

## **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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**Importance of continuous, holistic, person-centred care: Scroll down to [Specialist Publications](#) and 'Perceived barriers and facilitators in providing palliative care for people with severe dementia: The healthcare professionals' experiences' (p.7), in *BMC Health Services Research*.**

## **Canada**

### **Status report paints a grim picture for the future of residential hospice in Elgin**

ONTARIO | *St. Thomas Times-Journal* – 14 September 2018 – A status report from the Elgin Residential Hospice Planning Committee indicates efforts to bring residential hospice to Elgin County have stalled. The committee has been working with St. Joseph's Health Care Society and the Southwest Local Health Integration Network to move forward with its goal of building a residential hospice in Elgin County. The report says feasibility study was completed and a business plan was created to support the need for residential hospice in the county. The report noted there was community support to fundraise \$7.1 million to build it. The Southwest Local Health Integration Network passed a motion in March supporting an eight-bed residential hospice and subsequently a letter to the Ministry of Health & Long Term Care was sent requesting funding. The ministry responded by saying there would be no new funding for residential hospice beds. This announcement has all but stopped the efforts of the committee at this time, the June report says. <https://goo.gl/qy5RFi>

### **Patient navigation specialists are helping Indigenous cancer patients navigate their care**

ONTARIO | *The Globe & Mail* (Toronto) – 10 September 2018 – One Inuit cancer patient in Toronto wanted to return home to Nunavut to die. Another cancer patient wanted to smudge – a traditional cleansing ritual that involves burning sacred medicines such as sweet grass, sage, tobacco or cedar – while in hospital. And yet another was uncomfortable having male health professionals examine her and preferred to be seen by a female. In all of these cases, Leonard Benoit, an Aboriginal patient navigator with the Toronto Central Regional Cancer Program, was their advocate. Mr. Benoit's job ... was created to help address disproportionately high rates of cancer among Indigenous patients. According to an April report by Cancer Care Ontario, the most recent available information showed that between 1991 and 2010 the incidence rates for lung, colorectal, kidney and cervical cancer were all higher among the First Nations population, compared with the rest of the population of Ontario.<sup>1</sup> It also noted the First Nations population had poorer cancer survival rates. Part of the reason for this is because Indigenous patients may be living

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in areas where they don't have access to diagnostics or treatment, or because they lack the financial resources to get to where they can receive care... For some patients, there are language barriers or inter-generational trauma and post-traumatic stress disorder arising from their residential school experiences, he says. Moreover, cancer itself can be difficult to understand. "In a lot of Indigenous languages, cancer does not translate. There's no word for cancer," Mr. Benoit says. <https://goo.gl/ewkSHh>

1. 'Prevention System Quality Index,' Statistical Report, Cancer Care Ontario, April 2018. **Download/view at:** <https://goo.gl/z4zmKu>

Noted in Media Watch 20 August 2018 (#577, p.15):

- *SUPPORTIVE CARE IN CANCER* | Online – 14 August 2018 – '**In their own words: Patient navigator roles in culturally sensitive cancer care.**' Patient navigation has emerged as a promising strategy in reducing disparities among diverse cancer patients. However, little is known about navigators' own perspectives on their roles in providing culturally competent care. Survey respondents described the following 11 interrelated navigator roles in the provision of culturally competent care: 1) Assess and understand patient needs; 2) Tailor care to patient; 3) Build rapport/open communication; 4) Facilitate communication between patient and health care team; 5) Educate/provide resources to the patient; 6) Advocate; 7) Self-motivated learning; 8) Address barriers to care; 9) Involve/meet the needs of family or support people; 10) Educate/support health care team; and, 11) Support patient empowerment in care. **Full text:** <https://goo.gl/8GwDpg>

**N.B.** Selected articles on culturally sensitive end-of-life care for Canada's First Nations peoples noted in 3 September 2018 issue of Media Watch (#579, p.12).

## **U.S.A.**

### **A health care policy that puts the ending first**

CALIFORNIA | *Politico* – 12 September 2018 – Rod Hochman vividly remembers watching his father die the wrong way, laid out by a stroke at age 78, hooked up to a ventilator and an intravenous drip in an ICU, his last hours spent in a hospital. It was the most aggressive care modern medicine could offer, and the family later came to understand that it was unlikely to save him. It was not how he wanted to end his days. Millions of Americans have endured similar experiences, but Hochman is in a rare position to do something about it. He's a doctor and chief executive officer of Providence St Joseph health care system, one of the largest non-profit health systems in the country. Over the past year, his 51-hospital chain has undertaken a systematic effort to get every single patient age 65 and older – in other words, every Medicare patient, as well as younger people with serious diseases like cancer – to lay out and document their wishes for end-of-life care, and to designate

someone to make decisions on their behalf if they can no longer speak for themselves. That puts Providence on the cutting edge of a movement that could not only help older Americans and their families, but might help preserve Medicare itself, the old-age insurance program straining against rising costs and growing numbers of very old people. By 2050, according to current projections, Medicare's ranks will have swollen to more than 90 million people, costing 5.2% of America's entire Gross Domestic Product. About one-fourth of Medicare spending occurs in the last year of life. <https://goo.gl/bzfvN5>

#### **Specialist Publications**

**'Advance care planning in cognitively impaired older adults'** (p.8), in *Journal of the American Geriatrics Society*.

## Limited English may mean less-gentle death in ICU

REUTERS HEALTH | Online – 11 September 2018 – Death for patients in U.S. intensive care units may look a lot different for people with limited English proficiency than for native speakers, a large study suggests.<sup>1</sup> About 8.5% of U.S. adults don't speak English as their primary language... While communication is crucial for decision-making at the end of life, it's not been clear how language skills might influence the type of care dying patients receive. Researchers examined data on 27,523 patients admitted to intensive care units (ICUs) in a large academic hospital over a three-year period. The total included 779 people, or about 3%, with limited English proficiency. Death rates in the ICUs were the same no matter what language patients spoke most fluently, averaging 2.8% for both native speakers and those with limited English proficiency. But among patients who died in the ICU,

those with limited English proficiency were 62% less likely to have orders for comfort care before they died, and they took an average of 19 days longer to transition from active treatment to only measures designed to ease pain and suffering. Non-English speakers were also 26% more likely to be placed on breathing machines and 36% more likely to be put in restraints. <https://goo.gl/VmB4kZ>

### Specialist Publications

**'Exploring the "patient experience" of individuals with limited English proficiency: A scoping review'** (p.12), in *Journal of Immigrant & Minority Health*.

1. 'Differences in code status and end-of-life decision making in patients with limited English proficiency in the intensive care unit,' *Mayo Clinic Proceedings*, published online 9 August 2018. [Noted in 13 August 2018 issue of *Media Watch* (#576, p.11)] **Abstract (w. link to references):** <https://goo.gl/TkQioS>

**N.B.** Additional articles on patients with limited English proficiency in the context of end-of-life care noted in 20 August 2018 issue of *Media Watch* (#577, p.2).

