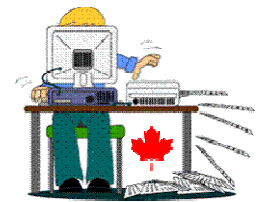


## Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

**Healthcare professionals need to be aware of the unstable nature of preferences for place of end-of-life care and death, include caregivers in place-of-care discussions, and pay attention to the context within which decisions are made.**

'Qualitative research shows that preferences for place of end-of-life care and death are shaped by the uncertainty of living with a life-limiting illness for patients and family caregivers and are neither synonymous nor stable' (p.7), in *Evidence Based Nursing*.

## Canada

### Nanaimo takes grief services mobile for children in need

BRITISH COLUMBIA | CBC News (Victoria) – 8 September 2019 – A new mobile outreach vehicle in Nanaimo is bringing counselling services to children coping with the loss of a loved one. The service, offered by the Nanaimo Community Hospice Society, is an extension of the grief counselling services already on offer for children and youth by the society, says executive director Paul Sibley. "People tend to think of hospice as a seniors' organization, but a lot of the work that we do is with people across the whole age demographic – and children have certainly been a big part of what we do," Sibley said. The specially retrofitted recreational vehicle (RV) has been made to resemble the play therapy room at the society's physical building, with art supplies, a wall of figurines and toys, and other objects of play. Because kids can't sit down and talk like adults about the loss of someone they love, Sibley said, the hospice society's specially trained counsellors use the toys to encourage the children to express their grief. The mobile unit can

reach children at school or at home – places where they already feel comfortable. Sibley says the RV will also be useful for reaching marginalized populations, like people experiencing homelessness. <http://bit.ly/2kAhqjK>

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

Supporting Grieving or Bereaved Children  
<http://bit.ly/2sQ2bLy>

### Specialist Publications

'Canadian guideline for Parkinson disease (Section on palliative care)' (p.6), in *Canadian Medical Association Journal*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CBC News (Montreal) – 11 September 2019 – ‘**Quebec judge overturns parts of federal, provincial laws on medically assisted dying.**’ A Quebec Superior Court justice has declared parts of both the federal and provincial laws on medically assisted dying unconstitutional because they’re too restrictive. Two Montrealers with degenerative diseases ... launched a court challenge seeking access to Quebec and Canada’s doctor-assisted dying laws. Both suffer from serious health problems that their lawyer argued cause persistent and intolerable suffering. Federal and provincial laws currently say only people who are facing “foreseeable death” can receive aid to die. <http://bit.ly/2kG4Kzg>

## U.S.A.

### Court: Difference of opinion is not hospice fraud

ALABAMA | *Hospice News* – 11 September 2019 – The Eleventh Circuit Court of Appeals partially affirmed a decision in favor of Arkansas-based hospice provider AseraCare in a False Claims Act (FCA) case that has widespread implications for the hospice industry. The appellate court agreed with the Northern District of Alabama that a mere difference of physician’s opinions on a terminal patient’s prognosis does not indicate falsity under the FCA. Arguments in *U.S. vs. Aseracare* have tried to untangle the complex question of whether live discharges from hospice care were the result of deliberate fraud or occurred because of the inherent difficulty of predicting a patient’s life expectancy. While partially affirming the Northern District’s decision, the Eleventh Circuit sided with the government’s position that the district court should have considered all the evidence in the record to determine whether grounds for trial existed. The case will be remanded back to the district court to resolve this, but the appellate court stipulated that any further evidence of falsi-

ty brought by the government must be linked to the specific 123 claims named in the case. When the initial case was filed, a physician witness for the government reviewed 233 patient records and found that most of the patients should have been found ineligible for the Medicare Hospice Benefit. The government appealed the case after a lower court sided with AseraCare on the grounds that physician witnesses could not reach consensus on the medical necessity of hospice care for the patients, making culpability unclear. The judge’s decision overruled the jury who had sided with the government. <http://bit.ly/2ITaS7l>

### Specialist Publications

‘Cost and utilization of lung cancer end-of-life care among racial-ethnic minority groups in the U.S.’ (p.13), in *The Oncologist*.

Noted in Media Watch 22 April 2019 (#611, p.2):

- *HOSPICE NEWS* | Online – 18 April 2019 – ‘**Wall Street Journal editorial debates hospice fraud case.**’ A major fraud case centered around live hospice discharges is being argued not only in 11th Circuit Court of Appeals but in the editorial pages of *The Wall Street Journal*.<sup>1</sup> Kyle Clark and Andrew George, trial lawyers for the Washington-based law firm of Baker Botts, published a recent editorial on the case of *U.S. vs. AseraCare*. Arguments have tried to untangle the complex question of whether the live discharges were the result of deliberate fraud or occurred because of the inherent difficulty of predicting a patient’s life expectancy. <http://bit.ly/2KQ5jD2>

1. ‘Medicare’s hospice rules could make your doctor a criminal,’ *The Wall Street Journal*, 21 March 2019. <https://on.wsj.com/2HO9VXa>



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## Right-to-try “remains a bust,” as many drug makers prefer Food & Drug Administration reviews

STAT | Online – 9 September 2019 – Despite the hubbub over the “right-to-try” law, a recent survey found that nearly half of drug makers indicated they would require regulators to review a decision to provide an experimental treatment to a person with a life-threatening disease. Specifically, 13 of 29 drug companies indicated they want a relevant regulatory authority to review requests that are granted to such people. Of these, six specified they would ask the Food & Drug Administration to conduct a review and five stated they require a research ethics committee or institutional review board, according to a report from the U.S. Government Accountability Office.<sup>1</sup> <http://bit.ly/2IRMCCU>

