

## Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

**Social media and palliative care: Scroll down to [Specialist Publications](#) and ‘#Deathbedlive: The end-of-life trajectory, reflected in a cancer patient’s tweets’ (p.8), in *BMC Palliative Care*.**

## Canada

### Innovative healthcare programs exist – and work

NOVA SCOTIA | *The Globe & Mail* – 23 January 2018 – Practitioners are, by definition, problem solvers. Sometimes, policy makers and administrators latch onto those solutions, and scale and spread them so others can benefit. Here’s one modest example, with the fitting name INSPIRED – a sort-of acronym for ‘Implementing a Novel & Supportive Program of Individualized care for patients and families living with REspiratory Disease.’ INSPIRED is designed to keep late-stage COPD (chronic obstructive pulmonary disease) patients out of hospital by providing support to them and their families in the community. The program began back in 2010 at Queen Elizabeth II Health Sciences Centre in Halifax, an initiative of respirologist Dr. Graeme Rocker, respiratory therapist Joanne Michaud-Young and spiritual care practitioner Dr. Catherine Simpson. The three were frustrated by the fact that care of COPD patients was largely reactive, insufficient and failing, leaving them lingering and suffering in hospital beds and placing tremendous stress on overwhelmed families when they were discharged. The INSPIRED team created a treatment model that was more holistic, proactive, community-based, and which empowered patients and caregivers, and they were largely successful. Like most good ideas, INSPIRED is quite straightforward, simple even. Dr. Rocker and his colleagues did something that’s not done often enough in Canadian health-care: They asked patients how their care could be improved, and then implemented the advice. <https://goo.gl/6ZpmQn>

#### Extract from *The Globe & Mail* article

INSPIRED identifies the neediest patients – those constantly in and out of hospital – and provides support, including:

A written action plan for managing COPD;

Routine follow-up phone calls after patients are discharged;

Education for caregivers that focuses on self-management;

Psychological support for patients and caregivers; and,

Advance care planning so there are no surprises at end of life.

**N.B.** Selected articles on palliative and end-of-life care for people living with chronic obstructive pulmonary disease noted in 4 September and 2 January 2017 issues of Media Watch (#528, p.13 and #493, p.9, respectively).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC ('The Sunday Edition') | Online – 27 January 2018 – **'The benefits and perils of organ donation after assisted death.'** It has been over a year since assisted death became legal in Canada, but doctors, lawyers and bioethicists are still debating many of the details. One area of ongoing ethical concern is the question of whether assisted death patients should be allowed to donate their organs. No federal law currently prohibits them from doing so, but the process is complicated and varies from province to province. Some bioethicists worry that allowing organ donation after assisted death may give people an additional incentive to end their lives, and that vulnerable patients could be pressured into giving up their organs for the good of society. Others believe that denying people the chance to help patients on the transplant list, and to find meaning at the end of their lives, is paternalistic and counterproductive. <https://goo.gl/T21jEz>
- *THE GLOBE & MAIL* | Online – 27 January 2018 – **'Fight to the death: Why Canada's physician-assisted dying debate has only just begun.'** Many physicians, after visiting their imminently dying patients on hospital rounds, simply wrote orders for sedatives and pain drugs to ease agitation and distress, and walked away assuming that nurses would deliver the medications... Sidestepping the intimacy of death has not been so easy since the Supreme Court ruled ... that grievously suffering patients had the right to ask for help in ending lives that had become intolerable. But the decision was suspended for a year, to give the government time to enact legislation, "if it so chose," that reconciled the Charter rights of individual doctors and patients in any "legislature and regulatory response." That's a key point, because under our system, universal health care is mandated under the Canada Health Act, but medical services are delivered and regulated provincially. <https://goo.gl/Q2hLev>
- ONTARIO | CBC News – 26 January 2018 – **'Health authority looking to hire someone to help people die.'** Are you an experienced nurse who isn't afraid of tough conversations? Then perhaps you'd be a good fit for the South West Local Health Integration Network (LHIN)'s new position as a medical assistance in dying (MAiD) navigator. The idea is to have someone based locally in south-western Ontario who can help patients and families make sense of the rules around medically assisted dying... Since August of 2017, there's been 413 medically-assisted deaths in Ontario, and 42 just in the South West LHIN... The MAiD navigator will also work with doctors and nurses, who might have their own questions about the process and how to make referrals. <https://goo.gl/1t9Czr>
- ONTARIO | *The Timmins Press* – 23 January 2018 – **'Timmins & District Hospital assisted dying policy encourages procedure outside hospital.'** An access to information request has revealed that the hospital's assisted dying policy encourages the procedure to be done outside the hospital itself. "The best practice will be to encourage and facilitate medical assistance in dying [MAiD] at the patient's home, or other suitable setting, such as a hospice or long term care facility," noted the policy... "Notwithstanding the hospital's readiness to accommodate MAiD, it will strongly recommend that whenever possible that MAiD not occur on hospital premises." This would help preserve "the patient's comfort and dignity" while "honoring their wishes." <https://goo.gl/mjV8WR>



### [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>

## U.S.A.

### **Congress passes, Trump signs family caregivers act “elevating caregiving to a priority”**

*FORBES* | Online – 24 January 2018 – It’s a topic that we all face or will face in one way or another in our lifetime, and with the Congressional passage this month and signing yesterday by the president, the Recognize, Assist, Include, Support & Engage (RAISE) Family Caregivers Act is poised to give Americans some hope on the caregiving front. The bi-partisan law directs the Secretary of Health & Human Services to develop and sustain a national strategy to recognize and support the more than 40 million family caregivers in the U.S. It also establishes an advisory body that will bring together stakeholders from the private and public sectors to make recommendations that communities, providers, government and others may take to help caregivers. While RAISE does not authorize additional funding for the U.S. Department of

Health & Human Services, it does mandate the development of a strategy within a 3-year period. <https://goo.gl/UjDSxN>

#### Specialist Publications

‘Barriers to hospice care in trauma patients: The disparities in end-of-life care’ (p.6), in *American Journal of Hospice & Palliative Medicine*.

‘The Federal Right-to-Try Act of 2017: A wrong turn for access to investigational drugs and the path forward’ (p.11), in *JAMA Internal Medicine*.

‘Cultural aspects of end-of-life care planning for African Americans: An integrative review of literature’ (p.14), in *Journal of Transcultural Nursing*.