## International

### Dementia: New report on end-of-life care and post bereavement support

U.K. (England) | *The Carer* – 14 September 2018 – In Autumn 2017, 'DEEP – The Dementia Engagement & Empowerment Project' (the U.K. network of Dementia Voices) and 'tide™ – together in dementia everyday' (the U.K. network of carers of people with dementia) held a series of workshops [on which the report is based<sup>1</sup>] ... to stimulate conversations about end-of-life care (EoLC) with people living with dementia and carers of people living with dementia.<sup>1</sup> People living with dementia and carers need much more support in enabling and empowering them to have these conversations about death and dying so that they can put some plans in place in a timely manner, whilst the person with dementia is cognitively able to do this. The discussions [at the workshops] revealed that the sense of these conversations being "difficult" was largely felt by the professionals, because of their own personal and professional vulnerabilities and lack of skills,

knowledge and competence to initiate and facilitate these conversations. It is clear that professionals need additional education and appropriate training and support to feel more confident to support people living with dementia more generally, but also specifically in their role in facilitating and empowering people living with dementia and their carers to begin discussing their plans around EoLC and post bereavement support. <https://goo.gl/v4J5x9>

### Specialist Publications

**'Perceived barriers and facilitators in providing palliative care for people with severe dementia: The healthcare professionals' experiences'** (p.7), in *BMC Health Services Research*.

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1. 'End-of-Life Care and Post Bereavement Support – Shifting the Conversation from Difficult to Important: Sharing the perspectives of people living with dementia and their carer,' Dementia Engagement & Empowerment Project and tide™ – together in dementia everyday, September 2018. **Download/view at:** <https://goo.gl/uveZZy>

**N.B.** Selected articles on palliative for people living with Alzheimer's and other forms of dementia noted in 6 August 2018 issue of Media Watch (#575, p.15). Articles specifically on advance care planning, etc., for this patient population noted in 27 August 2018 issue of the weekly report (#578, p.8).

### **People in most deprived areas 24% more likely to die alone – research**

U.K. (Scotland) | Press Association (Glasgow) – 13 September 2018 – The research says those living in the most deprived neighbourhoods are 24% more likely to die alone at home than those in the least deprived areas. They were also less likely to die in a hospice or care home, two researchers from Edinburgh Napier University found. The findings [presented at the recent British Sociological Association conference] have led academics to call for more insight into the circumstances of people nearing the end of their lives. Dr. Anna Schneider said: "Our research shows that neighbourhood deprivation has an influence on how people spend their last months of life in Scotland. End of life care (EoLC) has received much attention from policy makers in the last years, but in order to improve EoLC provision we need a better understanding of the social and economic inequalities in the circumstances people experience at the end of their lives. Administrative data such as we have used provide an unparalleled opportunity to do so." Dr Schneider. and Dr. Iain Atherton analysed data on all 53,517 people who died within a year after the Scottish census 2011, using the census and death record data. <https://goo.gl/G8vdar>

Noted in Media Watch 2 July 2018 (#570, p.9):

- *INTERNATIONAL JOURNAL OF POPULATION DATA SCIENCE* | Online – 11 June 2018 – '**End-of-life care in Scotland: Trends in the population in need of palliative care.**' This paper provides estimates of how many people require palliative care (PC) in Scotland and describes changes in the composition of this sub-population. What are their living arrangements? How have their medical conditions, health service use, and health trajectories changed? While a recent paper suggests that PC need in England & Wales has increased from 72.5% in 2006 to 74.9% in 2014,<sup>1</sup> the share of people with a PC need among all deaths in Scotland has decreased from 80.6% to 78.3% in the period of this study. **Abstract:** <https://goo.gl/s29y1X>
- 1. 'How many people will need palliative care in 2040? Past trends, future projections and implications for services,' *BMC Medicine*, published online 18 May 2017. [Noted in 22 May 2017 issue of Media Watch (#513, p.11)] **Full text:** <https://goo.gl/TP7U92>

**N.B.** Selected articles on palliative and end-of-life care in Scotland noted in this issue of Media Watch.

### **Specialist Publications**

'**Missed opportunities: Unnecessary medicine use in patients with lung cancer at the end of life – an international cohort study**' (p.9), in *British Journal of Clinical Pharmacology*.

'**A decalogue for end-of-life care in internal medicine**' (p.11), in *Italian Journal of Medicine*.

'**The Italian law on informed consent and advance directives: New rules of conduct for the autonomy of doctors and patients in end-of-life care**' (p.11), in *Journal of Critical Care*.

'**Why do neonatologists in Scandinavian countries and The Netherlands make life-and-death decisions so different?**' (p.15), in *Pediatrics*.

'**End-of-life care in the Dutch medical curricula**' (p.16), in *Perspectives on Medical Education*.

## Cancers “rising around the world”

FRANCE | BBC News (London) – 12 September 2018 – There will be 18.1 million new cases of cancer and 9.6 million people will die with the disease this year worldwide, a report predicts.<sup>1</sup> The rise, from 14.1 million cases and 8.2 million deaths in 2012, is partly due to a growing and ageing population. The figures suggest one in five men and one in six women will develop the disease in their lifetime. And as countries become wealthier, more people get cancers related to lifestyle rather than those linked to poverty. The International Agency for Research on Cancer provides regular snapshots of the scale of cancer around the world, looking closely at 36 different cancers in 185 countries. Researchers say while ways of measuring and collecting cancer data have improved over the years, the overall trend is that cancer rates and deaths have risen year on year. The latest report suggests lung cancer, female breast cancer, and bowel cancer are responsible for a third of all cancer cases and deaths worldwide. <https://goo.gl/7XBf8u>

International Agency  
Research on Cancer



World Health  
Organization

### Specialist Publications

**‘Improving patient and care-giver outcomes in oncology: Team-based, timely, and targeted palliative care’** (p.10), in *CA: A Cancer Journal for Clinicians*

**‘Cancer survivorship and palliative care: Shared progress, challenges, and opportunities’** (p.10), in *Cancer*.

1. ‘Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries,’ *CA: A Cancer Journal for Clinicians*, published online 12 September 2018. **Full text:** <https://goo.gl/pkz5Cn>

## In Hong Kong, it’s cheaper to die in a nursing home than a hospital, study finds

CHINA (Hong Kong) | *South China Morning Post* – 11 September 2018 – End-of-life care (EoLC) for people spending their last days in a nursing home costs almost a fifth less than for those who die in hospital, a study has found. The study, by Haven of Hope Christian Service ... looked at cost incurred and time spent in hospitals during the final year of 169 elderly people. Those studied had stayed in the organisation’s nursing home in Tseung Kwan O between 2010 and last year. Among them, 58 joined a scheme offered by the home allowing them to die there. The other 111 did not join and died in hospital. The study found that the median total of EoLC costs for those who joined the scheme was 17%, or HK\$66,080, less than for those who did not join. The government projected people aged 65 or older would account for 29.9% of the population by 2038. Based on estimates from other studies which showed every year about 5,250 nursing home residents preferred to die in those homes, the authors projected that if all those elderly people could spend their last days in nursing homes the government could save more than HK\$340 million on EoLC per year. <https://goo.gl/fqLFda>

## Fifth of care homes in England “inadequate” or “need improvement”

U.K. (England) | BBC News (London) – 11 September 2018 – One in every five care homes in England is judged not good enough by watchdogs, BBC analysis has found. Providers say while poor care must be tackled the Care Quality Commission (CQC) rating system is “inconsistent.” A poor rating has left some providers unable to get insurance or banking, which can lead to closures. The CQC said the “variability” in standards of care across the country was “a real concern” and vowed to continue to tackle “poor care.” The Commission uses four ratings – outstanding, good, requires improvement or inadequate. Across England, nearly 3,000 of the country’s 14,975 care homes are currently rated either inadequate or needing improvement. <https://goo.gl/gLShvm>