1. ‘Investigational Drugs: Food & Drug Administration and Drug Manufacturers Have Ongoing Efforts to Facilitate Access for Some Patients,’ U.S. Government Accountability Office, Washington DC, September 2019. **Down-load/view at:** <http://bit.ly/2IMza36>

Noted in Media Watch 5 August 2019 (#625, p..3):

- OHIO | WKRC Radio (Cincinnati) – 24 July 2019 – ‘**Why “right-to-try” created to help terminal patients hasn’t worked.**’ Experts say more than a year after the passage of the national “Right-to-Try” Act, little has changed. Dr. Arthur Caplan, a bioethicist at New York University Langone Health, considers “right-to-try” nothing more than feel-good politics, calling the law meaningless, “They promise what doesn’t happen. Caplan says ... the companies that make drugs still hold all the power. He would know. He currently sits on an independent committee which advises a major drug company on whether to approve requests for experimental treatments. <http://bit.ly/2TOR1zW>

**N.B.** Selected articles on “right-to-try” laws noted in 22 April 2019 issue of Media Watch (#611, p.7).

## International

### Providers should ensure more doc visits to patients at end of life, study finds

MCKNIGHT'S LONG-TERM CARE NEWS | Online – 13 September 2019 – Frequently interacting and providing emotional support to the relatives of dying long-term care (LTC) relatives has a strong impact on the family members’ satisfaction levels with the caregiving process, a new study has found.<sup>1</sup> Relatives’ evaluation of end-of-life (EoL) communication with providers was higher when doctors spent more time with the resident during their final days. It also was higher when the treating physician visited the resident three times in their last week of life or when palliative care was given. However, relatives felt worse about their communication with providers when the family members carried more emotional burdens. “Long-term care (facility) managers should organize care for dying residents in a way that enables frequent interactions between physicians and relatives, and emotional support to relatives to improve their satisfaction with (EoL) communication,” researchers concluded. A total of 736 relatives of deceased residents from 210 LTC facilities in Belgium, Finland, Italy,

The Netherlands and Poland participated in the study. <http://bit.ly/2IMEjrZ>

#### Specialist Publications

‘**Developing, promoting, and sustaining palliative care across Central and Eastern Europe**’ (p.8), in *Journal of Hospice & Palliative Nursing*.

‘**Implementation of best practice recommendations for palliative care in German comprehensive cancer centers**’ (p.8), in *The Oncologist*.

‘**Regulating voluntary assisted dying in Australia: Some insights from The Netherlands**’ (p.14), in *Medical Journal of Australia*.

‘**Imagining terminality: Anticipations of suicide with assistance in Switzerland**’ (p.14), in *Revista M. Estudos*.

1. ‘Factors associated with perception of the quality of physicians’ end-of-life communication in long-term care facilities: PACE cross-sectional study,’ *Journal of Post-Acute and Long-Term Care Medicine*, published online 11 September 2019. **Abstract:** <http://bit.ly/2mfLOTA>

## 86 people died in Lothian hospitals while waiting to go home

U.K. (Scotland) | *Edinburgh Evening News* – 12 September 2019 – New figures today revealed 86 people died in Lothian hospitals in 2018-2019 while waiting to be discharged, the highest number in Scotland. Age Scotland called the deaths “tragic” and called for urgent action to tackle the growing problem of delayed discharges and an over-stretched social care system. The figures, obtained through Freedom of Information legislation, reinforce concerns raised by previous research by the charity which found that people in Edinburgh and West Lothian have some of the longest waits for social care in the country. Across Scotland, 474 patients, mainly older people, died in Scottish hospitals after their discharge was delayed. The vast majority – 423 – were waiting for health and social care packages to be put in place. Age Scotland’s research earlier this year found the average waiting time for people to get social care after being assessed as having “critical” or “substantial needs” was five weeks in Edinburgh and more than six weeks in West Lothian, despite the Scottish Government’s six week guidelines.<sup>1</sup> The longest wait was more than 35 weeks. <http://bit.ly/2m9odbR>

1. ‘Waiting for care: Is Scotland meeting its commitment to older people,’ Age Scotland, May 2019. **Download/view at:** <http://bit.ly/2lOtl56>

Noted in Media Watch 2 September 2019 (#629, p.6):

- U.K. (Northern Ireland) | *The Belfast Telegraph* – 27 August 2019 – ‘**512 people told they could leave Northern Ireland hospitals died waiting to go home.**’ More than 500 people died in hospitals across Northern Ireland (NI) over three years while waiting to be discharged. Official figures highlight the scale of the crisis facing social and community care in NI, with 512 people medically fit for discharge dying in a hospital ward between 2016-2017 and 2018-2019. Bed-blocking, as it is known, is when a person has been assessed as no longer requiring hospital inpatient treatment, but is not discharged. This can happen for a range of reasons – in some cases, it is through patient choice, but the vast majority of cases happen because there is no community care package in place. <http://bit.ly/2HsgXzU>

## Research highlights need for palliative care awareness

U.K. (Northern Ireland) | *Daily Northern Ireland News* (Belfast) – 11 September 2019 – Enhanced public understanding of palliative care (PC) is required to improve provisions for end of life patients and their families in Northern Ireland, research conducted by Ulster University has found. Some 86% of people are familiar with the term which refers to the nursing care provided for people with chronic conditions, however many assumed it was only for older people, those in the final six months of life and only provided in a hospital setting. Lead researcher Professor Sonja McIlfratrick hopes the findings and recommendations of the study ... will contribute towards the ongoing development of a public health framework for PC. The study found that most people gained their knowledge from close friends and relatives receiving PC, with many misconceptions still existing around the issue. <http://bit.ly/2mcFfpG>

