the current team say unless the province offers more support, home PC in Scarborough, instead of expanding to fill a growing need, could collapse again. “Once again, the palliative services are in danger of being discontinued,” said Dr. David D’Souza... “We’re struggling to keep it alive.” Part of what ails the teams is the province’s Community Palliative On-Call Program, which pays \$171,140 annually to 29 groups which provide on-call palliative coverage. The Scarborough palliative team didn’t form at a time when those funds were available, so members of other teams get \$350 each time they attend to patients during nights or weekends. The Scarborough physicians get nothing. <https://goo.gl/ujUobM>

Noted in Media Watch 9 March 2015 (#400, pp.1-2):

- ONTARIO | *The Globe & Mail* – 2 March 2015 – **‘Ontario pledges palliative care teams for patients wishing to die at home.’** For nearly two years, Darren Cargill, a palliative medicine specialist in Windsor, Ontario, has been waiting for the money that he and his team of doctors and nurses were promised to provide round-the-clock support to gravely ill patients who want to die in their own homes. He finally received an e-mail from the provincial government saying the funding ... would begin to flow within 60 days, retroactive to 1 April 2013. The e-mail arrived ... after *The Windsor Star* highlighted the issue in a column accusing the province of incompetently managing an experiment in community palliative care that the Auditor-General had praised in her most recent report.<sup>1,2</sup> <https://goo.gl/bcvs38>

1. ‘Another sad tale of incompetence,’ *The Windsor Star*, 20 February 2015. [Noted in 2 March 2015 issue of Media Watch (#399, p.1)] <https://goo.gl/1z7Buh>
2. ‘2014 Report of the Office of the Auditor General of Ontario (Chapter 3: Ministry of Health & Long Term Care – Palliative Care, pp.258-288),’ 9 December 2014. [Noted in 15 December 2014 issue of Media Watch (#388, p.2)] **Download/view at:** <https://goo.gl/tbjnBx>



### Media Watch Online

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

## Palliative costs less than reported

ALBERTA | *The Medicine Hat News* – 30 January 2018 – The cost of a palliative care (PC) bed in hospital is less than the average per-day hospitalization cost reported when the decision to close the PC ward at the Medicine Hat Regional Hospital (MHRH) was made public. Alberta Health Services (AHS) chief zone officer Katherine Chubbs said in November that the average cost of hospitalization per day is about \$1,200 to \$1,500. According to data recently supplied by AHS, PC per day at MHRH is \$805. The numbers represent a standard, average cost used by AHS for budgeting purposes, and is not Medicine Hat-specific, an AHS spokesperson said. The hospital's PC ward and its 12 beds was permanently closed at the end of December. Carmel Hospice, operated by Covenant Health, has enough capacity to meet demand. Reports at the time said providing PC in two places resulted in neither operating at more than about 50% capacity. The closure is expected to save about \$5.5 million a year. Cost savings are derived from estimates of paying for one ward – in this case the hospice – at or near full occupancy. Covenant Health says its per-day costs for hospice care average out to \$440. <https://goo.gl/qB5UfH>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NOVA SCOTIA | CTV News (Halifax) – 1 February 2018 – **'Less than half of assisted suicide requests accepted in Nova Scotia: Report.'** Canadians have the legal right to ask for assisted suicide, but CTV News has learned fewer than half of Nova Scotians who requested it in the last six months were given medical assistance to die. Seventy-three requests have been made over the past six months, with only 28 of those receiving the procedure. The average age of those who received assistance was 70. Slightly more of them were male, and the most common diagnosis was cancer. Forty-five requests were not approved. The Nova Scotia Health Authority cites a variety of reasons, including requests that were withdrawn, mental capacity to move forward, and some died before getting assistance. <https://goo.gl/5EWxmz>
- ONTARIO | *The Globe & Mail* (Toronto) – 31 January 2018 – **'Religious doctors must perform referrals for medically assisted death: Ontario court.'** Requiring Christian doctors to refer patients to physicians willing to provide an assisted death is a reasonable limit on freedom of conscience, Ontario's Divisional Court ruled 3-0. "The evidence in the record establishes a real risk of a deprivation of equitable access to health care, particularly on the part of the more vulnerable members of our society, in the absence of the effective referral requirements," Justice Herman Wilton-Siegel wrote for the court. Groups representing 4,700 Christian doctors had challenged Ontario regulations obliging the referrals, saying that making such a referral was morally equivalent to participating in an assisted death. The case is the first to test the constitutional rights of doctors who object to assisted death on grounds of conscience. It comes as the faith-based medical community struggles to find a middle ground in the era of assisted dying, which has made it more difficult for some patients to obtain an assisted death in a timely way. Some hospitals run by Catholic, Jewish or other religious groups have declined to offer assisted dying. In those cases, patients are transferred to other facilities. <https://goo.gl/GC7TE4>  
  
**N.B.** Additional articles, reports, etc., on faith-based hospitals *vis-à-vis* medical assistance in dying noted in the 22 January 2018 issue of *Media Watch* (#547, p.1)]
- BRITISH COLUMBIA | CBC News (Vancouver) – 29 January 2018 – **'British Columbia has highest rate of medically assisted death in Canada.'** They stop thinking about dying. That is how Dr. Stefanie Green describes patients' reaction to being approved for medical assistance in dying (MAiD). Green, the president and co-founder of the Canadian Association of MAiD Assessors & Providers is also a MAiD provider on Vancouver Island, the region with the highest rate of assisted deaths in the country. In fact, in the first 11 months of 2017, nearly half of all medically assisted deaths in British Columbia happened in areas covered by Island Health. In this region, which includes Vancouver Island and the Gulf Islands, 3.5% of all deaths were medically assisted, compared to just 1.7% for the whole province. <https://goo.gl/TPVrQ4>

## U.S.A.

### Defining death

#### What does it mean to die?

CALIFORNIA | *The New Yorker* – 5 February 2018 – When Jahi McMath was declared brain-dead by the hospital her family disagreed. Her case challenges the very nature of existence. Like all states, California follows a version of the 1981 Uniform Determination of Death Act, which says someone who has sustained the “irreversible cessation of all functions of the entire brain, including the brain stem, is dead.” California law requires that hospitals permit “a reasonably brief period of accommodation” before disconnecting a ventilator – long enough to allow family to gather, but not so long that hospitals neglect the “needs of other patients and prospective patients in urgent need of care.” <https://goo.gl/qYchgD>

**N.B.** Additional articles on defining “brain dead” noted in the 20 November 2017 issue of Media Watch (#539, p.1).

#### New studies find America's silent workforce has a lot to say about their jobs as caregivers

*FORBES* | Online – 31 January 2018 – Despite the immense and ever-growing need for physical, financial and emotional relief for family caregivers, research indicates the nation’s estimated 40 million caregivers still find joy in caring for their loved ones. But they also need help like never before... The SCAN survey found that, from the perspectives of physical and emotional health, the implications of caregiving can be equally worrisome. Results show that, of senior caregivers: 82% have difficulty saying “no” to the job; 54% feel guilty about taking a break from their caregiving tasks to make time for themselves; 29% spend 40 hours a week or more caring for someone; 47% are concerned about the physical strains that comes with caregiving and 44% are concerned about the emotional strains; and, 44% are not confident that the person they’re a caregiver for would be able to find someone else to take care of them. The survey also explored the financial implications associated with caregiving. Some 47% of caregivers

#### Specialist Publications

‘Medical decision-making for adults who lack decision-making capacity and a surrogate: State of the science’ (p.9), in *American Journal of Hospice & Palliative Medicine*.