13 October 2018

<https://goo.gl/sxz85U>

## Doctors said the coma patients would never wake. Artificial Intelligence said they would – and they did

CHINA (Hong Kong) | *South China Morning Post* – 10 September 2018 – At least seven patients in Beijing who doctors said had “no hope” of regaining consciousness were re-evaluated by an artificial intelligence (AI) system that predicted they would awaken within a year. Some of China’s best neurologists conducted four rounds of assessments on his potential for recovery and gave him seven out of 23 points on a coma recovery scale, a score which meant his family had a legal right to unplug his life support. After going through his brain scans, however, the computer gave him more than 20 points, close to the full score. In another case, doctors gave a 41-year-old female stroke victim who had been in a vegetative state for three months a recovery potential score of six. The computer’s: 20/23. A young man, middle-aged woman and five other patients whom doctors believed would never recover woke up within 12 months of the brain scan, precisely as predicted. But the machine also made some mistakes. A 36-year-old man who suffered bilateral brainstem damage after a stroke was given low scores by both doctors and AI. He recovered fully in less than a year. The AI system, developed ... by the Chinese Academy of Sciences and the Peoples Liberation Army General Hospital in Beijing, has achieved nearly 90% accuracy on prognostic assessments, according to the researchers.<sup>1</sup> <https://goo.gl/djWcv8>



1. ‘Prognostication of chronic disorders of consciousness using brain functional networks and clinical characteristics,’ *eLife*, published online 14 August 2018. **Abstract:** <https://goo.gl/9iqJcG>

## South Africa: Hospices close doors nationwide after funding cuts

SOUTH AFRICA | All Africa (Cape Town) – 10 September 2018 – Funding troubles has forced HospiceWits (i.e., Hospice Association of the Witwatersrand) in Soweto to close its in-patient unit. The Soweto hospice and over 50 other facilities nationwide were dealt a crippling blow when one of its biggest international donors, the U.S. President's Emergency Plan for Aids Relief (Pepfar) reduced its funding by 40% in 2014. Non-profit hospice services took off in South Africa in the 1980s, catering largely for people with cancer and HIV in the era before treatment. As of March 2018, just over 4.2-million people in South Africa were on antiretrovirals (ARVs), according to a department of health presentation to Parliament. But as more people start HIV treatment and live longer, the U.S. government's funding focus has gradually shifted away from in-patient hospice care towards improving HIV treatment. Aids-related deaths have dropped by almost 60% since the government began to roll out free ARVs in earnest in 2007, 2018 Statistics South Africa data reveals. By contrast, the national cancer registry shows a 30% increase in cancer cases between 2010 and 2014. More than 60% of patients seen at the HospiceWits were there because of a cancer diagnosis. But after Pepfar support decreased, the township's only hospice couldn't raise the Rand 5-million in annual funding to continue to treat patients at the centre, HospiceWits chief executive Jacqui Kaye says. <https://goo.gl/mWYczJ>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SOUTH KOREA | *The Korea Herald* (Seoul) – 14 September 2018 – **‘More than 80% of Koreans support idea of “dignified death.”**’ More than 80% of South Koreans support the idea of “dignified death” – meaning they do not wish to receive life-prolonging treatment should they become terminally ill without the possibility of medical treatment curing their illness or relieving pain – according to a newly released study. The study by Seoul National University Hospital researchers came to the conclusion after surveying 1,241 members of the general public, 1,000 cancer patients, 928 medical doctors as well as 1,000 Koreans with family members with cancer. The study also found that nearly 30% of the surveyed Koreans support the idea of physician-assisted suicide, in which a doctor provides lethal drugs to terminally ill patients who wish to end their suffering. Physician-assisted suicide is illegal in Korea. <https://goo.gl/EtqLzH>

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- U.K. (Northern Ireland) | The Irish News (Belfast) – 12 September 2018 – **‘Particular religious beliefs influence people’s attitudes to euthanasia, study finds.’** People’s attachment to particular religious beliefs influence their attitudes to euthanasia, academics have found.<sup>1</sup> Attitudes to euthanasia also influenced how people valued health, including health states considered worse than being dead. Information was collected on a group of 160 individuals’ attachment to religious beliefs and their attitudes to euthanasia in Ireland. Those who attended religious services frequently were less likely to be in support of a doctor ending a person’s life due to having a painful incurable disease, in comparison to those who attended religious services less frequently. People who were less likely to support euthanasia were subsequently less likely to consider any health state as being worse than dead, regardless of severity. <https://goo.gl/hJjKYu>

1. ‘Euthanasia, religiosity and the valuation of health states: Results from an Irish EQ5D5L valuation study and their implications for anchor values,’ *Health & Quality of Life Outcomes*, published only 31 July 2018. **Full text:** <https://goo.gl/F5j1z8>

## Specialist Publications

### Journal Watch

**‘Beware of predatory journals: A caution from editors of three family medicine journals’** (p.18), in *Journal of the American Board of Family Medicine*.

**‘Some scientists publish more than 70 papers a year. Here’s how – and why – they do it’** (p.18), in *Science*.

**‘Too much academic research is being published’** (p.19), in *University World News*.

### **Perceived barriers and facilitators in providing palliative care for people with severe dementia: The healthcare professionals’ experiences**

*BMC HEALTH SERVICES RESEARCH* | Online – 12 September 2018 – The European Association for Palliative Care (EAPC) definition of palliative care (PC) in dementia emphasizes the importance of continuous, holistic and person-centred care. The findings of this study, however, indicate that healthcare professionals [i.e., study participants] experience several structural barriers that complicate the facilitation of PC according to the EAPC definition.<sup>1</sup> Increasing demands for economic rationality and standardization of practice lead to a lack of continuity in care, and the healthcare professionals noted this as the main threat to facilitating PC. Although resources are scarce, dying residents are always given priority by healthcare professionals either by the hiring of extra personnel or by the reorganization of tasks in a way that facilitates someone staying with the terminal resident. Advanced care planning was experienced as a facilitator for providing PC, but extensive use of temporary staff and patient relocations between sheltered and long-term wards threaten the continuity of planning and providing PC. The findings suggest a need for organizational changes with a greater focus on quality of care. Quality as well as economic rationalism is a goal in the New Public Management ideology. For healthcare professionals to be able to facilitate PC for the rapidly increasing population living and dying with dementia in long-term care facilities, organizational changes are needed. At present, long-term care facilities are not sufficiently adapted to the needs of people with dementia and their families. **Full text:** <https://goo.gl/2mbErT>



**NTNU**  
**Norwegian University of**  
**Science and Technology**

1. ‘White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,’ *Palliative Medicine*, published online 4 July 2013. [Noted in 8 July 2013 issue of *Media Watch* (#313, p.10)] **Abstract:** <https://goo.gl/eRTRnT>

Cont.

## Related

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 11 September 2018 – ‘**Advance care planning in cognitively impaired older adults.**’ This article recommends best practices for approaching advance care planning (ACP) for older adults with cognitive impairment. The importance of providing anticipatory guidance and eliciting values to guide future care to create a shared framework between clinicians, individuals, and surrogate decision-makers is emphasized. It is recommended that ACP be approached as an iterative process to continue to honor and support people’s wishes as cognitive impairment progresses and increasingly threatens independence and function. The article describes effective strategies for assessing decision-making capacity, identifying surrogate decision-makers, and using structured communication tools for ACP. **Abstract:** <https://goo.gl/brdwf1>

**N.B.** Selected articles on palliative for people living with Alzheimer’s and other forms of dementia noted in 6 August 2018 issue of Media Watch (#575, p.15). Articles specifically on advance care planning, etc., for this patient population noted in 27 August 2018 issue of the weekly report (#578, p.8).