## U.K. hospice forced to turn away dying patients

U.K. (England) | *The Guardian* (London) – 10 September 2019 – A hospice has been forced to close its doors to people wishing to spend their final days there because it cannot find a doctor to oversee its service. It is the first time one of the U.K.’s 220 hospices has had to turn away those needing end of life care as a result of the shortage of medical staff. St. Mary’s hospice in Ulverston, Cumbria, took the decision reluctantly after spending months trying but failing to recruit a replacement for its departing senior doctor. Dying patients who would have been admitted to the hospice from mid-October will have to be cared for elsewhere and some inpatients may even have to be moved. Terminally ill patients from Ulverston and nearby who require round-the-clock medical attention in a hospice may have to go instead to St. John’s hospice, 39 miles – and an hour’s drive – away in Lancaster, in north Lancashire. Val Stangoe, St Mary’s chief executive, said the hospice’s rural location helped explain its inability to recruit a new doctor and avoid what she hoped was a temporary three-month closure to inpatients. <http://bit.ly/2m3csDN>

**N B.** See ‘Hospice answers frequently asked questions after announcing inpatient freeze,’ *The Mail* (High Wycombe, Buckinghamshire), 10 September 2019. <http://bit.ly/2k5QSOM>

## ***Unrelieved pain in palliative care in England***

U.K. (England) | Office of Health Economics – Accessed 9 September 2019 – In England, an estimated 378,427 people receive palliative care (PC) each year in a range of specialised and generalised services. Overall, the quality of PC in England and the wider U.K. is widely regarded as excellent. However, despite the generally high level of care, many patients receiving PC die in pain every year. Yet, to date, there is little evidence of the scale of this problem. This study estimates that currently there are approximately 125,971 end-of-life patients receiving, or in need of, PC suffering from unrelieved pain. Of these, an estimated 16,130 patients experience no relief from their pain at all in the last three months of life. Some of these patients suffer unnecessarily because of variations in the quality of care across care settings (e.g., hospice versus at home services). However, even if unrelieved pain rates were the same as they are in hospices, where they are at their lowest since PC is excellent in hospices, there would still be 50,709 PC patients dying in some level of pain each year. Of these patients, 5,298 would still experience no pain relief at all in the last three months of life. Estimates include patients of all ages, including children (under 19) which only account for 0.83% of the registered deaths in England and Wales. This was dictated by the availability of evidence of the number of deaths by place of death, which does not differentiate by age. If we were to include only adults, the number of patients who experience no relief from their pain at all in the last three months of life would go from 16,130 to 15,996. Overall, this study has adopted conservative assumptions that will provide the lowest possible estimate of the number of patients dying with unrelieved pain. **Download/view at:** <http://bit.ly/2kz9hmT>

## **Palliative care patients in regional Victoria sometimes waiting for days for pain-relief medication**

AUSTRALIA (Victoria) | ABC News (Melbourne) – 7 September 2019 – Monash University School of Rural Health researchers have found that in remote and rural Victoria, that community nurses are on the frontline managing a patients last days, that includes prescribing and accessing urgent medication to deal with pain.<sup>1</sup> Associate Professor and lead author Dr. Hanan Khalil found some nurses were poorly trained in the use of these medications and often lacked support from doctors as well as finding doctors were unwilling to prescribe these medications, resulting in pharmacies not stocking them. She found regional doctors were reluctant to prescribe painkillers – or opioids – in fear they would be abused. Dr. Khalil said lack of anticipatory medications could lead to unnecessary hospital admissions and increased stress and anxiety for patients and their family. The Monash Rural Health researchers surveyed 29 community-based nurses in the Gippsland region. The survey found that 72% administered emergency medications in the home. A third of all the nurses in the survey said they did not have specific guidance regarding the use of these medications for the patients. <https://ab.co/2k4UnEV>

1. 'Medication safety challenges in the palliative care setting: Nurses' perspectives,' *Collegian*, 2019 (In print: Accessed 7 September 2019). **Abstract:** <http://bit.ly/2k4Mgbi>

**N.B.** Additional articles on the provision and delivery of palliative and end-of-life care in rural and remote regions of Australia noted in 28 August 2019 issue of Media Watch (#628, pp.5-6).



### **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://bit.ly/2RPJy9b>

## Specialist Publications

### **Patient safety incidents in advance care planning for serious illness: A mixed-methods analysis**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 6 September 2019 – The authors identified 70 reports in which advance care planning (ACP) caused a patient safety incident across three error categories: 1) ACP not completed despite being appropriate; 2) ACP completed but not accessible or miscommunicated between professionals; and, 3) ACP completed and accessible but not followed. Themes included staff lacking the knowledge, confidence, competence or belief in trustworthiness of prior documentation to create or enact ACP. Adverse outcomes included cardiopulmonary resuscitation attempts contrary to ACP, other inappropriate treatment and/or transfer or admission. This national analysis identifies priority concerns and questions whether it is possible to develop strong system

interventions to ensure safety and quality in ACP without significant improvement in human-dependent issues in social programmes such as ACP. Human-dependent issues (i.e., varying patient, carer and professional understanding, and confidence in enacting prior ACP when required) should be explored in local contexts alongside systems development for ACP documentation. **Abstract:** <http://bit.ly/2kyG2AO>

#### Publishing Matters

'Why are we publishing protocols?' (p.15), in *Journal of Palliative Medicine*.

