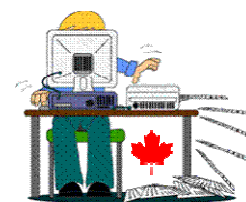


## Media Watch...

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.

6 May 2019 Edition | Issue #613



Compilation of Media Watch 2008-2019 ©

Compiled & Annotated by Barry R. Ashpole

**Important notice: The next issue of Media Watch will be published the w/o 20 May 2019. I am relocating and will need a few days “breather” to set up house, home – and office. Thank you for your understanding. BRA**

## Canada

### 10 Myths about palliative care infographic

CANADIAN VIRTUAL HOSPICE | Online – Accessed 2 May 2019 – Palliative care (PC) is still widely misunderstood in Canada. Canadian Virtual Hospice has developed an infographic about 10 myths that are often encountered in PC: 1) PC hastens death; 2) PC is only for people dying of cancer; 3) People in PC who stop eating die of starvation; 4) PC is only provided in a hospital; 5) We need to protect children from being exposed to death and dying; 6) Pain is part of dying; 7) Taking pain medication in PC leads to addiction; 8) Morphine is administered to hasten death; 9) PC means my doctor has given up and there is no hope for me; and, 10) I've let my family member down because he/she didn't die at home. The infographic is now available in French, Arabic, Catalan, Chinese, Cree, Hebrew, Inuinnaqtun, Japanese, Spanish and Tagalog. **Download/view English language infographic at:** <http://bit.ly/2LsnrU>

**N.B.** Links to non-English language infographics: <http://bit.ly/2DN3zEv>

### Specialist Publications

**'Canadian French and English newspapers' portrayals of physicians' role and medical assistance in dying (MAiD) from 1972 to 2016: A qualitative textual analysis'** (p.14), in *BMJ Open*.

**'Medical assistance in dying: Alberta approach and policy analysis'** (p.14), in *Canadian Journal on Ageing*.

**'Morality politics of physician-assisted suicide: Comparing Canada and the U.S.'** (p.15), in *International Journal of Canadian Studies*.

**'Comparing the attitudes of four groups of stakeholders from Quebec, Canada, toward extending medical aid in dying to incompetent patients with dementia'** (p.15), in *International Journal of Geriatric Psychiatry*.



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## U.S.A.

### **A rising trend in cancer care targets physical, existential threats patients confront**

*THE WASHINGTON POST* | Online – 4 May 2019 – Often called palliative care (PC) or integrative medicine, the comprehensive approach focuses on patients' emotional needs and physical symptoms in addition to treating the disease. In 2016 [*sic*], 1,831 U.S. hospitals – about three-quarters – had a PC program, compared to less than one-quarter in 2000, according to the Center to Advance Palliative Care.<sup>1</sup> While PC is often associated with terminal cases – and often confused with end-of-life hospice care – it's actually designed for patients suffering from many types of serious illnesses, regardless of how long they're expected to live. Cancer specialists have long recognized the importance of addressing patients' emotional concerns since the 1970s, when the field of psycho-oncology was

created. Studies have found that nearly a quarter of cancer patients suffer from depression, and cancer survivors are 50% more likely to die by suicide than the general population. Cancer specialists have long recognized the importance of addressing patients' emotional concerns since the 1970s, when the field of psycho-oncology was created. <https://wapo.st/2LiQGYW>

#### **Specialist Publications**

'Awareness of palliative care among a nationally representative sample of U.S. adults' (p.9), in *Journal of Palliative Medicine*.

1. 'Palliative care continues its annual growth trend...', Center to Advance Palliative Care, February 2018. Download/view at: <http://bit.ly/2Ydtn4D>

### **New palliative care playbook to support hospices in the provision of community-based palliative care**

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 30 April 2019 – The 'Palliative Care Playbook for Hospices' provides step-by-step instructions developed by hospice experts, to guide hospices in the development, implementation, and sustainability of a community-based palliative care program. Download/view at: <http://bit.ly/2DCrYfS>