### **Assessing the credibility and transferability of the patient compassion model in non-cancer palliative populations**

*BMC PALLIATIVE CARE* | Online – 13 September 2018 – A lack of evidence and psychometrically sound measures of compassion necessitated the development of the first known, empirically derived, theoretical Patient Compassion Model (PCM) generated from qualitative interviews with advanced cancer inpatients. Both patients’ personal perspectives of compassion prior to viewing the model and their specific feedback after being provided an overview of the model confirmed the credibility and transferability of the PCM. While new codes were incorporated into the original coding schema, no new domains or themes emerged from this study sample. These additional codes provided a more comprehensive understanding of the nuances within the domains and themes of the PCM that will aid in the generation of items for an ongoing study to develop a patient reported measure of compassion. A diverse palliative patient population confirmed the credibility and transferability of the PCM within palliative care, extending the rigour and applicability of the PCM that was originally developed within an advanced cancer population. The views of a diverse palliative patient population on compassion helped to validate previous codes and supplement the existing coding schema, informing the development of a guiding framework for the generation of a patient-reported measure of compassion. **Full text:** <https://goo.gl/FFUWGf>

### **Exploring the vagueness of religion and spirituality in complex pediatric decision-making: A qualitative study**

*BMC PALLIATIVE CARE* | Online – 12 September 2018 – Medical advances have led to new challenges in decision-making for parents of seriously ill children. Many parents say religion and spirituality (R&S) influence their decisions, but the mechanism and outcomes of this influence are unknown. Health care providers (HCPs) often feel unprepared to discuss R&S with parents or address conflicts between R&S beliefs and clinical recommendations. Parents from 13 cases [i.e., study participants] reported R&S directly influenced decision-making. Most HCPs were unaware of this influence. Fifteen R&S themes appeared in parent and HCP transcripts. Themes most often associated with decision-making were hope and faith, God is in control, miracles, and prayer. Despite instability in the child’s condition, these themes remained consistently relevant across the trajectory of illness. R&S influenced decisions about treatment initiation, procedures, and life-sustaining therapy, but the variance in effect of R&S on parents’ choices ultimately depended upon other medical and non-medical factors. **Full text:** <https://goo.gl/ziERch>

**N.B.** Selected articles on spirituality in the context of palliative and end-of-life care noted in 30 April and 18 June 2018 issues of Media Watch (#561, p.14 and #568, pp.7-8, respectively).



## 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.20.

**Missed opportunities: Unnecessary medicine use in patients with lung cancer at the end of life – an international cohort study**

*BRITISH JOURNAL OF CLINICAL PHARMACOLOGY* | Online – 5 September 2018 – A retrospective cohort study was conducted across two centers in the U.K. and the U.S. The prescribing of preventative medication was examined at hospital admission and discharge for patients who died of lung cancer; a zero-inflated negative binomial regression model was used to examine the association between preventative medications at discharge and patient- and hospital-based factors. Classes of preventative medication included: vitamins and minerals, anti-diabetic, anti-hypertensive, anti-lipid, and anti-platelet medications. In the U.K. site (125 people), the mean number of preventative medications was 1.9 on admission, and 1.7 on discharge, whilst in the U.S. site (191 people) the mean was 2.6 on admission and 1.9 on discharge. The model found a significant association between the number of preventative drugs on admission and the number of preventative medications on discharge; the model also found a significant association between the total number of drugs on discharge and the number of preventative medications on discharge. The use of preventative medication was common in lung cancer patients, despite undergoing discharge. Patient-based and hospital-based factors did not influence the prescribing of preventative medication. **Abstract:** <https://goo.gl/shnwTC>

**Ensuring and restoring balance on access to controlled substances for medical and scientific purposes: Joint statement from palliative care organizations**

*JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 10 September 2018 – The central principle of “balance” represents the dual obligation of governments to establish a system of control that ensures the adequate availability of controlled substances for medical and scientific purposes while simultaneously preventing their non-medical use, diversion, and trafficking, two primary goals of the international control system. On the one hand, although strong opioids, including morphine, are absolutely necessary for the relief of severe pain, legitimate access to opioids for pain treatment and palliative care (PC) is lacking in the majority of the world’s countries. On the other hand, in a few high-income countries with higher consumption of prescription opioids, diversion and non-medical use are increasingly prevalent. This report presents examples of unbalanced systems and a joint statement from global and regional PC organizations to promote development of balanced systems for optimal public health outcomes. Although non-medical use of controlled substances poses a risk to society, the system of control is not intended to be a barrier to their availability for medical and scientific purposes, nor to interfere in their legitimate medical use for patient care. **Abstract:** <https://goo.gl/JhTRBM>

Noted in Media Watch 23 July 2018 (#573, p.9):

- *DRUGS & AGING* | Online – 14 July 2018 – ‘**International Group for Reducing Inappropriate Medication Use & Polypharmacy: Position statement and 10 recommendations for action.**’ This article outlines current strategies to reduce inappropriate medication use, provides evidence for their effect, and then proposes recommendations for moving forward with 10 recommendations for action and 12 recommendations for research. The authors conclude that an urgent integrated effort to reduce inappropriate medication use and polypharmacy should be a leading global target of the highest priority. **Full text:** <https://goo.gl/zj4Q3Y>

Noted in Media Watch 2 July 2018 (#570, p.8):

- *EUROPEAN JOURNAL OF CLINICAL PHARMACOLOGY* | Online – 23 June 2018 – ‘**Adequate, questionable, and inadequate drug prescribing for older adults at the end of life: A European expert consensus.**’ The expert panel reached consensus on a set of 14 drug classes deemed as “often adequate,” 28 drug classes deemed “questionable,” and 10 drug classes deemed “often inadequate” for continuation during the last 3 months of life. The panel reached consensus on a set of 10 drug classes deemed “often adequate,” 23 drug classes deemed “questionable,” and 23 drug classes deemed “often inadequate.” Consensus remained unachieved for some very commonly prescribed drug treatments... **Full text:** <https://goo.gl/wtWTJ7>

## **Improving patient and caregiver outcomes in oncology: Team-based, timely, and targeted palliative care**

*CA: A CANCER JOURNAL FOR CLINICIANS* | Online – 13 September 2018 – Over the past decade, a large body of evidence has accumulated supporting the integration of palliative care (PC) into oncology practice for patients with advanced cancer. The question is no longer whether PC should be offered, but what is the optimal model of delivery, when is the ideal time to refer, who is in greatest need of a referral, and how much PC should oncologists themselves be providing? These questions are particularly relevant given the scarcity of PC resources internationally. In this state-of-the-science review directed at the practicing cancer clinician, the authors first discuss the contemporary literature examining the impact of specialist PC on various health outcomes. Then, conceptual models are provided to support team-based, timely, and targeted PC. Team-based PC allows the interdisciplinary members to address comprehensively the multidimensional care needs of patients and their caregivers. Timely PC, at its best, is preventive care to minimize crises at the end of life. Targeted PC involves identifying the patients most likely to benefit from specialist PC interventions, akin to the concept of targeted cancer therapies. Finally, the strengths and weaknesses of innovative care models, such as outpatient clinics, embedded clinics, nurse-led PC, primary PC provided by oncology teams, and automatic referral, are summarized. **Full text:** <https://goo.gl/nMXtmG>