#### **Related**

- *JOURNAL OF CLINICAL NURSING* | Online – 7 September 2019 – '**Barriers to advance care planning with patients as perceived by nurses and other healthcare professionals: A systematic review.**' Barriers to advance care planning (ACP) are lack of education and insufficient time. ACP appears to be well supported and nurses and healthcare professionals report themselves to be comfortable and confident to take on the responsibility. But, there is a need for greater education and training. In particular, there needs to be better understanding of professional and legal responsibilities. The need for sufficient time to be made available to allow these conversations, in often busy settings, will need institutional and financial support. **Abstract:** <http://bit.ly/2kCwdSf>

### **Using a frame of reference for talking to patients about death and dying**

*BRITISH JOURNAL OF NURSING* | Online – 13 September 2019 – Recent years have seen a recognition of the importance of talking openly to patients at the end of life (EoL) about death and dying. This article aims to add to the existing body of literature on this subject. Conversations at the EoL can be difficult, particularly if the patient is experiencing mental distress alongside their terminal illness. A number of factors can disrupt a constructive and supportive conversation around death and dying. This article offers a frame of reference for nurses to consider when having such conversations. **Abstract:** <http://bit.ly/2IPeOpO>

### **Canadian guideline for Parkinson disease [Section on palliative care]**

*CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2019;191(36): E989-E1004. There is growing information with respect to palliative care (PC) in Parkinson disease (PD) and the guideline panel therefore thought that the topic was an important addition to the new guideline. People with PD and their family members and caregivers (as appropriate) should be offered opportunities to discuss the prognosis of their condition. These discussions should promote people's priorities, shared decision-making and patient-centred care. People with PD and their family members and caregivers should be given appropriate verbal and written information about the following, and it should be recorded that the discussion has taken place: 1) Progression of PD; 2) Possible future adverse



Cont.

effects of medicines for PD; 3) Advance care planning (ACP), including orders for advanced decisions to refuse treatment and do not attempt resuscitation, and lasting power of attorney for finance and health and social care; 4) Options for future management; 5) could happen at the end of life (EoL); and, 6) Available support services (for example, personal care, equipment and practical support, financial support and advice, care at home and respite care. When discussing PC, it should be recognized that family members and caregivers may have different information needs from the person with PD. PC requirements ... should be considered throughout all phases of the disease; this includes an option of medical assistance in dying. EoL choices, including ACP with an open and frank discussion with the patient and the person designated as decision-maker, should be initiated early in the disease process. Conversations occurring in the ambulatory setting are likely to be more productive and less crisis driven than leaving such conversations until an acute stay in hospital. **Download/view guideline :at <http://bit.ly/2kniP4B>**

Noted in Media Watch 15 July 2019 (#622, p.9):

- *BMC PALLIATIVE CARE* | Online – 9 July 2019 – ‘**Palliative care for persons with Parkinson’s disease: A qualitative study on the experiences of healthcare professionals.**’ Healthcare professionals supported the development of palliative care (PC) for Parkinson’s disease (PD), but needed to better understand the essence of PC. They struggle to identify persons’ needs due to interfering PD-specific symptoms such as cognitive decline and communication deficits. Timely addressing the personal preferences for providing PC was identified as an important facilitator. Healthcare professionals acknowledged being aware of their lack of knowledge... **Full text:** <http://bit.ly/2xDD29a>

Noted in Media Watch 17 September 2018 (#581, p.13):

- *JOURNAL OF PARKINSON’S DISEASE* | Online – 20 August 2018 – ‘**Parkinson matters.**’ A report by Public Health England provides insight on trends in deaths associated with neurological diseases in England between 2001 to 2014.<sup>1</sup> Data suggest the end-of-life for Parkinson’s disease (PD) patients is often unplanned, occurring in hospitals or care homes. Although there are undeniably instances when dying in a hospital is more appropriate than dying at home, most patients indicate a preference for dying at home. The vast majority of hospital admissions of PD patients are unplanned, resulting from either complications of the disease or its treatments or comorbidities. **Full text:** <http://bit.ly/2NNGbhu>

1. ‘Deaths associated with neurological conditions,’ Public Health England, February 2018. **Download/view at:** <http://bit.ly/2XEYJ3g>

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 September 2018 – ‘**Top ten tips palliative care clinicians should know about Parkinson’s disease and related disorders.**’ Parkinson’s disease (PD) affects 1-2% of individuals older than 60 years and is the 14th leading cause of death in the U.S. People with PD, across all stages of the disease, suffer from a significant symptom burden that includes many non-motor symptoms and most will ultimately die from complications of this degenerative and incurable illness. Even at diagnosis, a palliative care approach can help the patient adjust to his or her diagnosis and maintain an optimal quality of life. **Abstract:** <http://bit.ly/2YTAYpL>

**N.B.** Additional articles on the palliative and end-of-life care for patients living with PD noted in 20 August 2018 issue of Media Watch (#577, p.9).

### **Qualitative research shows that preferences for place of end-of-life care and death are shaped by the uncertainty of living with a life-limiting illness for patients and family caregivers and are neither synonymous nor stable**

*EVIDENCE BASED NURSING* | Online – 5 September 2019 – Healthcare professionals need to be aware of the unstable nature of preferences for place of end-of-life care and death, include caregivers in place-of-care discussions, and pay attention to the context within which decisions are made. Research that captures preferences for place of care and death at one point in time must be treated with caution given the instability of these preferences when living with, or caring for someone with, a life-limiting illness. **Key points:** <http://bit.ly/2kzBYiD>

**N.B.** Commentary on “‘It all depends!’: A qualitative study of preferences for place of care and place of death in terminally ill patients and their family caregivers,” *Palliative Medicine*, 3 May 2019. [Noted in 6 May 2019 issue of Media Watch (#613, p.12)] **Abstract:** <http://bit.ly/2IWKALQ>

## End-of-life care in New Zealand

### **Optimising compassionate nursing care at the end of life in hospital settings**

*JOURNAL OF CLINICAL NURSING* | Online – 8 September 2019 – In this discussion paper, the authors explore synergies between the newly developed *Kapakapa Manawa Framework: A bi-cultural approach to providing compassionate care at the end of life* and the Fundamentals of Care (FoC). They argue that the framework can be used to support the implementation of the relational component of the FoC and the delivery of compassionate nursing practice in hospitals in Aotearoa, New Zealand. Whilst the Kapakapa Manawa bi-cultural compassionate care framework has grown out of research conducted with people nearing the end of their lives, it has the potential to improve nursing care for all hospital inpatients. In addition, addressing the wider policy and health system factors detailed in the FoC will support its implementation in the clinical setting. **Abstract:** <http://bit.ly/2kzWe4L>

**N.B.** Additional articles on Māori beliefs and practices in the context of end of life and end-of-life care noted in 27 August 2018 issue of Media Watch (#578, p.15).