‘Dying behind bars’ (p.11), in *Journal of Gerontological Nursing*.

‘The growing demand for hospice and palliative medicine physicians: Will the supply keep up?’ (p.12), in *Journal of Pain & Symptom Management*.

report having to tighten their belts financially because of their caretaking responsibilities. Among those who have experienced financial strain: 34% have cut back on their own discretionary spending; 20% have used personal savings to provide care; 8% have accrued credit card debt to provide care; 5% have asked for donations or financial support from friends or family; and, 2% have taken out a loan to provide care. And yet despite all of the statistics, some 86% of respondents indicated that their responsibility is a rewarding experience. <https://goo.gl/T4Cv9s>

#### Specialist Publications

“‘I didn’t want to be in charge and yet I was.’: Bereaved caregivers’ accounts of providing home care for family members with advanced cancer’ (p.15), in *Psycho-Oncology*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | *The Denver Post* – 2 February 2018 – ‘**69 Coloradans got aid-in-dying prescriptions during law’s first year, report says.**’ Sixty-nine Colorado patients were prescribed aid-in-dying medication during 2017, the first year of the law approved by voters, and 50 of those patients filled the prescription, according to a report by the Colorado Department of Public Health & Environment (CDPHE).<sup>1</sup> Although 56 of those 69 patients died, the data don’t reveal which ones died as a result of the drugs, or even if the deceased had filled their prescription. But the CDPHE report does shed light on the characteristics of patients who pursued help through the law, and noted that Colorado’s data closely reflect that of other states that have medical aid-in-dying laws. <https://goo.gl/J2Lrhd>
  1. Colorado End-of-Life Options Act: Year One 2017 Data Summary,’ Colorado Department of Public Health & Environment, February 2017. **Download/view at:** <https://goo.gl/XqoHx6>
- STAT | Online – 31 January 2018 – ‘**Physician-assisted suicide won’t atone for medicine’s “original sin.”**’ Centuries from now, one of the things our era will be known for is the plague of dying badly. A growing number of physicians believe one solution is helping their dying patients choose to end their lives. I disagree. I’m proud of being a physician and a lifelong political progressive. I ardently believe in human rights. But there are some things doctors must not do. Intentionally ending patients’ lives is chief among them. Prolonged suffering before death emerged as a public health crisis in the mid-20th century. This first-world scourge, so persistent that few dare to imagine it can be eradicated, is a direct result of modern medicine’s original sin: believing that we can vanquish death. <https://goo.gl/zz7kqb>
- STAT | Online – 31 January 2018 – ‘**I’m a doctor with end-stage cancer. I support medical aid in dying.**’ I’m a doctor with incurable stage 4 prostate cancer. When my suffering becomes intolerable, I hope my doctors will permit me the option to end it peacefully with medical aid in dying – something I have been working to get explicitly authorized in Massachusetts, where I live. Medical aid in dying gives mentally capable, terminally ill adults with six months or less to live the option to request a prescription medication they can choose to take in order to end unbearable suffering by gently dying in their sleep. When I was in my 40s, I watched my mother and my father-in-law suffer agonizing deaths from cancer. <https://goo.gl/j4pPz9>

## International

### End-of-life care in Africa

#### Doctors want palliative care for terminally ill patients

AFRICA (Nigeria) | News Agency of Nigeria – 3 February 2018 – The World Medical Association (African Region) has called for strengthening of palliative care (PC) for patients with terminally ill ailments across Africa. The association made the call in a *communiqué* issued at the end of its conference hosted by the Nigerian Medical Association (NMA). Professor Mike Ogirima, president of the NMA, identified mechanisms toward strengthening PC including national policies for such care, increased funding, as well as creating national and regional PC centres. Adopting such mechanisms will go a long way in ensuring the effectiveness of PC for patient with terminal dis-

eases. Ogirima said that there were yet to be policies on end-of-life issue in most African countries, except in Botswana, Kenya, Nigeria and Zambia where some initiatives have been taken on PC. <https://goo.gl/KH5Nxg>

#### Specialist Publications

‘**Factors affecting palliative care development in Africa: In-country Experts’ perceptions in seven countries**’ (p.12), in *Journal of Pain & Symptom Management*.

Cont.

Noted in Media Watch 8 January 2018 (#545, p.4):

- AFRICA | Devex – 3 January 2018 – ‘Africa needs investment in palliative care.’ Nineteen percent of African countries do not have identified palliative services and 71% of the services that do exist are concentrated in Uganda, South Africa and Kenya. A decrease in funding is negatively affecting palliative care (PC) service delivery and development in many countries across the continent. New research shows that while PC developed rapidly in South Africa, the proliferation of earmarked funds for hospices mean programs are often only allowed to care for patients with HIV.<sup>1</sup> <https://goo.gl/rQ69Hw>

1. ‘Atlas of Palliative Care in Africa,’ African Palliative Care Association, Kampala, Uganda, January 2018. Download/view at: <https://goo.gl/94wUHP>

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

#### **Not enough cancer patients are getting end-of-life care – new study**

U.K. | *The Conversation* – 2 February 2018 – Over the last 20 years, there has been rapid advancement in the treatment of cancer, leading to impressive survival rates for many and a general perception that we’re getting this cancer business cracked. But the stark reality is that half of all patients diagnosed with cancer in the U.K. still die of the disease. The vast majority of research funding is directed towards developing new treatment options or towards strategies to improve early diagnosis – with less than 0.3% of the £500 million spent on cancer research allocated to palliative and end-of-life care (EoLC).<sup>1</sup> Typically, patients who require EoLC still receive anti-cancer treatment. Through both routine care and participation in clinical trials, patients and their oncologists are united in the common goal of preserving life for as long as possible. But the repeated cycles of treatment and cumulative side effects can often have a detrimental impact upon the quality of a person’s life, with minimal benefits in terms of extending survival. Unlike treatment, palliative care (PC) aims to help patients live as well as possible for as long as possible. This is done by focusing on the effective management of symptoms (both physical and psychological) rather than curing disease. And research has shown that for patients with advanced cancer it can have a significant benefits in terms of quality of life for patients – including in some cases improved survival. But as recent research found, a large number of patients who die from cancer are not referred to specialist PC services at all.<sup>2</sup> <https://goo.gl/Y5u9TL>

1. ‘Research challenges in palliative and end-of-life care,’ *BMJ Supportive & Palliative Care*, 2016;6(1):2-4. [Noted in the 22 February 2016 issue of Media Watch (#450, p.10)] Full text: <http://goo.gl/WNJeLB>
2. ‘Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study,’ *BMJ Open*, published online 31 January 2018. Full text: <https://goo.gl/Ha3vQU>