### **Related**

- *CANCER* | Online – 11 September 2018 – ‘**Cancer survivorship and palliative care: Shared progress, challenges, and opportunities.**’ In parallel to the growing attention to caring for cancer survivors, an increased focus over the past 20 years on integrating palliative care (PC) or patients with cancer has highlighted potential benefits. However, the field faces significant challenges. As with survivorship care, to the authors’ knowledge there is no consensus regarding the best approach with which to integrate PC into routine practice and readily available, cost-effective mode have not been widely disseminated into clinical settings. Likewise, the increased workforce demands necessitate new delivery models across settings with diverse resources and levels of PC expertise. **First page view:** <https://goo.gl/7tUd5q>

## **Do new neuroimaging findings challenge the ethical basis of advance directives in disorders of consciousness?**

*CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS* | Online – 10 September 2018 – Some authors have questioned the moral authority of advance directives (ADs) in cases in which it is not clear if the author of the AD is identical to the person to whom it later applies. This article focuses on the question of whether the latest results of neuroimaging studies have moral significance with regard to the moral authority of ADs in patients with disorders of consciousness (DOCs). Some neuroimaging findings could provide novel insights into the question of whether patients with DOCs exhibit sufficient psychological continuity to be ascribed diachronic personal identity. If those studies were to indicate that psychological continuity is present, they could justify the moral authority of ADs in patients with DOCs. This holds at least if respect for self-determination is considered as the foundation for the moral authority of ADs. The non-identity thesis in DOCs could no longer be applied, in line with clinical and social practice. **Abstract (inc. list of references):** <https://goo.gl/VcufdQ>

### **Related**

- *SOCIAL SCIENCE & MEDICINE*, 2018;215(10):16-22. ‘**Forecasting and foreclosing futures: The temporal dissonance of advance care directives.**’ Advance care directives (ACDs) situate persons as rational and self-determining actors who can make anticipatory plans about their futures. This author critically examines how people interpret individual and future-oriented approaches to medical decision-making with limited access to information and knowledge, and reduced opportunities to prepare and document their care preferences. Revealed a discord between planning for a finite future and the contingencies and continuities of social life. It unsettles the detached reasoning that is privileged in end-of-life decision-making and reveals limitations to “do-it-yourself” approaches to ACDs which, it is argued, not only forecasts potential futures but also forecloses them. **Abstract:** <https://goo.gl/h6qHGw>

## “Who would want to die like that?” Perspectives on dying alone in a long-term care setting

*DEATH STUDIES* | Online – 12 September 2018 – The discourse of dying alone is negatively weighted and models of a good death identify not dying alone as a key outcome. Understanding why dying alone is viewed negatively and its effects on care is a priority. In separate focus groups with long-term care residents, family caregivers, and staff, the authors identified evidence for four different perspectives on the importance of presence at the time of death. However, while each individual had their own unique perspective on dying alone, the predominant view expressed across respondent groups was that having human connection near the end of one’s life was important. **Abstract:** <https://goo.gl/uSYH4n>

Noted in Media Watch 12 June 2017 (#516, p.9):

- *JOURNAL OF CANADIAN STUDIES*, 2017;50(2):396-421. ‘**Intensifying relational care: The challenge of dying in long-term residential care.**’ Although the culture change movement has sought to transform residential care facilities from *warehouses of death* into homes for living, there is growing recognition of the need to address dying within these settings. Drawing on data from an international and interdisciplinary study, the authors explore the state of end-of-life care in residential care facilities, identifying barriers to the provision of compassionate care for the dying, as well as promising practices and areas for future inquiry. **Abstract (w. link to references):** <https://goo.gl/f37VGM>

Noted in Media Watch 18 December 2017 (#543, p.17):

- *MORTALITY* | Online – 13 December 2017 – “**I’ve no fear of dying alone**”: **Exploring perspectives on living and dying alone.**’ Dying alone is portrayed as undesirable in terms of policy, health and social care provision, the wishes of family and friends, and in popular culture. Despite this, people do often die alone, both in institutional and domestic settings. This article suggests that dying alone may be a problem for survivors, rather than for the person who is dying. **Abstract:** <https://goo.gl/4CmTRU>

### End-of-life care in Italy

#### A decalogue for end-of-life care in internal medicine

*ITALIAN JOURNAL OF MEDICINE* | Online – 10 September 2018 – Since a large number of patients with chronic medical diseases die in hospital, often in an internal medicine ward, internists are urged to improve their expertise in end-of-life care (EoLC), which is a neglected part of their academic education. Recently, the Italian Federation of the Associations Hospital Doctors on Internal Medicine has addressed EoL-medicine in many ways, promoting many scientific meetings on this and allied topics, providing educational material made available in its website on a free basis and establishing an *ad hoc* committee charged with the task of organizing dedicated events annually. The Committee has also elaborated a series of recommendations on EoLC in internal medicine (a decalogue), reflecting largely shared visions. It has been endorsed also by the Association of the Italian Nurses working in an internal medicine department). The decalogue for EoLC in internal medicine is issued here, and calls for its diffusion and implementation. The driving concept is that doctors and nurses must feel responsible for disregarding appropriate EoLC for the dying patients, because delaying it means to add suffering and discomfort to them in the final phase of their existence. **Abstract:** <https://goo.gl/7p6zUY>

**N.B.** Click on pdf icon to access full, English language text.

#### Related

- *JOURNAL OF CRITICAL CARE*, 2018;48(12):178-182. ‘**The Italian law on informed consent and advance directives: New rules of conduct for the autonomy of doctors and patients in end-of-life care.**’ The law provides for fundamental ethical principles and important guidelines: respect for patients’ self-determination in all phases of life, option to refuse or interrupt life-sustaining treatments, including artificial nutrition and hydration, the legitimacy of end-of-life decisions, and the implementation of palliative care to ease suffering and pain. The effects of the new law must be tested in the field. Its objectives will be achieved if, in clinical practice, advance directives are able to satisfactorily represent informed personal preferences through patients’ relationships with their physicians, as part of personalized advance care planning. **Abstract:** <https://goo.gl/Z4JSpE>

## Exploring the “patient experience” of individuals with limited English proficiency: A scoping review

*JOURNAL OF IMMIGRANT & MINORITY HEALTH* | Online – 10 September 2018 – Individuals with limited English proficiency (LEP) face barriers to safe and high-quality health care. “Patient-experience” is increasingly viewed as an important component of health care quality. However, the impact of language proficiency on “patient-experience” is not well-described. This scoping review mapped the literature on the patient experience of individuals with LEP. The authors reviewed sixty qualitative and mixed-methods studies from EMBASE and MEDLINE published between 2007 and 2017. They identified four major themes: 1) Communication, language barriers, and health literacy; 2) Relationships with health care professionals; 3) Discrimination and intersection with other dimensions of identity; and, 4) Cultural safety. The authors also identified factors that may improve LEP patient experience, including: mitigating language barriers through interpretation or language-concordant providers, offering translated patient resources, and educating health care professionals about cultural safety. **Abstract (inc. list of references):** <https://goo.gl/EzVHxf>

**N.B.** Additional articles on patients with limited English proficiency in the context of end-of-life care noted in 20 August 2018 issue of Media Watch (#577, p.2).

