

## 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

**'Palliative care and public health: An asymmetrical relationship?'  
(p.12), in *Palliative Care: Research & Treatment*.**

## Canada

### **People with developmental disabilities in Ontario more likely to die young, report suggests**

ONTARIO | CBC News (Toronto) – 21 February 2019 – People with developmental disabilities are more likely than those who aren't disabled to encounter problems with Ontario's healthcare system regardless of age, sex or class...<sup>1</sup> Research from the Institute for Clinical Evaluative Sciences found people with developmental disabilities were significantly more likely to die young, languish in hospital without plans for appropriate aftercare, spend time in long-term care, or have repeat hospitalizations and emergency room visits than their non-disabled peers. The study ... said the findings held true regardless of what disability was specifically at play. They also transcended a variety of boundaries that usually serve as strong predictors of poor health outcomes, such as age and socioeconomic status. <http://bit.ly/2VcSm6s>

1. 'Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario,' Centre for Addictions & Mental Health and the University of Ontario Institute of Technology, February 2019. **Download/view at:** <http://bit.ly/2tvU3m>

Noted in Media Watch 26 November 2018 (#591, pp.13-14):

- *LEARNING DISABILITY PRACTICE*, 2018;21(5). '**Helping young people who have learning disabilities and their families to plan end-of-life care: the ADVANCE toolkit.**' This article introduces the ADVANCE toolkit featuring a values-based framework that aims to help caregivers who work with young people who have learning disabilities, including nurses, social workers and care assistants, develop their confidence and skills in end-of-life care (EoLC) planning. The toolkit enables insight in knowing how, when and with whom to discuss the sensitive topic of planning for EoLC. Six activities are included for readers to complete with a view to enabling engagement with the material presented. **Abstract:** <http://bit.ly/2T8St1>

**N.B.** Additional articles on EoLC for people living with developmental and intellectual disabilities noted in this issue of Media Watch. See also 11 February 2019 issue of the weekly report (#601, p.15).

### Specialist Publications

**'Access to palliative care for cancer patients living in a northern and rural environment in Ontario, Canada: The effects of geographic region and rurality on end-of-life care in a population-based decedent cancer cohort'** (p.7), in *Clinical Medicine Insights: Oncology*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | CBC News (Toronto) – 20 February 2019 – **‘Lack of public information on medically assisted death has “polarized” debate, critics argue.’** It might be the only thing that the two sides in the debate over medically assisted dying agree on: more information is needed to have a proper debate. While there are different rules in different provinces, in Ontario, there has been a ban on releasing any documents under Freedom of Information laws related to medical assistance in dying (MAiD) since May 2017. “The difficulty is the actual further information which is really what we need to know if our quote unquote social experiment is really being controlled or not,” says Alex Schadenberg, of the Euthanasia Prevention Coalition. “You can’t get any information on who’s doing what and who’s providing MAiD,” says Shanaaz Gokool of Dying with Dignity Canada. The province is quick to point out that it does release information about assisted dying through the coroner’s office. This includes stats on the age of the patient (ranges from 22 to 105), the underlying condition (63% are cancer-related), and the total numbers (2,529 in Ontario since 2016). There is also some regional background, showing that the 11 assisted deaths in Greater Sudbury is far less than the 55 in Nipissing district and the 20 in the Algoma district. Health Canada is also gathering data that is expected to be released in some form at some point. But the lobby groups say what remains private are details of how the requests are being handled and how the system is functioning. <http://bit.ly/2GTJONY>

## U.S.A.

### The U.S. may be facing a “caregiver crisis”

COLORADO | 9News (Denver) – 22 February 2019 – Every day in the U.S., 10,000 people turn 65. By the year 2020, there will be 56 million Americans age 65 or older. Many of them will need care. The problem is, as the number of older Americans increases, the supply of family caregivers continues to shrink. Right now, 95% of caregivers are family members and the government says they are currently the backbone of the country’s long-term care (LTC) system. Caregivers are primarily women and almost all of them, at some level or at some moment in the process, suffer from emotional distress. Experts say long-term caregivers regularly develop serious health problems such as anxiety, depression and chronic and disabling physical disabilities. Studies have shown that an influential factor in a caregivers decision to place an impaired relative in a LTC facility is the family caregivers own physical health. Last year, the work family caregivers go for their loved ones was valued at \$232 billion dollars. A recent survey found 83% of Americans now want to the Government to come up with some type of funding to help with the caregiver crisis. <https://on9news.tv/2GH2Yav>

### Specialist Publications

**‘Lower extremity amputation and healthcare utilization in the last year of life among Medicare beneficiaries with end-stage renal disease’** (p.8), in *Journal of the American Society of Nephrology*.

**‘Development of curricular milestones for hospice and palliative medicine fellowship training in the U.S.’** (p.10), in *Journal of Pain & Symptom Management*.

**‘Multiple stakeholders’ perspectives regarding barriers to hospice enrollment in diverse patient populations: A qualitative study’** (p.11), in *Journal of Pain & Symptom Management*.

**‘If physician-assisted suicide is the modern woman’s last powerful choice, why are White women its leading advocates and main users?’** (p.14), in *Professional Psychology: Research & Practice*.

Cont.



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Noted in Media Watch 23 July 2018 (#573, p.2):

- **THE WALL STREET** | Online – 20 July 2018 – ‘**America is running out of family caregivers, just when it needs them most.**’ For generations, the nation has relied on family members to keep aging loved ones in their homes. Today, many Americans are growing older without family nearby, offering a glimpse of what the future may hold for the cohort of Americans who are approaching retirement. The caregiving crunch comes at a time when Americans reaching retirement age are in a squeeze unseen in generations. Their median incomes, including Social Security and retirement fund receipts, haven’t risen in years. And if they’re counting on family to care for them, too, they may well find their families too small and far-flung to meet the task. <https://goo.gl/gZ1ff8>

## House approves law requiring parental notification for medical DNR orders

MISSOURI | *News Press* (Jefferson City) – 21 February 2019 – A law that would stop medical officials from placing do-not-resuscitate (DNR) orders on children without telling their parents won initial approval in the House... House Bill 138 ... would stop medical officials from acting without parental consent to decide their child’s end-of-life (EoL) plans. The legislation was inspired by the death of Simon Crosier, who was diagnosed with Trisomy 18, a life-threatening developmental disorder, when he was born in 2010. Three months later, doctors at Mercy Hospital St. Louis placed a DNR order on Simon’s medical chart without his mother or father knowing. The bill, which Kidd has been trying to pass for four years, requires at least one parent and two witnesses present when discussing with the doctors what should be done if the child needs to be resuscitated. If a child is in the custody of the state, the decision-making falls to the juvenile courts to decide the EoL plans. Once the bill gets final House approval, it moves to the Senate for consideration. <http://bit.ly/2BKQjPy>

**N.B.** Additional articles on the passage of House Bill 138, commonly know as Simon’s Law, noted in 3 April 2017 issue of Media Watch (#506, p.2).

