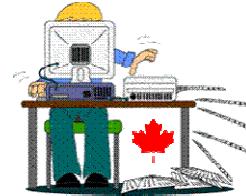


## **Media Watch...**

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.

**10 April 2017 Edition | Issue #507**



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**Compiled & Annotated by Barry R. Ashpole**

**Preferred place of care:** Scroll down to [Specialist Publications](#) and ‘Innovative urgent care for the palliative patient at home’ (p.11), in *Home Healthcare Now*.

## **Canada**

### **Up to 30% of medical care Canadians receive is unnecessary: Report**

THE GLOBE & MAIL | Online – 6 April 2017 – Canadians undergo more than a million medical tests and treatments every year that they may not need, according to a new report that reveals big variations in the ordering of some procedures.<sup>1</sup> The study puts a spotlight on unnecessary medical care that ranges from MRI scans for run-of-the-mill back pain to preoperative tests for low-risk colonoscopy patients and the over-prescribing of some drugs for seniors and children. The report is part of a national effort to cut waste in the health-care system and prevent the harm to patients that can sometimes flow from superfluous care. Wendy Levinson, a professor of medicine at the University of Toronto, launched the Canadian incarnation of the campaign in 2014. Dubbed Choosing Wisely, it was modelled on a program that aimed to reduce unnecessary care in the U.S., where a 2012 report from the influential Institute of Medicine (IOM) found the health-care system squandered about \$750-billion a year, much of it on procedures patients did not need.<sup>2</sup> But unlike the IOM report, the Canadian study avoids talking about dollars and cents. <https://goo.gl/mafbuO>

### **Global perspective**

#### **High number of terminal patients unnecessarily treated, study finds**

AUSTRALIA | ABC News (Sydney) – 27 June 2016 – Doctors have called for the public to discuss end-of-life care (EoLC) with their loved ones after a study revealed one third of elderly patients with an advanced or terminal illnesses receive unnecessary treatment in the last six months of their lives.<sup>1</sup> The global analysis of 38 studies of EoLC found a significant number of patients received treatments that were of no benefit to them. These included chemotherapy, radiotherapy and CPR, when a person had a not-for-resuscitation order. Non-beneficial treatment was defined in the research as medicine, procedures, or tests administered when a patient was naturally dying, but which did not improve their chances of survival or their quality of life. [Noted in Media Watch 4 July 2016, #469 (p.7)] <http://goo.gl/rBeFJ2>

1. Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem, *International Journal for Quality in Healthcare*, 27 June 2016. <http://goo.gl/4mwpLS>

1. ‘Unnecessary Care in Canada,’ Canadian Institute for Health Information, 2017. <https://goo.gl/sRDUU3>

2. ‘Best Care at Lower Cost,’ Institute of Medicine, 2012. <https://goo.gl/5NTfG2>

Cont.

Noted in Media Watch, 10 November 2014, #383 (p.14):

- **MAYO CLINIC PROCEEDINGS** | Online – 28 October 2014 – ‘**Medical futility and non-beneficial interventions.**’ In 2005, 87% of Canadian intensivists surveyed believed that they had provided futile medical interventions during the past year. A 2013 study of 5 academic intensive care units found that physicians considered nearly 20% of all interventions provided over a 3-month period to be futile. <http://goo.gl/vqEjKL>
- **CRITICAL CARE MEDICINE** | Online – 5 November 2014 – ‘**Non-beneficial treatment in Canada: Definitions, causes, and potential solutions from the perspective of healthcare practitioners.**’ Canadian nurses and physicians perceive current means of resolving non-beneficial treatment are inadequate, and we need to adopt new techniques of resolving non-beneficial treatment. Most promising strategies to reduce non-beneficial treatment are felt to be improved advance care planning... <http://goo.gl/oxOlqJ>

### Specialist Publications

‘The “surprise question” for predicting death in seriously ill patients: A systematic review and meta-analysis’ (p.10), in *Canadian Medical Association Journal*.

‘Measuring palliative and end-of-life care for cancer patients who die in hospital in Canada’ (p.12), in *Journal of Clinical Oncology*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *The Ottawa Citizen* – 7 April 2017 – ‘**Medically assisted deaths see uptick in Ottawa; more procedures taking place in homes.**’ People as old as 101 and as young as 35 have undergone medically assisted death in Ontario since it was legalized last year. As of the end of February, 305 assisted deaths had taken place in Ontario, according to statistics from the office of the chief coroner. About one-third of cases involved people who had other underlying conditions, including ALS. The stats show more Ontario cases had taken place in hospitals than in private residences – 168 in hospital compared with 110 in private residences. But that trend is changing as more people request medical assistance in death in their homes, according to officials. <https://goo.gl/4D7G30>
- QUEBEC | *The Globe & Mail* – 3 April 2017 – ‘**Quebec pushes the boundaries on assisted dying once again.**’ On 24 March, Health Minister Gaétan Barrette announced a three-pronged approach aimed at potentially broadening the eligibility requirements for medical aid in dying. First, a provincial commission will examine the more than 250 requests for the procedure that have been either rejected or withdrawn since the practice was legalized. A group of experts will subsequently re-examine the question of allowing advance consent for medical aid in dying (MAiD) by people diagnosed with degenerative diseases such as Alzheimer’s and other forms of dementia. Quebec’s Justice Ministry, meanwhile, will ask the courts to clarify the federal MAiD law’s limit of the practice to only those facing a “reasonably foreseeable” death, which health professionals have complained is too vague. The Alzheimer Society of Canada argues that “MAiD should only be possible when a person is deemed competent at the time of MAiD. ... [P]eople with dementia need to be safeguarded as they will be extremely vulnerable at the end of their life [and] do not have the capacity to make an informed decision and consent to end their life at the later stages of the disease.” <https://goo.gl/Vb611Y>
- ONTARIO | CTV News (Toronto) – 2 April 2017 – ‘**Ontario to create service for medically assisted dying access.**’ Ontario is setting up a new service for people seeking medically assisted death that will allow them to reach out for help directly, bypassing health-care providers who object to assisted suicide on conscience grounds. Health Minister Eric Hoskins says a “care co-ordination service” for medically assisted death will be up and running as early as May. The service will allow patients to contact central staff who will connect them with health-care providers prepared to handle requests for a medically assisted death. <https://goo.gl/oA3wwX>

### Related

- BRITISH COLUMBIA | *The Vancouver Sun* – 3 April 2017 – ‘**B.C. quietly creates system to help patients access medically assisted dying.**’ While other provinces try to piece together programs coordinating care for patients who want medical help ending their lives, B.C.’s health authorities have quietly created a system winning praise from advocates. Each of B.C.’s five regional health authorities now has a MAiD (medical assistance in dying) patient-care coordinator whose job it is to provide information about the process and connect people with doctors who can help. <https://goo.gl/W88fFP>

## U.S.A.

### **Rule changes for terminally ill hunters in South Dakota**

SOUTH DAKOTA | Newscenter1 (Pierre) – 7 April 2017 – The South Dakota Game, Fish & Parks Commission expanded a rule that allows for the allocation of a deer, antelope or turkey license to terminally ill South Dakota residents. This allowance is available to a resident who has been diagnosed to have a terminal illness that is expected to substantially shorten their life expectancy; or to a resident under the age of 26 who has been diagnosed with cancer or other life-threatening illness. <https://goo.gl/DVw8lv>

### **Coming full circle, doulas now cradle the dying**

USA TODAY | Online – 7 April 2017 – Doulas, an ancient Greek term that loosely means a woman helping another woman, have long comforted women during birthing. But the definition has broadened, and doula programs – a combination of male and female volunteers and paid certified staff – are increasingly helping elderly patients fulfill wishes to die at home rather than in hospitals or nursing homes. End-of-life doula specialists are now in at least a half-dozen states, including New York, Colorado and Texas. <https://goo.gl/ULkQbu>

**N.B.** Selected articles on “death doulas” or “death midwives,” in the context of end-of-life care, are noted in Media Watch 18 July 2016, #471 (p.1).