### **Developing, promoting, and sustaining palliative care across Central and Eastern Europe**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 10 September 2019 – Worldwide, health-care is becoming more complex and multifaceted. Nurses, who spend more time at the bedside or out in the community with patients and their families than any other healthcare professional, need leadership-building skills in order to navigate these challenging times. New guidelines focus on interprofessional and holistic care, emphasizing the importance of building leadership skills and abilities. The World Health Organization and the European Association for Palliative Care have shown interest in influencing the development and implementation of palliative care (PC) services globally, given the increasingly aging population, the growing incidence of cancer, and the human immunodeficiency virus/AIDS epidemic. Despite challenges in developing leadership skills in nurses throughout Central and Eastern Europe (CEE), visionary nursing leaders throughout these countries have taken the opportunity to develop the Transformational Palliative Nursing Leadership Program, which has been designed to improve the leadership abilities of PC nurses throughout CEE countries. The purpose ... is to equip PC nurses with the ability to promote, develop, and sustain this specialized care in CEE countries or any other part of the world. **Abstract:** <http://bit.ly/2kkgXcP>

### **Silent illumination: A case study exploring the spiritual needs of a transgender-identified elder receiving hospice care**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 10 September 2019 – With a growing population of transgender-identified elders in the U.S., their unique spiritual end-of-life (EoL) needs are coming to light. This article presents a case study of a hospice volunteer who used skillful means as an artist to help a transgender-identified woman express her spirituality in the last 6 months of her life. Four themes emerged related to the expression of spirituality by lesbian, gay, bisexual, transgender, and queer (LGBTQ) elders at EoL: 1) The human element in advocacy for spiritual care; 2) The importance of safe spaces for reflection and meditation; 3) The importance of skillful means to work with LGBTQ people; and, 4) Acknowledgement of gender identity as a spiritual need. This case study serves as a springboard to advance research into the EoL needs of LGBTQ elders and the ways in which members of the hospice team can support spiritual care and alleviate suffering for this population. **Abstract:** <http://bit.ly/2lSjuuY>

**N.B.** Additional articles on end-of-life care for LGBTQ people noted in 2 September 2019 issue of Media Watch (#629, p.8).



Closing the Gap Between Knowledge & Technology

<http://bit.ly/2DANDFB>



## **Transforming the workforce for primary palliative care through a system-wide educational initiative**

*JOURNAL OF NURSING ADMINISTRATION* | Online – 2 September 2019 – Palliative care (PC) is a national and global priority, yet there is insufficient knowledge regarding PC among generalist clinicians. An interdisciplinary educational initiative was implemented to enhance a hospital workforce's PC knowledge and skills. More than 1,000 clinicians attended at least 1 of 27 educational offerings. Measurable gains were evident in key outcome measures including PC referrals and advanced directive documentation. Changes reflected a transformation of workforce culture and resulted in two national awards for improving PC. **Abstract:** <http://bit.ly/2m63xBJ>

**"My family wants something different"**

## **Discordance in perceived personal and family treatment preference and its association with do-not-resuscitate order placement**

*JOURNAL OF ONCOLOGY PRACTICE* | Online – 11 September 2019 – Patients make treatment decisions based not only on what they want, but what they think their families want. Discordance in such perceived preferences may therefore pose challenges for advance care planning. This study examines discordance in preference for life-extending care versus comfort-focused care and its association with do-not-resuscitate (DNR) order placement. One hundred eighty-nine patients with advanced cancers refractory to at least one chemotherapy regimen were enrolled in a multi-site observational study. In structured interviews, patients reported their preference for treatment maximizing either life extension or comfort; patients also indicated their perception of their families' preference. DNR placement was reported by patients and verified using medical records. Approximately 23% of patients perceived discordance between their preference and their families' preference. Patients who perceived discordance were less likely to have completed a DNR compared with those who perceived concordance, even after controlling for relevant confounds... DNR placement rate was lowest among discordant subgroups, where there was either a personal or family preference for comfort care, followed by patients who perceived concordance for wanting life-extending care and by patients who perceived concordance in wanting comfort-focused care. **Abstract:** <http://bit.ly/2IN9Xpf>

Noted in Media Watch 23 May 2018 (#463, p.12):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 May 2016 – ‘**Good concordance between patients and their non-professional carers about factors associated with a “good death” and other important end-of-life decisions.**’ Only 69% of patients [i.e., study participants] stated they had discussed their preferences for end-of-life (EoL) care with their respective carer. The rankings were similar for the patient and the carer's views of what was important for the patient, although the patients ranked “to be involved in decisions about my care” as less important than the carers, while the carers ranked “to have sorted out my personal affairs” as less important than the patients. When discussions around EoL choices do occur, carers generally appear to agree with the patients' preferences around EoL treatment, and preferred place of death. **Abstract:** <http://bit.ly/2YIFfIY>

## **Top ten tips palliative care clinicians should know about caring for children in neonatal and pediatric intensive care units**

*JOURNAL OF PALLIATIVE MEDICINE*, 2019;22(9):1149-1153. Over the past several years, pediatric critical care units increasingly count on the expert advisement of palliative care (PC) specialists. Given the limited availability of pediatric PC specialists, all PC clinicians may be required to care for pediatric patients and their families. Special considerations in caring for these patients include the relative importance of prognosis, involvement of child life, music and pet therapy, incorporation of parents in end-of-life rituals, care for siblings, use of medical technology, and prolonged duration of stay. The following top 10 tips provide recommendations for caring for seriously ill infants, children, adolescents, and the families of these critically ill pediatric patients. **Abstract:** <http://bit.ly/2krWVNH>

Cont.