## International

### **Russia’s lower house of parliament adopts palliative care bill**

RUSSIA | Russian Legal Information Agency (Moscow) – 21 February 2019 – The State Duma, the lower house of Russian parliament, passed a palliative care (PC) bill in a final third reading... The bill specifies the concept of PC that would involve a package of measures including medical treatment, after care and psychological actions aimed to improve the quality of terminally ill patients’ living and oriented to the amelioration of pain. The draft law confirms the right of terminal patients to pain relief including drug preparations and medical devices. Such assistance would be rendered on an outpatient basis and at hospital by health workers who underwent special training. Palliative patients would also receive social and psychosocial support as well as religious care, according to the bill. Volunteers, social workers and representatives of religious confessions would be involved in these services. <http://bit.ly/2EmIEcc>

### Specialist Publications

‘**Prevalence of advance care directives in the community: A telephone survey of three Australian States**’ (p.10), in *Internal Medicine Journal*.

‘**A review of end-of-life care for people with dementia in U.K. care homes: Staff and family carer perceptions**’ (p.8), in *Journal of Community Nursing*.

‘**Bereavement support in palliative care: A national survey of Australian services**’ (p.11), in *Journal of Palliative Medicine*.

‘**Primary palliative care in southern Brazil: The legacy of Cicely Saunders**’ (p.13), in *Palliative Care: Research & Treatment*.

‘**Pathos, death talk and palliative care in the assisted dying debate in Victoria, Australia.**’ (p.14), in *Mortality*.

‘**The media’s failure to report on religious voices in the public square: The euthanasia debate as a test case**’ (p.15), in *University of Notre Dame Australia Law Review*.

## Figures show soaring number of homeless hospital patients [in England]

U.K. (England) | *The Guardian* (London) – 20 February 2019 – Thousands of homeless people in England are arriving at hospital with Victorian-era illnesses such as tuberculosis, as well as serious respiratory conditions, liver disease and cancer, with hospital admissions for such conditions surging over a decade... Austerity, cuts to vital welfare services and an ageing homeless population have been blamed for the dramatic surge in largely preventable illnesses, including a sevenfold rise in pneumonia and a tenfold increase in hepatitis C. Deaths in hospital and palliative care (PC) for homeless patients have also surged since 2008, National Health Service (NHS) figures show. The data ... has been described as a “huge underestimate” by experts, who say the majority of NHS hospitals and care centres are not equipped to treat homeless patients and record high-quality information about their care. Deaths recorded at NHS hospitals more than quadrupled, rising from 18 to 95 in the last 10 years. PC treatment from patients with no fixed abode rose from one in 2008-2009 to 45 last year. <http://bit.ly/2E0QEy0>

**N.B.** Additional articles on PC for the homeless in the U.K. noted in 28 January 2019 issue of Media Watch (#59, p.12).

## Royal Flying Doctor Service report reveals looming aged care crisis in remote Australia

AUSTRALIA (SOUTH AUSTRALIA) | ABC News (Port Lincoln) – 18 February 2019 – Many older patients are receiving emergency medical transfers for illnesses that could have been prevented with access to consistent primary care, a report by the Royal Flying Doctor Service (RFDS) has found.<sup>1</sup> Between 1 July 2014 and 30 June 2017, the RFDS transferred more than 23,000 patients over the age of 65 from remote Australia to hospital. RFDS CEO Martin Laverty said the Royal Commission into Aged Care needed to address the aged care situation in remote Australia. “[It has] the opportunity to chart the needs of remote Australia, and get ahead of what’s going to be an inevitable increase in conditions of ageing in remote Australia,” he said. According to the report, the number of people over the age of 65 in remote Australia is increasing at 2.9% each year – a rate higher than in urban areas. The RFDS

today is looking at a 50% increase in dementia and Alzheimer’s in people living in remote and regional Australia. Alongside neurological conditions, the report also showed that Australians living in remote areas were more like to suffer from cancers and preventable heart conditions – conditions that will place additional strain on the RFDS, regional medical practices, and metropolitan hospitals as demand grows. <https://ab.co/2SHyZph>



### Extract from Royal Flying Doctor Service report

Rates of all cancers are higher in rural and remote areas than in cities, but country areas lack reasonable access to oncology, haematology and palliative care.

1. 'Health Ageing in Remote & Regional Australia: Challenges to Overcome,' Royal Flying Doctor Service, February 2019. **Download/view at:** <http://bit.ly/2NbmlZb>

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

- **RURAL & REMOTE HEALTH** | Online – Accessed 10 November 2018 – ‘**Palliative and end-of-life care is everyone’s business: A mapping study to guide a palliative approach in far west New South Wales, Australia.**’ The vast network [within the region studied] demonstrates extensive long-term involvement in palliative care (PC) as well as established connections and opportunities for improving communication between the services and providers involved in PC. Palliative practice is varied and challenging; challenges include communication, early identification, and education. Mapping the existing networks, resources, and relationships proved invaluable to guide the implementation of a palliative approach to care. **Abstract:** <http://bit.ly/2Natqzo>

**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 24 September 2018 issue of Media Watch (#582, p.14).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Daily Mail* (London) – 21 February 2019 – ‘**Assisted dying can cause “inhumane” deaths for patients who don’t pass out and some take as long as a week to die.**’ Assisted suicide can lead to “inhumane” deaths when the drugs don’t work quickly enough or cause unpleasant side effects, experts have warned. The practice is hotly debated but illegal in the U.K., but it’s legal in some U.S. states, Canada and European countries including The Netherlands and Belgium. Patients may be given or take a drug or pill to induce unconsciousness and then death. But, despite the aim for death to be painless and without distress, a review has found this is not always the case. Patients may have difficulty taking doses, either by swallowing or due to vomiting, and some have awoken from a coma or taken up to a week to die, evidence shows. International researchers have said there should be more measures to confirm a person is not “accidentally aware” as they die.<sup>1</sup> <https://dailym.ai/2VdPK5>

1. ‘Legal and ethical implications of defining an optimum means of achieving unconsciousness in assisted dying,’ *Anaesthesia*, published online 20 February 2019. **Full text:** <http://bit.ly/2XcOfJz>