### Care Quality Commission (England)

#### **Shock report criticises bullying and culture at children’s hospice**

U.K. (England) | *Wigan Today* – 2 February 2018 – A children’s hospice which provides vital end-of-life care and respite for Wigan families has had its staff culture criticised in a shock report. Derian House, which gives palliative care to some of the borough’s most vulnerable and seriously-ill youngsters and also has an army of Wigan fund-raisers supporting it, is the subject of the damning findings of the Care Quality Commission (CQC). Inspectors found a working environment that was “extremely unhealthy and broken” at the Chorley-based hospice and examples of staff feeling bullied. However, the CQC said this was all kept extremely well hidden from the young patients and their families... Inspectors went to Derian House after receiving information whistleblower and spoke to 57 past and present employees in an “unprecedented” investigation. Derian House says its trustees and management team are now working on an ac-

Cont.

tion plan “to address any areas of concern identified by the CQC.” The CQC downgraded Derian House from an overall rating of “good” to one of “requires improvement” following the unannounced six-day inspection in October. Of five categories examined, two – caring and responsive – were classified as good, while safe, effective and well-led were all deemed to be in need of improvement. <https://goo.gl/xED7Xj>

#### Related

- U.K. (England) | *This is Oxfordshire* – 31 January 2018 – ‘**Desperate finances force Helen & Douglas House to scrap adult services and make 60 redundancies.**’ Drastic steps to save a historic Oxford hospice will see it close of one of two core care hubs. A radical shake-up at Helen & Douglas House has spelled the end of its adult services and a raft of 60 redundancies. It will revert to its original children-only model, reducing its age range from 0-35 to 0-18, affecting more than a third of patients. The much-loved charity has warned it will run out money in two years if major cutbacks are not made. <https://goo.gl/rK1gMQ>

#### Are we missing the real opioid drug crisis?

U.K. | BBC – 1 February 2018 – While the U.S. suffers a much discussed overdose epidemic, less attention is paid to the fact that much of the rest of the world misses out on vital painkillers such as morphine. It may not be surprising that richer countries have better access to these medicines, but the global inequality of access to pain relief is particularly striking and even more extreme than the general inequality in health-care. Diederik Lohman, from Human Rights Watch, says not giving people access to these medicines essentially amounts to torture. The problem, he says, is that the availability of pain relief has been traditionally seen through the same prism as illegal drugs such as heroin. Opioids have been pulled into the so-called “war on drugs” discourse, instead of being seen from a medical perspective, he says. “For many decades, the discussions at the international level ... around drugs were completely focused on illegal drugs, to the point where the fact that these same substances also have important medical uses was just completely off the radar,” Mr Lohman says. Another major challenge is ensuring medical staff in all countries understand how medicines such as morphine should be used, so

they feel confident about giving them to patients. It is a fine balance to strike, ensuring people who need these medicines have access to them, but that they are not so easily available as to allow abuse. <https://goo.gl/ywSfho>

#### Opioid pain relief in different countries

**U.S.** gets 30 times more opioid pain relief medication than it needs

**Mexico** gets only 36% of what it needs

**China** gets about 16% of what it needs

**India** gets 4% of what it needs

**Nigeria** gets just 0.2% of what it needs

**Source:** The Lancet Commission on Global Access to Palliative Care & Pain Relief: <https://goo.gl/h8eBLc>

**N.B.** ‘Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,’ *The Lancet*, published online 12 October 2017. [Noted in the 16 October 2017 issue of Media Watch (#534, p.14)]  
**Full text:** <https://goo.gl/i7r9M1>

Noted in Media Watch 13 November 2017 (#538, p.9):

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 6 November 2017 – ‘**Appeal to physicians – opioids have their place. Let’s avoid an unintended tragedy.**’ A well-known tragedy has occurred with respect to opioids – the crisis of overdose deaths from opioids that were obtained from various legitimate and illegitimate sources. This has necessitated urgent government and public action. A second, preventable tragedy is beginning to occur as an unintended consequence of the first. The stigma around opioid use has become so strong that patients, families, and health care practitioners are afraid to receive or prescribe them... **Full text:** <https://goo.gl/VzahC4>

## More terminal cancer patients turn to home hospice services in Korea

SOUTH KOREA | *The Korea Bizwire* (Seoul) – 31 January 2018 – According to data released by the Ministry of Health & Welfare and the National Cancer Center over 1,000 terminal cancer patients took advantage of home hospice services during a trial period between March 2016 and last July. Among the 785 patients who died in 2016, 71% passed away at medical institutions, while nearly 21% did so at home. The government began allowing home hospice services for terminally ill patients after launching a pilot program in March 2016, offering assistance to those who suffer from terminal cancer, AIDS, chronic liver cirrhosis, and chronic obstructive pulmonary disease. <https://goo.gl/XD3VKS>

## Specialist Publications

### End-of-life communication: Nurses co-creating the closing composition with patients and families

*ADVANCES IN NURSING SCIENCE*, 2018;41(1):2-17. Communication is imperative for end-of-life decision-making; however, descriptions of key strategies used by nurses are missing. A phenomenological approach was used to interpret interviews from 10 hospice/palliative nurses. The overarching pattern is the closing composition. Key communication strategies/patterns include establishing context, acknowledging through attentive listening, making it safe for them to die, planning goals of care, and being honest. Essential is the awareness that nurse, patient, and family all hold expertise in the subject matter. It is imperative that pre-/post-nursing licensure curriculum be expanded to include training in mutual influence communication practices and mentoring in the skill of orchestration. **Abstract:** <https://goo.gl/f5KBZk>

#### Related

- *JOURNAL OF INTELLECTUAL DISABILITY RESEARCH* | Online – 31 January 2018 – ‘**Involvement of nurses in end-of-life discussions for severely disabled children.**’ Parents primarily discuss end of life (EoL) with nurses [i.e., study participants] before and after the meeting with the physician. Nurses who were involved in EoL discussions with parents and physicians assisted them by giving factual information about the child and by providing emotional support. Some nurses ... were not involved in EoL discussions, even if they had cared for the child for a long period of time. Some of the nurses had moral or religious objections to carrying out the decisions. **Abstract:** <https://goo.gl/gafN33>

### Do not resuscitate order: Islamic views

*AL-QANATIR: INTERNATIONAL JOURNAL OF ISLAMIC STUDIES*, 2018;9(1):35-43. Performing do not resuscitate (DNR) order by means of withholding resuscitation procedures such as cardiopulmonary resuscitation (CPR), intubation, defibrillation, mechanical ventilation, and cardiac drugs in end-of-life care is a process of accepting natural death to take its own course. The DNR order is proposed by medical team in cases of medical futility and when death is inevitable. There are many controversial ethical challenges that arise in the management of the death and dying. One of the issues is concerning the religious and cultural background of the patient. All patients irrespective of their religious beliefs should be treated with human dignity and respect. In Islam, Muslims believe that life is sacred and must be preserved and protected. Development of modern medicine and technology enables the prolonging of one's life which resulted in prolonged misery and suffering of the dying patient who is terminally ill with incurable disease. In this instance, the DNR order will usually be initiated by a physician. However, end-of-life issues and DNR still leave moral and ethical dilemma to physicians and next of kin. It is vital to understand the issues arising from DNR and from the Islamic perspective. There is also a dire need for recommendations from the guiding principles of Islamic jurisprudence such as the Quran, the tradition of Prophet Muhammad, and juridical opinions from past and current Muslim scholars. **Abstract:** <https://goo.gl/uR6Ngw>

**N.B.** Selected articles on the Islamic perspective on end-of-life and end-of-life care noted in the 14 August 2017 issue of *Media Watch* (#525, p.15).