### **Pittsburgh hospice to assist patients who are still trying to be cured**

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 23 January 2018 – More than a million Medicare beneficiaries a year receive hospice care before dying, but government officials and hospice providers believe more would opt for the service – and for a longer time span – if it did not require abandoning efforts to cure their disease. This month ... a Pittsburgh-area hospice provider is partnering with the federal Centers for Medicare & Medicaid Services in a pilot program in which the government pays for hospice supportive services at the same time as medical treatment intended to prolong life. The Sivitz Jewish Hospice of the Jewish Association on Aging is one of 141 hospice programs across the country approved to receive monthly payments of up to \$400 to offer services to each Medicare patient still receiving specialized treatment. The patients must be diagnosed as terminally ill with either cancer, HIV/AIDS, congestive heart failure or chronic obstructive pulmonary disease, or COPD. <https://goo.gl/UJdrFw>

### **When a tattoo means life or death. Literally**

NATIONAL PUBLIC RADIO | Online – 21 January 2018 – In the U.S., the standard way to tell doctors you want to be allowed to die is to sign an official form saying you don’t want to be resuscitated. But signing the official form doesn’t guarantee your wishes will be followed. If you lose consciousness and end up in the emergency room, for example, the form may not come with you, in which case many doctors err on the side of intervening. “A lot of doctors say, ‘Look, you can always be dead later. Don’t take a course that’s irreversible,’” explains Dr. Kenneth Goodman, a medical ethicist for the University of Miami hospital and the man Dr. Gregory Holt [an emergency room doctor at the University of Miami Hospital] called when he saw [a 70-year-old] man’s [DNR] tattoo. “Our big concern was, is this real?” remembers Holt. The only previous example they could find in the medical literature was a case from 2012, in which a man with a chest tattoo that read “DNR.” told doctors it was the result of a drunken bet, and that it didn’t reflect his wishes.<sup>1</sup> And, even if this tattoo was real, it was initially unclear whether it should carry the same weight as an official form stating the same thing. Goodman advised the doctors to take the tattoo seriously. The man got sicker and sicker overnight. They didn’t do CPR. The man died. And social workers eventually found the man had an out-of-hospital form on file with the Florida Department of Health that backed up his tattoo. Holt published a case study about the patient ... thinking it might be helpful for other doctors.<sup>2</sup> <https://goo.gl/qaNoer>

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1. 'DNR tattoos: A cautionary tale,' *Journal of General Internal Medicine*, 2012;27(10):1383. [Noted in 1 October 2012 issue of Media Watch (#273, p.9)] **Abstract:** <https://goo.gl/VkR6ct>
2. 'An unconscious patient with a DNR tattoo,' *New England Journal of Medicine*, 2017;377(22):2192-2193. [Noted in 4 December 2017 issue of Media Watch (#541, p.3)] **Full text:** <https://goo.gl/JU3b2r>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **KAISER HEALTH NEWS** | Online – 26 January 2018 – **'As doctors drop opposition, aid-in-dying advocates target next battleground states.'** The American Medical Association (AMA), the dominant voice for doctors nationwide, opposes allowing doctors to prescribe life-ending medications at a patient's request, calling it "fundamentally incompatible with the physician's role as healer." But in December, the Massachusetts Medical Society became the 10th chapter of the AMA to drop its opposition and take a neutral stance on medical aid in dying. Most of those changes occurred in the past two years. They proved a pivotal precursor to getting laws passed in California, Colorado and Washington D.C. (The practice is also legal in Washington, Oregon, Vermont and Montana.) <https://goo.gl/ZXuQjS>
- **CALIFORNIA** | *The Mercury News* (San Jose) – 24 January 2018 – **'California's right-to-die law is working, but challenges remain.'** California's right-to-die law has been embraced by many around the state – from scores of patients and their families to individual doctors, some hospice caregivers and several health care systems. But as positive as the reception appears to be so far, plenty of challenges remain, according to testimony offered from experts and other stakeholders during an almost 3½ hour-long legislative hearing at the state capitol. Several of those who spoke at the first Select Committee on End-of-Life Health Care meeting ... said terminally ill patients still have a hard time finding doctors willing to prescribe the lethal prescription drugs since the law went into effect in June 2016. And even if they manage to locate the two doctors needed to sign off on the law's required documentation, they may face unnecessary delays in obtaining the drugs from a limited number of pharmacies. Worse, by the time the dying patient has made his or her request known, they may be too sick to make it through the law's required 15-day-waiting period to ensure that patients are not making an impulsive decision. <https://goo.gl/fAkUDg>

## International

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

#### Charities call to improve end-of-life care for seriously ill children

U.K. (England) | *The Daily Mail* (London) – 26 January 2018 – Too many seriously ill children and their families are still unable to access decent end-of-life (EoL) care, with a "cruel postcode lottery" meaning many cannot decide where they die, charities have warned. Having to plan and prepare for a child's EoL care and death is the "most stressful, heart-breaking, lonely and isolating thing that any parent can face," they argued. But despite a government commitment to EoL choice, access to good EoL care support, planning and care based on choice is not available to all families, the coalition of charities said. They said 5,000 babies, children and young people in the U.K. under the age of 19 die every year, a significant number of whom are children with life-limiting or life-threatening conditions who need EoL care. But they said there are too few doctors and nurses with the skills and knowledge needed, while children's hospices need more funding. Almost half (46%) of local National Health Service planning and funding organisations in England are failing to implement the government's EoL care choice commitment for children and young people and have no plans to do so. And just two thirds (67%) of clinical commissioning groups in England plan and fund community children's nursing teams to provide care out of hours and at weekends, the coalition, which also includes Together for Short Lives, the Brain Tumour Charity, CLIC [Cancer & Leukaemia in Childhood] Sargent, Marie Curie and the National Gold Standards Framework Centre in End-of-Life Care, said. <https://goo.gl/YXW2Uz>

**N.B.** Additional articles on end-of-life care for children in the U.K. noted in 20 November and 18 September 2017 issues of Media Watch (#539, p.7 and #530, p.7, respectively).