Noted in Media Watch 22 July 2019 (#623, p.11):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(4):333-343. **'Parents' wishes for what they had or had not done and their coping after their infant's or child's neonatal intensive care unit/pediatric intensive care unit/emergency department death.** Mothers wished they spent more time with the child, chosen different treatments, advocated for care changes, and allowed the child his or her wishes. Fathers wished they had spent more time with the child and gotten care earlier. Mothers wished they had not agreed to child's surgery/treatment, taken her own actions (self-blame), and left the hospital before the death. Fathers wished they had not been so hard on the child, agreed with doctors/treatment, and taken own actions (self-blame). Most coping strategies were religious activities, self-care, and talking about/with the deceased child. **Abstract:** <http://bit.ly/2GcuKK9>

Noted in Media Watch 24 June 2019 (#619, p.11):

- *PEDIATRIC CRITICAL CARE MEDICINE* | Online – 14 June 2019 – **'When a child dies in the PICU: Practice recommendations from a qualitative study of bereaved parents.'** Bereaved parents identified several areas for care delivery and improvement across three time periods: during hospitalization; during the dying phase; and, during bereavement. During hospitalization, parents' recommendations focused on improved communication, changes to the physical environment, better self-care resources, and provision of family support. During the dying phase, parents suggested private, demedicalized rooms, familiar staff members, and support to leave the hospital. Recommendations for care after death focused mainly on the provision of ongoing support from the hospital or local bereavement services, as well as improved information delivery. **Abstract:** <http://bit.ly/2Ko5MuV>

## Palliative care: Across boundaries, conditions, groups and settings

*JOURNAL OF RESEARCH IN NURSING*, 2019; 24(6):363-365. In 2014, the World Health Assembly passed a resolution calling for all member states to develop, strengthen and implement palliative care (PC) as part of universal health care covered. Despite this, many services remain underdeveloped and even non-existent in many parts of the world. Changing demographics, such as an ageing population and an increase in comorbidities, have resulted in an increase in the number of people requiring palliative and end-of-life (EoL) care across different conditions, settings and services. Globally, it has been estimated that, in 2014, 20 million people worldwide required PC at the EoL. A recent *Lancet* publication on the future burden of serious health related suffering requiring palliative care estimated that, by the year 2060, 48 million people (47% of all deaths globally) will die with serious health-related suffering, and that this need will increase most rapidly amongst people over 70 years of age, with dementia as the condition with the highest proportional increase.<sup>1</sup> Such stark figures highlight not only the importance but also the ethical, moral and professional need for action and for PC research that will

both enhance services and care. That is why this focused edition on PC is timely and of vital importance, particularly for nursing. **Full text:** <http://bit.ly/2kBLfrq>



1. 'The escalating global burden of serious health-related suffering: Projections to 2060 by world regions, age groups, and health conditions,' *The Lancet Global Health*, published online 22 May 2019. [Noted in 10 June 2019 issue of Media Watch (#617, p.11)] **Full text:** <http://bit.ly/30BUwA2>

## Bereavement practices employed by hospitals and medical practitioners toward attending funeral of patients: A systematic review

*MEDICINE*, 2019;98(36). Bereavement practices offered by hospitals included memorial services, letters, and services provided by bereavement coordinators. Bereavement practices employed by medical practitioners (MPs) included answering or making phone calls, attending family meetings, and sending condolence letters. MPs' attendance at a patient's funeral was influenced by MPs' gender, age years of experience the medical specialty. Perceived benefits of MPs' attendance at a patient's funeral included providing support to the family, extending the professional relationship, illustrating respect to the patient and the family, resolving guilt and personal growth. Barriers to the attendance included a lack of time, blurring of professional boundaries, personal discomfort with death, emotional arousal, and discouragement by colleagues. General practice had an attendance rate of 71%. Attendance rates for palliative care, oncology, and psychiatrists ranged from 63% to 81%, 7.1% to 67%, and 15% to 67%, respectively. Intensivists had an attendance rate of 22%. Funeral attendance is an uncommon bereavement practice. MPs' attitudes toward attending a patient's funeral are understudied in many specialties. Patient factors that influence MPs' participation in bereavement practices are poorly understood. **Full text:** <http://bit.ly/2kzyEVH>

Noted in Media Watch 12 November 2018 (#589, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 November 2018 – ‘**Beyond right or wrong: Attitudes and practices of physicians, nurses, psychologists, and social workers regarding attendance at patient funerals.**’ Attendance at patient funerals [by participants in this study] was predicted by age, telling colleagues about own funeral attendance practices, having discussions with colleagues about funeral attendance, having long relationships with patients, and having a majority of patients at the end of life. Non-attendance was predicted by believing they cannot attend all funerals, they prefer not to attend any, feeling colleagues disapprove of funeral attendance, believing attending funerals is crossing the line between the personal and the professional... **Abstract:** <http://bit.ly/2lYzkj1>