### **Against a history of medical mistreatment, African Americans are distrustful of hospice care**

MASSACHUSETTS | STAT News (Boston Globe Media) – 5 April 2017 – Medical researchers who are working to unpack the issue view minority access to hospice care as a matter of social justice. It's typically paid for by the government, can reduce patient suffering, and relieve family members of the burdens of caring for a dying loved one. Why should African Americans continue to suffer more at life's end than others? There's a lot to sift through, starting with the medical industry's long and at times ugly history of neglect and abuse of blacks. Doctors can also fail to account for the pervasive belief among many African American faithful that God has an ability to heal the sick through miracles. Finally, there's the reality that some in tighter-knit African American communities can direct harsh judgments toward those who choose hospice. Some see hospice as an abdication of caretaking responsibilities, at best, or, at worst, a hastening of a loved one's death. Research actually shows hospice patients live longer than those who opt for more aggressive end-of-life treatments. <https://goo.gl/mU0b6v>

### **Specialist Publications**

**‘Integrating palliative care to promote earlier conversations and to increase the skill and comfort of non-palliative care clinicians: Lessons learned from an interventional field trial’** (p.6), in *American Journal of Hospice & Palliative Medicine*.

**‘End-of-life care transition patterns of Medicare beneficiaries’** (p.7), in *Journal of the American Geriatrics Society*.

**‘Seeking and accepting: U.S. clergy theological and moral perspectives informing decision making at the end of life’** (p.6), in *Journal of Palliative Medicine*.

**‘Confidence with and barriers to serious illness communication: A national survey of hospitalists’** (p.7), in *Journal of Palliative Medicine*.

**‘Preferences for care towards the end of life when decision-making capacity may be impaired: A large scale cross-sectional survey of public attitudes in Great Britain and the U.S.’** (p.16), in *Plos One*.

Cont.

### **Selected articles on disparities in the provision and delivery of hospice and palliative care**

- **PROCEEDINGS OF THE NATIONAL ACADEMY OF SCIENCES** | Online – 23 January 2017 – ‘**Death of family members as an overlooked source of racial disadvantage in the U.S.**’ Racial differences in U.S. life expectancy suggest black Americans would be exposed to significantly more family member deaths than white Americans from childhood through adulthood, which, given the health risks posed by grief and bereavement, would add to the disadvantages they face. [Noted in Media Watch 30 January 2017, #497 (p.13)] <https://goo.gl/ZBie7H>
- **NEW ENGLAND JOURNAL OF MEDICINE** | Online – 29 December 2016 – ‘**Racial differences persist in end-of-life care.**’ In multiple studies, black patients consistently received more aggressive intervention than did white patients. Over the years, U.S. studies have suggested that African American patients tend to receive more aggressive medical intervention than white patients near the end of life. In 2016, a groundswell of research confirmed those earlier observations. [Noted in Media Watch 2 January 2017, #493 (p.14)] <https://goo.gl/bRlm76>
- **JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED**, 2016;27(1):219-237. ‘**Toward eliminating hospice enrollment disparities among African Americans: A qualitative study.**’ Participants identified several barriers to hospice enrollment and reported how they were able to overcome these barriers by reframing/prioritizing cultural values and practices, creating alternative goals for hospice care, and relying on information obtained outside the formal health system. [Noted in Media Watch 8 February 2016, #448 (p.14)] <http://goo.gl/Q6XS8f>

**N.B.** The focus of the February 2016 issue of the *Journal of Palliative Medicine* is on palliative and end-of-life care for African Americans. [Noted in Media Watch 8 February 2016, #448 (p.15)] Journal contents page: <http://goo.gl/6fapNx>

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

Representative sample of recent news media coverage:

- **MAINE** | *The Rutland Herald* – 7 April 2017 – ‘**Judge upholds death-with-dignity law.**’ A federal judge has dismissed a challenge from two medical groups to Vermont’s death-with-dignity law over whether they must tell their patients about medical aid in dying. U.S. District Court Judge Geoffrey Crawford threw out challenges from the Vermont Alliance for Ethical Healthcare Inc., as well as a national group, the Christian Medical & Dental Associations Inc., based in Tennessee. Since Vermont’s “death with dignity” law went into effect in 2013, a total of 48 terminally ill Vermonters have obtained prescriptions from their doctors to end their lives. The total number of Vermonters who have taken advantage of the law is not known... Crawford, in his 19-page decision April 5, said the two groups lacked legal standing to challenge the Vermont law, and as a result he dismissed their request for an injunction against the law, Act 39. <https://goo.gl/xvY2yt>

### **Specialist Publications**

‘**Characterizing 18 Years of the Death with Dignity Act in Oregon**’ (p.17), in *JAMA Oncology*.

### **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>



## International

### A surprisingly good place to die: How Mongolia excels at palliative care

MONGOLIA | *The Independent* (England) – 4 April 2017 – Mongolia is punching above its weight in palliative care (PC), the branch of medicine that supports people with terminal or complex illnesses. PC takes a magpie approach, borrowing from other medical disciplines and addressing a whole range of issues at once, ranging from pain and other symptoms to spiritual, social and psychological support. Mongolia is performing far better than any comparable economy, and is ahead of several European states with much more developed healthcare systems and greater spending power, including Greece, Hungary and Lithuania. It also eclipses several big economies, including its two giant neighbours, Russia and China. In little more than a decade, Mongolia's approach to PC has become a shining example of doing more with less. Mongolia's achievements have turned it into an example for many middle-income countries struggling with similar health problems but which, for a variety of reasons, maintain much stricter rules on opioid use. Doctors from former socialist states in particular have been coming to Mongolia to learn from its experience, their mutual past ties to Russia giving them a common language and training background.

<https://goo.gl/3oXVg1>



Noted in Media Watch 9 November 2015, #435 (p.4):

- MONGOLIA | National Public Radio (U.S.) – 5 November 2015 – ‘**How one woman changed the way people die in Mongolia.**’ Dr. Odontuya Davaasuren has one goal: to improve the way people die in Mongolia. “My father died of lung cancer, my mother died, my mother-in-law died because of liver cancer,” she says. “Even though I was a doctor, I could do nothing.” The feeling of helplessness, and the unnecessary pain her relatives suffered, is what Davaasuren has set out to fix. She has white hair because of it, says the family doctor and professor at the Mongolian National University of Medical Sciences in Ulaanbaatar. <https://goo.gl/Kuge4b>

**N.B.** Mongolia was ranked 28th of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore. See case study p.19. [Noted in Media Watch 12 October 2015, #431 (p.6)]  
<http://goo.gl/bT3PV5>

### Limited life chances of disabled people in Britain revealed by damning report

U.K. (England, Scotland & Wales) | *The Guardian* – 3 April 2017 – Disabled people are being left behind and are living in poverty with very poor life chances, a damning report has concluded.<sup>1</sup> The report, billed as the most comprehensive analysis of the rights of disabled people in Britain, also found that changes to benefit rules have had a particularly disproportionate, cumulative impact on their right to live independently. <https://goo.gl/A1CSNZ>

1. ‘Being Disabled in Britain: A Journey Less Equal,’ Equality & Human Rights Commission (an independent statutory body), April 2017. <https://goo.gl/cgpJ6b>

#### Extract from Equality & Human Rights Commission report

Do not attempt resuscitation (DNAR) notices are being placed on patients’ files without their consent or knowledge.