## Specialist Publication

### Physicians’ attitudes toward end-of-life decisions in amyotrophic lateral sclerosis

*AMYOTROPHIC LATERAL SCLEROSIS & FRONTOTEMPORAL DEGENERATION* | Online – 21 February 2019 – This study aimed to assess physicians’ attitudes toward different palliative end-of-life (EoL) practices in amyotrophic lateral sclerosis (ALS) care, including forgoing artificial nutrition and hydration (FANH), continuous sedation until death (CSD), withdrawing invasive ventilation (WIV), and toward physician-assisted dying (PAD), including physician-assisted suicide and euthanasia. The authors explored variables influencing these attitudes. Fifty physicians from European ALS centers and neurological departments completed a survey. Short-term prognosis had a positive impact on attitudes toward offering FANH and CSD, as well as on attitudes toward performing CSD and euthanasia. Predominantly, psycho-existential suffering was associated with a more favorable attitude toward WIV, but influenced attitudes toward performing CSD negatively. Regression analysis showed that religiosity was associated with more reluctant attitudes toward palliative EoL practices

and PAD, whereas training in palliative care (PC) was associated with more favorable attitudes toward palliative EoL practices only. ALS physicians seem to acknowledge psycho-existential suffering as a highly acceptable motive for WIV, but not CSD. They appear to be comfortable with responding to the patient’s requests, but more reluctant to assume a proactive role in the decision-making process. PC training may support ALS physicians in these challenging situations. **Abstract:** <http://bit.ly/2U2MEUA>

#### Publishing Matters

‘**Predatory journals: Do not judge journals by their editorial board members**’ (p.15), in *Medical Teacher*.

‘**To maintain trust in science, lose the peer review**’ (p.16), in *MedScape*.

Noted in Media Watch 19 November 2018 (#590, p.10):

- *HOLISTIC NURSING PRACTICE*, 2019;33(1):3-8. ‘**Elucidating the end-of-life experience of persons with amyotrophic lateral sclerosis.**’ A multi-database search retrieved 31 qualitative research articles that addressed persons with end-of-life (EoL) experiences with amyotrophic lateral sclerosis (ALS). First-person data extraction from the final articles represented emergence of three themes significant to persons with ALS: 1) Decisions for life-sustaining support; 2) Coping and fear of what is to come; and, 3) Communication with providers. Tracheostomy and ventilation as a means of prolonging life were important considerations for individuals with ALS. Persons with ALS struggled emotionally with their sudden loss of control and facing their demise. **Abstract:** <https://goo.gl/o1L6iX>

Cont.

Noted in Media Watch 27 August 2018 (#578, p.8):

- *EUROPEAN MEDICAL JOURNAL: NEUROLOGY*, 2018;6(1):68-76. '**Palliative care in neurology: Integrating a palliative approach to amyotrophic lateral sclerosis care.**' This review examines connections between neurology, specialist palliative care (PC), and an integrated palliative approach to care for people living with neurodegenerative conditions. To illustrate the complexities of including PC in the management of neurodegenerative conditions, amyotrophic lateral sclerosis (ALS) is used as a case study. ALS care and smooth care transitions between multiple services and healthcare professionals are discussed, including the timing of PC delivery in ALS; the education and training needs of healthcare professionals; and, misperceptions of PC... **Full text:** <https://goo.gl/NnPabM>

### Editorial

#### **Palliative medicine physicians: Doomed to burn?**

*BMJ SUPPORTIVE & PALLIATIVE CARE*, 2019;9(1):45-46. On the first day of term, we academics and clinicians watch our first-year physician students file into the lecture theatre full of joy and altruistic dynamism. They have a burning passion to gain the knowledge, expertise and practical wisdom to cure and care for their fellow humans in times of sickness and decline. Our hope is that each of their dreams and aspirations are realised, to the full, in a healthy educational and work setting. This should be one which openly appreciates, values and rewards their contribution, in the service of life in a practical and verbal fashion. That environment must support them when their bodies fatigue, hearts break and minds become overburdened watching (at times) unnecessary suffering and respond to challenging situations regarding life and death. We hope that the flame of their passions does not burn out due to lack of provision and time for self-care. **Introductory paragraph:** <http://bit.ly/2SmGtsZ>

### **Related**

- *MORTALITY* | Online – 17 February 2019 – '**About caregiver suffering in hospice care.**' Caregiver suffering and burnout amongst professionals in palliative care settings are increasingly discussed phenomena in the media and the specialized journals alike. However, we still lack anthropological understandings of the ways this distress is related to the dynamics, practices and representations of PC institutions. This article, based on a 2011-2012 fieldwork conducted in one of the 27 independent hospices of the province of Quebec, aims to contribute to the question in showing how the ways the staff conceive their roles in caring for the dying. The authors explore how the suffering is related to the nature of these roles and to the institutional framework, the "good death." **Abstract:** <http://bit.ly/2TUdqOV>

Noted in Media Watch 7 January 2019 (#596, p.7):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(1):21-28. '**Compassion fatigue in palliative care nursing: A concept analysis.**' Palliative care (PC) nurses are routinely exposed to pain, trauma, and the suffering they witness by nature of ongoing symptom management and end-of-life (EoL) care delivery; however, the focus of care is on healthy EoL management rather than preservation of life. The literature was reviewed to provide clarification of compassion fatigue for PC nurses to assist in future identification and direction in the profession. Identification of compassion fatigue for this profession helps facilitate the recognition of symptoms for a group that deals with patient suffering on a regular basis. **Full text:** <http://bit.ly/2BIEKZo>

**N.B.** Additional articles on burnout (i.e., compassion fatigue) noted in 24 September 2018 issue of Media Watch (#582, pp.2-3, 6).

### [Corrections & Clarifications](#)

'More and more people opting to pass away at home,' a report from swissinfo.com noted in 18 February 2019 issue of Media Watch (#602, p.5), referred to "a newly-published report." The source of 'Death in Switzerland: Individual and societal perspectives,' however, was not identified. Swissinfo.com has since identified the source as the Swiss National Science Foundation. **Download/view report at:** <http://bit.ly/2SS9ku5>

## **Access to palliative care for cancer patients living in a northern and rural environment in Ontario, Canada: The effects of geographic region and rurality on end-of-life care in a population-based decedent cancer cohort**

*CLINICAL MEDICINE INSIGHTS: ONCOLOGY* | Online – 14 February 2019 – Many challenges and barriers exist in providing palliative care (PC) to residents in northern and rural settings in Ontario, Canada. In this study, PC was significantly associated with reduced use of aggressive end-of-life (EoL) care; however, disparities exist in rural locations, especially those in the north. Higher usage of emergency department and hospital resources at EoL in rural locations also reflects differing roles of rural community hospitals compared with urban hospitals. Improving access to PC in rural and northern locations is an important care issue and may reduce use of potentially aggressive EoL care. **Abstract (w. list of references):** <http://bit.ly/2Gy55xe>

**N.B.** Additional articles on PC in rural and remote regions of Canada noted in 14 January 2019 issue of Media Watch (#597, p.18).