### **Will ties to a Catholic hospital system tie doctors' hands?**

CALIFORNIA | *Kaiser Health News* – 29 April 2019 – As Catholic healthcare systems across the country expand, the University of California's flagship San Francisco (UCSF) hospital has become the latest arena for an emotional debate: Should the famously progressive medical center increase its treatment space by joining forces with a Catholic-run system that restricts care according to religious doctrine? At issue is a proposal that UCSF Medical Center affiliate with Dignity Health, a massive Catholic healthcare system that, like other Catholic chains, is bound by ethical and religious directives from the U.S. Conference of Catholic Bishops. Among other prohibitions on services, Dignity hospitals ban abortions unless the mother's life is at risk, in vitro fertilization and physician-assisted death. The affiliation would not keep UCSF from performing such procedures at its own medical center and outpatient clinics, and both entities would remain independent. UC doctors with practicing privileges at Dignity would be free to discuss all treatment options and could refer patients to other facilities when necessary. But they would have to abide by Dignity's care restrictions while practicing at Dignity hospitals. For opponents of the plan, the issue boils down to a clear-cut principle: How can a public hospital that has been a leader in women's healthcare and medical services for the gay and transgender community partner with a private system that not only denies such services but also casts them as immoral? <http://bit.ly/2vtsmJ6>

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Would this article be of interest to a colleague?

Noted in Media Watch 18 March 2019 (#606, p.7):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2019;321(11):1103-1104. ‘**Disclosure of religious identity and healthcare practices on Catholic hospital websites.**’ Among U.S. Catholic hospitals, 21% did not explicitly disclose their Catholic identity on their websites, and only 28% specified how religious affiliation might influence patient care. A recent review demonstrated that patients are more likely to encounter reproductive restrictions at Catholic facilities compared with non-Catholic facilities; less is known about end-of-life care restrictions. If patients are unaware of the affiliation and encounter restrictions, refusal of or delay in care due to the need to go elsewhere can result in increased medical risk and contribute to wasted healthcare expenditures. **Full text:** <http://bit.ly/2TAZX2e>

**N.B.** Additional articles on Catholic perspectives on palliative and end-of-life care in the U.S. noted in 13 August 2018 issue of Media Watch (#576, p.2) and in 6 November 2017 issue of the weekly report (#537, pp.8-9).

## How to make doctors think about death

*THE NEW YORK TIMES* | Online – 27 April 2019 – Modern healthcare accomplishes great feats of healing every day. But life ends; there are patients for whom real healing has become impossible. Their bodies have simply taken too many hits. Aggressive care can push back their death for a few days, but it is unlikely to keep them from dying soon. These situations tend to be obvious to clinical staff, and especially nurses. We administer the hands-on care. But for those around us – physicians, families and the hospital generally – they are not at all clear, and too easily clouded by emotion. That’s why we need end-of-life treatment guidelines. Such guidelines exist for a host of conditions: cardiac arrest, diabetes, depression. Though they can be controversial – viewed as too restrictive in some cases, in other instances too loose – they set a bar for an appropriate course of care. A simple treatment guideline for clinical situations like my octogenarian patient’s might look like this: For patients who have one terminal illness that is either resistant to treatment or can’t be safely treated, combined with a second very serious illness or complication, along with a high degree of physiological frailty, physicians should consider comfort measures instead of cure. To me, a hospice nurse, this guideline reads like common sense. <https://nyti.ms/2UO2mSU>

## International

### End-of-life care in Australia

#### **Doctors slam Queensland’s palliative care “lottery”**

AUSTRALIA (Queensland) | *Yahoo News* – 28 April 2019 – Many Queenslanders die before their palliative care (PC) packages are approved, doctors say in a damning submission to a state government inquiry. The state government is delving into the adequacy of aged care, end-of-life and PC, and whether there is support for state laws to allow voluntary assisted dying. Specialist PC doctors say there’s a yawning gap between demand and the capacity to support dying Queenslanders, and the situation can no longer be ignored. They say patients and their families are struggling to negotiate the complexities in arranging care and sometimes it’s not available, particularly in regional and remote communities. Wrangling with the likes of National Disability Insurance Scheme, My Aged Care and Queensland Community Care is resulting in “unacceptable delays in provision of care, or in

some instances no care at all,” the Queensland Specialist Palliative Care Services Directors’ Group says in its submission. The doctors paint a dire picture of what it’s like for terminally ill Queenslanders in regional and remote centres, which often lack direct access to specialist PC. The inquiry is due to report back to the government by 30 November. <https://yhoo.it/2VDc1QE>

### Specialist Publications

‘**Goals-of-care discussions for adult patients nearing end of life in emergency departments: A systematic review**’ (p.7), in *Emergency Medicine Australasia*.