## End-of-life care in Portugal

### Study finds “great need” for more palliative care for adults, children

PORTUGAL | *The Portugal News* (Lagoa) – 24 January 2018 – Portugal has a “great need” for more palliative care (PC), “both for adults and for children,” according to a major study.<sup>1</sup> In Portugal, “71% of deaths in adults and 33% of deaths in children are due to illnesses that are recognised as requiring PC.” Although these estimates are in line with figures from other European countries, Portugal “lacks capacity to respond, above all for children.” The study “shows that it is urgent to assess the sustainability of the current model of healthcare and social support to meet these needs...” Cancer, for example, “is responsible for an ever greater proportion of deaths with palliative needs (34% in adults and 38% in children).” In a second study, researchers looked at data from more than a million people who died in Portugal between 1987 and 2012, consulting specialists in public health, PC and paediatrics, “to better understand the reality in Portugal.”<sup>2</sup> It found two “key characteristics that define the way that Portuguese society deals with advanced illnesses and the end of life... On the one hand, there is a tradition of support from the broader family – we try to care for our own at home... On the other hand, we are extremely dependent on hospitals – we think that there we will find the best healthcare.” This dual model ... results in Portugal having one of the world’s highest rates of deaths in hospital, above all among young people and cancer sufferers. <https://goo.gl/6bMxnp>

1. ‘End-of-life decision making in palliative care and recommendations of the Council of Europe: Qualitative secondary analysis of interviews and observation field notes,’ *Journal of Palliative Medicine*, published online 3 January 2018. [Noted in 8 January 2018 issue of *Media Watch* (#545, p.15)] **Abstract:** <https://goo.gl/kzbJjV>
2. ‘Trends in cause and place of death for children in Portugal (a European country with no paediatric palliative care) during 1987-2011: A population-based study,’ *BMC Pediatrics*, published online 22 December 2017. **Full text:** <https://goo.gl/b8BrSh>

**N.B.** Additional articles on palliative and end-of-life care in Portugal noted in 1 January 2018 issue of *Media Watch* (#544, p.22).

## End-of-life care in New Zealand

### Quality end-of-life care should be nation’s priority

NEW ZEALAND | *The Wanganui Chronicle* – 20 January 2018 – The current debate around proposed legislation that will allow for assisted dying, euthanasia and the right to die is a deeply profound distraction that suits politicians well. It is simply palliative legislation. The definition of the term palliative includes the words “relieving the pain without dealing with the cause of the condition.” The legislation as it stands suits the government as the current discourse avoids the more painful subject of costs to the taxpayer of providing effective palliative services. The government has avoided the option of more funding for effective palliative care (PC) and having hospice facilities set up all around the country to ensure access to this level of medical management because they are aware this would be expensive and scare the taxpayer/voters. The current legislative approach has successfully by-passed this angle despite the very clear evidence that PC does provide quality end-of-life care (EoLC) that is responsive to the needs of patients and their families. There are well-researched existing models of PC that do provide quality of life and dignity in death for those with terminal conditions. EoLC plans and palliative medical care can make a huge difference to the final days prior to death from terminal illness. <https://goo.gl/S1nRgn>

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Noted in Media Watch 9 October 2017 (#533, p.7):

- NEW ZEALAND | Stuff.com.nz (Wellington) – 2 October 2017 – ‘**When life is coming to a close: Common myths about dying.**’ On average 85 New Zealanders die every day. Most will know that they are at the end of their lives. Hopefully, they had time to contemplate and achieve the “good death” we all seek. It’s possible to get a good death in New Zealand thanks to our excellent healthcare system – in 2015, our death-care was ranked third in the world.<sup>1</sup> We have an excellent but chaotic system. Knowing where to find help, what questions to ask, and deciding what you want to happen at the end of your life is important. But there are some myths about dying that perhaps unexpectedly harm the dying person and deserve scrutiny. <https://goo.gl/hy2DPz>

1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit (London, U.K.), October 2015. Commissioned by the Lien Foundation of Singapore [Noted in 12 October 2015 issue of Media Watch (#431, p.6)] <https://goo.gl/zXrniA>

**N.B.** See ‘The Adult Palliative Care Services in New Zealand: Review and Action Plan,’ Ministry of Health, Government of New Zealand, March 2017. [Noted in 3 April 2017 issue of Media Watch (#506, p.6)]  
**Download/view at:** <https://goo.gl/PT64BW>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. Scotland) | *The Times* – 22 January 2018 – ‘**75% of Scots back change to assisted suicide law.**’ Three quarters of Scots support a change in the law on assisted suicide that will allow doctors to help terminally ill people end their lives, according to a poll for *The Times*. Public backing on the issue remains high and appears to have grown since the last attempt to pass legislation at Holyrood in 2015. Only one in ten of those polled said that they opposed moves to bring in a new law allowing assisted suicide. <https://goo.gl/opR4T2>

### Specialist Publications

#### Barriers to hospice care in trauma patients: The disparities in end-of-life care

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 January 2018 – The authors’ data demonstrate prominent racial and socioeconomic disparities exist, with uninsured and minority patients being less likely to receive hospice services and having a delay in transition to hospice care when compared to their insured Caucasian counterparts. Patient’s transition to hospice found patients with cardiac disease, bleeding and psychiatric disorders, chemotherapy, cancer, diabetes, cirrhosis, respiratory disease, renal failure, cirrhosis, and cerebrovascular accident affected transfer. Logistic regression analysis after controlling for covariates showed uninsured patients were discharged to hospice significantly less than insured patients. Asian, African American, and Hispanic patients all received less hospice care than Caucasian patients. Negative binomial regression analysis with margins for length of stay showed Medicare patients were transferred to hospice 1.2 days sooner than insured patients while uninsured patients remained in the hospital 1.6 days longer. When compared to Caucasians, African Americans patients stayed 3.7 days longer in the hospital and Hispanics 2.4 days longer prior to transfer to hospice. In all patients with polytrauma, African Americans stayed 4.9 days longer and Hispanics 2.3 days longer as compared to Caucasians. **Abstract:** <https://goo.gl/1Ybo6S>

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#### 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 p.17.

Noted in Media Watch 1 January 2018 (#544, p.21):

- *JOURNAL OF TRAUMA & ACUTE CARE SURGERY* | Online – 20 December 2017 – ‘**Examining racial disparities in the time to withdrawal of life-sustaining treatment in trauma.**’ When time from admission to time to withdrawal of life-sustaining treatment (WLST) increases so does the potential for ineffective care, healthcare 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. **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. noted in 16 October and 17 April 2017 issues of Media Watch (#534, p.3 and #508, p.10, respectively).