## Managing medicines for patients dying at home: A review of family caregivers’ experiences

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 September 2018 – This review highlights a number of potential implications for practice alongside an underlying concern about whether family caregivers (FCGs) have any “choice,” in practice, about whether or not they take on this caring role. There are a number of moral consequences for FCGs if they choose not to take on this role, and practical implications for services if FCGs do not want to, or are not able to, administer medications. Therefore, there is a broader question for policy and practice concerning whether we should continue to place this expectation on FCGs. Implications for practice, therefore, might be to take on effective training and ongoing support of FCGs alongside a greater emphasis on enabling health care professionals (HCPs) to effectively administer medication to people who want to remain at home, thereby reducing the expectations on FCGs. This review also demonstrates that when FCGs do want to take on a role of administering medications at the end of life (EoL) access to written and telephone information, and advice and home visits from HCPs, is essential for appropriate information and support. Further to this, medications management at the EoL may need to be simplified by health professionals actively rationalising all unnecessary medications. In addition to such practical issues discussions about the ethical implications FCGs may face and the potential to “debrief” with HCPs after medications have been given and/or the death has occurred may be required. **Full text:** <https://goo.gl/X6S9KW>

Noted in Media Watch 11 September 2017 (#529, p.10):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 September 2017 – ‘**Pain management concerns from the hospice family caregivers’ perspective.**’ This study confirmed that hospice family caregivers face a variety of challenges: caregiver-centric issues, caregiver’s medication skills and knowledge, communication and teamwork, organizational skill, and patient-centric issues. **Abstract:** <https://goo.gl/EN14ZM>



### [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>

## Parkinson matters

*JOURNAL OF PARKINSON'S DISEASE* | Online – 20 August 2018 – Recent epidemiological observations have drawn attention to the rapid rise in the burden caused by Parkinson's disease (PD) over the past years, emphasizing that PD is a matter of serious concern for our future generations. A recent report by Public Health England corroborates this message, providing new insight on trends in deaths associated with neurological diseases in England between 2001 to 2014.<sup>1</sup> The report indicates mortality associated with PD and related disorders increased substantially between 2001 and 2014. This trend is partially explained by increased longevity in the population. However, it is possible changes in exposure to risk factors, recent improvements in multidisciplinary care (leading to prolonged survival), and improved diagnostic awareness or improved registration also influenced the observed trend. Furthermore, patients with PD and related disorders were found to die at an advanced age, and the majority die in a care home or hospital, despite a preponderant preference for many patients and their families to spend their last days at home. To combat these concerning observations, future efforts should be focused on providing resources for vulnerable elderly Parkinson patients, avoiding unplanned hospital admissions and out-of-home deaths as much as possible. Possible solutions include a community-based network of specifically trained allied health therapists, personal case managers for Parkinson patients, dedicated Parkinson nursing homes, and improved centralised support services from university clinics to regional community hospitals aimed at facilitating optimal wide-scale care delivery. **Full text:** <https://goo.gl/6qq6MU>

### Extract

Data suggest that, despite recent improvements, the end-of-life (EoL) for Parkinson's disease (PD) patients is often unplanned and 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. Family caregivers also typically indicate their own home as the preferred place of care for their relatives towards the EoL. Furthermore, the vast majority of hospital admissions of PD patients are unplanned, resulting from either complications of the disease or its treatments or comorbidities.

1. Deaths associated with neurological conditions,<sup>1</sup> Public Health England, February 2018. **Download/view at:** <https://goo.gl/Hz4W9S>

### Related

- *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 (PC) approach can help the patient adjust to his or her diagnosis and maintain an optimal quality of life. The "Top 10" format emphasizes the most relevant issues to enable PC clinicians to provide optimal care for those suffering with this complex neurodegenerative disease. **Abstract:** <https://goo.gl/h5pM4y>

**N.B.** Selected articles on the end-of-life care for patients living with Parkinson's disease noted in 20 August 2018 issue of Media Watch (#577, p.9).

## Palliative care for people with non-malignant respiratory disease and their carers: A review of the current evidence

*JOURNAL OF RESEARCH IN NURSING* | In print – Accessed 11 September 2018 – Internationally, non-malignant respiratory disease (NMRD) is on the increase. However, although palliative care (PC) is recommended as an appropriate healthcare option for this client group, evidence suggests that these patients and their carers do not receive the same standards of PC as patients with a malignant lung condition. A review of the literature was conducted in July 2015 and updated in October 2017, focused on the PC service provision for patients with interstitial lung disease, chronic obstructive pulmonary disease (COPD) and bronchiectasis. Seventy-one empirical studies were included in the review and grouped in to

two main themes: 1) Patient and carer's bio-psychosocial symptom needs and management; and, 2) and PC service provision for patients with non-malignant respiratory disease and their carer. The majority of palliative research focuses on patients with a diagnosis of COPD. A deeper insight is required into the palliative service provision experienced by those with other forms of non-malignant respiratory disease such as bronchiectasis and interstitial lung disease. **Full text:** <https://goo.gl/AzEqBJ>

### Ten key messages of the guidelines for family-centered care in intensive care medicine

*MEDIZINISCHE KLINIK – INTENSIVMEDIZIN UND NOTFALLMEDIZI* | Online – 10 September 2018 – The family plays an important role in the care of the critically ill patient. There is a substantial psychological burden to family members during the intensive care management of the patient. The family has to bear the pitiable state of the patient with the feeling of helplessness. The critically ill patient is frequently unable to actively decide on the processes of intensive care. Therefore, the family has to take over the responsibility of representing the values and wishes of the patient and become involved in decision making, for which most family members are not prepared. A considerable proportion of family members suffers from stress, anxiety and depression. This psychological burden also continues after the conclusion of the intensive care management. Therefore, structured approaches are needed to support family members of critically ill patients during the intensive care management. In this short review, we present the ten key messages of the recent guidelines for family-centered care in the intensive care unit by the Society of Critical Care Medicine.<sup>1</sup> **Abstract (inc. list of references):** <https://goo.gl/GBeQkm>

1. 'Family-Centered Care in the ICU,' Society of Critical Care Medicine, January 2017. **Download/view at:** <https://goo.gl/MfjF3c>

**N.B.** German language article.

Noted in Media Watch 16 July 2018 (#572, p.6):

- *BMC HEALTH SERVICES RESEARCH* | Online – 9 July 2018 – “**It’s better to have three brains working instead of one**”: **A qualitative study of building therapeutic alliance with family members of critically ill patients.** The four dimensions of therapeutic alliance prove analytically useful to highlight current strength in ICU provider-family relationships. The authors identify several opportunities to improve these relationships in the areas of family integration and empowerment. Multiple interventions are likely needed to continually foster positive relationships, mitigate identified barriers and transform the ICU into a more interprofessional and family-centered therapeutic environment to enhance patient and family outcomes. **Full text:** <https://goo.gl/gB9kkn>

### The musical eulogy and other functions of funeral music

*OMEGA – JOURNAL OF DYING & DEATH* | Online – 13 September 2018 – This article has drawn attention to various functions of funeral music and has revealed how music functions on several levels. The analysis of funeral music in relation to its specific place in the funeral show that funeral music is related to three main themes: the funeral itself, identity, and emotion. As these themes are also important aspects of ritual, music during funerals adds to the ritual dimension of the funeral: music functions as a building block of the funeral and stylizes and formalizes the funeral; funeral music is often related to the deceased and therefore presents part of the deceased person's identity; and, music regulates emotions. **Full text:** <https://goo.gl/FMv8h5>



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

## Children's perspectives on living with a sibling with a chronic illness

*PEDIATRICS*, 2018;142(2). Clinical guidance emphasizes the importance of considering the whole family when caring for a child with a pediatric chronic illness. However, there is a lack of research specific to sibling experience. Parental accounts are used in studies to examine family experiences; consequently, the direct voices of siblings are neglected. A thematic synthesis identified two overarching themes providing new insights. The first, "changing relationships," had two sub-themes: "changing family relationships" and "changing relationship to self." The second, "managing changes," had three sub-themes: "coping and acceptance," "support from friends, peers, and support groups," and "negative reactions from others." Studies were often descriptive with little explicit qualitative analysis. The findings are used to outline how changes in family relationships often result in reduced commu-

nication and a suppression of healthy siblings' needs. Siblings develop strategies to help them cope with and accept their circumstances, including finding new prosocial ways of meeting their needs in the form of skills and roles they develop. **Abstract:** <https://goo.gl/u2fyhZ>

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

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

**N.B.** Word search "siblings" in 'Children's Support Services for Grieving or Bereaved Children Needs Assessment (Literature Search).'