‘**Tracking end-of-life decisions: A survey**’ (p.10), in *Medical Journal of Australia*.

## Aging in Thailand : Nation must learn to talk about death

THAILAND | *Business News* (Bangkok) – 27 April 2019 – Refusing life-sustaining medical technology during one’s terminal illness is now the right of every Thai under the law. Yet most people still don’t know about this. Nor do they know about palliative care (PC) services which help terminal patients die “naturally” and comfortably instead of being kept alive artificially. According to recent research ... more than 75% of Thai people do not know that PC is available for terminal patients.<sup>1</sup> Moreover, 79% have not heard of a “living will,” a written directive prepared in advance to refuse life-prolonging medical technology. Why do the majority of Thais refuse to prepare themselves for a good death? The reason is simple. It’s still a huge taboo to talk about death in Thai society. Bringing it up is considered a bad omen, a curse even. Even when one is not afraid of death for oneself, suggesting preparations for the imminent death of a family member who has a chronic or severe illness is blasphemy, making that person blatantly rude in the eyes of others. <http://bit.ly/2GRxPJG>

1. ‘Greying nation must talk about death,’ an overview of ‘Public Awareness and Attitudes toward Palliative Care in Thailand,’ Thailand Development Research Institute, April 2019. <http://bit.ly/2W6fsMV>

## Specialist Publications

### When clinical advances outpace ethics

*AMA JOURNAL OF ETHICS*, 2019;21(5):E375-379. Many factors motivate the continued advancement and use of life-sustaining therapies. In an era of “do everything” medicine, the tendency to prolong life by whatever means necessary should be mitigated by caution in order to avoid inappropriate uses of these therapies for heart failure. Professional society guidelines are lacking, and hospital policies regarding the use of mechanical circulatory support vary widely. In this issue of *AMA Journal of Ethics*, contributors use the evolution of cardiopulmonary resuscitation (CPR) and hemodialysis to illustrate the successes and warn of the pitfalls of extracorporeal membrane oxygenation (ECMO). In addition to their practical implications, life-sustaining therapies have deep philosophical underpinnings that are worth exploring. As long as illness and disease plague patients, virtue and ingenuity can inspire physicians to propel medicine forward. This theme issue explores clinical and ethical complexities of life-sustaining technologies, such as left ventricular assist devices and ECMO, and offers a path forward. We must educate physicians, develop and refine policies, and promote interdisciplinary collaboration when caring for patients with heart failure. **Full text:** <http://bit.ly/2VJmUAD>

### **Palliative care for patients on mechanical circulatory support**

*AMA JOURNAL OF ETHICS*, 2019;21(5):E435-442. Palliative care (PC) teams are primed to support patients with advanced illness, including patients with mechanical circulatory support (MCS), and are increasingly being called upon to help care for these patients. Detailed guidelines for PC engagement are lacking despite key stakeholders’ endorsements of collaboration. PC should encompass the decision-making period, the duration of therapy, and end-of-life care. PC teams can assist with symptom management, advance care planning, and communication across the continuum of MCS care. However, the current state of MCS and PC collaboration is variable and can be hindered by staffing challenges and clinician discomfort. To best care for patients who receive advanced cardiopulmonary life-sustaining therapies, meaningful engagement of PC during all phases of MCS is essential. **Full text:** <http://bit.ly/2JdmziP>

**N.B.** Additional articles on PC for patients living with heart failure noted in 4 March 2019 issue of *Media Watch* (#604, p.8)

**N.B.** Journal contents page: <http://bit.ly/2GXVTRE>

## Examining the artist-patient relationship in palliative care. A thematic analysis of artist reflections on encounters with palliative patients