Cont.

## Related

- *PSYCHOGERIATRICS* | Online – 26 January 2018 – ‘**Why do older people refuse resuscitation? A qualitative study examining retirement village residents’ resuscitation decisions.**’ Older people in this study were able to make reasoned decisions about resuscitation based on balancing their subjective estimations of quality of life (QoL) and the presumed consequences of resuscitation. The majority [67.6%] of the participants [from two retirement villages in Auckland, New Zealand] decided against resuscitation, 27.0% wanted resuscitation, and 5.4% were ambivalent about their resuscitation preferences. **Abstract:** <https://goo.gl/8NJbgM>

## Medical decision-making for adults who lack decision-making capacity and a surrogate: State of the science

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 February 2018 – Adults who lack decision-making capacity and a surrogate (“unbefriended” adults) are a vulnerable, voiceless population in health care. But little is known about this population, including how medical decisions are made for these individuals. The main findings of this study include: 1) Various terms were used to refer to adults who lack decision-making capacity and a surrogate; 2) The number of unbefriended adults was sizable and likely to grow; 3) Approaches to medical decision-making for this population in health-care settings varied; and, 4) Professional guidelines and laws to address the issues related to this population were inconsistent. There have been no studies regarding the quality of medical decision-making and its outcomes for this population or societal impact. **Abstract:** <https://goo.gl/LLcxSH>

Noted in Media Watch 22 January 2018 (#547, p.11):

- *CANADIAN JOURNAL ON AGING* | Online – 17 January 2018 – ‘**Going it alone: A scoping review of unbefriended older adults.**’ The purpose of this study was to review the peer-reviewed and grey literature to determine the scope of available research on unbefriended older adults in Canada and the U.S. The authors found limited research examining unbefriended older adults. No Canadian studies or reports were located. These findings demonstrate a stark scarcity of studies on unbefriended older adults. **Abstract:** <https://goo.gl/KehmsZ>

**N.B.** Additional articles on decision-making for “unbefriended” or “unrepresented” patients in the context of palliative and end-of-life care noted in the 18 September 2017 issue of Media Watch (#530, p.14).

## When paediatricians and families can’t agree

*ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 30 January 2018 – Recent high-profile cases have highlighted the difficulties that professionals caring for terminally ill or technology dependent children face. Occasionally there is science and evidence behind the decisions we make, but not always. Medicine does have its black and white disciplines – it is either cancer or it isn’t; or you either need to have an operation or you don’t. But paediatrics is often a discipline of uncertainty dealing with many shades of grey. Paediatricians learn to live with uncertainty and similarly have to support parents and young people to accept this uncertainty. Sometimes we have to wait for nature to reveal itself or for the future to unfold as it should. Herein lies the art of paediatrics: the ability to watch and wait, intervening in a timely fashion when required to do so and recognising the sad eventuality of having to let go of life at times. This is our craft: to do what is in the child’s best interests and use therapies that will help with life’s quality but not unnecessarily prolong inevitable death. However there are competing interests in this delicate balance in doing what is right for the child. **Abstract:** <https://goo.gl/X3trdc>

## Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## **A review of apps for calming, relaxation, and mindfulness interventions for pediatric palliative care patients**

*CHILDREN*, 2018;5(2). Patients and families increasingly use mobile apps as a relaxation and distraction intervention for children with complex, chronic medical conditions in the waiting room setting or during inpatient hospitalizations; and yet, there is limited data on app quality assessment or review of these apps for level of engagement, functionality, aesthetics, or applicability for palliative pediatric patients. The pediatric palliative care (PC) study team [at the Children's Hospital & Medical Center, Omaha, Nebraska] searched Smartphone application platforms for apps relevant to calming, relaxation, and mindfulness for pediatric and adolescent patients. Apps were reviewed using a systematic data extraction tool. Validated Mobile Application Rating Scale scores were determined by two blinded reviewers. Apps were then characterized by infant, child, adolescent, and adult caregiver group categories. Reviewer discussion resulted in consensus. Sixteen of the 22 apps identified were included in the final analysis. The apps operated on either iOS or Android platforms. All were available in English with four available in Spanish. Apps featured a relaxation approach, soothing images, and breathing techniques [see table below]. Mood and sleep patterns were the main symptoms targeted by apps. Provision of mobile apps resource summary has the potential to foster pediatric PC providers' knowledge of app functionality and applicability as part of ongoing patient care. **Full text:** <https://goo.gl/puUgWD>

### **The Canada Health Act**

#### **Medicare and the care of First Nations, Métis and Inuit**

*HEALTH ECONOMICS, POLICY & LAW* | Online – 1 February 2018 – The Canada Health Act 1984 (CHA) is considered foundational to Canada's publicly funded health care system (known as Medicare). The CHA provides for the federal transfer of funding to the provinces/territories, in exchange for provincial/territorial adherence to Medicare's key principles of universality; comprehensiveness; portability; accessibility; and, public administration. Medicare is a decentralized health care system, managed independently by Canada's 10 provincial and three territorial governments, allowing for regional adaptations to fit varying degrees of urbanity, remoteness and needs. The Act is silent on its relationship to the Indigenous health care system – what some have described as Canada's 14th health care system. The CHA has not kept pace with Indigenous self-government activities that have since spread across Canada. It has unfortunately crystallized the federal/provincial/territorial/Indigenous jurisdictional fragmentation that perpetuates health inequities and has failed to clarify these jurisdictions' obligations towards Indigenous peoples. As a result of these omissions, access to health services remains a concern for many Indigenous Canadians, resulting in poorer outcomes and premature mortality. The author argues that Medicare renewal must: make an explicit commitment to Indigenous health equity; clarify jurisdictional obligations; establish effective mechanisms for addressing areas of jurisdictional dispute and/or confusion; and explicitly recognize First Nations and Inuit health care services as integral yet distinct systems, that nevertheless must be welcomed to seamlessly work with provincial health care systems to ensure continuity of care. **Abstract (w. list of references):** <https://goo.gl/Wqexyx>

Noted in Media Watch 1 January 2018 (#544, p.1):

- CANADA (Ontario) | TV Ontario (Toronto) – 20 December 2017 – **'How redefining palliative care is bringing end-of-life services to First Nations.'** 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 in the near future. EoLC, which can involve large immediate and tight-knit extended families. <https://goo.gl/qyfq8P>

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

## Surveying care teams after in-hospital deaths to identify preventable harm and opportunities to improve advance care planning

*THE JOINT COMMISSION JOURNAL ON QUALITY & PATIENT SAFETY*, 2018;44(2):84-93. As part of a quality improvement initiative, a post-death care team survey was developed to explore how it might augment the existing process for learning from deaths. A survey was sent to the care team for all inpatient deaths on the hospital medicine and medical ICU services at one institution. Survey responses were reviewed to identify cases that required further investigation. During the distribution period ... 82 patients died, and 191 care team members were surveyed. Based on the survey responses, 5 patients (6.1%) not identified by other review processes were investigated further, resulting in the identification of several important opportunities for improvement. The free-text comment analysis revealed themes around the importance of advance care planning in seriously ill patients, as well as evidence of the emotional and psychological strain on clinicians who care for patients who die. **Abstract:** <https://goo.gl/ggWJUf>

### End-of-life care in Italy

## In-hospital palliative care: Should we need to reconsider what role hospitals should have in patients with end-stage disease or advanced cancer?