### Related

- *DEATH STUDIES* | Online – 12 September 2018 – '**Emotional security theory: An application to sibling bereavement.**' The present study investigated the relevance of emotional security theory in a sample of 72 young adults who experienced sibling bereavement. The authors investigated (1) whether perceptions of prolonged parental grief predicted key aspects of emotional security (disengagement, preoccupation, and security), and (2) whether emotional security mediated a relation between perceptions of prolonged parental grief and young adult emotional functioning. Results supported the potential utility of emotional security theory as a theoretical framework for understanding sibling bereavement. **Abstract:** <https://goo.gl/Brzv1X>

## Why do neonatologists in Scandinavian countries and The Netherlands make life-and-death decisions so different?

*PEDIATRICS*, 2018;142(Suppl.1):S585-S589. An examination of the policies regarding the care of extremely premature newborns reveals unexpected differences between Scandinavian countries and The Netherlands. Three topics related to decision-making at the beginning and at the end of life (EoL) are identified and discussed. Advances in medicine and technology have resulted in considerable changes in the care of premature infants. Over the last decade, more premature newborns survive, and the prognosis of survivors continues to improve. At the same time, it becomes clear that even in highly developed countries, significant variations of practice occur. Practice variations exist at the beginning and at the EoL. The former is illustrated in the wide variation in recommendations about management of extremely preterm deliveries by professional organizations across countries... The latter is supported in reports about the differences in death and dying in NICUs within countries (the U.S.) and between culturally different countries (the U.S., Canada, and The Netherlands). The reports revealed that physicians differed in how comfortable they were with withholding or withdrawing life support on the basis of quality-of-life consideration. In this observation, the researchers explain, partly, why survival rates of extremely premature newborns vary across countries. **Full text:** <https://goo.gl/2X7Y3z>

Cont. next page



Media Watch: Behind the Scenes  
<http://goo.gl/XDjHxz>

Noted in Media Watch 30 July 2018 (#574, p.4):

- SINGAPORE | *The Straits Times* – 28 July 2018 – ‘**New guidelines in caring for vulnerable babies launched by Lien Centre for Palliative Care.**’ The centre’s clinicians, together with those from HCA Hospice Care, KK Women’s & Children’s Hospital, National University Hospital and Singapore General Hospital, have developed Singapore’s first set of guidelines to address the complex needs of vulnerable or dying babies.<sup>1</sup> Other countries have come up with similar guidance documents since the 1990s, but may not have a set of formalised guidelines. Britain developed a similar set of comprehensive guidelines in 2014.<sup>2</sup> <https://goo.gl/hLSRT8>
  1. ‘Guidance on Supportive & Comfort Care in Vulnerable Babies,’ Lien Centre for Palliative Care, July 2018. **Download/view at:** <https://goo.gl/NzHYLU>
  2. ‘Practical Guidance for the Management of Palliative Care on Neonatal Units,’ Royal College of Paediatrics & Child Health, 2014. **Download/view at:** <https://goo.gl/KVpGmg>

### **End-of-life care in the Dutch medical *curricula***

*PERSPECTIVES ON MEDICAL EDUCATION* | Online – 5 September 2018- This study shows that end-of-life care (EoLC) is sparsely described in the Dutch blueprint for medical education: it is not explicitly mentioned as a compulsory subject and not all domains that are considered essential knowledge and skills by the international standards are represented in the national blueprint. This has consequences for the planning and execution of the medical *curricula* at the faculty level. First of all, EoLC was part of the formal *curricula*, but none of the faculties taught all the subjects that were considered a necessary basis for EoLC practice. Moreover, EoLC was not offered as an individual course in any of the Dutch bachelor and master medical *curricula*. Secondly, none of the medical faculties taught the five domains on EoLC and met international criteria. To improve EoLC education, the authors recommend addition of all the EoLC domains that are internationally accepted to the national blueprint. Besides, they recommend medical faculties to offer a separate compulsory course on EoLC to educate and prepare their future doctors properly, so that people in an ageing world can rely on young medical doctors who feel ready and well-informed when providing appropriate EoLC. **Full text:** <https://goo.gl/h5qHVQ>

### **Complicated grief: Recent developments in diagnostic criteria and treatment**

*PHILOSOPHICAL TRANSACTIONS OF THE ROYAL SOCIETY B* | Online – 16 July 2018 – Although grief is a natural response to loss among human beings, some people have a severe and prolonged course of grief. In the 1990s, unusual grief persisting with a high level of acute symptoms became known as “complicated grief” (CG). Many studies have shown that people who suffer from CG are at risk of long-term mental and physical health impairments and suicidal behaviours; it is considered a pathological state, which requires clinical intervention and treatment. DSM-5 (2013 Diagnostic & Statistical Manual of Mental Disorders, 5th Ed.) proposed “persistent complex bereavement disorder” as a psychiatric disorder; it is similar to CG in that it is a trauma- and stress-related disorder. In recent years, there has been considerable research on the treatment of CG. Randomized controlled trials have suggested the efficacy of cognitive behavioural therapy including an exposure component that is targeted for CG. However, experts disagree about the terminology and diagnostic criteria for CG. The International classification of diseases (11th revision) beta draft proposed prolonged grief disorder as a condition that differs from persistent complex bereavement disorder with respect to terminology and the duration of symptoms. This divergence has arisen from insufficient evidence for a set of core symptoms and the biological basis of CG. Future studies, including biological studies, are needed to reach consensus about the diagnostic criteria for CG. **Abstract:** <https://goo.gl/Lxo8gp>

**N.B.** This article is included in a special issue of the journal, ‘Evolutionary thanatology: Impacts of the dead on the living in humans and other animals.’ **Contents page:** <https://goo.gl/hNp6bL>

Cont.

Noted in Media Watch 3 April 2017 (#506, p.12):

- *BEHAVIORAL SCIENCES* | Online – 25 March 2017 – ‘**Death of an ex-spouse: Lessons in family communication about disenfranchised grief.**’ The death of a loved one is an emotional-laden experience, and while grief and mourning rituals are less formal today in many communities, there remain some social norms for individuals to process loss. The death of an ex-family member, such as a former spouse, is more complicated and expectations for how to respond are fraught with uncertainty. This article explores the concept of disenfranchised grief, which is “grief that is experienced when loss cannot be openly acknowledged, socially sanctioned, or publicly mourned.” **Full text:** <https://goo.gl/iRvEhW>
- *PSYCHO-ONCOLOGY* | Online – 28 March 2017 – ‘**Pre-loss grief in family caregivers during end-of-life cancer care: A nationwide population-based cohort study.**’ Severe grief symptoms in family caregivers during end-of-life (EoL) cancer trajectories are associated with complicated grief and depression after the loss. Nevertheless, severe grief symptoms during EoL caregiving in caregivers to cancer patients have been scarcely studied. In this population-based prospective study of 3,635 caregivers to 9,512 patients severe pre-loss grief symptoms were significantly associated with distress, low preparedness, and little communication during caregiving. **Abstract:** <https://goo.gl/x9JqM>