## **Discussions about palliative sedation in hospice: Frequency, timing and factors associated with patient involvement**

*EUROPEAN JOURNAL OF CANCER CARE* | Online – 17 February 2019 – The authors investigate whether and when palliative sedation (PS) was discussed with hospice patients with cancer and/or with their families and factors associated with patient involvement in such discussions. Medical records of all patients with cancer who died in an Italian hospice ... were retrospectively reviewed. PS discussion was in 51.8% of the cases reported in the record. In most of the cases, discussions were conducted preemptively. PS was used for 67.3% of the patients who were involved in the discussion and for 32.7% of the patients when the topic was discussed only with the family. Patient involvement in PS discussions was negatively associated with living with others, and positively associated with awareness of prognosis and days of survival after hospice admission. Policies encouraging patient involvement in palliative care decision-making, including PS, should be implemented and their adoption should be carefully examined. Prospective studies addressing this topic are needed. **Abstract:** <http://bit.ly/2BF0cys>

**N.B.** Additional articles on PS noted in 18 February 2019 issue of Media Watch (#602, p.14).

## **The role of palliative care in the cardiac intensive care unit**

*HEALTHCARE* | Online – 19 February 2019 – In the last few years, important changes have occurred in the clinical and epidemiological characteristics of patients that were admitted to cardiac intensive care units (CICU). Care has shifted from acute coronary syndrome patients towards elderly patients, with a high prevalence of non-ischemic cardiovascular diseases and a high burden of non-cardiovascular comorbid conditions: both increase the susceptibility of patients to developing life-threatening critical conditions. These conditions are associated with a significant symptom burden and mortality rate and an increased length of stay. In this context, palliative care programs, including withholding/withdrawing life support treatments or the deactivation of implanted cardiac devices, are frequently needed, according to the specific guidelines of scientific societies. However, the implementation of these recommendations in clinical practice is still inconsistent. In this review, the authors analyze the reasons for this gap and the main cultural changes that are required to improve the care of patients with advanced illness. **Full text:** <http://bit.ly/2XmIbhJ>

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## Related

- *JOURNAL OF CARDIOVASCULAR NURSING*, 2019;34(2):e9-e18. ‘**Healthcare providers’ perceived communication barriers to offering palliative care to patients with heart failure: An integrative review.**’ Ten articles met the authors’ full inclusion criteria. Most studies were qualitative or non-experimental studies of good quality. Authors of several studies found that healthcare providers lacked basic knowledge about palliative care (PC) or did not possess sufficient knowledge to effectively provide care. Poor knowledge of PC created a barrier between the provider and the patient. Inadequate education or inexperience in PC led to the resistance of health providers to implementing a palliative approach. **Abstract:** <http://bit.ly/2GMA0Fg>

**N.B.** Additional articles on PC for patients living with heart failure noted in 21 January 2019 issue of Media Watch (#598, pp.7).

### **Lower extremity amputation and healthcare utilization in the last year of life among Medicare beneficiaries with end-stage renal disease**

*JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY* | Online – 19 February 2019 – Although lower extremity amputation is common among patients with end-stage renal disease (ESRD) and often portends a poor prognosis, little is known about end-of-life care among these patients. Analysis of a national cohort of Medicare beneficiaries finds that patients with ESRD are far more likely than those without ESRD to undergo amputation during their final year of life. Among patients with ESRD, having a lower extremity amputation was associated with admission to and prolonged stays in acute and sub-acute care settings during their last year of life, as well as with dying in the hospital, discontinuing dialysis, and fewer days receiving hospice services. These findings likely signal unmet palliative care needs among seriously ill patients with ESRD who undergo lower extremity amputation. **Abstract:** <http://bit.ly/2E4ILZL>

### **A review of end-of-life care for people with dementia in U.K. care homes: Staff and family carer perceptions**

*JOURNAL OF COMMUNITY NURSING* | Inprint – Accessed 19 February 2019 – Dementia is the leading cause of death in England & Wales. Since the Dementia Strategy there has been an increasing emphasis on advance care planning (ACP), empowering people with dementia to express their wishes before mental capacity is lost, in order to promote a “good death” enabling them to “die well.” This literature review of end-of-life care for people with dementia in English care homes shows that dementia is still not widely regarded as a “terminal condition” and residents of care homes sometimes face unnecessary admissions to hospital in the dying phase. People with dementia at the end of their lives are still not accessing appropriate and timely palliative care routinely and ACP is still not part of routine dementia care despite the evidence and recommendations. This denies them the known benefits of reduced patient and carer distress, reduced hospital admissions, inappropriate treatments, upholding the principles of person centred care, decision making and ensuring that people with dementia can expect a “good death.” **Abstract:** <http://bit.ly/2EgGg6v>

**N.B.** Additional articles on ACP, advance directives and end-of-life decision-making for people living with Alzheimer’s disease and other forms of dementia noted in 18 February 2019 issue of Media Watch (#602, pp.8-9).

#### **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>



## Accounts of family conflict in home hospice care: The central role of autonomy for informal caregiver resilience

*JOURNAL OF FAMILY NURSING* | Online – 17 February 2019 – End-of-life caregiving is a highly stressful experience often fraught with conflict and tension. However, little is known about the ways family conflict manifests for informal caregivers of home hospice patients (IHCs). The purpose of this study was to provide nurses and other healthcare professionals with an empirical understanding of how IHCs experience family conflict and tensions associated with caregiving. A second aim was to determine what strategies IHCs use to manage these family conflicts. Data used in this qualitative secondary analysis were originally collected as part of a randomized clinical trial of an IHC support intervention. Based on thematic analysis of data from 25 IHCs who reported family conflict, a conceptual model of caregiver resilience was developed from the themes and categories that emerged during the coding stage. Autonomy was identified as a central tension. IHCs used several strategies to address family conflict including communication,

formal support, and emotional self-care. **Abstract:** <http://bit.ly/2EjpeVE>

### Challenging the meaning of home at the end of life

*ANTHROPOLOGY & AGING*, 2019;40(1):5-11. Older people have a lifetime of experience of homemaking, and therefore may have various and perhaps contradictory understandings of what is “home,” and what [is] not. People’s lived experience shapes the way they envision their death and process of dying. Older people can have specific ideas of what they want to happen in life, but their experience of their bodies, relationships and space can develop and evolve in unpredictable ways right up until the moment of death. Hence, the fluidity of and temporality of homemaking has to be taken into account when thinking about good policy and practice. By understanding “home” as a complex multi-layered concept, “home deaths” potentially could occur in any setting, may it be the dwelling, hospital, nursing home or hospice. **Full text (click on pdf icon):** <http://bit.ly/2loyUC3>