### **Place of death for people with HIV: A population-level comparison of eleven countries across three continents using death certificate data**

*BMC INFECTIOUS DISEASES* | Online – 25 January 2018 – People dying from HIV were, in all studied countries, most likely to die in hospital as compared to people dying of cancer. This indicates a particular challenge to provide high quality end-of-life care (EoLC) for those facing HIV-related death. Not enough is known about what is done clinically in hospitals to achieve a “good death” for people with HIV. Arguably, this lack of evidence on the quality of death also exists for deaths in nursing homes, hospices, or other places, notably the home. Except in Mexico, we found that less than a fifth of persons with HIV died at home. Local policy is likely to be highly influential, for example in Korea there are legal difficulties in providing medical services outside of hospital settings. This variability is also reflected in state and national laws on advance care plans, living wills and other relevant mechanisms. There is within-country variability (e.g., by state in the U.S.) and also between-country (for example in Germany home palliative care is a legal right; in the U.K. individuals have a legal right to appoint a proxy or make an advance directive) Further research is needed to determine EoLC preferences regarding care setting among people with HIV, on place of care in the last months of life, and the reasons why they do not spend their final hours or days at home. The availability of death registries in low income countries is also a future priority, so that those countries with poorest antiretroviral therapy coverage can also study place of death. With increasing comorbidity among people ageing with HIV, it is essential that EoLC preferences are established, and that plans are made and carried out for those who prefer to die at home or in a hospice, or a hospital. In this study the authors identify a high proportion of hospital deaths, and inequity in place of death. This new knowledge highlights the importance of ensuring a “good death” for people with HIV, alongside efforts to optimise treatment. **Full text:** <https://goo.gl/CWFUxS>

### **Palliative and end-of-life care research in Scotland 2006–2015: A systematic scoping review**

*BMC PALLIATIVE CARE* | Online – 26 January 2018 – The Scottish Government set out its 5-year vision to improve palliative care (PC) in its Strategic Framework for Action 2016-2021.<sup>1</sup> This includes a commitment to strengthening research and evidence based knowledge exchange across Scotland. A comprehensive scoping review of Scottish PC research was considered an important first step. The aim of the review was to quantify and map PC research in Scotland over the ten-year period preceding the new strategy (2006-2015). There was a steady increase in Scottish PC research during the decade under review. Research output was strong compared with that reported in an earlier Scottish review (1990-2005) and a similar review of Irish PC research (2002-2012). A large amount of descriptive evidence exists on living and dying with chronic progressive illness in Scotland; intervention studies now need to be prioritised. Areas highlighted for future research include palliative interventions for people with non-malignant illness and multi-morbidity; physical and psychological symptom assessment and management; interventions to support carers; and bereavement support. Knowledge exchange activities are required to disseminate research findings to research users and a follow-up review to examine future research progress is recommended. **Full text:** <https://goo.gl/CwMGZu>

1. ‘Strategic Framework for Action on Palliative & End-of-Life Care: 2016-2021,’ Scottish Government, December 2015. [Noted in the 21 December 2015 issue of Media Watch (#441, p.8)] **Download/view at:** <http://goo.gl/CKePjU>

## #Deathbedlive: The end-of-life trajectory, reflected in a cancer patient's tweets

*BMC PALLIATIVE CARE* | Online – 22 January 2018 – Results [of this study] indicate that the data posted by terminal patients on Twitter can provide insights that may be comparable to, or compliment, those garnered using more traditional qualitative research techniques. 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 (PC) services to meet their needs at different stages. Further research is warranted to extend this analysis across the wider trajectory of life-limiting illness and to a variety of disease types, as well as to explore the use of data mining and pattern recognition techniques to study larger cohorts and different social media platforms. As part of a wider agenda for "palliative social media," the authors recommend efforts to engage health professionals in exploring how digital end-of-life trajectories may inform the provision of supportive and PC, to improve the quality of life and death for patients like Kate. **Full text:** <https://goo.gl/mEqpPu>



Noted in Media Watch 8 September 2014 (#374, p.6):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 2 September 2014 – 'Social media and palliative medicine: A retrospective 2-year analysis of global twitter data to evaluate the use of technology to communicate about issues at the end of life.' A lot of discussion about palliative care is taking place on Twitter, and the majority of this is positive. Social media presents a novel opportunity for engagement and ongoing dialogue with public and professional groups. The most popular terms include "end-of-life" and "palliative care." Sentiment was high with 89% of tweets rated more positive than all other tweets sent on Twitter during this period. **Abstract:** <https://goo.gl/qktZHp>

## Collaborative practice model: Improving the delivery of bad news

*CLINICAL JOURNAL OF ONCOLOGY NURSING*, 2018;22(1):23-27. Ideal bad news delivery requires skilled communication and team support. The literature has primarily focused on patient preferences, impact on care decisions, healthcare roles, and communication styles, without addressing systematic implementation. This article describes how an interdisciplinary team, led by advanced practice nurses, developed and implemented a collaborative practice model to deliver bad news on a unit that had struggled with inconsistencies. The authors explored current processes, role perceptions and expectations, and perceived barriers to developing the model, which is now the standard of care and an example of inter-professional team collaboration across the healthcare system. This model for delivering bad news can be easily adapted to meet the needs of other clinical units. **Abstract:** <https://goo.gl/Uksa3q>

Noted in Media Watch 9 October 2017 (#533, p.17):

- *REVISTA BRASILEIRA DE ENFERMAGEM*, 2017;70(5):1089-1095. 'Communicating bad news: An integrative review of the nursing literature.' This review enabled the authors to learn the reality of breaking bad news in the cultural and professional context, showing the strong cultural influence on the work process of nurses in developed countries; where they have greater autonomy in discussing news with patients. However, it is notable that the cultural issue influences nurses, making them a submissive and non-autonomous professional in the communication of news to patients and their families. Sometimes this behavior becomes comfortable for the nurse, when compared to other health professionals. **Full English language text:** <https://goo.gl/vMrkHF>

**N.B.** Additional articles on communicating bad news in the context of palliative and end-of-life care noted in 25 September 2017 and 21 November 2016 issues of Media Watch (#531, pp.13-14 and #488, pp.13-14, respectively).

## **It's time to talk: Challenges in providing integrated palliative care in advanced congestive heart failure**

*CURRENT CARDIOLOGY REVIEWS* | Online – 23 January 2018 – Evidence suggests that a palliative care (PC) approach may be beneficial – and is currently recommended – in advanced congestive heart failure but these services remain underutilized. The authors identified ten key challenges to access and delivery of PC services in this patient population: 1) Prognostic uncertainty; 2) Provider education/training; 3) Ambiguity surrounding coordination of care; 4) Timing of PC referral; 5) Inadequate community supports; 6) Difficulty communicating uncertainty; 7) Fear of taking away hope; 8) Insufficient advance care planning; 9) Inadequate understanding of illness; and, 10) Discrepant patient/family care goals. Provider and patient education, early discussion about prognosis, and a multidisciplinary team-based approach are recommended as we move towards a model where symptom palliation exists concurrently with active disease-modifying therapies. **Abstract:** <https://goo.gl/LsnJtH>

**N.B.** Additional articles on palliative and end-of-life care for people living with cardiovascular disease noted in 13 November 2017 issue of Media Watch (#538, pp.4-5).