## **Bereavement benefit cuts: Cruel, stingy, wrong**

U.K. (England, Northern Ireland & Wales) | *The Guardian* – 2 April 2017 – The worst of the [government budget] cuts are the changes to bereavement payments. Families with young children who lose a parent on Thursday, when the cuts take effect, rather than on Wednesday, when the old system still applies, will lose out by thousands of pounds – more than £100,000 in rare cases where there are very young children. Until now, the system has reflected the value of national insurance payments made by the dead person. The benefit was paid in lieu of the pension they had not lived to receive. In other words, it was an earned entitlement. In future there will be a tax-free lump sum of £2,500 for childless widows or widowers, or £3,500 for those with children; and a monthly tax-free payment of £100 for the childless or £350 for a parent, for a mere eighteen months. The Department for Work & Pensions says this is a mere updating, intended to reflect families' changing working patterns. That might be marginally more credible if it applied to unmarried couples too. After all, nearly half of births last year were to parents who are not married. It is nothing to do with modernisation. It is a nasty, chiselling, mean piece of official stinginess, offered up by a department under pressure to meet a target for cuts that was only ever meant to be a piece of electoral positioning, to a benefit that accounts for barely a quarter of one percent of Britain's benefits budget.  
<https://goo.gl/vG0XMz>

## **Specialist Publications**

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

#### **Integrating palliative care to promote earlier conversations and to increase the skill and comfort of non-palliative care clinicians: Lessons learned from an interventional field trial**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 April 2017 – While the uptake of palliative care (PC) in the U.S. is steadily improving, there continues to be a gap in which many patients are not offered care that explicitly elicits and respects their personal wishes. This is due in part to a mismatch of supply and demand; the number of seriously ill individuals far exceeds the workload capacities of PC specialty providers. The authors conducted a field trial of an intervention designed to promote the identification of seriously ill patients appropriate for a discussion of their goals of care and to advance the role of non-PC clinicians by enhancing their knowledge of and comfort with primary PC skills. At 3 large Midwestern academic medical centers, a PC physician or nurse clinician embedded with a selected non-PC service line or unit on a regularly scheduled basis for up to 6 months. Using agreed-upon criteria, patients were identified as being appropriate for a goals of care conversation; conversations with those patients and/or their families were then conducted with the PC specialist providing education, coaching, and mentoring to the non-PC clinician, when possible. All of the sites increased the presence of PC within the selected service line or unit, and the non-PC clinicians reported increased comfort and skill at conducting goals of care conversations. This intervention is a first step toward increasing patients' access to PC to alleviate distress and to more consistently deliver care that honors patient and family preferences. <https://goo.gl/ui3lqX>

### **Related**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 April 2017 – ‘**Seeking and accepting: U.S. clergy theological and moral perspectives informing decision making at the end of life.**’ Clergy are uniquely positioned to help patients consider medical decisions at or near the end of life within a religious/spiritual framework. Clergy [i.e., study participants] had poor knowledge of end-of-life care (EoLC); 75% desired more training. Qualitative analysis revealed a theological framework for decision making in serious illness that balances seeking life and accepting death. Clergy viewed comfort-focused treatments as consistent with their faith traditions’ views of a good death. They employed a moral framework to determine the appropriateness of end-of-life decisions, which weighs the impact of multiple factors and upholds the importance of God-given free will. They viewed EoLC choices to be the primary prerogative of patients and families. <https://goo.gl/SDWi8s>

Cont.

Noted in Media Watch 13 February 2017, #499 (p.13):

- **JOURNAL OF PAIN & SYMPTOM MANAGEMENT** | Online – 6 February 2017 – ‘**U.S. clergy religious values and relationships to end-of-life discussions and care.**’ While clergy interact with approximately half of U.S. patients facing end-of-life (EoL) medical decisions, little is known about clergy-congregant interactions or clergy influence on EoL decisions. Clergy [i.e., survey respondents] with lower medical knowledge were less likely to have certain EoL conversations. The absence of a clergy-congregant hospice discussion was associated with less hospice and more ICU care in the final week of life. <https://goo.gl/aj2qRX>
- **JOURNAL OF PALLIATIVE MEDICINE** | Online – 4 April 2017 – ‘**Confidence with and barriers to serious illness communication: A national survey of hospitalists.**’ On most or every shift, many participants [i.e., survey respondents] reported having concerns about a patient’s or family’s understanding of prognosis (53%) or the patient’s code status (63%). Most participants were either confident or very confident in discussing goals of care (93%) and prognosis (87%). Fewer were confident or very confident in responding to patients or families who had not accepted the seriousness of an illness (59%) or in managing conflict (50%). Other frequently cited barriers were lack of time, lack of prior discussions in the outpatient setting, unrealistic prognostic expectations from other physicians, limited institutional support, and difficulty finding records of previous discussions. <https://goo.gl/ofIMKZ>
- **JOURNAL OF PALLIATIVE MEDICINE** | Online – 4 April 2017 – ‘**Maryland’s Medical Orders for Life-Sustaining Treatment form use: Reports of a state-wide survey.**’ Advance directives (ADs) and Physicians Orders for Life-Sustaining Treatment (POLST) orders perform different but complementary functions in documenting a patient’s treatment preferences and translating them into actionable orders that change in keeping with the patient’s evolving clinical picture. Maryland’s Medical Orders for Life-Sustaining Treatment (MOLST) form developed through a stakeholder-driven process that deviates from other POLST forms. While a patient or surrogate can decline discussing MOLST orders with a clinician, clinicians must write MOLST orders for certain patients (e.g., those admitted to a nursing home, assisted living facility, hospice, home health agency, or dialysis center, discharged from a hospital to any of these facilities, or transferred between hospitals). <https://goo.gl/b09YIO>

#### **End-of-life care transition patterns of Medicare beneficiaries**

**JOURNAL OF THE AMERICAN GERIATRICS SOCIETY** | Online – 3 April 2017 – More than 80% decedents (i.e., Medicare beneficiaries aged 66 and older who died from July to December 2011) had at least one transition within the last 6 months of life; 218,731 had four or more transitions within the last six months of life. The most-frequent transition pattern ... was home to hospital, back to home or skilled nursing facility, to hospital again, and then to settings other than hospital, ending with four or more transitions. The average number of transitions in the last 6 months of life varied substantially across states, ranging from 1.8 in Alaska to 3.1 in New Jersey. Transitions became more intensive for decedents approaching death. In multi-variable analyses, women, blacks, individuals younger than 85, and individuals without dementia were more likely to have four or more transitions... <https://goo.gl/vM2Ygh>

Noted in Media Watch 24 February 2014, #346 (p.9):

- **JOURNAL OF GENERAL INTERNAL MEDICINE** | Online – 21 February 2014 – ‘**Regardless of age: Incorporating principles from geriatric medicine to improve care transitions for patients with complex needs.**’ This article provides a framework for incorporating geriatrics principles into care transition activities... <http://goo.gl/U2GhgM>



#### **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.19.

## **The voice of surrogate decision makers: Family responses to prognostic information in chronic critical illness**

*AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE* | Online – 7 April 2017 – Information from clinicians about the expected course of the patient's illness is relevant and important for decision-making by surrogates for chronically critically ill patients on mechanical ventilation. Sixty-six audio recorded meetings involving 51 intervention group surrogates for 43 patients were analyzed... Six main categories of surrogate responses to prognostic information were identified: 1) Receptivity; 2) Deflection/rejection; 3) Emotion; 4) Characterization of patient; 5) Consideration of surrogate role; and 6) Mobilization of support. Surrogates responded in multiple and even antithetical ways, within and across meetings. Prognostic disclosure by skilled clinician communicators evokes a repertoire of responses from surrogates for the chronically critically ill.. <https://goo.gl/BftwuD>

**N.B.** Selected articles on the role of surrogate decision makers in the context of end-of-life care are noted in Media Watch 27 March 2017, #505 (p.4).