### Related

- *AMRC OPEN RESEARCH* | Online – 19 February 2019 – ‘**Adult family carers’ perceptions of their educational needs when providing end-of-life care: A systematic review of qualitative research.**’ Throughout the illness trajectory carers were either enabled or hindered in their role by the nature and way information and education were provided. Enabling factors included: a sense of trust in health professionals; timely and accurate information delivered compassionately; access to professionals for information and support particularly during out-of-hours. Where carers experienced a lack of information or support this added to the strain of caring. Carers then felt the need to take on a more active role, acting both as an advocate and decision maker. **Full text:** <http://bit.ly/2SidC93>
- *EUROPEAN JOURNAL OF CANCER CARE* | Online – 19 February 2019 – ‘**Barriers to the early integration of palliative home care into the disease trajectory of advanced cancer patients: A focus group study with palliative home care teams.**’ The findings of this study confirm the many barriers found in previous studies, such as lack of financial resources and the perception of palliative care (PC) as terminal care. Oncologists’ lack of knowledge about the content and role of PC is also confirmed. Furthermore, professional caregivers working in the home context are lacking information on oncology therapies necessary to provide optimal PC. **Abstract:** <http://bit.ly/2Eno4sf>

## Serious choices: A systematic [U.S.] environmental scan of decision aids and their use for seriously ill people near death

*JOURNAL OF HOSPITAL MEDICINE* | Online – 20 February 2019 – Seriously ill people near death face difficult decisions about life-sustaining treatments such as cardiopulmonary resuscitation and mechanical ventilation. Patient decision aids may improve alignment between patients’ preferences and the care they receive, but the quantity, quality, and routine use of these tools are unknown. The authors conducted a systematic environmental scan to identify all decision aids for seriously ill people at high risk of death facing choices about life-sustaining treatments, assess their quality, and



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explore their use in clinical settings. Concerning content, 14 of 27 decision aids for seriously ill people near death were for people with specific diseases and conditions (i.e., advanced cancer or kidney disease); concerned individual life-sustaining treatment decisions (i.e., cardiopulmonary resuscitation or mechanical ventilation). Only two focused on more general care pathways (i.e., life-sustaining intervention, palliative care, and hospice). Twenty-four of 27 decision aids presented options in a balanced way; 23 identified funding sources, and 19 of 27 reported their publication date. Just 11 used plain language. A minority, 11 of 27, listed evidence sources, five documented rigorous evidence-synthesis methods, six disclosed competing interests, and three offered update policies. Preliminary results suggest that few health systems use decision aids in routine patient care. Although many decision aids exist for life-sustaining treatment decisions during serious illness, the tools are deficient in some key quality areas.

**Abstract:** <http://bit.ly/2VhXztV>

#### Related

- *HEALTH EXPECTATIONS* | Online – 8 January 2019 – ‘**End-of-life priorities of older adults with terminal illness and caregivers: A qualitative consultation.**’ This consultation identified priorities and preferences by consumers through their experiences of end-of-life (EoL) care. It confirmed the health system still faces two persistent barriers to the delivery of satisfactory, safe and high quality EoL care for consumers: shortage of strategies to address the unmet needs of terminally ill older adults and caregivers, and the need for health professionals to deliver more skilled communication incorporating personal values. Unfounded perceptions that patients and carers are not open to EoL conversations or shared decisions on goals-of-care need to be revisited. **Full text:** <http://bit.ly/2NjSBdd>
- *INTERNAL MEDICINE JOURNAL* | Online – 20 February 2019 – ‘**Prevalence of advance care directives in the community: A telephone survey of three Australian States.**’ Despite long-standing efforts to increase advance care planning, community prevalence of advance care directives (ACDs) remains low, particularly for instructional ACDs. This study found some different predictors for instructional ACDs compared with appointing ACDs, and also a potential role for experiential factors in triggering uptake. These findings suggest supplementing general community awareness campaigns with more nuanced and targeted efforts to improve ACD completion. **Abstract:** <http://bit.ly/2U23qTT>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 February 2019 – ‘**Towards a conceptual model of affective predictions in palliative care.**’ How patients think they and others will feel in the future ... may influence difficult medical decisions. These affective predictions are often biased, which may contribute to sub-optimal care outcomes by influencing decisions related to palliative care (PC) and advance care planning (ACP). Three features of the PC and ACP context may contribute to biased affective predictions: 1) Early treatment decisions are made under heightened emotional states and with insufficient information; 2) PC decisions influence life domains beyond physical health; and, 3) PC decisions involve multiple people. **Abstract:** <http://bit.ly/2TcWR3x>
- *NEW BIOETHICS*, 2019;25(1):39-59. ‘**Should human rights and autonomy be the primary determinants for the disclosure of a decision to withhold futile resuscitation?**’ Do not attempt cardiopulmonary resuscitation decisions are considered good medical practice for those dying at the end of natural life. Historically, informing patients of these decisions was discretionary to avoid undue distress. Recent legal rulings have altered clinical guidance: disclosure is now all but obligatory. The basis for these legal judgments was respect for the patient’s autonomy as an expression of their human rights. This paper explores other bioethical considerations and the potential harms if they are ignored. **Abstract (inc. link to references):** <http://bit.ly/2Nkiw4w>

#### Development of curricular milestones for hospice and palliative medicine fellowship training in the U.S.

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 February 2019 – A physician workgroup of the American Academy of Hospice & Palliative Medicine sought to define curricular milestones (CM) for hospice and palliative medicine (HPM) fellowship programs. The developed list of CMs would serve as components upon which to organize curriculum and standardize what to teach during training. These would complement entrustable professional activities (EPA’s) previously developed by this group and new

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specialty specific reporting milestones (RM's) for HPM developed through the Accreditation Council for Graduate Medical Education. A group consensus method strengthened by inclusion of a national survey to HPM fellowship educators resulted in a CM document that is both carefully developed and broadly vetted. Along with EPA's and new specialty specific RM's, these CM's offer educators and trainees tools to create more comprehensive curricula and behaviorally based assessment tools for HPM fellowships and their stakeholders. **Abstract (inc. link to references):** <http://bit.ly/2NbBs5t>