*ARTS & HEALTH*, 2019;11(1):67-78. Although therapeutic arts are used in the palliative care (PC) setting, little has been described about what happens during the artist-patient encounter and how these interactions can complement and integrate into the interdisciplinary model of PC. The authors reviewed 229 reports written by artists about encounters with palliative patients, and performed thematic analysis on 95. Artists describe physical, emotional and spiritual responses by patients including relaxation, invigoration and accessing spirituality, some of which were unique to the artist-patient interaction. Artists also described personal reactions including themes of professional fulfillment, kinship and empathy with patient suffering. Themes surrounding the artist-patient bond and trust also emerged. The artist-patient encounter has an effect on both patients and artists, and can create a therapeutic relationship between them. Artists provide unique perspectives and contribute to care paradigms when integrated with the palliative team.

**Abstract (w. link to references):** <http://bit.ly/2WgagWU>

### [Publishing Matters](#)

'Editors should declare conflicts of interest' (p.15), in *Journal of Bioethical Inquiry*.

'Cabell's predatory journal blacklist: An updated review' (p.16), in *The Scholarly Kitchen*.

## Prediction of life-story narrative for end-of-life surrogate's decision-making is inadequate...

*BMC MEDICAL ETHICS* | Online – 3 May 2019 – Substituted judgment assumes adequate knowledge of patient's mind-set. However, surrogates' prediction of individual healthcare decisions is often inadequate and may be based on shared background rather than patient-specific knowledge. It is not known whether surrogate's prediction of patient's integrative life-story narrative is better. The results of this study support the following main conclusions: 1) Intra-family predictions of life-story narrative, decision-control preference, and healthcare-outcomes acceptability were similarly inadequate and were not associated with expressed confidence in surrogate's decision-making or familiarity with healthcare-outcomes preferences; 2) Even in non-stressful settings and despite being specifically directed, surrogates were more likely to project their own life-story narratives than to simulate those of their family members; 3) The accuracy of adjusted prediction of life-story narrative was more than expected by chance or by having similar background, positively associated with surrogate's decision-making confidence, and highest in the sibling-sibling sub-group and lowest in the parent-child subgroup; and, 4) In contrast, prediction accuracy of decision-control preference and healthcare-outcomes acceptability were not associated with surrogate's decision-making confidence or familiarity with healthcare-preferences. However, prediction accuracy of healthcare-outcomes acceptability was also highest in the sibling-sibling subgroup and worse in the parent-child subgroup. **Full text:** <http://bit.ly/2IZP2tr>

## Palliative care for patients with motor neurone disease and their bereaved carers: A qualitative study

*BMC PALLIATIVE CARE* | Online – 26 April 2019 – This qualitative study, involving sample of 13 bereaved carers recruited using the Northern Ireland Motor Neurone Disease (MND) Register, illuminated the need for the integration of neurology and palliative care (PC) when designing services for patients with MND as a key priority. This would facilitate the sharing of expertise and better support healthcare professionals to engage in advance care planning with patients with MND, and their carers. In addition a good understanding of neuromuscular respiratory impairment and its overlap with psychological symptoms at the end of life in MND is imperative for those delivering PC to patients. This would enable symptoms to be identified in a timely manner and effectively managed. Finally, establishing the optimal model of integration of neurology and specialist PC services could serve as a template for the management of other progressive neurodegenerative disorders. **Full text:** <http://bit.ly/2UMDDPb>

Cont.

Noted in Media Watch 28 January 2019 (#599, p.13):

- *PALLIATIVE CARE: RESEARCH & TREATMENT* | Online – 21 January 2019 – ‘**Palliative care in motor neurone disease: Where are we now?**’ Palliative care has an important role in the care of patients with motor neurone disease and their families. There is increasing emphasis on the multidisciplinary assessment and support of patients within guidelines, supported by research, including the telling of the diagnosis, the assessment and management of symptoms, consideration of interventions, such as gastrostomy and ventilatory support, and care at the end of life. **Full text:** <http://bit.ly/2TemjTa>

Noted in Media Watch 25 January 2016 (#446, p.10):