## **The influence of end-of-life care on organ donor potential**

*AMERICAN JOURNAL OF TRANSPLANTATION* | Online – 29 March 2017 – The authors conducted a prospective observational study in seven hospitals in The Netherlands to define the number of unrecognized potential organ donors outside intensive care units (ICU), and to identify the effect that end-of-life care (EoLC) has on organ donor potential. Records of all patients who died between January 2013 and March 2014 were reviewed. Of the 5,170 patients screened, the authors found 72 additional potential organ donors outside ICU. Initiation of EoLC in acute settings and lack of knowledge and experience in organ donation practices outside ICU can result in under-recognition of potential donors equivalent to 11-34% of the total pool of organ donors. <https://goo.gl/hOIFrL>

**N.B.** Additional articles on organ transplantation in the context of end-of-life care are noted in Media Watch 14 November 2016, #487 (p.6); 27 January 2014, #342 (p.10); and, 8 July 2013, #313 (p.10).

## **Moral psychology and “difficult” clinician-patient relationships**

*AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS*, 2017;19(4):317-409. Most clinicians have encountered patients they might label as “difficult.” But clinicians’ attitudes and intentions are also critical moral psychological contributors to when and how patient-clinician relationships go wrong. Social, cultural, and environmental factors also influence the quality and therapeutic capacity of patient-clinician relationships. This issue [of the journal] considers possible origins of “difficult” as a label and how it disadvantages patients. Some contributors reiterate the importance of nurturing virtues such as compassion and empathy in clinical practice. Others suggest what it means for clinicians to make good on their professional obligations to try to repair damaged patient-clinician relationships. Beliefs and biases can shape patients’ and clinicians’ perceptions of each other’s communication and behaviors and are particularly important to evaluate from an ethics perspective when clinical encounters don’t go well. Journal contents page: <https://goo.gl/vnckdr>

### **“A crisis in caring”: A place for compassionate care in today’s medicine**

*JOURNAL OF THE ROYAL SOCIETY OF MEDICINE* | Online – 6 April 2017 – Every measure should be taken towards encouraging and fostering an environment of compassionate care in the workplace and throughout medical education and training. Arguably, the fairly recent implementation of communication skills as a mandatory component to pass medical school could be thought to address this, at least in part. However, on the contrary, despite this intervention, a desensitisation process has been found to take place for the majority of medical professionals at some point during their medical training. This gives one the impression that communication skills’ training seems to only teach one to “wear a mask of detached concern” or “smile through clenched teeth” instead of cultivating true compassion. Studies have shown that the degree of compassion shown by medical students progressively declines over their course of training, most markedly during their final clinical years. <https://goo.gl/LH3DhX>

Cont.

Noted in Media Watch 20 March 2017, #504 (p.10):

- *JOURNAL OF CLINICAL PSYCHOLOGY IN MEDICAL SETTINGS* | Online – 10 March 2017 – ‘**Managing difficult patients: Roles of psychologists in the age of interdisciplinary care.**’ This article explores how psychologists in medical settings can serve as a resource that improves patient care for difficult patients, supports provider wellness, provides relevant education to clinical providers, and reduces the stress difficult patients place on the healthcare system. <https://goo.gl/0aP6j7>

### Interpreting “do not resuscitate”: A cautionary tale of physician influence

*ANNALS OF THE AMERICAN THORACIC SOCIETY*, 2017;14(4):491-492. Care intensity at the end of life is known to vary across geography and health care systems, yet very little work has identified mechanisms that drive such variation. Existing literature has been unable to attribute such differences consistently to patient characteristics, raising the possibility that individual health care center factors or physicians' practice patterns drive much of the variation. Indeed, intensive care units (ICU) vary dramatically in how they manage care for patients with already established preferences for treatment limitations or those facing imminent death, suggesting the existence of local ICU cultures or institutional norms that determine such care. Other studies have demonstrated that individual physicians are associated with decisions to withhold or withdraw life support or in hospice enrollment, even more so than any patient characteristics. <https://goo.gl/YGDMGP>

#### Related

- *JOURNAL OF APPLIED GERONTOLOGY*, 2017;36(4):401-415. ‘**Clinician perspectives on challenges to patient-centered care at the end of life.**’ Discussions regarding patient preferences for resuscitation are often delayed and preferences may be neglected, leading to the receipt of unwanted medical care. Analysis [of survey findings] revealed barriers to patient wishes being identified and followed, including discomfort conducting end-of-life (EoL) discussions, difficulty locating patients' preferences in medical records, challenges with expiring do not resuscitate (DNR) orders, and confusion over terminology. Based on these findings, the preventive ethics team proposed new terminology for code status preferences, elimination of the local policy for expiration of DNR orders, and enhanced systems for storing and retrieving patients' EoL preferences. <https://goo.gl/GjctUy>
- *POSTGRADUATE MEDICAL JOURNAL*, 2017;93:1098. ‘**Reducing futile attempts at resuscitation.**’ A recent review in the *British Medical Journal* has drawn attention to major concerns about ‘Do Not Attempt Cardio-Pulmonary Resuscitation’ (DNACPR) forms.<sup>1</sup> One of these concerns is with the distressing number of deaths that are surrounded by futile attempts at cardio-pulmonary resuscitation. Such attempts occur for a number of reasons. Some patients with terminal illnesses, or who are elderly and frail, do not have a form, perhaps because their doctors were too busy or never got round to raising the issue. Other patients may have deteriorated very soon after admission, or more quickly than anyone expected, so that no-one had a chance to discuss their wishes with them in advance. A few patients may have refused consent to having DNACPR on their records because of their beliefs, in spite of having diseases likely to lead to death. In all these circumstances, doctors who are called at the time of death will typically feel they have no authority to withhold CPR, or they fear the legal risks of doing so – in spite of knowing that what they are doing is pointless. <https://goo.gl/JWn2aC>

1. ‘Resuscitation policy should focus on the patient, not the decision,’ *British Medical Journal*, published online 28 February 2017. [Noted in Media Watch 6 March 2017, #502 (p.9) <https://goo.gl/e88gY1>

## Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## **Do not resuscitate, brain death, and organ transplantation: Islamic perspective**