*JOURNAL OF CLINICAL MEDICINE* | Online – 30 January 2018 – Traditionally, palliative care (PC) systems focused on the needs of advanced cancer patients, but most patients needing PC have end-stage organ diseases. Similarly, PC models focus on the needs of patients in hospices or at home; however, in most cases PC is provided in acute hospitals. Indeed, the symptom burden these patients experience in the last year of life frequently forces them to seek care in emergency departments. The majority of them are admitted to the hospital and many die. This issue poses important concerns. Despite the efforts of attending healthcare professionals, in-hospital patients do not receive optimal care near the end of life. Also, evidence is emerging that delay in identifying patients needing PC have a detrimental impact on their quality of life (QoL). Therefore, there is an urgent need to identify, early and properly, these patients among those hospitalized. Several trials reported the efficacy of PC in improving the QoL in these patients. Each hospital should ensure that a multidisciplinary PC team is available to support attending physicians to achieve the best QoL for both PC patients and their families. **Full text:** <https://goo.gl/CVG7wB>

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

## Dying behind bars

*JOURNAL OF GERONTOLOGICAL NURSING*, 2018;44(1):2-3. Despite the push in nursing research to devote attention to the process of healthy aging, and to better understand the needs faced by the aging population, injustice has occurred for a marginalized group of aging Americans. The prison population is aging rapidly. In 2008, more than 74,000 men and 4,000 women older than 55 were in prisons nationwide. In upcoming decades, that number is likely to skyrocket because approximately 162,000 individuals are currently serving life sentences. For the subset of the population destined to age and die in prison, current research on healthy aging is inadequate. As a community of nurse scientists, we have neglected the prison population while focusing our attention on the benefits of hospice care and our human right to choose how we die. We must ask ourselves: What mes-

sage are we sending to the most vulnerable among us, by placing our attention on providing a “good death” for some, but not all of humanity? What value system allows us to neglect the most underserved of our population, as if their past mistakes have some bearing on their right to a good death? **Full text:** <https://goo.gl/irwMof>

### Palliative Care Network

#### Prison Hospice: Backgrounder

End-of-life care in the correctional/prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, etc., noted in past issues of the weekly report can be downloaded/viewed at: <https://goo.gl/LtewPi>

## The growing demand for hospice and palliative medicine physicians: Will the supply keep up?

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 February 2018 – The need for hospice and palliative care is growing rapidly as the population increases and ages and as both hospice and palliative care become more accepted. Hospice and palliative medicine (HPM) is a relatively new physician specialty, currently training 325 new fellows annually. Given the time needed to increase the supply of specialty trained physicians, it is important to assess future needs to guide planning for future training capacity. The current U.S. supply of HPM specialists is 13.35 per 100,000 adults 65 and over. This ratio varies greatly across the country. Using alternate assumptions for future supply and demand, the authors project need in 2040 will range from 10,640 to almost 24,000 HPM specialist physicians. Supply will range from 8,100 to 19,000. Current training capacity is insufficient to keep up with population growth and demand for services. HPM fellowships would need to grow from the current 325 graduates annually to between 500 to 600 per year by 2030 to assure sufficient physician workforce for hospice and palliative care services given current service provision patterns. **Abstract:** <https://goo.gl/jPGwPB>

Noted in Media Watch 29 January 2018 (#548, pp.9-10):

- *HEALTH ECONOMICS, POLICY & LAW* | Online – 23 January 2018 – ‘**Projecting shortages and surpluses of doctors and nurses in the Organisation for Economic Co-operation & Development: What looms ahead.**’ The authors work develops a projection model for the demand of doctors and nurses by Organisation for Economic Co-operation & Development (OECD) countries in the year 2030. The model is based on a country’s demand for health services, which includes the following factors: per capita income, out-of-pocket health expenditures, and the ageing of its population. The authors project a shortage of nearly 400,000 doctors across 32 OECD countries and shortage of nearly 2.5 million nurses across 23 OECD countries in 2030. The authors discuss the results and suggest policies that address the shortages. **Abstract:** <https://goo.gl/up8Hwi>

**N.B.** Selected articles on the “growing workforce shortage in palliative care” noted in 1 January 2018 issue of Media Watch (#544, p.4).

## Factors affecting palliative care development in Africa: In-country Experts’ perceptions in seven countries

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 February 2018 – Factors contributing to and impeding palliative care (PC) development in Africa can provide insights into current strategies for advancing PC. Emerged themes included: drivers, strengths, challenges, and aspirations for PC development in Africa. Drivers included advocates and pioneering organizations, HIV/AIDS, culture of caregiving, and the World Health Assembly PC Resolution. Strengths included community health workers, the special role of nurses, diversity of services, and short training courses. Challenges included lack of PC education, lack of standardization in implementation, limited availability of and/or accessibility to morphine, poverty and disease burden, and lack of funding for PC. Aspirations included integration of PC, specialization in PC, nurse prescribing, and strong partnerships with Ministries of Health. Factors already highlighted in the literature were only briefly discussed. The key factors underpinning PC development in the seven countries contributed to the beginnings of PC in Africa, fueled by advocates that built on existing strengths to maximize opportunities. However, the current approach is high-risk in terms of its sustainability and strategies for maximizing existing resources and growing infrastructure support are needed moving forward. **Abstract:** <https://goo.gl/5YCUHj>

Noted in Media Watch 5 September 2016 (#478, p.9):

- *eCANCERMEDICALSCIENCE* | Online – 30 August 2016 – ‘**Best practices in developing a national palliative care policy in resource limited settings: Lessons from five African countries.**’ There are several lessons learnt from each of the countries where a national palliative care (PC) policy has been developed. Firstly, there should be assessments performed prior to policy development to help countries identify key gaps that need to be covered and addressed by policy implementation. This will include models for PC delivery that need strengthening as well as training and human resource needs.

Cont.