## **“Don't bother about me.” The grief and mental health of bereaved adolescents**

*DEATH STUDIES* | Online – 24 January 2018 – Death of a relative or friend is a potentially disruptive event in the lives of adolescents. To provide targeted help, it is crucial to understand their grief and mental health experiences. Thematic 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>

## **Is “end of life” a special case? Connecting Q with survey methods to measure societal support for views on the value of life-extending treatments**

*HEALTH ECONOMICS* | Online – 19 January 2018 – Preference elicitation studies reporting societal views on the relative value of end-of-life (EoL) treatments have produced equivocal results. This paper presents an alternative method, combining Q methodology and survey techniques (Q2S) to determine the distribution of three viewpoints on the relative value of EoL treatments identified in a previous, published, phase of this work. These were Viewpoint 1, “A population perspective: value for money, no special cases”; Viewpoint 2, “Life is precious: valuing life-extension and patient choice”; and Viewpoint 3, “Valuing wider benefits and opportunity cost: the quality of life and death.” A Q2S survey of 4,902 respondents across the U.K measured agreement with these viewpoints; 37% most agreed with Viewpoint 1, 49% with Viewpoint 2, and 9% with Viewpoint 3. Regression analysis showed associations of viewpoints with gender, level of education, religion, voting preferences, and satisfaction with the National Health Service. The Q2S approach provides a promising means to investigate how in-depth views and opinions are represented in the wider population. As demonstrated in this study, there is often more than one viewpoint on a topic and methods that seek to estimate that averages may not provide the best guidance for societal decision-making. **Full text:** <https://goo.gl/6ozv6Z>

## **Projecting shortages and surpluses of doctors and nurses in the Organisation for Economic Co-operation & Development: What looms ahead**

*HEALTH ECONOMICS, POLICY & LAW* | Online – 23 January 2018 – There is little debate that the health workforce is a key component of the health care system. Since the training of doctors and nurses takes several years, and the building of new schools even longer, projections are needed to allow for the development of health workforce policies. The authors work develops a projection model for the demand

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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 supply of doctors and nurses is projected using country-specific autoregressive integrated moving average models. Our work shows how dramatic imbalances in the number of doctors and nurses will be in OECD countries should current trends continue. For each country in the OECD with sufficient data, we report its demand, supply and shortage or surplus of doctors and nurses for 2030. 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. We 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).

### **Complex contradictions in conceptualisations of "dignity" in palliative care**

*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2018;24(1):12-21. Internationally, increasing attention is being paid to understanding patient experiences of health care. Within palliative care, the 'Views of Informal Carers – Evaluation of Services' (VOICES) questionnaire is commonly used for this purpose. Among its objectives is to ask family members if their relatives were treated with dignity at the end of life (EoL). This is regarded as useful for understanding the quality of the health care received. Bereaved family members' self-reports of dignity in EoL care captured using survey methods alone are inadequate to understand the complex ways in which individuals conceptualise and experience dignity within a health care context. The authors advocate consideration of multiple, complementary approaches to gathering consumer experiences of EoL care, as well as research which enables service users to interrogate what dignity in care means in an EoL context. **Abstract:** <https://goo.gl/F1aRFS>

### **Reflections on wisdom at the end of life: Qualitative study of hospice patients aged 58-97 years**

*INTERNATIONAL PSYCHOGERIATRICS* | Online – 24 January – 2018 – This study explored the possible impact of a diagnosis of a terminal illness on the conceptualization and evolution of wisdom while facing the end of life (EoL). Broad concepts of wisdom described by the hospice patients [i.e., study participants] align with the extant literature, thereby supporting those general conceptualizations. In addition, they described how their life perspectives shifted after being diagnosed with a terminal illness. Post-illness wisdom can be characterized as a dynamic balance of actively accepting the situation while simultaneously striving for galvanized growth. This delicate tension motivated the patients to live each day fully, yet consciously plan for their final legacy. The EoL offers a unique perspective on wisdom by highlighting the modulation between actively accepting the current situation while continuing the desire to grow and change at this critical time. This paradox, when embraced, may lead to even greater wisdom while facing one's own mortality. **Abstract (w. list of references):** <https://goo.gl/mDJf9K>

Noted in Media Watch 23 January 2017 (#496, p.7):

- *COUNSELLING PSYCHOLOGY QUARTERLY* | Online – 9 January 2017 – '**Wisdom at the end of life: Hospice patients' reflections on the meaning of life and death.**' Most participants [in this study] cited humility as a key component of wisdom, emphasizing that "wisdom is when we realize 'I don't really know much.'" Other components included self-knowledge, rationality, experiential learning, listening to and learning from others, and sharing knowledge with others. Participants offered advice to others based on their experiences facing illness and mortality. **Abstract:** <https://goo.gl/YHxv6N>

Noted in Media Watch 12 October 2015 (#431, p.12):

- *JOURNALS OF GERONTOLOGY* | Online – 5 October 2015 – '**Wisdom at the end of life: An analysis of mediating and moderating relations between wisdom and subjective well-being.**' Wisdom was positively related to subjective well-being in the later years [in this study], even after controlling for physical health, socioeconomic status, financial situation, social involvement, age, gender, race, and marital status. The association between wisdom and well-being was significantly stronger in the nursing home and hospice sample than the community sample. **Full text:** <https://goo.gl/Olr2yR>

## The Federal Right-to-Try Act of 2017: A wrong turn for access to investigational drugs and the path forward

*JAMA INTERNAL MEDICINE* | Online – 22 January 2018 – Fueled by emotionally charged anecdotes re-circulated by libertarian political activists, 38 states have passed right-to-try laws. In 2017, the U.S. Senate approved a bill that would create a national law. As of December 2017, the U.S. House of Representatives was considering the bill. Although the Food & Drug Administration (FDA) has an expanded access option for utilizing experimental drugs outside of clinical trials, right-to-try laws create an alternative pathway that by-passes the agency. Moreover, the term “right-to-try” is a misnomer; the legislation creates a right for a patient to ask a company to provide a product, the same right that currently exists. **First page preview:** <https://goo.gl/FFvc3A>

Noted in Media Watch 15 January 2018 (#546, p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 10 January 2018 – ‘**Federal right-to-try legislation – threatening the U.S. Food & Drug Administration’s public health mission.**’ The Food & Drug Administration (FDA) created “expanded access” pathways to give desperate patients without other options access to promising products before approval, while still providing oversight. The agency received more than 5,000 requests under those pathways between 2010 and 2014. But in August 2017, the Senate passed the Right-to-Try Act, which would sharply curtail the FDA’s oversight of access to investigational drugs for patients with life-threatening illnesses. **Full text:** <https://goo.gl/47Fgn4>

**N.B.** Additional articles on “right-to-try” laws noted in 7 August 2017 issue of Media Watch (#524, p.2).

## Voluntarily stopping eating and drinking among patients with serious advanced illness – clinical, ethical, and legal aspects