*AVICENNA JOURNAL OF MEDICINE*, 2017;7(2):35-45. Muslim patients and families are often reluctant to discuss and accept fatal diagnoses and prognoses. In many instances, aggressive therapy is requested by a patient's family, prolonging the life of the patient at all costs. Islamic law permits the withdrawal of futile treatment, including life support, from terminally ill patients allowing death to take its natural course. "Do not resuscitate" is permitted in Islamic law in certain situations. Debate continues about the certainty of brain death criteria within Islamic scholars. Although brain death is accepted as true death by the majority of Muslim scholars and medical organizations, the consensus in the Muslim world is not unanimous, and some scholars still accept death only by cardiopulmonary criteria. Organ transplantation has been accepted in Islamic countries (with some resistance from some jurists). Many fatwas (decrees) of Islamic Jurisprudence Councils have been issued and allowed organs to be donated from living competent adult donor; and, from deceased (cadavers), provided that they have agreed to donate or their families have agreed to donate after their death (usually these are brain-dead cases). A clear and well-defined policy from the ministry of health [in Syria] regarding do not resuscitate, brain death, and other end-of-life issues is urgently needed for all hospitals and health providers in most (if not all) Muslim and Arab countries. <https://goo.gl/NW9OkG>

**N.B.** Additional articles on the Islamic perspective on end-of-life and end-of-life care are noted in Media Watch 14 November 2016, #487 (p.11), and 7 November 2016, #486 (p.10).

## **Final conversations: Overview and practical implications for patients, families, and healthcare workers**

*BEHAVIORAL SCIENCES* | Online – 5 April 2017 – This article presents a summary of a 12-year body of research on final conversations, which will be useful for healthcare providers who work with patients and family nearing the end-of-life (EoL), as well as for patients and their family members. Final conversations encompass any and all conversations that occur between individuals with a terminal diagnosis and their family members (all participants are aware that their loved one is in the midst of the death journey). Final conversations take the family member's perspective and highlights what are their memorable messages with the terminally ill loved one. The authors highlight the message themes present at the EoL for both adults and children, the functions each message theme serves for family members, and lastly, the communicative challenges of final conversations. Additionally, the authors discuss the current nature and future of final conversations research, with special attention paid to practical implications for healthcare providers, patients, and family members; also, scholarly challenges and future research endeavors are explored. <https://goo.gl/9lgjqm>

Noted in Media Watch 21 November 2016, #488 (p.7):

- *DEATH STUDIES* | Online – 15 November 2016 – 'Wished for and avoided conversations with terminally ill individuals during final conversations.' Analyses revealed the following wished for and avoided conversations: 1) Negative relationship characteristics; 2) Death and dying; 3) Post-death arrangements; and, 4) Personal information. Furthermore, participants indicated the following reasons for not discussing the aforementioned topics during final conversations: 1) Emotional protection; 2) Relational differences; and, 3) Condition of the dying. Theoretical and practical implications for end-of-life communication are discussed. <https://goo.gl/393xK9>

## **The “surprise question” for predicting death in seriously ill patients: A systematic review and meta-analysis**

*CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2017;189(13):E484-E493. "Would I be surprised if this patient died in the next 12 months?" has been used to identify patients at high risk of death who might benefit from palliative care (PC) services. The "surprise question" (SQ) is intended to be a simple and feasible screening test to identify patients with hospice and PC needs, but it performs poorly to modestly

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when used to predict death at 6 to 18 months, with poorer performance among patients with non-cancer illness. Based on these findings, the SQ should not be used as a stand-alone prognostic tool, and we do not know whether it is more accurate for identifying patients with unmet palliative needs than it is for those in the final year of life. The high false-positive rate for SQ may be of concern if it is used as a routine trigger for time-consuming, costly or poorly available assessments for hospice and PC. Developing accurate, reliable and automated means of identifying patients with hospice and PC needs in a variety of settings remains a high-priority area of research. <https://goo.gl/H2uUxy>

Noted in Media Watch 20 February 2017, #500 (p.13):

- **JOURNAL OF PALLIATIVE MEDICINE** | Online – 16 February 2017 – ‘**Using the surprise question to identify those with unmet palliative care needs in emergency and inpatient settings: What do clinicians think?**’ Following implementation of the surprise question (SQ) in the acute care setting, the authors sought to explore hospital-based providers’ perceptions of the tool. Modest [study participants] reported that the SQ influenced care delivery as well as goals of care. At least some advance care planning discussions were prompted by the SQ. Team discussions were influenced by SQ use for more than half of each group. Most respondents expressed some concern that their SQ responses could be inaccurate. <https://goo.gl/cjh58n>

### Pediatric palliative care

**CURRENT ANESTHESIOLOGY REPORTS** | Online – 27 March 2017 – Palliative care is a rapidly evolving specialty with the pediatric component being a rather unique part of that care. Physicians are becoming increasingly aware that not all acute care interventions are in the patient’s best interest and under these circumstances, care that is focused on comfort measures is indicated. This transition to a focus on comfort and symptom-based care is often subtle and gradual and is especially so for children and their families. <https://goo.gl/Gv4ut2>

#### Related

- **ARCHIVES OF DISEASE IN CHILDHOOD** | Online – 4 April 2017 – ‘**Specialist paediatric palliative care services: what are the benefits?**’ Eight studies were identified [in this review], most of which were retrospective surveys undertaken within single institutions; three were surveys of bereaved parents and three were medical notes reviews. Together they represented a heterogeneous body of low-level evidence. Cross-cutting themes suggest that specialist paediatric palliative care services improve the quality of life and symptom control and can impact positively on place of care and family support. <https://goo.gl/PqBNih>
- **PATIENT EDUCATION & COUNSELING** | Online – 1 April 2017 – ‘**“Just gripping my heart and squeezing”: Naming and explaining the emotional experience of receiving bad news in the paediatric oncology setting.**’ Study participants’ emotional experiences during their bad news consultation were examined. They included bodily sensations, affective states, and cognitive conditions. Experiences related to the news and perceived consequences, more than its delivery. Strong emotional experiences do not necessarily indicate an ineffectual interaction. <https://goo.gl/Febi4R>

### Innovative urgent care for the palliative patient at home

**HOME HEALTHCARE NOW**, 2017;35(4):196-201. Palliative and end-of-life (EoL) patients in their homes are at risk of developing symptom crises requiring urgent care. The usual care for these patients involves transport to an emergency department (ED) despite the preference of most palliative patients to stay home. The objective of this initiative was to develop an innovative strategy to provide collaborative care in the home to alleviate symptoms and avoid transport. A partnership was created among emergency medical services, community care staff, physicians, and leaders to enable patients to stay at home with existing resources during symptom crisis. As a result of the initiative, patients were able to stay at home more frequently. When patients required transport to the ED, it occurred after attempted symptom management in the home. A total of 110 calls were tracked in the first 18 months of the initiative; 61% ended with the patient staying home, in alignment with their preferred place of care at the EoL. <https://goo.gl/1xWtdH>

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## **Related**

- **BMC PALLIATIVE CARE** | Online – 8 April 2017 – ‘**A process evaluation of systematic risk and needs assessment for caregivers in specialised palliative care.**’ The tasks of palliative care (PC) staff in relation to caregivers are often unclear in the daily practice. Assessment is recommended to establish risk and needs, and standards for caregiver support are available. Still, the feasibility of applying these standards among caregivers in everyday clinical practice has not been tested so far. This study showed that an intervention based on key elements of the “bereavement support standards” was feasible. <https://goo.gl/1pAvID>
- **DEMENTIA** | Online – 30 March 2017 – ‘**Gaps in understanding the experiences of homecare workers providing care for people with dementia up to the end of life: A systematic review.**’ Synthesis of the findings from the broader literature revealed three overarching themes: 1) Value of job role; 2) Emotional labour; and, 3) Poor information and communication. The role of homecare workers supporting a person with dementia up to the end of life remains under-researched, with unmet needs for informational, technical and emotional support reported. The effective components of training and support are yet to be identified. <https://goo.gl/THKIUj>