- *BRITISH JOURNAL OF OCCUPATIONAL THERAPY* | Online – 14 January 2016 – ‘**Existential concerns for people with motor neurone disease: Who is listening to their needs, priorities and preferences?**’ The U.K. Motor Neurone Disease Association practice guidelines recommend that multidisciplinary health and social care professionals should focus upon psychological, functional and medical management.<sup>1</sup> Valuable opportunities may be lost to discuss and document patient needs, priorities and preferences for end-of-life care before a person loses their ability to communicate by any means. **Abstract:** <http://bit.ly/2UKQ4uL>

1. ‘Palliative and end-of-life care,’ Motor Neurone Disease Association, 2015. **Download/view at:** <http://bit.ly/2XOVff5>

### **Palliative care for patients with communication and cognitive difficulties**

*CANADIAN FAMILY PHYSICIAN*, 2019;65(Suppl 1):S19-S24. Pain and psychological and emotional distress are important issues for individuals with intellectual and developmental disabilities (IDD), as they can be difficult to assess and measure, and often present atypically, especially in those with limited communication skills. Further, little is known about end-of-life (EoL) needs in the adult population with IDD, especially for those living in community residences. The conducted literature review of patient, caregiver, and clinician experiences exposed considerable barriers, including incorrect assumptions about patients’ capacity to understand and discomfort of both caregivers and clinicians with open communication. This has resulted in exclusion of adults with IDD from their own care, which has proven harmful. Maximizing time in familiar surroundings and establishing trust and continuity are crucial. Sometimes trial and error with empiric use of comfort medications is necessary, but this can be mitigated with careful examination of distress patterns and judicious use of diagnostic testing. It is always best to integrate the palliative approach into the existing pattern of care. The validated tools and recommendations provided will assist with communication, symptom interpretation, treatment decisions, advanced care planning, addressing grief, and important considerations in EoL care. **Full text:** <http://bit.ly/2DCuH93>

Noted in Media Watch 11 February 2019 (#601, p.15):

- *RESEARCH IN DEVELOPMENTAL DISABILITIES*, 2019;87(4):21-30. ‘**Personal relationships during end-of-life care: Support staff views of issues for individuals with intellectual disability.**’ Life expectancy for persons with intellectual disability has increased dramatically over the past decade, which has seen an associated rise in the need for end-of-life care. Analysis identified three key thematic areas: 1) Relationships with family, relationships with friends and staff roles; 2) Relationships with friends had two sub-themes of “positive experiences” and “negative experiences”; and, 3) Staff roles had two sub-themes of “loss of contact” and “default decision making.” A lack of counselling support was noted as potentially impairing the individual’s friends’ ability to cope with death. **Abstract:** <http://bit.ly/2TASJav>

**N.B.** Additional articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in 26 November 2018 issue of Media Watch (#591, pp.13-14).



Closing the Gap Between Knowledge & Technology  
<http://bit.ly/2DANDFB>

## **High-intensity end-of-life care among children, adolescents, and young adults with cancer who die in the hospital: A population-based study from the French national hospital database**

*CANCER* | Online – Accessed 1 May 2019 – Efforts to improve the quality of end-of-life (EoL) care depend on better knowledge of the care that children, adolescents, and young adults with cancer receive, including high-intensity EoL (HI-EoL) care. This population-based, retrospective study included 1,899 individuals from 345 hospitals; 61.4% experienced HI-EoL care. HI-EoL was increased with social disadvantage, hematological malignancies, complex chronic conditions, and care delivered in a specialty center. HI-EoL was reduced in cases of palliative care. These findings should now be discussed with patients, families, and professionals to define the optimal EoL. **Abstract:** <http://bit.ly/2GYaP2t>

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

## **Trends in site of death and healthcare utilization at the end of life: A population-based cohort study**

*CMAJ OPEN* | Online – 26 April 2019 – In this population-level retrospective cohort study of adult decedents in Ontario, Canada, the authors found decreasing rates of deaths in hospital and a corresponding increase in the provision of palliative care to dying Canadians. However, other markers of end-of-life (EoL) care did not change over time, with about three-quarters of decedents being admitted to hospital and about 1 in 5 being admitted to the ICU during the last 6 months of life. Rates of hospitalization before death were higher for those living in more rural and economically disadvantaged neighbourhoods. It is possible that increased capacity for palliative, hospice and home care at the EoL may help to better align health system resources with the preferences of most patients, a topic that should be explored in future studies. **Full text:** <http://bit.ly/2LafgLJ>