### **Multiple stakeholders' perspectives regarding barriers to hospice enrollment in diverse patient populations [in the U.S.]: A qualitative study**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 February 2019 – Although studies show disparities in hospice care utilization, many questions remain regarding the causes of these disparities. Most studies focus on a single ethnic/racial group, and most utilize physician informants. None compare and contrast views of multiple stakeholders or utilize a systems approach within a single geographic region. Participants [in this study], self-identifying from a wide variety of ethnic backgrounds, included physicians, nurses, social workers, chaplains, nursing assistants, administrators and caregivers. Five themes emerged regarding patient and provider level barriers to hospice enrollment: 1) Universal challenges of goals-of-care (GoC) conversations; 2) Cultural norms and beliefs; 3) Language barriers; 4) Provider specific challenges; and, 5) Trust. In minority populations, the central theme of GoC conversation challenges was intensified by the other four themes. Suggested solutions included: 1) Increased palliative care training; 2) "Cultural interpreters" from local communities; 3) Specially trained "GoC language interpreters"; 4) Improved workforce diversity; and, 5) Community level advocacy. The disparity in hospice enrollment among diverse patient populations is a complex and nuanced problem involving numerous interrelated barriers. Addressing this disparity will require innovative solutions at multiple levels. **Abstract (inc. link to references):** <http://bit.ly/2DQFtYI>

### **Top ten tips palliative care clinicians should know about caring for patients with left ventricular assist devices**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 February 2019 – Left ventricular assist devices (LVADs) can improve both the quantity and quality of life for those suffering with advanced heart failure (HF). Palliative care (PC) clinicians are being asked with increasing frequency to assist HF teams to manage patients with LVADs in the pre-implantation, post-operative, and end-of-life (EoL) settings, although not all PC providers feel comfortable with this technology. This article seeks to improve PC providers' knowledge of LVADs and will prepare PC teams to counsel and support LVAD patients and their families from pre-implantation to the EoL. **Abstract:** <http://bit.ly/2E54zmN>

Noted in Media Watch 30 July 2018 (#574, p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 July 2018 – '**Getting to the heart of the matter: A regional survey of current hospice practices caring for patients with heart failure receiving advanced therapies.**' No guidelines exist regarding care for patients with advanced heart failure (HF) receiving hospice care while continuing advanced HF therapies such as left ventricular assist devices (LVADs) or continuous inotropes. Hospice specialists reported widely varied practice experiences caring for patients with HF receiving advanced therapies, noted specific challenges for care of these patients, and expressed a desire for targeted HF education. Forty-six respondents representing 23 hospices completed the survey. **Abstract:** <http://bit.ly/2EqtkE8>

### **Bereavement support in palliative care: A national survey of Australian services**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 February 2019 – The authors assessed equity of access to bereavement support across Australian palliative care (PC) services by using survey data to compare services according to location (metropolitan vs. regional). They also evaluated changes in bereavement support over the last decade by comparing findings to results of a previous Australian study.

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One hundred and eighty services (84%) responded. Of these, 91% provided bereavement support. Most offered support to all bereaved persons connected to the service. More than 80% of services provided a wide range of support types. Metropolitan services were more likely than regional services to offer specialist bereavement interventions. The staff most involved in coordinating and delivering bereavement support were social workers, nurses (particularly in regional areas), and bereavement coordinators/counselors (particularly in metropolitan areas). Resource limitations presented barriers to provision of bereavement support. Across Australia, in principle, access to bereavement support through PC services remains largely equitable. Nevertheless, observed variations in the type of professional delivering care and the level of support indicate that a more consistent approach is required. An increase in the range of supports available compared with a decade ago signifies a more comprehensive approach to bereavement support by many Australian PC services. **Abstract:** <http://bit.ly/2lxnplK>

### **Palliative care and public health: An asymmetrical relationship?**

*PALLIATIVE CARE: RESEARCH & TREATMENT* | Online – 20 February 2019 – Interest in the potential for public health (PH) and palliative care (PC) to work together is now widely established. Based on a mapping review of existing literature, the authors describe for the first time the ways in which PH has entered PC policy and practice and how this has been specifically articulated. They then go on to pursue analytical and critical lines of enquiry that are largely absent from the existing literature. The authors do this in three ways: 1) By considering why the link between PH and PC has become so ubiquitous within PC policy; 2) By establishing how this has been constructed; and, 3) By exploring PH as a “reference discipline” from which its “secondary deployment” can become embedded inside another disciplinary field. From this, the authors develop a range of critical perspectives on the relationship between PH and PC by scrutinising its claims of utility and effectiveness and questioning the strength of the interdisciplinary interaction between the two disciplines. They see their relationship in a “cross disciplinary” context which is still largely symbolic and tactical in nature. The authors conclude by considering the significance of these insights for policy and practice, with two possible scenarios. If the use of PH is essentially figurative and its resources are not unique, the particular and exclusive use of the term becomes insignificant. Progressive and effective policy and practice is possible, independent of any explicit PH label. If however PH is considered to have intrinsic and definable worth, the authors suggest that this currently asymmetrical association needs to be significantly developed with much higher levels of theoretical, practical and critical engagement between the two disciplines. Such work would result in more reflective and robust policy and practice. **Full text:** <http://bit.ly/2Xhk1oG>

Noted in Media Watch 4 February 2019 (#600, p.9):

- *HEALTH PROMOTION INTERNATIONAL* | Online – 27 January 2019 – ‘**Unpacking “the cloud”: A framework for implementing public health approaches to palliative care.**’ The Health Impact Change Model (HICM) was developed to unpack the complexities associated with the implementation and evaluation of a Canadian compassionate communities intervention. The HICM offers utility for citizens, leaders and decision-makers who are engaged in the implementation of population health level strategies or other social approaches to care, such as compassionate cities and age or dementia-friendly communities. The HICM’s concepts can be adapted to address a community’s healthcare context, needs, and goals for change. **Abstract:** <http://bit.ly/2RrPpgd>

**N.B.** Additional articles on public health approaches to PC noted in this issue of Media Watch.



Media Watch: Behind the Scenes

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



Closing the Gap Between Knowledge & Technology

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

## Primary palliative care in southern Brazil: The legacy of Cicely Saunders

*PALLIATIVE CARE: RESEARCH & TREATMENT* | Online – 18 February 2019 – Sixty years after publication of her first article and 100 years after she was born, the legacy of Cicely Saunders still resonates. In the cases presented, we see many echoes of the “total pain” she first described in 1964. As the authors try to show, the context of suffering is also highly relevant to its understanding and amelioration. Poverty, a lack of resources, barriers to accessing medication, difficulties in obtaining specialist appointments and diagnostic examinations, these all frame a set of experiences that require greater priority from public policies. Combined with personal and psychological problems, spiritual concerns and challenging family circumstances, they create a form of “structural violence” that is inflicted on whole communities and which exacerbates the experience of illness and loss. *Estar ao Seu Lado* [Cuidados Paliativos na Atenção Primária] is one of the few primary palliative care (PC) projects in Brazil and advocates for greater PC awareness and the need to build compassionate communities. It is here, in local communities, that PC has much to offer, alongside and within the provision of primary care services. It is here that early identification of people who can benefit from PC interventions can take place. It is here that a person can be followed through the trajectory of illness and where family members can be supported, including in bereavement. As Cicely Saunders recognised, a pro-active attitude, specific skills and competencies and attention to the essence of care can have powerful effects. She once observed “we are caring for persons and as persons.” To this, we can add persons in community. We need to better understand how PC can operate in community contexts of many types as well as how and if ‘compassionate communities’ can be fostered and sustained. The stories presented here, echoing Cicely Saunders’ approach, indicate there is much important and necessary work to be done. **Full text:** <http://bit.ly/2SZm29Q>