*JAMA INTERNAL MEDICINE*, 2018;178(1):123-127. Patients with advanced illnesses sometimes request that physicians help hasten their death. Increasingly in North America and Europe, legal options allow physicians to perform this role. Among death-hastening options, the spotlight has been on physician-assisted death. However, voluntarily stopping eating and drinking (VSED) is also a course that patients may choose. Although VSED theoretically does not require physician involvement, clinician participation is critical in terms of initial assessment and ongoing management. In this review, the authors examine both clinical issues in assessing patients who are considering VSED and the clinical challenges that may emerge during VSED. **Abstract:** <https://goo.gl/4wN5mX>

Noted in Media Watch 15 January 2018 (#546, p.12):

- *JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 10 January 2018 – ‘**Voluntarily stopping eating and drinking: A normative comparison with refusing lifesaving treatment and advance directives.**’ Refusal of lifesaving treatment, and such refusal by advance directive, are widely recognized as ethically and legally permissible. Voluntarily stopping eating and drinking (VSED) is not. Ethically and legally, how does VSED compare with these two more established ways for patients to control the end of life? Is it more questionable because with VSED the patient intends to cause her death, or because those who assist it with palliative care could be assisting a suicide? In fact the ethical and legal basis for VSED is virtually as strong as for refusing lifesaving treatment and less problematic than the basis for refusing treatment by advance directive. **Abstract:** <https://goo.gl/xzMKiA>

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Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

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

- *BMC MEDICINE* | Online – 27 December 2017 – ‘**Advice and care for patients who die by voluntarily stopping eating and drinking is not assisted suicide.**’ 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 argue 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. **Full text:** <https://goo.gl/w7mtn1>

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

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

#### Care planning for inpatients referred for palliative care consultation

*JAMA INTERNAL MEDICINE*, 2018;178(1):48-54. Care planning is a critical function of palliative care (PC) teams, but the impact of advance care planning (CP) and goals of care discussions by PC teams has not been well characterized. This was a prospective cohort study conducted between 1 January 2013 and 31 December 2016. Seventy-eight inpatient PC teams from diverse U.S. hospitals in the Palliative Care Quality Network, a national quality improvement collaborative. Patients [i.e., the patient population in this study] referred for CP were older, less likely to have cancer, and slightly more often had a clinical order of full code at the time of referral. PC teams identified CP needs in 52,825 of 73,145 patients (72.2%) overall, including 42,467 of 49,713 patients (85.4%) referred for CP and in 10,054 of 17,475 patients (57.5%) referred for other reasons. Through CP conversations, surrogates were identified for 10,571 of 11,149 patients (94.8%) and 9,026 patients (37.4%) elected to change their code status. Substantially more patients indicated that a status of do not resuscitate/do not intubate was consistent with their goals... However, an advance directive was completed for just 2,160 of 67,955 patients (3.2%) and a Physicians Orders for Life-Sustaining Treatment (POLST) form was completed for 8,359 of 67,955 patients (12.3%) seen by PC teams. CP was the most common reason for inpatient PC consultation, and CP needs were often found even when the consultation was for other reasons. Surrogates were consistently identified, and patients’ preferences regarding life-sustaining treatments were frequently updated. However, a minority of patients completed legal forms to document their care preferences, highlighting an area in need of improvement. **Abstract:** <https://goo.gl/qMysRF>



**N.B.** The Palliative Care Quality Network (PCQN) is a national quality improvement collaborative comprised of specialty palliative care teams from a diverse range of hospitals across the U.S. PCQN website: <https://goo.gl/6oCX4p>

#### Related

- *BMC GERIATRICS* | Online – 25 January 2018 – ‘**Description of an advance care planning intervention in nursing homes: Outcomes of the process evaluation.**’ The content of advance care planning (ACP) was considered relevant for the daily work in the unit, and the education seminars and material were often experienced as spot-on for practical use. Monthly communication with the family was the most frequently conducted communication from the patient log, and the predefined criteria for successfully implemented ACP were largely achieved. Nursing home routines and engagement of leaders and staff were crucial facilitators, whereas lack of time and competence limited the success of implementation. This study provides detailed descriptions of the implementation process, the definition of successful implementation and information on the involvement of staff, which facilitates replicability and meaningful comparisons with future studies as well as the adaptability of the knowledge to the clinical field. **Full text:** <https://goo.gl/cFrq8F>

## Law as clinical evidence: A new constitutive model of medical education and decision-making

*JOURNAL OF BIOETHICAL INQUIRY* | Online – 18 January 2018 – Over several decades, ethics and law have been applied to medical education and practice in a way that reflects the continuation during the twentieth century of the strong distinction between facts and values. The authors explain the development of applied ethics and applied medical law and report selected results that reflect this applied model from an empirical project examining doctors' decisions on withdrawing/withholding treatment from patients who lack decision-making capacity. The model is critiqued, and an alternative "constitutive" model is supported on the basis that medicine, medical law, and medical ethics exemplify the inevitable entanglement of facts and values. The model requires that ethics and law be taught across the medical education curriculum and integrated with the basic and clinical sciences and that they be perceived as an integral component of medical evidence and practice. Law, in particular, would rank as equal in normative authority to the relevant clinical scientific "facts" of the case, with graduating doctors having as strong a basic command of each category as the other. The normalization of legal knowledge as part of the clinician's evidence base to be utilized in practice may provide adequate consolation for clinicians who may initially resent further perceived incursions on their traditional independence and discretion. **Abstract (w. list of references):** <https://goo.gl/sTJR7h>

### End-of-life care in Canada

#### **Predictors of specialized pediatric palliative care involvement and impact on patterns of end-of-life care in children with cancer**

*JOURNAL OF CLINICAL ONCOLOGY* | Online – 22 January 2018 – The impact of specialized pediatric palliative care (SPPC) teams on patterns of end-of-life (EoL) care is unknown. Using a provincial childhood cancer registry, the authors assembled a retrospective cohort of Ontario children with cancer who died between 2000 and 2012 and received care through pediatric institutions with an SPPC team. Patients were linked to population-based administrative data capturing inpatient, outpatient, and emergency visits. Children were classified as having SPPC, general palliative care (PC), or no PC on the basis of SPPC clinical databases, physician billing codes, or inpatient diagnosis codes. Of the 572 children, 166 (29%) received care from an SPPC team for at least 30 days before death, and 100 (17.5%) received general PC. SPPC involvement was significantly less likely for children with hematologic cancers, living in the lowest income areas, and living further from the treatment center. SPPC was associated with a five-fold decrease in odds of intensive care unit admission, whereas general PC had no impact. Similar associations were seen with all secondary indicators. When available, SPPC, but not general PC, is associated with lower intensity care at the EoL for children with cancer. However, access remains uneven. **Abstract:** <https://goo.gl/V3G7En>