Secondly, PC policy development commits governments to bring back PC both as a discipline and as a service package of health care it must deliver. This is happening in a situation where much of PC has been provided by non-government agencies (NGOs). In addition, this becomes a first step for government to start committing resources, however little to PC delivery. Thirdly, this makes PC advocacy easier across government departments, NGOs, and private sector players within these countries when and if there is a national document that commits government. Fourthly, policies act as a reminder for government to deliver on their regional and global commitments such as the African Common Position on pain medications and controlled substances of 2012 as well as the World Health Assembly PC resolution of 2014. At a regional level, when some countries adopt their PC policies it becomes easier to engage other countries without having to support them to develop theirs. Finally, the presence of national PC policies helps other regional and global entities to create awareness about PC and also lobby for more funding for PC. <http://goo.gl/L7bdd0>

### **Palliative sedation for existential suffering: A systematic review of argument-based ethics literature**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 January 2018 – While unanimity exists on using palliative sedation (PS) for controlling refractory physical suffering in end-of-life situations, using it for controlling refractory existential suffering (PS-ES) is controversial. Complicating the debate is that definitions and terminology for existential suffering are unclear, ambiguous, and imprecise, leading to a lack of consensus for clinical practice. The authors identified 18 articles that met the inclusion criteria. Their analysis revealed mind-body dualism, existential suffering, refractoriness, terminal condition, and imminent death as relevant concepts in the ethical debate on PS-ES. The ethical principles of double effect, proportionality, and the four principles of biomedical ethics were used in argumentations in the PS-ES debate. There is a clear need to better define the terminology used in discussions of PS-ES and to ground ethical arguments in a more effective way. Anthropological presuppositions such as mind-body dualism underpin the debate and need to be more clearly elucidated using an interdisciplinary approach.

**Abstract:** <https://goo.gl/SSNcyj>

**N.B.** Additional articles on continuous/palliative sedation noted in the 27 November and 17 July 2017 issues of *Media Watch* (#540, p.17 and #521, p.16, respectively).

### **Perspectives on palliative care in cancer clinical trials: Diverse meanings from multidisciplinary cancer care providers**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 February 2018 – Palliative care (PC) is often misunderstood as exclusively pertaining to end-of-life care (EoLC), which may be consequential for its delivery. There is little research on how PC is operationalized and delivered to cancer patients enrolled in clinical trials. The authors conducted qualitative semi-structured interviews with 19 key informants, including clinical trial principal investigators, oncology fellows, research nurses, inpatient and outpatient nurses, spiritual care providers, and PC fellows. Questions elicited information about the meaning providers assigned to the term “palliative care,” as well as their experiences with the delivery of PC in the clinical trial context. Four main themes emerged regarding the meaning of PC: 1) The holistic nature of PC; 2) The importance of symptom care; 3) Conflict between PC and curative care; and, 4) Conflation between PC and EoLC. Three key themes emerged with regard to the delivery of PC: 1) Dynamics among providers; 2) Discussing PC with patients and family; and, 3) The timing of PC delivery. **Abstract:** <https://goo.gl/5n1ZaF>

### **Demoralisation in palliative care**

*THE LANCET ONCOLOGY*, 2018;19(2):168. “A mental state of lowered morale and poor coping, characterised by feelings of hopelessness, helplessness, loss of meaning and loss of purpose in life.” This is how Professor David Kissane (Monash University, Melbourne, VIC, Australia) introduced attendees of the Cicely Saunders International Annual Lecture 2017 to the concept of demoralisation.<sup>1</sup> Kissane went on to detail these defining components, establishing the foundations for demoralisation as an “existential psychosocial syndrome” that has been described in wide-ranging populations; from those with a terminal illness, to substance abusers, patients with chronic conditions such as motor-neurone disease, and postnatal mothers. **Abstract:** <https://goo.gl/EZxiNz>

## Expensive care? Resource-based thresholds for potentially inappropriate treatment in intensive care

*MONASH BIOETHICS REVIEW* | Online – 8 January 2018 – In intensive care, disputes sometimes arise when patients or surrogates strongly desire treatment, yet health professionals regard it as potentially inappropriate. While professional guidelines confirm that physicians are not always obliged to provide requested treatment, determining when treatment would be inappropriate is extremely challenging. One potential reason for refusing to provide a desired and potentially beneficial treatment is because (within the setting of limited resources) this would harm other patients. Elsewhere in public health systems, cost effectiveness analysis is sometimes used to decide between different priorities for funding. The authors explore whether cost-effectiveness could be used to determine the appropriateness of providing intensive care. They explore a set of treatment thresholds: the probability threshold (a minimum probability of survival for providing treatment); the cost threshold (a maximum cost of treatment); the duration threshold (the maximum duration of intensive care); and, the quality threshold (a minimum quality of life). One common objection to cost-effectiveness analysis is that it might lead to rationing of life-saving treatment. The analysis might be used to inform debate about the implications of applying cost-effectiveness thresholds to clinical decisions around potentially inappropriate treatment. **Full text:** <https://goo.gl/7fuApS>

### Related

- *PERSPECTIVES IN BIOLOGY & MEDICINE*, 2018;60(3):331-335. **'Futile treatment and conquering death.'** Pragmatically speaking, there is a stronger case for using the language of "futility" than "potentially appropriate" for end-of-life care. The latter obscures the reality of death as a part of human life. Do patients die because death always wins in the end? Or do they die because physicians run out of ways to treat them? In the end, modern medicine has made the conquest of death its *de facto* goal. That is a fundamental error, one which the language of "potentially appropriate" is unwittingly supportive of. **Abstract:** <https://goo.gl/Dp2phL>

**N.B.** This focus of this issue of *Perspectives in Biology & Medicine* is medical futility. Journal contents page: <https://goo.gl/H6arWq>

Noted in Media Watch 27 November 2017 (#540, p.10):

- *BRITISH JOURNAL OF ANAESTHESIA*, 2017;119(Suppl 1):i90-i98. **'Demands and requests for "inappropriate" or "inadvisable" treatments at the end of life: What do you do at 2 o'clock in the morning when ...?'** In the shift from paternalism to patient choice, we can struggle to know what to do when faced with a patient, their family, or both requesting or demanding inadvisable, inappropriate, or futile treatments. It can feel as if we are being asked to subject patients to intrusions and interventions that "just feel wrong." The authors look at how ethical frameworks, legal statute, case law, and professional guidance, as they apply in the U.K., interact when we make these decisions, and they discuss some of the conflicts and challenges that such guidance pose. **Full text:** <https://goo.gl/ckDpsh>

## The incompatibility of healthcare services and end-of-life needs in advanced liver disease: A qualitative interview study of patients and bereaved carers

*PALLIATIVE MEDICINE* | Online – 2 February 2018 – Liver disease represents the third commonest cause of death in adults of working age and is associated with an extensive illness burden towards the end of life (EoL). Despite this, patients rarely receive palliative care (PC) and are unlikely to be involved in advance care planning discussions. Evidence addressing how existing services meet EoL needs, and exploring attitudes of patients and carers towards PC, is lacking. Participants described escalating physical, psychological and social needs as liver disease progressed, including disabling symptoms, emotional distress and uncertainty, addiction, financial hardship and social isolation. EoL needs were incompatible with the healthcare services available to address them; these were heavily centred in secondary care, focussed on disease modification at the expense of symptom control and provided limited support after curative options were exhausted. Attitudes towards PC were mixed, however, participants valued opportunities to express future care preferences (particularly relating to avoidance of hospital admission towards the EoL) and an increased focus on symptomatic and logistical aspects of care. **Abstract:** <https://goo.gl/2tyZu7>