## **Recruitment and retention in clinical and experimental bereavement research: Lessons learned from creating a research registry**

*DEATH STUDIES* | Online – 3 May 2019 – A small body of research investigates recruitment and retention of bereaved people in experimental and intervention research. The present study compares the effectiveness of different recruitment strategies implemented by a grief laboratory at a large state university in order to optimize recruitment efforts. The most effective method is letters sent to bereaved community members identified through online newspaper obituaries. Despite a small overall response rate, the large population from which to sample provides continuous accrual every month. Other methods include electronic/print media, community institution referrals, word of mouth and community outreach. Best practices for recruitment and retention are recommended. **Abstract:** <http://bit.ly/2Jear1b>

## **Goals-of-care discussions for adult patients nearing end of life in emergency departments: A systematic review**

*EMERGENCY MEDICINE AUSTRALASIA* | Online – 1 May 2019 – There was no consensus on the meaning of goals-of-care (GoC), which is often confused with advanced care planning and treatment limitation. Emergency clinicians can identify most patients needing discussions following training. There was no evidence for how to involve stakeholders, nor how to adapt conversations to meet cultural and linguistically diverse needs. Expert panels have suggested requirements and content for conversations with little supporting evidence. There was no evidence for how emergency conversations differ to those in other settings, nor for harms or benefits for holding GoC conversations in emergency departments (Eds). Increased GoC conversations increased hospice referral and reduced in-patient admissions. Most studies were of moderate quality only, outcomes were not standardised and sample sizes were small. “Goals-of-care” is used inconsistently across the literature. This is the first systematic review regarding GoC discussions in EDs. Further research is needed on all aspects of these conversations. **Abstract:** <http://bit.ly/2vwqFdR>

Noted in Media Watch 23 April 2018 (#560, p.10):

- *EMERGENCY MEDICINE AUSTRALASIA* | Online – 16 April 2018 – ‘**Testing a new form to document “goals-of-care” discussions regarding plans for end-of-life care for patients in an Australian emergency department.**’ There is limited literature to inform the content and format of goals-of-care forms for use by doctors when they are undertaking these important conversations. This study supports having a goals-of-care form in emergency medicine. The ideal contents of the form, however, was not determined. **Abstract:** <http://bit.ly/2LjF4Vx>

### **Compassionate use of unauthorized drugs: Legal regulations and ethical challenges**

*EUROPEAN JOURNAL OF INTERNAL MEDICINE* | Online – 26 April 2019 – Compassionate use (also referred to as expanded access) is therapeutic use of unauthorized drugs outside of clinical trials. The objective of this review is to discuss practical aspects of the current legal regulations concerning compassionate use that have been introduced in the European Union, the U.S. (both the Food & Drug Administration regulations and right-to-try laws), Canada and Australia. The authors present main ethical challenges associated with use of unauthorized drugs such as possible difficulties with obtaining informed consent and fair patient selection. They discuss guidelines, especially those contained in the Declaration of Helsinki, which may aid doctors in the ethical conduct of compassionate treatments. **Abstract (w. link to references):** <http://bit.ly/2Y6x8sb>

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

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

### **Does decision-making in end-of-life care differ between graduating medical students and experienced physicians?**

*IN VIVO*, 2019;33(3):903-909. The authors’ aim was not to affirm right or wrong answers to the questions presented, although some basic skills in decision-making during end-of-life care (EoLC) were evaluated. Nevertheless, the majority of dying patients are taken care by GPs in Finland, and just graduated junior doctors are expected to work as a GP. The study’s results offer some insight into the educational needs, because the decision-making in EoLC should include the same clinical principles for every patient regardless of the experience of a physician. Medical students have been found to feel underprepared to have discussions about EoLC with a patient. Furthermore, their knowledge about assisted dying, DNR orders, advance directives and many aspects of palliative medicine (PM) is still known to be inadequate. On the other hand, undergraduate curricula in PM increases students’ knowledge on palliative care and their attitudes towards EoLC change after an observational experience in hospice. This calls for well-planned educational programmes in PM in every medical school and continuous postgraduate education. **Full text:** <http://bit.ly/2INYOyt>