Noted in Media Watch 12 June 2017 (#516, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 8 June 2017 – **'The validity of using health administrative data to identify the involvement of specialized pediatric palliative care teams in children with cancer in Ontario, Canada.'** Population-based research to identify underserved populations and the impact of palliative care (PC) is limited as the validity of such data to identify PC services is largely unknown. In this study, health administrative data identified involvement of specialized pediatric PC teams with good sensitivity, but low specificity. Studies using such data alone to compare patients receiving and not receiving specialized pediatric PC are at significant risk of misclassification and potential bias. **Abstract:** <https://goo.gl/TDXZfu>

#### **Taking psychedelics seriously**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 January 2018 – Even with an expanding evidence base confirming safety and benefits, political, regulatory, and industry issues impose challenges to the legitimate use of psychedelics. The federal expanded access program and right-to-try laws in multiple

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states provide precedents for giving terminally ill patients access to medications that have not yet earned Federal Drug Administration approval. Given the prevalence of persistent suffering and growing acceptance of physician-hastened death as a medical response, it is time to revisit the legitimate therapeutic use of psychedelics. Palliative care clinicians occasionally encounter patients with emotional, existential, or spiritual suffering, which persists despite optimal existing treatments. Such suffering may rob people of a sense that life is worth living. Data from Oregon show that most terminally people who obtain prescriptions to intentionally end their lives are motivated by non-physical suffering. This paper overviews the history of this class of drugs and their therapeutic potential. Clinical cautions, adverse reactions, and important steps related to safe administration of psychedelics are presented, emphasizing careful patient screening, preparation, setting and supervision. **Abstracts:** <https://goo.gl/DkgKZT>

#### From the archives

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2008;15(5):234-237. **'Can psychedelic drugs play a role in palliative care.'** Psychedelic drugs are agents that may assist a person in approaching existential issues. They enjoy a rich history in ancient, non-Western cultures and, more recently, in psychiatric research of the 1960s. After a 40-year hiatus, international trials are now underway to revisit the role of psychedelic drugs in assisting patients with terminal cancer to explore – and resolve – anxiety-inducing existential issues surrounding their illness.

N.B. Access to this article requires a subscription. Journal contents page: <https://goo.gl/18KwMX>

#### Cultural aspects of end-of-life care planning for African Americans: An integrative review of literature

*JOURNAL OF TRANSCULTURAL NURSING* | Online – 22 January 2018 – Advance directive completion rates among the general population are low. Studies report even lower completion rates among African Americans are affected by demographic variables, cultural distinctives related to patient autonomy, mistrust of the health care system, low health literacy, strong spiritual beliefs, desire for aggressive interventions, importance of family-communal decision making, and presence of co-morbidities. Nurses educate patients and families about end-of-life planning as mandated by the Patient Self-Determination Act of 1991. Implementation of advance directives promote patient and family centered care, and should be encouraged. Clinicians must be sensitive and respectful of values and practices of patients of diverse cultures, and initiate conversations with open-ended questions facilitating patient trust and sharing within the context of complex beliefs, traditions, and lifeways. **Abstract:** <https://goo.gl/irLEs1>

Noted in Media Watch 17 April 2017 (#508, p.10):

- *JOURNAL OF RACIAL & ETHNIC HEALTH DISPARITIES* | Online – 13 April 2017 – **'Reversing racial inequities at the end of life: A call for health systems to create culturally competent advance care planning programs within African American communities.'** Racial and cultural barriers inherent in health systems have made the delivery of culturally relevant end-of-life (EoL) care that aligns with patient preferences a particular challenge across African American patient populations. The (EoL) experience has been cited as a public health crisis by the Institute of Medicine,<sup>1</sup> and this crisis is one felt even more acutely by patients of this minority race. **Abstract:** <https://goo.gl/FvKT3m>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in 22 September 2014 issue of Media Watch (#376, p.4)] **Full report:** <http://goo.gl/mm4o6W>

#### Advance directives for dementia: Honoring patient wishes when you don't know what they are

*NEUROLOGY ADVISOR* | Online – 23 January 2018 – Advance care directives (ACD) were originally developed to provide guidance to family and healthcare practitioners about end-of-life (EoL) decisions for patients faced with a terminal prognosis. Because of the extended time frame of dementia, however, the standard ACD applied to managing negative outcomes of disease is often left unconsidered as long as

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the patient still has cognition. In a commentary published in *JAMA* in December 2017,<sup>1</sup> Gaster & Larson point out that ACD are not “helpful” within the context of loss of cognitive function, and typically address specific conditions that have more definable prognoses involving pain and loss of consciousness. Because quality of life in dementia can be maintained with assistance, family and caregivers have difficulty determining when and how EoL decisions should be made. **Full text:** <https://goo.gl/1JQDbx>

1. ‘Advance directives for dementia: Meeting a unique challenge,’ *Journal of the American Medical Association*, 2017;318(22):2175-2176. **First page view:** <https://goo.gl/Y7t9DK>

**N.B.** Additional articles on palliative and end-of-life care for people living with Alzheimer’s and other forms of dementia noted in 22 & 1 January 2018 issues of *Media Watch* (#547, p.16 and #544, p.12, respectively).

### **Nursing the person experiencing homelessness towards end of life**

*NURSING STANDARD* | Inprint – Accessed 23 January 2018 – Homelessness is a complex, multi-dimensional problem with origins that are often multifaceted and deep-rooted. Providing palliative and end-of-life (EoL) care to those experiencing homelessness is challenging both to the client or patient receiving care and to the nursing teams aiming to meet often quite complex need. This article reviews what is understood as “homeless” and the barriers to effective health care services for those with life-limited disease. Current research is reviewed with a reflection on the present gaps in knowledge, notably around a lack of a strong evidence-based regarding what homeless people prioritise when considering EoL care. Current service provision is considered, with suggested future needs. **Abstract:** <https://goo.gl/o4e9uy>

**N.B.** This study offers a U.K. perspective on the issue of end-of-life care for the homeless. Additional articles with a similar focus noted in 4 December 2017 issue of *Media Watch* (#541, p.7).