**“I didn't want to be in charge and yet I was.”: Bereaved caregivers' accounts of providing home care for family members with advanced cancer**

*PSYCHO-ONCOLOGY* | Online – 1 February 2018 – Sixty-one bereaved caregivers (30 intervention, 31 control) were interviewed, including spouses (33), adult children (19), and other family (9). There were no differences in themes between control and intervention groups. The core category of “taking charge” encompassed caregivers' assumption of active roles in care, often in the face of inadequate formal support. There were four interrelated sub-categories: 1) Navigating the system – navigating the complexities of the home care system to access resources and supports; 2) Engaging with professional caregivers – interacting with visiting personnel to advocate for consistency and quality of care; 3) Preparing for death – seeking out information about what to expect at the end of life; and, 4) Managing after death – managing multiple administrative responsibilities in the emotionally charged period following death. Caregivers were often thrust into assuming control in order to compensate for deficiencies in formal palliative home care services. Policies, quality indicators and guidelines are needed to ensure the provision of comprehensive, interdisciplinary home palliative care. **Abstract:** <https://goo.gl/hDtJTh>

**Do not click “Like” when somebody has died: The role of norms for mourning practices in social media**

*SOCIAL MEDIA & SOCIETY* | Online – 25 January 2018 – Social media constitute new social spaces where the topics of death, loss, and mourning are increasingly encountered and negotiated. Users might either engage in mourning practices themselves or be confronted with other users' mourning during their everyday social media use. The omnipresence of mourning in social media poses challenges to the users and increases the need for norms on how to engage in online mourning practices and how to react toward expressions of grief and mourning. This article systematically reviews 25 internationally published journal articles on norms guiding mourning practices and (non-)reactions toward these practices in social media. Three different types of norms related to different forms of practices are identified in the review. Results show that norms for mourning in social media are in flux and consistently negotiated between users. However, norms for mourning in social media often adhere to traditional norms that are adapted and reconfigured. **Full text:** <https://goo.gl/Y1vkwa>

**N.B.** This issue of *Social Media & Society* includes several articles on the “mediatization, emotion, and digital mourning.” **Journal contents page:** <https://goo.gl/3TPs5x>

Noted in Media Watch 29 January 2018 (#548, p.8):

- *BMC PALLIATIVE CARE* | Online – 22 January 2018 – ‘#Deathbedlive: The end-of-life trajectory, reflected in a cancer patient's tweets.’ While the authors' analysis was at the structured end of the digital ethnographic spectrum, it nevertheless shows the value of such methods for understanding how terminal disease is experienced by and affects individuals, how they cope, how support is sought and obtained and how patients feel about the ability of palliative care services to meet their needs at different stages. **Full text:** <https://goo.gl/mEqpPu>

Cont. next page



**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>

Noted in Media Watch 8 May 2017 (#511, p.14):

- *MORTALITY* | Online – 2 May 2017 – ‘**Mourning and memory in the twittersphere.**’ Emerging work in the field of social media and mourning suggests that social media spaces have changed the landscape of grief by encouraging mourners to form communities online, post public statements about loss, and maintain continuing bonds with the deceased. While existing studies restrict their analyses to public or private online spaces. The authors examine a space that is suited to both private communication and information broadcast. **Abstract (click on ‘References’ to access same):** <https://goo.gl/emsYyn>

### **Bio-psycho-social-spiritual needs of adolescents and young adults with life-threatening illnesses: Implications for social work practice**

*SOCIAL WORK IN HEALTH CARE* | Online – 29 January 2018 – Adolescents and young adults (AYA) are situated between childhood and adulthood (ages 15-25) and have distinct biopsychosocial and spiritual needs unique to their developmental stage. Having a life-threatening or terminal illness directly challenges normal AYA developmental tasks and identity formation. AYA experience more troubling physical symptoms during the dying process compared to other age groups, which leads to significant psychological distress and an increased need for pharmacological treatments. In general, AYA desire to be fully informed and involved in the health care decision-making process, leading to ethical dilemmas when the AYA is a minor and

their wishes differ from the wishes of their legal guardian(s). Social workers are especially well-equipped to serve this population due to aligning professional standards and ability to advocate for holistic care within interdisciplinary teams.

**Abstract:** <https://goo.gl/KqMdYn>

CANADIAN  
**Virtual Hospice**  Portail CANADIEN EN SOINS  
**palliatifs**

Supporting Grieving or Bereaved Children  
<http://goo.gl/ydHfq9>

Noted in Media Watch 29 January 2018 (#458, p.9):

- *DEATH STUDIES* | Online – 24 January 2018 – “‘**Don’t bother about me.**’ **The grief and mental health of bereaved adolescents.**’ Analysis of 39 semi-structured telephone interviews yielded two themes: grieving apart together, and personal growth. High self-reliance and selective sharing were common. Feelings of guilt and “why” questions seemed more pronounced among the suicide bereaved. There was strong evidence of personal growth, increased maturity and capacity to deal with personal mental health/suicidality. Despite its devastating effects, experiencing a death can be a catalyst for positive mental health. **Abstract:** <https://goo.gl/d6bSrK>

### **Related**

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 1 February 2018 – ‘**Personalized and yet standardized: An informed approach to the integration of bereavement care in pediatric oncology settings.**’ Psychosocial standards of care for centers serving pediatric cancer patients recommend maintaining at least one meaningful contact between the healthcare team and bereaved parents to identify families at risk for negative psychosocial sequelae and to provide resources for bereavement support. This study assessed how this standard is being implemented in current healthcare and palliative care practices, as well as barriers to its implementation. Inconsistent types of bereavement services and varying duration of care was common. Twenty-eight percent of participants indicated that their center has no systematic contact with bereaved families after the child’s death. Among centers where contacts are made, the person who calls the bereaved parent is unknown to the family in 30% of cases. Few centers (5%) use a bereavement screening or assessment tool. Abstract (w. list of references): <https://goo.gl/2rn75F>

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

### **The challenge of sustainability in healthcare systems: Frequency and cost of diagnostic procedures in end-of-life cancer patients**

*SUPPORTIVE CARE IN CANCER* | Online – 1 February 2018 – The authors firmly believe that costs for healthcare services in the last year of life are high, despite the fact that a recent study has advocated the “myth” of a costly end-of-life care (EoLC), which would represent only a minority of the total annual expenditure in the U.S.<sup>1</sup> However, most authors agree in considering the costs of EoLC a major item of healthcare expenditure. The discussion regarding the high-cost population in the U.S. has often focused on the population at the end of life, relying on evidence suggesting that those at the end of life drive health care spending. This evidence is biased, however, in that most studies have examined only Medicare expenditures and, therefore, only the Medicare population. Although health care for older adults is generally more costly and the majority of costs in the last year of life are paid by Medicare, such analyses exclude the substantial health care costs paid by Medicaid, private insurers, and individuals themselves. Furthermore, whereas on an individual basis the last year of life may be significantly more expensive than preceding years, between-individual differences in health care costs at any stage in life outweigh within-individual differences. These substantial limitations of the existing evidence characterizing the high-cost population in the U.S. may have hindered policymakers’ attempts to rein in health care costs. **Full text:** <https://goo.gl/GocFmt>