## What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis

*PALLIATIVE MEDICINE* | Online – 18 February 2019 – The number of older people living and dying with frailty is rising, but our understanding of their end-of-life (EoL) care needs is limited. A total of 4,998 articles were retrieved. Twenty met the inclusion criteria, providing evidence from 92,448 individuals (18,698 with frailty) across seven countries. Thirteen different measures or definitions of frailty were used. People with frailty experience pain and emotional distress at levels similar to people with cancer and also report a range of physical and psychosocial needs, including weakness and anxiety. Functional support needs were high and were highest where people with frailty were cognitively impaired. Individuals with frailty often expressed a preference for reduced intervention, but these preferences were not always observed at critical phases of care. People with frailty have varied physical and psychosocial needs at the EoL that may benefit from palliative care. **Abstract:** <http://bit.ly/2SaPIMz>

Noted in Media Watch 1 October 2018 (#583, p.9):

- *BMC MEDICINE* | Online – 21 September 2018 – ‘**Frailty trajectories to identify end of life: A longitudinal population-based study.**’ This longitudinal population-based study demonstrates that it is possible to use a frailty index calculated within electronic healthcare records to identify people who are at a higher risk of dying within one year. This has potential application in health services to support clinicians in identifying older adults dying with frailty who may have been overlooked by traditional approaches and to help ensure appropriate care is offered. **Full text:** <http://bit.ly/2GyMuRw>

**N.B.** Additional articles on recognising older frail patients near the end of life noted in 8 January 2018 issue of Media Watch (#545, p.5).



### Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.17.

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMC MEDICAL ETHICS* | Online – 18 February 2019 – ‘**Truth-telling and doctor-assisted death as perceived by Israeli physicians.**’ Close to 60% of the [survey] respondents supported doctor-assisted death, while one third rejected it. Half of the respondents opposed disclosure of the full truth about a poor medical prognosis, and the others supported it. Support for truth-telling was higher among younger physicians, and support for doctor-assisted death was higher among females and among physicians practicing in hospitals. One quarter of respondents supported both truth-telling and assisted death, thereby exhibiting respect for patients’ autonomy. This approach characterizes younger doctors and is less frequent among general practitioners. Another quarter of the respondents rejected truth-telling, yet supported assisted death, thereby manifesting compassionate pragmatism. This was associated with medical education, being more frequent among doctors educated in Israel, than those educated abroad. All this suggests that both personal attributes and professional experience affect attitudes of physicians to ethical questions. **Full text:** <http://bit.ly/2EgvRba>
- *BMC MEDICINE* | Online – 19 February 2019 – ‘**Factors associated with requesting and receiving euthanasia: A nationwide mortality follow-back study [in The Netherlands] with a focus on patients with psychiatric disorders, dementia, or an accumulation of health problems related to old age.**’ A relatively small group of people who died non-suddenly received euthanasia and assisted suicide (EAS), but even fewer of those with (also) psychiatric disorders, dementia, or an accumulation of health problems. Partly, this can be explained by the belief that the due care criteria cannot be met. Another explanation is that patients with these conditions are less likely to request for it. Given the aging society and the related rising of the number of EAS requests from people suffering from dementia and/or an accumulation of health problems, the question of how policy makers and care providers should respond to these requests is highly relevant. EAS in deceased patients with psychiatric disorders, dementia, and/or an accumulation of health problems is relatively rare. Partly, this can be explained by the belief that the due care criteria cannot be met. Another explanation is that patients with these conditions are less likely to request EAS. **Full text:** <http://bit.ly/2NlyeMH>
- *BMC PSYCHIATRY* | Online – 19 February 2019 – ‘**Euthanasia and physician-assisted suicide in patients suffering from psychiatric disorders: A cross-sectional study exploring the experiences of Dutch psychiatrists.**’ Although the incidence of euthanasia and assisted suicide EAS (requests) from psychiatric patients increased over the past two decades, EAS in psychiatric patients remains relatively rare. This is most likely due to difficulties for psychiatric patients to meet the due care criteria and for psychiatrists to determine whether the criteria are met. Training and support might enable psychiatrists to address this complex and sensitive issue in their work better. **Full text:** <http://bit.ly/2U19OdP>
- *MORTALITY* | Online – 17 February 2019 – ‘**Pathos, death talk and palliative care in the assisted dying debate in Victoria, Australia.**’ Many submissions made by individuals to an Australian Parliamentary inquiry into end-of-life care (EoLC) which supported assisted dying used narratives of bad deaths of family or friends, or included stories by people suffering from chronic terminal illness. The submissions used the emotional tugs (pathos) of these narratives to support their case and to highlight the contemporary weaknesses of EoLC. This paper analyses the submissions, showing how pathos-based arguments were used in the public debate. Pathos-based arguments are a significant – and potentially very influential – feature in the debate on assisted dying. This paper also analyses the arguments advanced by proponents of assisted dying to show the weaknesses of Victoria’s current arrangements for EoLC, including the significant suffering of family member or friends; lack of access to good palliative care; and that patient needs were not met, sometimes for religious or value-based reasons. **Abstract:** <http://bit.ly/2ljEtBL>
- *PROFESSIONAL PSYCHOLOGY: RESEARCH & PRACTICE*, 2019;50(1):39-50. ‘**If physician-assisted suicide is the modern woman’s last powerful choice, why are White women its leading advocates and main users?**’ Women, particularly educated White women, are at the forefront of the U.S. physician-assisted-suicide (PAS) legalization movement, as advocates and leaders. They also represent half of decedents by PAS, though they are a minority among unassisted-suicide decedents. The dominant PAS narrative is framed in terms of choice. This article focuses on the rhetoric and the

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reality of choice in PAS for White women in the U.S., consistent with an intersectional perspective and with attention to context. It examines the idea of choice in PAS in light of women's lives, and also considering dominant narratives of PAS and of femininity. A mix of privilege (e.g., White women's good-enough experiences with medical systems, relative to ethnic-minority women) and disadvantage (e.g., White women's economic and care challenges, given their longevity but in poor health), combined with dominant PAS rhetoric (e.g., PAS as a death of dignity and graceful self-determination) and dominant-femininity ideals (e.g., femininity as graceful self-abnegation), likely contribute to White women's strong participation in PAS. The implications for professional psychology of intersectional and contextual perspectives on discourses and practices are discussed. **Abstract:** <http://bit.ly/2Nd2JEU>