**N.B.** Additional articles on the topic of attending patient funerals noted in this issue of Media Watch.

## Death without distress? The taboo of suffering in palliative care

*MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 6 September 2019 – Palliative care (PC) names as one of its central aims to prevent and relieve suffering. Following the concept of “total pain,” which was first introduced by Cicely Saunders, PC not only focuses on the physical dimension of pain but also addresses the patient's psychological, social, and spiritual suffering. However, the goal to relieve suffering can paradoxically lead to a taboo of suffering and imply adverse consequences. Two scenarios are presented: First, PC providers sometimes might fail their own ambitions. If all other means prove ineffective terminal sedation can still be applied as a last resort, though. However, it may be asked whether sedating a dying patient comes close to eliminating suffering by eliminating the sufferer and hereby resembles physician-assisted suicide (PAS), or euthanasia. As an alternative, PC providers could continue treatment, even if it so far prove unsuccessful. In that case, either futility results or the patient might even suffer from the perpetuated, albeit fruitless interventions. Second, some patients possibly prefer to endure suffering instead of being relieved from it. Hence, they want to forgo the various bio-psycho-socio-spiritual interventions. PC providers' efforts then lead to paradoxical consequences: Feeling harassed by PC, patients could suffer even more and not less. In both scenarios, suffering is placed under a taboo and is thereby conceptualised as not being tolerable in general. However, to consider suffering essentially unbearable might promote assisted dying not only on an individual but also on a societal level insofar as unbearable suffering is considered a criterion for euthanasia or PAS. **Abstract (w. list of references):** <http://bit.ly/2lEQMxE>

## Emergency department docs can identify patients likely to die within 1 month

*MEDSCAPE* | Online – 13 September 2019 – Emergency department (ED) physicians who answered the question “Would you be surprised if your patient died in the next 1 month?” could identify patients over age 65 years who indeed died within a month, according to results of a study...<sup>1</sup> A palliative care plan can ease the end of life (EoL) for patients and cut costs, but identifying which patients are in the last months of their lives is not an exact science. One strategy is for a provider to answer the “surprise question” – “Would you be surprised if your patient died in the next 1 month?” An ED is a particularly likely place to find patients nearing the EoL. Studies have shown about three quarters of older adults with serious health conditions visit the ED during the final 6 months of life, and such visits may signal a turning point towards accelerated physical decline. **Full text:** <https://wb.md/2IVm5nS>

1. ‘Association of emergency clinicians’ assessment of mortality risk with actual 1-month mortality among older adults admitted to the hospital,’ *JAMA Open Network*, published online 13 September 2019. **Full text:** <http://bit.ly/2IORh8u>

Noted in Media Watch 26 August 2019 (#628, p.8):

- *EMERGENCY MEDICINE JOURNAL* | Online – 13 August 2019 – ‘**End-of-life care in the emergency department.**’ The importance of end-of-life care (EoLC) for patients and their families is well documented, however, the skills and knowledge of emergency clinicians in delivering EoLC is not widely understood but it is clear from the existing literature that we fall short in delivering consistently good EoLC although there is recognition of the need to improve. The author acknowledges the challenges of delivering good EoLC in the emergency department (ED) but more importantly considers practical ways of improving EoLC in the ED in line with best practice guidelines on EoLC. **Abstract:** <http://bit.ly/2ZaD4km>

**N.B.** Additional articles on palliative and EoLC in the ED noted in 5 August 2019 issue of Media Watch (#625, pp.9-10).

## Children’s hospice launches trailblazing transition support role

*NURSING TIMES* | Online – 9 September 2019 – Derian House Children’s Hospice has created a role to focus on helping young patients develop a support network outside of the hospice to lean on once they turn 26 and have to move into adult services. The appointment of a “transition support worker” ... is believed to be the first of its kind in the sector. Clinical director Lynn Grayson ... said progressions in healthcare meant the hospice was helping more patients into adult services. However, she highlighted how young people risked being “socially cut off” after leaving the hospice, based in Chorley, Lancashire. The hospice’s newly-appointed transition support worker ... will work with more than 20 young people at Derian House, helping them to reach out to friends in the outside world and ensuring they have links with other support agencies. **Full text:** <http://bit.ly/2IMnME5>



### Current thinking in paediatric palliative care and transition to adult care

A selection of articles that focus on the “current thinking” in paediatric palliative care, including a selection of articles specific to end-of-life care for adolescents and their transition to adult care, posted 8 July 2019 on the European Association for Palliative Care blog at: <http://bit.ly/2XC24jA>



Would this article be of interest to a colleague?

## **Implementation of best practice recommendations for palliative care in German comprehensive cancer centers**

*THE ONCOLOGIST* | Online – 10 September 2019 – In 2017, the Palliative Medicine Working Group in the network of the German Comprehensive Cancer Centers (CCCs) published the best practice recommendations it had developed for the integration of palliative medicine in CCCs in Germany. In order to evaluate the level of implementation of the recommendations, an online survey of the CCC directors was established. The majority of German CCCs fulfil elementary organizational and structural requirements. However, there is still room for improvement in the provision of a basic qualification for general palliative care and emergency admission personnel. **Abstract:** <http://bit.ly/2kG52WR>

## **Cost and utilization of lung cancer end-of-life care among racial-ethnic minority groups in the U.S.**

*THE ONCOLOGIST* | Online – 9 September 2019 – Minority patients with lung cancer have significantly higher end-of-life (EoL) medical expenditures than non-Hispanic white patients, which may be explained by a greater intensity of care in the EoL period. The findings of this study may lead to a better understanding of the racial-ethnic disparities in EoL care, which can better inform future EoL interventions and help healthcare providers develop less intensive and more equitable care, such as culturally competent advanced care planning programs, for all patients. **Abstract:** <http://bit.ly/2kdpH4r>

**N.B.** Additional articles on ethnic and racial disparities in the provision and delivery of palliative and end-of-life care in the U.S. noted in 9 September 2019 issue of Media Watch (#630, p.7).