1. ‘The myth regarding the high cost of end-of-life care,’ *American Journal of Public Health*, 2015; 105(12):2411-2415, first published online 15 October 2015 [Noted in the 19 October 2015 issue of Media Watch (#432, p.12)] **Full text:** <https://goo.gl/tSJrxW>

#### **Related**

- *SOCIAL SCIENCE & MEDICINE*, 2018;200(3):107-113. ‘**Political economy of hope as a cultural facet of biomedicalization: A qualitative examination of constraints to hospice utilization among U.S. end-stage cancer patients.**’ Previous studies have examined hospice underutilization among end-stage cancer patients and have identified barriers stemming from patient and physician characteristics or health insurance reimbursement policies. Yet, these studies do not provide an organized synthesis of how barriers articulate, how they are part of the longitudinal decision-making process, or describe the socio-cultural context surrounding hospice care enrollment decisions. This article focuses on U.S.-specific mechanisms and is based on qualitative, in-depth, interviews with physicians at an academic hospital. **Abstract:** <https://goo.gl/q7SDko>

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

Representative sample of recent journal articles:

- *JOURNAL OF MEDICAL ETHICS* | Online – 29 January 2018 – ‘**Dutch practice of euthanasia and assisted suicide: A glimpse at the edges of the practice.**’ Within The Netherlands, euthanasia and assisted suicide (EAS) has wide acceptance, and the public in general seems to favour a liberal interpretation of both of these requirements. Physicians are expected to use “their own moral compass” to decide about personal participation, and it is generally possible and permissible to find a substitute physician if the patient meets the legally required criteria but the physician is not comfortable assisting. Over the years, multiple quantitative and qualitative studies have explored the Dutch practice of EAS, but relatively little is known about the edges of what counts as meeting these criteria and how acceptable the practice is for physicians who participate. The study by Snijderman *et al* gives a glimpse of these boundaries and suggests that at least sometimes the criteria are being stretched and adapted to meet the perceived needs of patients, and some participating physicians are relatively uncomfortable with some of the requests with which they are faced.<sup>1</sup> **Abstract:** <https://goo.gl/1SEF8y>
1. ‘Developments in the practice of physician-assisted dying: Perceptions of physicians who had experience with complex cases,’ *Journal of Medical Ethics*, published online 5 August 2016. [Noted in the 15 August 2016 issue of Media Watch (#475, p.14)] **Abstract:** <https://goo.gl/zSsnS9>

Cont.

## Related

- *INTERNATIONAL JOURNAL OF ENVIRONMENTAL STUDIES* | Online 25 – January 2018 – ‘**Dialectics of lead: Fifty years of Dutch euthanasia and its lessons.**’ The Netherlands has the broadest experience with organizing voluntary euthanasia and assisted suicide. In 1968-1985 euthanasia was vividly debated but, as it was illegal, it was at best tolerated. Since 1985, beginning with a verdict of the Supreme Court, euthanasia became officially tolerated and gradually legalized in 2002, after which the numbers stabilized until 2006. The onset of the third phase was in 2007. Since that year, the numbers tripled, new pathologies were accepted as a reason for euthanasia, the number of people with a long life expectancy increased, and mobile euthanizing teams were established that provide euthanasia without a prior doctor-patient relationship. **Abstract:** <https://goo.gl/4Kwefg>
- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 1 February 2018 – ‘**The right to live and to die.**’ Some argue that the integrity and morale of the medical profession – or even the fundamental right to life – are under threat in The Netherlands. An important part of this right to life is the right to choose to avoid what an individual considers an undignified and distressing death. Most of the time, we can achieve this by applying good palliative care. In occasional cases of unendurable suffering without any prospects of improvement, euthanasia becomes an extension of our commitment to relieve suffering. **Full text:** <https://goo.gl/4BFUeV>
- *PERSPECTIVES IN BIOLOGY & MEDICINE*, 2018;60(3):415-422. ‘**Medical futility and involuntary passive euthanasia.**’ Conflicts between providers and patients or their families surrounding end-of-life care are both regrettable and extremely challenging, interpersonally and ethically, for all involved. These conflicts often implicate the concept of medical futility. The concept of futility is too often conflated with distinct concepts that are more ethically salient, including the fiduciary responsibility to assess surrogate decision-making, and distributive justice. By distinguishing these concepts from futility, it becomes clear that there are some situations in which forgoing life-sustaining treatment over objection is permissible, and perhaps even obligatory. But the justification lies in the constellation of rights and responsibilities surrounding surrogate decision-making, or in distributive justice, but not futility. **Abstract:** <https://goo.gl/26ypK6>

## Worth Repeating

### Reality of evidence-based practice in palliative care

*CANCER BIOLOGY & MEDICINE*, 2015;12(3):193-200. Evidence-based medicine (EBM) ... is based on fundamental assumptions about the rigor of various research methodologies and relies upon the broad availability of literature that meets such pre-defined criteria of quality. It is becoming increasingly unacceptable to make clinical decisions in the absence of such “rules of evidence by which we can agree on who will do what to whom.” However, clinicians in palliative care (PC) find themselves hampered in the age of EBM by a significant dearth of well-designed and adequately powered research on relevant and useful clinical questions. It remains true in 2015 that despite the growth in published literature, PC is not an evidence-based discipline, or at least it is not informed by the level of evidence which most would require to label it such. This is for entirely predictable and understandable reasons. The patient population, the unique aims of treatment and the trajectory of incurable disease all conspire to make the traditional “gold-standard” of randomised controlled trials (RCTs) a challenging and, at times, inappropriate model with which to drive improvements in care. Despite the challenges inherent in PC research, the increasingly collaborative and well-organized research community has recognized the need for high-quality research and has begun to produce examples of excellence. This has been achieved by a combination of resourcefulness, in which non-RCT methodologies of equivalent validity and size are utilized; collaboration, in which resources are pooled; and, creativity in which multiple research tools are used in combination with a “mixed method” approach. The future of research in PC will include expansion of collaborative research networks, use of standardized data collection tools and registries, and development of an active EBM culture within PC organizations. The EBM model is also likely to grow more flexible as the traditional unimodal top-down approach is replaced by the use of multiple diverse methodologies as a research tool kit. Such a mixed-method approach will be viewed not as a means by which to dodge the challenge of conducting methodologically rigorous work in PC. Instead, a multi-faceted approach can be regarded as a more valuable scheme with which to address the complex and subtle questions that define the objective of the PC research agenda. [Noted in the 23 November 2015 issue of *Media Watch* (#437, p.15)] **Full text:** <https://goo.gl/CRckM1>

## 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.

## Media Watch: Online

### **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']

### **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>

Cont.

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/5d1l9K>

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

---

**Barry R. Ashpole**  
Guelph, Ontario CANADA

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