## **Measuring palliative and end-of-life care for cancer patients who die in hospital in Canada**

*JOURNAL OF CLINICAL ONCOLOGY* | Online – Accessed 8 Apr 2017 – This analysis reports on indicators that describe the current landscape of acute-care hospital utilization at end-of-life (EoL) and indirectly examines access to palliative care in patients who died of cancer in a hospital. A total of 48,987 (43%) cancer patient deaths occurred in an acute-care hospitals, with 70% admitted through the emergency department. Preliminary analysis revealed interprovincial variation in the cumulative length of stay in hospital 6 months prior to death from a median stay of 17 to 25 days. Some variation was also seen in the proportion of patients admitted to hospital two or more times in the last month of life (ranging from 18% to 33%), and the proportion of cancer patients admitted to ICU in the last 14 days of life (ranging from 15% to 6%). Patient demographics (age, sex, place of residence) and clinical factors (cancer type) were often predictors of hospital utilization at EoL. <https://goo.gl/0xbAo9>

Noted in Media Watch 25 January 2016, #446 (p.1):

- **CANADA** | CBC NEWS – 19 January 2016 – ‘**End-of-life care in Canada more hospital-centric than in U.S., Europe.**’ Canada has the highest proportion of people with cancer dying in hospital among seven developed countries, despite a mismatch with the type of end-of-life care many Canadians say they want, the author of a new study says.<sup>1</sup> <http://goo.gl/UZ7g3q>
  1. ‘Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries,’ *Journal of the American Medical Association*, 2016;315(3):272-283. <http://goo.gl/UWG881>

## **Investigating the factors that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services: An interview study**

*JOURNAL OF INTELLECTUAL DISABILITY RESEARCH* | Online – 7 April 2017 – Most staff working in intellectual disability services will be confronted with people with intellectual disabilities who need support around death, dying and bereavement. Staff [i.e., study participants] found supporting people with intellectual disabilities around death and dying extremely difficult and tended to avoid communication about the subject. The following factors had a particularly strong influence on staff practice around communicating death-related bad news: 1) Fear and distress around death; 2) Life and work experience; and, 3) Organisational culture. Staff attitudes to death communication had a stronger influence than their client’s level of cognitive or communicative abilities. Managers were important role models. Service managers should ensure not only that all their staff receive training in death, loss and communication but also that staff are enabled to reflect on their practice, through emotional support, supervision and team discussions. <https://goo.gl/MPN8db>

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Noted in Media Watch 6 February 2017, #498 (p.11):

- **JOURNAL OF INTELLECTUAL DISABILITY RESEARCH**, 2017;61(1):89-98. ‘**A matter of life and death: Knowledge about the body and concept of death in adults with intellectual disabilities.**’ The results of this study support previous studies suggesting that understanding of death in adults with intellectual disabilities (ID) varies from partial to full comprehension and is associated with level of ID. The study highlights the relationship between knowledge about the goal of human body functioning and death comprehension in adults with ID. The potential that learning to adopt a “vitalistic” approach to human functioning may have on the acquisition of a greater understanding of death and dying, understanding illness and supporting end-of-life planning is discussed. <https://goo.gl/ExE91T>

#### End-of-life care in Belgium

#### **Understanding patient needs without understanding the patient: The need for complementary use of professional interpreters in end-of-life care**

*MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 3 April 2017 – In linguistically and culturally diverse societies, language discordant consultations become daily practice, leading to difficulties in eliciting patient preferences toward end-of-life care. Although family members invariably act as informal interpreters, this may cause some ethical dilemmas. The authors present a case of a palliative patient whose son acted as an interpreter. This case generated a triple-layered ethical dilemma: 1) How to safeguard patient autonomy against paternalistic interventions by family members; 2) How to respect the relational context in which patient autonomy can be realized; and, 3) How to respect the ethno-cultural values of the patient and his family. These issues are discussed and reflected upon within the framework shared decision making involving informal- and professional interpreters. The complementary use of professional interpreters next to family members acting as informal interpreters is recommended. <https://goo.gl/thpFmR>

Noted in Media Watch, 20 June 2016, #467 (p.15):

- **PSYCHO-ONCOLOGY** | Online – 15 June 2016 – ‘**Promoting quality care in patients with cancer with limited English proficiency: Perspectives of medical interpreters.**’ Language barriers and underuse of medical interpreters have been widely identified as obstacles to equitable and quality care; however, the rate of professional interpreter use remains unknown. Further, no known study has explored patients’ reasons for refusing interpreter assistance, rather, existing studies have largely focused on physician and parental barriers. <http://goo.gl/VSe218>

**N.B.** Additional articles on patients with limited English proficiency in the context of end-of-life care are noted in this issue of Media Watch.

#### **Judicial oversight of life-ending withdrawal of assisted nutrition and hydration in disorders of consciousness in the U.K.: A matter of life and death**

*MEDICO-LEGAL JOURNAL* | Online – 3 April 2017 – Mr. Justice Baker delivered the Oxford Shrieval Lecture ‘A Matter of Life and Death’ on 11 October 2016.<sup>1</sup> The lecture created public controversies about who can authorise withdrawal of assisted nutrition and hydration (ANH) in disorders of consciousness (DOC). The law requires court permission in “best interests” decisions before ANH withdrawal only in permanent vegetative state and minimally conscious state. Some clinicians favour abandoning the need for court approval on the basis that clinicians are already empowered to withdraw ANH in other common conditions of DOC (e.g., coma, neurological disorders, etc.) based on their best interests assessment without court oversight. The authors set out a rationale in support of court oversight of best interests decisions in ANH withdrawal intended to end life in any person with DOC (who will lack relevant decision-making capacity). This ensures the safety of the general public and the protection of vulnerable disabled persons in society. <https://goo.gl/46hm8u>

1. ‘A Matter of Life & Death,’ Mr. Justice Baker, Oxford Shrieval Lecture 2016. <https://goo.gl/PiWeCJ>

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Noted in Media Watch 2 January 2017, #493 (p.15):

- **JOURNAL OF MEDICAL ETHICS** | Online – 16 December 2016 – ‘**A matter of life and death: Controversy at the interface between clinical and legal decision-making in prolonged disorders of consciousness.**’ Best interests decision-making and end-of-life care for patients in permanent vegetative or minimally conscious states (VS/MCS) is a complex area of clinical and legal practice, which is poorly understood by most clinicians, lawyers and members of the public. The Oxford Shrieval lecture by Mr. Justice Baker<sup>1</sup> and its subsequent reporting in the public press has sparked debate on the respective roles of clinicians, the Court of Protection and the Mental Capacity Act 2005 in decisions to withhold or withdraw life-sustaining treatments from patients with disorders of consciousness. <https://goo.gl/UQcVVi>