- **UNIVERSITY OF NOTRE DAME AUSTRALIA LAW REVIEW** | Online – Accessed 23 February 2019 – **'The media's failure to report on religious voices in the public square: The euthanasia debate as a test case.'** Good facts are necessary for good ethics, so let's start by taking the current euthanasia/physician-assisted suicide debate in Australia as a situation in which to explore the media's unbalanced reporting in their failure to report anti-euthanasia voices – often religious ones – in the public square in this debate, and their fulsome reporting of the pro-euthanasia voices. It shows the very one-sided, pro-euthanasia approach taken by the media, whether by reporting and supporting the pro case or suppressing the anti-euthanasia one. Sometimes, suppression of the anti-euthanasia arguments is overt and direct. In considering the topic of religious liberty and the media, we must address the question, "What is the media's role and what is ethically required of them in relation to fair and balanced reporting by including in their reports the arguments of religious voices in the public square and, in particular, in relation to decisions about important foundational societal values, such as the legalizing of euthanasia debate entails?" Freedom of religion ... requires freedom of speech and expression, which includes freedom of communication. The media are the major gatekeepers of the opportunities to communicate in the public square and they must fulfill that role ethically. This requires identifying situations which involve "positive gatekeeping" (the gatekeeper's decision results in a positive benefit for the gatekeeper or his or her allies) and "negative gatekeeping" (the gatekeeper's decision harms another to the benefit of the gatekeeper or his or her allies) which are both unethical conflict of interest situations that must be avoided. We should also keep in mind that information communicated through mainstream media (MSM) has a credibility that information communicated through other channels does not and that means fairness in access to communicating through MSM is ethically required. And finally, if the reader of this article is that rare bird, a journalist with socially conservative values, then *noli timere* – be not afraid – and *bon courage*. **Download/view full text at:** <http://bit.ly/2tzs5Du>

## [Publishing Matters](#)

### **Predatory journals: Do not judge journals by their editorial board members**

*MEDICAL TEACHER* | Online – 22 February 2019 – Given that often the quality of journals is based on its editors, the objective of this study was to describe quantitatively the profiles of members of editorial boards (MEBs) of presumed predatory journals. The following information was retrieved from 1,015 editors taken from journals listed in Beall's list: country, university, position, and degree. The Scopus website was used to identify the number of citations, documents, and h-index. Presumed open access predatory journals are including all types of profiles as their MEBs, which include fake and unqualified editors, but mostly very high-qualified scientists who are professors, medical doctors and/or had a PhD. MEBs were located in 74 different countries, most had an affiliation in the U.S. (44.4%). The median of publications per editor was 43, number of citations 664 and h-index 14. The results dispute the common belief that it is possible to identify predatory journals by checking their editorial boards. Scientists should not rely on the editors to determine if a journal is predatory. If an author has doubt, the editors should be contacted. **Abstract:** <http://bit.ly/2E4rSgC>



**N.B.** A cautionary tale: Not too long ago, I stumbled across a case in which a distinguished university professor in the U.K. was unaware that he was listed as a member of the editorial board of a palliative care journal. Alerted to this fact, swift action by the university's legal department resulted in the professor's name being promptly removed from the list. **BRA**

## To maintain trust in science, lose the peer review

*MEDSCAPE* | Online – 19 February 2019 – “Trust me, I’m a doctor.” In the Internet age, that phrase has never been more fraught. Uncertainty is the rule in medicine and science. In an ideal world, doctors, scientists, and laypeople would independently evaluate the evidence behind any scientific or medical statement. Instead, scientific and medical evidence increasingly comes from small groups of sub-specialists who write in obscure prose for academic publications that few can access. That leaves the media to disseminate findings from thinly read scientific journal articles that are held up as totems of authority. But there’s a hitch. The Internet’s democratization of all voices allows misinformation – unintentional or malicious – to easily spread. Experts are scared. Recently, the editors-in-chief of the world’s top cardiology journals issued a joint statement warning about the spread of medical misinformation.<sup>1</sup> Their examples were patient distrust in statins and vaccines. These editors warn us that “individuals who are neither physicians nor scientists, but often with a specific agenda, have outsized influence over our lives.” They exhort the media to “do a better job.” [See side bar right.] The editors claim that they carefully evaluate each piece of information their journals publish because “lives are at stake.” In truth, scientific journals have always been a weak check on misinformation. For every journal article published, only a few volunteer reviewers evaluate the work before publication. The vulne-

rabilities of “peer review” have been described even by those charged with managing it, such as former *British Medical Journal* editor Richard Smith.<sup>2</sup> He and his colleagues have intentionally introduced errors into manuscripts sent for peer review, and found that these deliberate errors were often missed. Reviewers vary greatly in how closely they examine a manuscript; they often have their own agenda and conflicts biasing their evaluation; if flaws are identified after publication, the study is almost never retracted.<sup>3</sup>

**Full text:** <https://wb.md/2SR2cy8>

### A journalist’s guide to writing health stories

The print and electronic media have an enormous influence on how the public views health issues. Both health policymakers and scientists recognize journalists’ effect on public understanding. Reporting health stories requires judgment about how to interpret evidence and about the implications of evidence for the public. But most journalists have little formal training in assessing the validity of evidence that bears on health issues, so inaccurate or deceptive reporting seems common. To begin to address this problem, we have built on others’ work and developed a set of guidelines to help journalists understand and interpret health stories.<sup>1</sup>

1. ‘A Journalist’s Guide to Writing Health Stories,’ *American Medical Writers Association Journal*, 1999;14(1): 32-42. **Download view at:** <http://bit.ly/2Xis1Wf>

1. ‘Medical misinformation: Vet the message!’ *Journal of the American Heart Association*, published online 28 January 2019. **Full text:** <http://bit.ly/2EoYKIt>
2. ‘Peer review: A flawed process at the heart of science and journals,’ *Journal of the Royal Society of Medicine*, 2006;99(4):178-182. **Full text (via PubMed):** <http://bit.ly/2Vcbots>
3. ‘What a massive database of retracted papers reveals about science publishing’s “death penalty,”’ *Science*, published online 25 January 2018. **Full text:** <http://bit.ly/2GCCwPe>

### 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.

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### 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://bit.ly/2ThijkC](http://bit.ly/2ThijkC)**

### Media Watch: Access on Online

#### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/2HyIG5w>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU> ]

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2G2jqko>

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

#### **Canada**



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

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#### **Europe**



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <http://bit.ly/2G2tf1W>

HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

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U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

**South America**

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

**United States**

NEBRASKA | Center for Health Policy & Ethics, Creighton University: <http://bit.ly/2DAED3f>

[Scroll down to 'Barry Ashpole's Media Watch']

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