**N.B.** Additional articles on complicated grief noted in 27 March 2017 issue of Media Watch (#505, p.10).

### **Decision-making in the moments before death: Challenges in prehospital care**

*PREHOSPITAL EMERGENCY CARE* | Online – 5 September 2018 – The primary charge of Emergency Medical Services (EMS) is to save lives. However, EMS personnel are frequently called to scenes where prolonging life may not be the primary goal. When someone is nearing death, family members may feel compelled to call 911 because they are feeling uncertain about how to manage symptoms at the end of life (EoL). The authors explored prehospital providers’ perspectives on how the awareness of dying and documentation of EoL wishes influence decision-making on emergency calls near the EoL. Their findings illustrate the relationship between awareness of dying and documentation of wishes in EMS calls. The four decisional contexts are: 1) Awareness of dying-wishes documented: Families were prepared but validation and/or support was needed in the moment; 2) Awareness of dying-wishes undocumented: EMS must initiate treatment, medical control guidance was needed; 3) Unaware of dying-wishes documented: Shock, expectation that EMS can stop the dying; and, 4) Unaware of dying-wishes undocumented: Families were unprepared, uncertain, frantic. This study illustrates that EMS providers are acutely aware of the impact of their decisions and actions on families at the EoL. How emergency calls near the EoL are handled influences how people die, whether their preferences are honored and the appropriate use of ambulance transport and ED care. The findings highlight how the intersection of awareness of dying and documentation of wishes influence prehospital decision-making in EoL emergencies and demonstrate the key role EMS providers have in this critical period. **Abstract:** <https://goo.gl/uxKH1P>

### **The earlier the better: The role of palliative care consultation on aggressive end of life care, hospice utilization, and advance care planning documentation among gynecologic oncology patients**

*SUPPORTIVE CARE IN CANCER* | Online – 12 September 2018 – Two hundred and four patients were eligible to take part in this study. Forty-one percent underwent at least one marker of aggressive care at the end of life (EoL). Most (53%) had a palliative care consultation (PCC) prior to death, and of these most were inpatient (89%). Patients with a PCC had higher odds of hospice enrollment before death and higher odds of advance care planning (ACP) documentation before death. Among patients with an inpatient PCC, 44% underwent a marker of aggressive medical care at the EoL and 82% enrolled in hospice before death. Among patients with an outpatient PCC, 25% underwent a marker of aggressive medical care at the EoL and 92% enrolled in hospice before death. Patients with outpatient PCC were engaged in palliative care longer than patients with inpatient PCC. PCC increased hospice enrollment and ACP documentation. Patients with outpatient PCC had lower rates of aggressive medical care and higher rates of hospice enrollment when compared to inpatient PCC. Location of initial PCC plays an important role in EoL care outcomes. **Abstract (inc. list of references):** <https://goo.gl/fcqq3k>

Cont.

Noted in Media Watch 20 August 2018 (#577, p.9):

- **GYNECOLOGIC & OBSTETRIC INVESTIGATION** | Online – 10 August 2018 – ‘**Gynecologic oncologists’ perceptions of palliative care and associated barriers: A survey of the Society of Gynecologic Oncology.**’ Members of the Society of Gynecologic Oncology (SGO) were invited to participate in an anonymous online survey. A total of 174 (16%) gynecologic oncologists completed the survey. The majority (75%) agreed or strongly agreed that palliative care (PC) should be integrated into cancer care at diagnosis of advanced or metastatic cancer. The most frequently perceived PC barriers included patients’ unrealistic expectations (54%), limited access to specialty PC (25%), poor reimbursement (25%), time constraints (22%), and concern of reducing hope or trust (21%). **Abstract (w. list of references):** <https://goo.gl/D1U7jp>

**N.B.** Additional articles on palliative care in gynecology noted in this issue of Media Watch.

## Journal Watch

### **Beware of predatory journals: A caution from editors of three family medicine journals<sup>1</sup>**

*JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE*, 2018;31(5):671-676. We all share responsibility for addressing the threats of predatory publishing. Authors can avoid submitting work to such journals, even if promised sure acceptance and prompt publication. Readers can be vigilant when assessing the sources of published reports. Journal editors can check submitted manuscripts for duplicate publication, refuse to consider work already published in predatory journals, and carefully review article references before publication. Reviewers should be suspicious of requests from unfamiliar journals and refuse involvement with predatory journals and publishers. Professional organizations that sponsor journals can renew their commitments to quality, control, and access. Investigators can write grant budgets to include processing fees for publication in reputable journals. Academic institutions can restructure their criteria for academic advancement to favor quality over quantity of scholarly publications. What is at stake is the soundness of our science, the quality of our scholarly literature, and the public’s trust in our work.

**Full text:** <https://goo.gl/XkhgSX>

1. *Journal of the American Board of Family Medicine, Family Medicine and Annals of Family Medicine.*

### **Some scientists publish more than 70 papers a year. Here’s how – and why – they do it**

*SCIENCE* | Online – 12 September 2018 – Some researchers are unusually prolific publishers, appearing as an author on as many as 72 scientific papers a year – or about every 5 days. John Ioannidis, a statistician at Stanford University in Palo Alto, California, wondered whether some of them were gaming the system. So he and colleagues dove into the academic journal database Scopus and identified 265 “hyperprolific authors” between 2000 and 2016, finding that their ranks had increased 2.5-fold since 2001. Ioannidis’s group was able to make contact with 81 of these scientists. Few abided by what are supposed to be strict guidelines for determining who receives authorship credit on a paper, the team reports today in *Nature*.<sup>1</sup> Ioannidis discussed the repercussions of his findings with *Science*, as well as what he thinks can be done to fix things. **Full text:** <https://goo.gl/T591kU>

1. ‘Thousands of scientists publish a paper every five days,’ *Nature*, published online 12 September 2018. **Full text:** <https://goo.gl/k19uzy>



Photo: Lori Waselchuk. Philadelphia, PA

### **Prison Hospice: Backgrounder**

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 August 2018) is available on request. Contact information at the foot of p.20.

## Too much academic research is being published

UNIVERSITY WORLD NEWS | Online – 7 September 2018 – There is a crisis in academic publishing – too much pressure on top journals, too many books of marginal quality, the rise of predatory journals, and publishers that publish low or marginal quality research and tremendous pressure on academics worldwide to publish. The decision by *The Review of Higher Education*,<sup>1</sup> a highly respected academic journal, to temporarily suspend submissions due to a backlog of more than two years' worth of articles awaiting reviews or publication set off a twitter storm and much debate in the corridors of academia about the future of academic publishing, and in particular its very foundation, blind peer review. These fundamental problems are artefacts of several developments in global higher education in the past half-century – especially massification and the rise of global and national rankings of universities. **Full text:** <https://goo.gl/GKnZD6>



1. 'Update to *The Review*,' *The Review of Higher Education*, association for the Study of Higher Education, August 2018. <https://goo.gl/SgowPk>

### Media Watch: Editorial Practice

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

### Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

[Search Back Issues of Media Watch @ http://goo.gl/frPgZ5](http://goo.gl/frPgZ5)

## Media Watch: Access on Online

### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/fJczV6>

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

PALLIATIVE CARE NETWORK: <https://goo.gl/YBP2LZ>

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

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/ZRngsv>

[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

### Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

[Scroll down to 'Additional Resources']

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

### Europe

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/L7D2hw>

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

### South America



Academia Nacional de Cuidados Paliativos (Brazil): <https://goo.gl/b5CV31>

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