### **Researching people who are bereaved: Managing risks to participants and researchers**

**NURSING ETHICS** | Online – 3 April 2017 – This article draws on personal experiences to highlight ethical issues and risks encountered by both participants and researchers throughout all phases of a research project. Beginning in recruitment, the authors discuss the risk of secondary distress in participants arising from researcher contact and then explore the concept of informed consent during grief and bereavement research. They then focus on risks present during data collection, examining risks for participants, such as emotional distress, and potential safety risks for the research team. Finally, the authors consider the risks which arise in data analysis, including both confidentiality and the possibility of researcher burnout. Previous recommendations are summarised, with new management strategies suggested based on lessons learned along the way. <https://goo.gl/pU1Jz5>

Noted in Media Watch 2 November 2015, #434 (p.14):

- **PALLIATIVE & SUPPORTIVE CARE** | Online – 29 October 2015 – ‘**The potential therapeutic value for bereaved relatives participating in research: An exploratory study.**’ The results of this study center around six recurring concepts: 1) An opportunity to share the narrative accounts of the final hours of their relative’s life; 2) A search for sense and meaning in loss; 3) An ongoing bond/attachment with the deceased; 4) Altruistic motivations; 5) Oscillation between loss and restorative orientations; and, 6) A sense of resilience. Overall, the participants found that taking part in the research was valuable and that it could be described as offering therapeutic benefits. <https://goo.gl/PxMm28>

Noted in Media Watch 1 June 2015, #412 (p.11):

- **CRITICAL CARE MEDICINE** | Online – 22 May 2015 – ‘**Research participation for bereaved family members: Experience and insights from a qualitative study.**’ Bereavement research is possible after loss of a loved one in the ICU and may even be beneficial for family members. Exploring families’ experiences of research participation helps define specific family needs in this setting. They need opportunities to voice their feelings about their experience in the ICU and to give meaning to the end-of-life process; families also need to feel they are still cared for. <https://goo.gl/QkrpnB>

### **End-of-life care in England**

#### **Practice improvement as a result of an end-of-life care programme for care homes**

**NURSING OLDER PEOPLE**, 2017;29(3):23-27. The Six Steps+ programme promotes a culture of high quality, compassionate, person-centred and dignified holistic care to meet the needs of residents who may have increasing complex requirements throughout their last year or more of life. Through integrated working and a reduction in avoidable hospital admissions, residents are enabled to die in their place of choice where possible. Case studies show that participating in the Six Steps+ programme increases care home staff’s knowledge, skills and confidence and enhances the quality of end-of-life care (EoLC) for residents. With the cost of the education and support required essentially covered by six avoided hospital admissions throughout the one-year course, the Six Steps+ programme is an attractive and cost-effective approach to improving EoLC. <https://goo.gl/Vjj1IX>

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Noted in Media Watch 6 February 2017, #498 (p.13):

- **NURSING OLDER PEOPLE** | Online – 31 January 2017 – ‘**Developing, implementing and evaluating an end-of-life care intervention.**’ A two-phase exploratory mixed methods design was used, evaluating the effect of an end-of-life care (EoLC) toolkit and associated training in care homes, facilitated by a specialist palliative care team. Staff [i.e., study participants] confidence in receiving emotional and clinical support and managing EoLC symptoms increased post-intervention, but confidence in discussing death and dying with residents and relatives decreased. <https://goo.gl/ELtQVD>

Noted in Media Watch 2 November 2015, #434 (p.11):

- **HEALTH SERVICES MANAGEMENT RESEARCH** | Online – 27 October 2015 – ‘**The cost of providing end-of-life care for nursing care home residents: A retrospective cohort study.**’ Thirty-eight nursing care homes took part, comprising 2,444 individual residents. Death in hospital vs. in the nursing care home was associated with an average increase in costs of £4,223. Interventions are needed which help nursing care home staff to identify when an individual is dying, and have the skill and confidence to make difficult decisions regarding care provision at the end of life. <https://goo.gl/HHuz9b>

### **Prisoner peer caregiving: A literature review**

**NURSING STANDARD** | Online – 5 April 2017 – The main themes identified were: 1) The benefits of prisoner caregiving; 2) Training needs; and, 3) The organisational implications of implementing prisoner caregiving. The narrative literature review identified a range of methodological approaches used to undertake research in prisons. Challenges to undertaking research in prisons included practical issues, the influence of power on relationships and the difficulty for researchers not to take the side of either the prisoners or prison staff. The role of prisoner caregiver is increasingly recognised as important, and is associated with several benefits to individual prisoners and the prison community. However, further training is required for prisoner

caregivers, and there is a need for further research into the prisoner caregiving role, using a methodology that is suitable for the prison setting. <https://goo.gl/p3GQO5>

### **Palliative Care Network Community**

#### **Prison Hospice: Backgrounder**

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of the articles, reports, etc., noted in past issues of the weekly report ([updated 4 April 2017](#)) is available at: <http://goo.gl/ZpEJyQ>

### **What do we know about different models of providing palliative care? Findings from a systematic review of reviews**

**PALLIATIVE MEDICINE** | Online – 5 April 2017 – A wide range of organisational models of palliative care (PC) exist. However, decision makers need more information about which models are likely to be most effective in different settings and for different patient groups. Much of the evidence relates to home-based PC, although some models are delivered across care settings. Reviews report several potential advantages and few disadvantages of models of PC delivery. However, under-reporting of the components of intervention and comparator models are major barriers to the evaluation and implementation of models of PC. Irrespective of setting or patient characteristics, models of PC appear to show benefits and some models of PC may reduce total healthcare costs. However, much more detailed and systematic reporting of components and agreement about outcome measures is essential in order to understand the key components and successfully replicate effective organisational models. <https://goo.gl/thpFmR>

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## **Related**

- **MEDICINE, HEALTH CARE & PHILOSOPHY** | Online – 3 April 2017 – ‘**Suffering and dying well: On the proper aim of palliative care.**’ In recent years a large empirical literature has appeared on suffering at the end of life. In this literature it is recognized that suffering has existential and social dimensions in addition to physical and psychological ones. The non-physical aspects of suffering, however, are still understood as pathological symptoms, to be reduced by therapeutical interventions as much as possible. But suffering itself and the negative emotional states it consists of are intentional states of mind which, as such, make cognitive claims: they are more or less appropriate responses to the actual circumstances of the patient. These circumstances often are such that it would rather be a pathological symptom not to be sad and not to suffer. Suffering, therefore, is sometimes and to some extent a condition to be respected. <https://goo.gl/H6tRq3>
- **PALLIATIVE MEDICINE** | Online – 3 April 2017 – ‘**Initial perceptions of palliative care: An exploratory qualitative study of patients with advanced cancer and their family caregivers.**’ The authors explored initial perceptions of palliative care (PC) when this is first raised with patients with advanced cancer and their families in Australian settings. PC was negatively associated with a system of diminished care, which is seen as a “lesser” treatment alternative, diminished possibilities for hope and achievement of ambitions previously centred upon cure, and diminished choices for the circumstances of one’s care given all other options have expired. While there is an increasing move towards early integration of PC, this study suggests that patient and caregiver understandings have not equally progressed. <https://goo.gl/g49Exw>

## **Making death, compassion and partnership “part of life” in school communities**

**PASTORAL CARE IN EDUCATION** | Online – 28 March 2017 – Death can be considered a social taboo, a common source of fear and public avoidance. School communities are not immune to this, as the topic of death is constantly avoided. It is vital to understand how we can socially and culturally cultivate a positive regard for death, dying and bereavement in our school communities. Community members need to discuss these difficult issues and use strategies to enhance compassion, connectedness and support. In this literature review the authors reason that death is specifically not “part of life” in school communities. Due to the dearth of school community-based literature on this issue and the progressive literature residing in palliative care (PC), the authors aim to coalesce PC and school-based research, evaluate it and highlight compassion and partnership as a way forward for school communities. Essentially, our societal attitudes about death and dying have been profoundly altered and our community ownership of these normal life events has largely disappeared. This is demonstrated, for example, by PC moving from the social grass roots “modern hospice movement” formed in the 1960s and being reintegrated into the mainstream health care system by the end of the 1990s, resulting in an overall medicalised morphing of death, dying and bereavement issues. <https://goo.gl/V4H7NR>

**N.B.** Selected articles on including the topic of dying and death into the school curriculum are noted in Media Watch 27 February 2017, #501 (pp.1-2).