### **Serious illness conversations: Paving the road with metaphors**

*THE ONCOLOGIST* | Online – 25 January 2018 – Effective use of core communication techniques, such as active listening and empathic statements, allows for a deeper understanding of the patients’ goals, concerns, communication preferences and questions. Metaphors can be used to augment end-of-life care planning. Used inappropriately, metaphors can cause misunderstandings and confusion. Applied skillfully, metaphors can personalize challenging discussions, improving patient comprehension and helping patients and their families to plan ahead. The art of communication is to use the right tool for the right person at the right time. This article provides guidance for preparing for such conversations, including examples of the use of metaphors to personalize and improve communication. **Full text:** <https://goo.gl/Zza1nT>

#### **Metaphor in End-of-Life Care Project**

#### **Metaphors for “good” and “bad” deaths: A health professional view**

*METAPHOR AND THE SOCIAL WORLD* | Online – Accessed 23 June 2015 – Interviews, conducted for the large-scale Metaphor in End-of-Life Care project, are set against the background of contemporary practices and discourses around end-of-life care, dying and quality of death. The difference between good and bad deaths is partly expressed via different frequencies of contrasting metaphors, such as “peacefulness” and “openness” as opposed to “struggle” and “pushing away” professional help. Metaphors are used to evaluate deaths and the dying, justify those evaluations, present a remarkably consistent view of different types of deaths, and promote a particular “framing” of a good death [Noted in 29 June 2015 issue of *Media Watch* (#416, p.11)] **Full text (click on pdf icon):** <http://eprints.lancs.ac.uk/74105/>

### **Spiritual care training in healthcare: Does it really have an impact?**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 23 January 2018 – Spiritual care has formed an integral part of palliative care (PC) since its inception. People with advanced illnesses, however, frequently report their spiritual needs are not attended to by their medical care team. This study examined and describes

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The impact of a spiritual care training program on practice and cultural change in a Canadian hospice. The authors' data suggest the program had a profound personal impact on attendees and contributed to a slight shift in practice patterns in their organization. Using a program not specifically tailored to local and organizational cultural contexts resulted in some unanticipated challenges such as the range of tensions between personal and cultural boundaries. Although some people criticized parts of the program or questioned the program's value, a general agreement suggests the program had a positive impact and meaningfully benefited the hospice. "What will happen next?" was the question most frequently voiced by interviewees. The present study suggests a systematic approach to spiritual care training that includes the concepts of workplace spirituality and sensitive practice offer useful frameworks for the development and implementation of spiritual care training in other institutions. **Abstract:** <https://goo.gl/4DBeKQ>

**"You either need help...you feel you don't need help...or you don't feel worthy of asking for it:" Receptivity to bereavement support**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 21 January 2018 – Although the needs of the bereaved have been identified widely in the literature, how these needs translate into meaningful, appropriate, and client-centered programs needs further exploration. The application of receptivity to support is a critical factor in participation by the bereaved in palliative care (PC) bereavement programs. This study explored factors that influence receptivity to bereavement support from PC services in rural, regional, and remote Western Australia. Findings revealed that a range of individual, social, and geographical factors influence receptivity to bereavement support and can impact on utilization of bereavement support services. Receptivity provides a frame of reference to enhance understanding of factors influencing engagement in psychosocial support in bereavement. It promotes a shift of service provider perspectives of effective supportive care to consumer-centric reasons for engagement. **Abstract:** <https://goo.gl/f6m1cw>

Noted in Media Watch 26 June 2017 (#518, p.12):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 21 June 2017 – **'The meaning and experience of bereavement support: A qualitative interview study of bereaved family caregivers.'** The authors report on one aspect of a broader study that explored a range of experiences of both patients and caregivers. Themes identified: socio-cultural constructions of bereavement support (BS) as for the incapable or socially isolated; perceptions of services as narrow in scope; the "personal" character of bereavement and subsequent incompatibility with formalized support; and, issues around the timing and style of approaches to being offered support. **Abstract (w. list of references):** <https://goo.gl/5qYu6f>

Noted in Media Watch 20 July 2015 (#419, p.9):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 July 2015 – **'Looking through the lens of receptivity and its role in bereavement support: A review of the literature.'** There is a dearth of research that specifically focuses on individuals' receptivity in relation to bereavement support (BS). Understanding this receptivity in rural areas is important, particularly as BS is an important area of service to the community by palliative care services. Receptivity to bereavement services has been identified as a critical factor in participation in BS programs. **Abstract (w. list of references):** <https://goo.gl/qcFe37>

**Related**

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 23 January 2018 – **"We take care of people. What happens to us afterwards?" Home health aides and bereavement care in hospice.'** The authors conducted focus groups and individual interviews with hospice home health aides (HHAs). They found a high burden of grief reactions; many HHAs often developed very close patient relationships. HHAs also noted that they often started working with new patients almost immediately after a death, leaving little time to process the loss. However, HHAs found support from other HHAs, their supervisors, as well as family, friends, and spiritual practices to be helpful in coping with their grief. **Abstract:** <https://goo.gl/TFDmiE>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *SAGE OPEN* | Online – 20 January 2018 – ‘**Attitudes toward active voluntary euthanasia among community-dwelling older subjects.**’ The findings of this study show that differences in age, health conditions, and culturally related behaviors and values between the baby boomers and the very old profiles are predictive of the, respectively, positive or negative attitudes toward active voluntary euthanasia between the two age groups. This underlines the relevance of cultural differences for attitudes toward end-of-life (EoL) issues deriving also from the different intergenerational perspectives characterizing the two cohorts. The results both suggest important implications for medical assistance in dying, particularly when dealing with vulnerable groups, and stress the importance of additional research aimed at exploring the increasingly different perceptions of EoL issues among older people. The author offers significant suggestions for policy makers in Italy, considering both the slow legislative process on the bill on living wills and the urgent need to recalibrate institutional care to EoL situations to ensure adequate and effective palliative care, pain therapies, and extended social support for dying patients and their families. **Full text:** <https://goo.gl/KRb2na>

### 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>

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>

## Journal Watch

### Three decades of peer review congresses

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2018; 319(4):350-353. Journal peer review is often time-consuming, arduous, and fraught with suspicion, not least because the identities of reviewers usually remain hidden from the authors. Despite these flaws, and the fundamental problem that the efficiency and effectiveness of peer review have yet to be measured satisfactorily, authors, editors, reviewers, and readers have become comfortable with it. Editors like anointing colleagues as experts, reviewers appreciate peer review because it tends to confirm their own impressions of themselves as experts, and no one has created a better system to vet the validity of scientific reports. Authors may complain but also may be grateful for expert appraisal and criticism and subsequent improvement in their manuscripts. They realize that their work has been taken seriously and recognize that the incorporation of reviewers democratizes beyond the editor this part of the scientific enterprise. Readers feel assured that articles have been evaluated by experts, and the public at large, imagining a much deeper degree of scrutiny than is customary or possible, assumes that articles that are published in most peer-reviewed journals have passed some universal standard of quality. **Full text:** <https://goo.gl/sLf5w6>



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

#### 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.

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