## **Adaptation and psychometric evaluation of the short version of Family Sense of Coherence Scale in a sample of persons with cancer in the palliative stage and their family members**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 9 September 2019 – For patients' entire families, it can be challenging to live with cancer during the palliative stage. However, a sense of coherence buffers stress and could help health professionals identify families that require support. Therefore, the short version of the Family Sense of Coherence Scale (FSOC-S) was translated, culturally adapted, and validated in a Swedish sample. Content validity was supported by experts, persons with cancer, and family members. Homogeneity among items was satisfactory for persons with cancer and family members as well as internal consistency. Factor analyses supported unidimensionality. FSOC-S correlated with hope, anxiety, and symptoms of depression, which supported convergent validity. The test-retest reliability for items ranged between fair and good. The FSOC-S has satisfactory measurement properties to assess family sense of coherence in persons with cancer and their family members. FSOC-S could be used to identify family members who experience low levels of perceived family sense of coherence which provides health care professionals with insight into families' needs and ability to live with cancer in the palliative stage. **Abstract (w. list of references):** <http://bit.ly/2keKPr2>

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

Representative sample of recent journal articles:

- *BMC MEDICAL ETHICS* | Online – 11 September 2019 – **'Public and physicians' support for euthanasia in people suffering from psychiatric disorders: A cross-sectional survey study.'** A survey was distributed amongst a random sample of Dutch 2,641 citizens (response 75%) and 3,000 physicians (response 52%). Of the general public 53% were of the opinion that people with psychiatric disorders should be eligible for EAS, 15% was opposed to this, and 32% remained neutral. Higher educational level, Dutch ethnicity, and higher urbanization level were associated with higher acceptability of EAS whilst a religious life stance and good health were associated with lower acceptability. The percentage of physicians who considered performing EAS in people with psychiatric disorders conceivable ranged between 20% amongst medical specialists and 47% amongst general practitioners. The majority of the psychiatrists were of the opinion that it is possible to establish whether a psychiatric patient's suffering is unbearable and without prospect and whether the request is well-considered. **Full text:** <http://bit.ly/2kk58Ds>

Cont.

- *MEDICAL JOURNAL OF AUSTRALIA* | Online – 8 September 2019 – ‘**Regulating voluntary assisted dying in Australia: Some insights from The Netherlands.**’ As other Australian states consider reform to permit voluntary assisted dying (VAD), debate about how best to regulate this practice will continue. In particular, how can a system best facilitate safe and timely access to VAD for eligible patients but ensure that others who are not eligible do not have access? While Victoria’s VAD legislation will of course be considered, its potential limitations must be weighed. Drawing on Dutch experience and data, the authors raise safety and access concerns both in relation to the need for pre-authorisation of VAD and limiting access to practitioner administration of the VAD medication. Regardless of the model adopted, accountability in how the system operates is essential. A key learning from the Dutch experience is that rigorous evaluation of VAD is critical to promote transparency in decision making in the system and to drive practice improvements. **Full text:** <http://bit.ly/2IEcXUS>
- *NEW JOURNAL OF EUROPEAN CRIMINAL LAW* | Online – 2 September 2019 – ‘**The Italian Constitutional Court and the constitutionality of the criminalisation of assisted suicide of patients suffering from serious and incurable diseases.**’ On 16 November 2018, the Italian Constitutional Court addressed for the first time the controversial issue of the constitutionality of the criminalisation of assisted suicide of patients suffering from serious and incurable diseases. In its judgment, the Court held that the criminalisation of assisted suicide is not contrary to the Constitution, rejecting the existence of a right to die, in line with the European Court of Human Rights case law. Nevertheless, the Constitutional Court recognised that in cases of patients suffering from serious and incurable diseases, an absolute prohibition on assisted suicide could run contrary to the freedom of self-determination and the constitutional principles of human dignity and equality. The present note describes and analyses the facts of the case and the reasoning of the Constitutional Court, especially the structure of the argument and the new “decision technique” adopted. **Abstract:** <http://bit.ly/2kwAsic>
- *REVISTA M. ESTUDOS*, 2019;4(7):45-59. ‘**Imagining terminality: Anticipations of suicide with assistance in Switzerland.**’ This article explores how people who solicit assistance in dying imagine and anticipate their own terminality. Its objective consists in describing and interpreting the fact that these individuals go beyond their medical condition when commenting on such a request and on their engagement in this process. Based on an ongoing ethnographic inquiry funded by the Swiss Science Foundation and carried out in Switzerland, where assistance with suicide is permitted within a unique legal framework, the article shows the importance of taking into consideration the role that affective and imaginative internalized contents – imagination, broadly conceived – play in the realization of assisted suicide. These contents are key to appreciating a decision to request to die with assistance as well as its justifications. **Summary:** <http://bit.ly/2IBRY4W>

## Publishing Matters

### Why are we publishing protocols?

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 August 2019 – Readers who conduct studies in the same area of science as the published protocol may gain insights into the direction the funded research is taking that may inform their future work. Ideas about theoretical framing, recruitment, measures, and analysis plans are gained when reading a protocol for both experienced and junior researchers. For instance, in advance care planning research, a major challenge has been to identify means for evaluating whether the patient care comported with the advance directive. In addition, we asked these authors to tell us about study implementation challenges and solutions. Lessons learned and shared help others to avoid similar challenges. Palliative care research is often fraught with challenges such as enrolling difficult-to-access populations and attrition. Rarely do investigators publish study failure. Researchers benefit from publishing their protocols particularly in the case of large sample complex designs such as those described in this supplement. Journal word limits for completed studies impose a need to be concise about the methods to report and discuss the study results in more detail. A protocol article affords detail about the methods and gains an additional publication from the study grant that benefits the authors and the funder. Publishing cutting edge research protocols benefits readers and researchers. **Full text:** <http://bit.ly/2kuWbr6>

Cont.

**N.B.** In this special supplement to the *Journal of Palliative Medicine* there are nine articles whose authors describe their competitively reviewed Patient Centered Outcomes Research Institute-funded studies. **Contents page:** <http://bit.ly/2IQZNnM>

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