## **Preferences for care towards the end of life when decision-making capacity may be impaired: A large scale cross-sectional survey of public attitudes in Great Britain and the U.S.**

**PLOS ONE** | Online – 5 April 2017 – There is continuing public debate about treatment preferences at the end of life (EoL), and the acceptability and legal status of treatments that sustain or end life. However, most surveys use binary yes/no measures, and little is known about preferences in neurological disease when decision-making capacity is lost, as most studies focus on cancer. This study investigates changes in public preferences for care towards the EoL, with a focus on measures to sustain or end life. Public opinion was uniform between Great Britain and U.S., but markedly heterogeneous. Despite contemporaneous capacitous consent providing an essential legal safeguard in most jurisdictions, there was a high prevalence of preference for “measures to end my life peacefully” when decision-making capacity was compromised, which increased as dementia progressed. In contrast, a significant number chose preservation of life at all costs, even in end stage dementia. It is challenging to respect the longstanding values of people with dementia concerning either the inviolability of life or personal autonomy, whilst protecting those without decision-making capacity. <https://goo.gl/xepNVi>

## No matter the species

### A compassionate journey (Part 3): The client experience

*THE VETERINARY NURSE* | Online – 28 March 2017 – The role of the practice team in the client's end-of-life journey with their pet is one that can make or break the client's experience. Euthanasia experiences are remembered by the pet owner days, weeks, and even years later. For an owner, whose emotions will already be heightened by the quality-of-life decisions they face, and the turmoil of losing a treasured companion, sensitivity to the veterinary environment and their experiences "front-of-house" will play a role in shaping their impressions. It is important that the non-clinical aspects of euthanasia or end-of-life care are comprehensively assessed within a practice, and the support team trained in the customer care aspects of the final client journey. <https://goo.gl/Q5t0BO>

**N.B.** Part 1: <https://goo.gl/kWoZbe>; Part 2: <https://goo.gl/Dq3OhI>. The parallel to be drawn between the practice and philosophy of hospice and palliative care and how end-of-life care for domestic animals has evolved in recent years has occasionally been highlighted in Media Watch, e.g., 19 December 2016, #492 (p.9); 3 October 2016 #482 (p.13); and, 11 April 2016, 457 (p.14).

### Assisted (or facilitated) death

Representative sample of recent journal articles:

- **NEUROLOGY**, 2017;17(7):31-32. ‘**Physician-assisted death tenable for surveyed MS patients if pain is unbearable.**’ A survey showing that many multiple sclerosis (MS) patients would consider physician-assisted suicide under certain scenarios underscores the need for greater attention to managing depression and MS symptoms, neurologists say. More than one-third of surveyed multiple sclerosis patients said they would definitely or probably consider physician-assisted death if experiencing unbearable pain, researchers from the U.S. and Canada reported. In addition to being white and female, those with current depression or anxiety, moderate to severe pain, and who are not undergoing immunotherapy were most likely to say they would consider physician-assisted death. <https://goo.gl/ZFdKwT>
  1. ‘High hypothetical interest in physician-assisted death in multiple sclerosis,’ *Neurology*, published online 15 March 2017. [Noted in Media Watch 3 April 2017, #506 (p.5)] <https://goo.gl/Hyw3p0>

Noted in Media Watch 3 April 2017, #506 (p.5):

- **MULTIPLE SCLEROSIS JOURNAL** | Online – 22 March 2017 – ‘**Multiple sclerosis and suicide.**’ Mortality rates are elevated in people with multiple sclerosis (MS) relative to the general population. Epidemiological data suggest that the standardized mortality ratio for suicide in MS is approximately twice that of the general population with younger males in the first few years following diagnosis most at risk. <https://goo.gl/RQtpfv>
- **SOCIAL & LEGAL STUDIES** | Online – 31 March 2017 – ‘**Older lesbians, gay men and the “right to die” debate.**’ The author’s argument is that older lesbians and gay men are multiply disadvantaged 1) By an increased risk of feeling that life is not worth living due to affective inequalities (inadequate informal and formal social support); and, 2) By a denial of access to the right to die both under such circumstances and/or if they wish to resist the normativities associated with a passive, medicalized death. The author argues for the need to distinguish between a wish to die because of deficiencies in the care system and a wish to die in order to control how, when and where one’s life ends. Her analysis highlights the contextual contingencies of “vulnerability” in relation to the right to die and interrogates the heterosexist and disciplinary reproductive normativities underpinning the notions of “natural” deaths. <https://goo.gl/y319xB>
- **JAMA ONCOLOGY** | Online – 6 April 2017 – ‘**Characterizing 18 Years of the Death with Dignity Act in Oregon.**’ In this analysis of publicly available data, about two-thirds of patients prescribed lethal medication under Oregon’s Death with Dignity act consumed the medication and subsequently died. Cancer was the most common underlying disease. Physician aid-in-dying makes up only a small fraction of Oregon resident deaths, accounting for 38.6 deaths per 10 000 total deaths, but it offers considerable potential benefits to many patients who are near the end of their life. <https://goo.gl/xSHrl>

## **Worth Repeating**

### **Narratives of “terminal sedation” and the importance of the intention-foresight distinction in palliative care practice**

*BIOETHICS*, 2013;27(1):1-11. The moral importance of the “intention-foresight” distinction has long been a matter of philosophical controversy, particularly in the context of end-of-life care. Previous empirical research in Australia has suggested that general physicians and surgeons may use analgesic or sedative infusions with ambiguous intentions, their actions sometimes approximating “slow euthanasia.” The authors report findings from a qualitative study of 18 Australian palliative care (PC) medical specialists, using in-depth interviews to address the use of sedation at the end of life. In contrast to their colleagues in acute medical practice, these Australian PC specialists were almost unanimously committed to distinguishing their actions from euthanasia. This commitment appeared to arise principally from the need to maintain a clear professional role, and not obviously from an ideological opposition to euthanasia. While some respondents acknowledged that there are difficult cases that require considered reflection upon one’s intention, and where there may be some “mental gymnastics,” the nearly unanimous view was that it is important, even in these difficult cases, to cultivate an intention that focuses exclusively on the relief of symptoms. They present four narratives of “terminal” sedation – cases where sedation was administered in significant doses just before death, and may well have hastened death. Considerable ambiguities of intention were evident in some instances, but the discussion around these clearly exceptional cases illustrates the importance of intention to PC specialists in maintaining their professional roles. [Noted in Media Watch 7 January 2013 #287 (p.7)] <https://goo.gl/s9wVMX>

### **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**

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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/dxmEdJ>

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

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

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

### **Canada**

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/lOSNC7>

### **Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1l9K>

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

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