### **Study of shadowing experiences among chaplains in the Coleman Palliative Medicine Fellowship**

*JOURNAL OF HEALTH CARE CHAPLAINCY* | Online – 29 April 2019 – While shadowing is a relatively common practice in the education of many health professionals, it is not widely used in chaplaincy education. In interviews with seven fellows who shadowed more experienced palliative care (PC) chaplains and the five mentors who were shadowed at their work settings, participants reported opportunities for mutual learning, self-reflection, and collegiality. Fellows observed how members of a PC team collaborate and contribute equally to the care of patients. Mentors found shadowing was a rare opportunity to share their chaplaincy practice with colleagues. It helped them to appreciate different aspects of their work settings and to distinguish between PC and generalist chaplaincy. The authors discuss the challenges participants experienced while shadowing and offer recommendations for incorporating the practice more widely into chaplaincy education. **Abstract:** <http://bit.ly/2VBO0JU>

**N.B.** Additional articles on the role of chaplains in PC noted in 1 April 2019 issue of Media Watch (#608, p.11).



## Teamwork when conducting family meetings: Concepts, terminology, and the importance of team-team practices

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 April 2019 – Family meetings, which bring together members of a seriously ill patient's family and the interprofessional team (IPT), have been widely recognized as promoting shared decision making for hospitalized patients, particularly those in intensive care units. The planning and conducting of interprofessional family meetings is hampered, however, by a lack of clarity about who is doing what and when, which in turn can lead to inefficiencies and uncoordinated efforts. The authors describe how members of the IPT interact with one another (termed team-team practices), distinguishing these interactions from how the IPT engages directly with family members (team-family practices) in preparing for and conducting family meetings. While most research and guidelines have focused on team-family practices that directly affect patient and family level outcomes (e.g., safety and satisfaction), team-team practices are needed to coordinate team contributions and optimize the skills of the diverse team. Team members' knowledge and attitudes also contribute to patient and family outcomes as well as team outcomes. Yet without attention to team-team practices prior to, during, and after a family meeting, the family level outcomes are less likely to be achieved as are team wellbeing

outcomes (e.g., reduced burnout and staff retention). Drawing upon team theory, the authors present a set of key concepts and corresponding terms that enable a more precise description of team-team practices as well as team-family practices, aiming to help with team training and evaluation and to enable future research of these distinct yet inter-related practices. **Abstract:** <http://bit.ly/2GPxe0A>

### How clinician-family interactions potentially impact clinicians' conceptualization and discussions regarding prognostic uncertainties

*JOURNAL OF PALLIATIVE CARE* | Online – 30 April 2019 – The authors identified two main factors that influence how clinicians perceive prognostic uncertainty and their perceptions about whether and why they communicate prognostic uncertainties to families: 1) Communicating uncertainty to “soften the blow”; and, 2) Communicating uncertainty in response to clinicians' interpretations of surrogate decision makers' perceptions of prognostic uncertainty. The authors also identified several sub-themes. **Abstract:** <http://bit.ly/2GZy6Bb>

**N.B.** Additional articles on clinicians' comfort levels low with life expectancy discussions noted in 29 April 2019 issue of Media Watch (#612, p.10).

Noted in Media Watch 29 April 2019 (#612, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 17 April 2019 – ‘**Interprofessional team member communication patterns, teamwork, and collaboration in pre-family meeting huddles in a pediatric cardiac intensive care unit.**’ In this study physicians spoke for an average of 83.9% of each meeting's duration; non-physicians averaged 9.9%. Significant differences in physician and non-physician perceptions of collaboration were found in 3 out of 10 observed meetings. Interprofessional team members' interactions in team meetings provide important information about team dynamics, revealing potential opportunities for improved collaboration and communication in team meetings and subsequent family meetings. **Abstract (w. link to references):** <http://bit.ly/2URQ3u1>

## Awareness of palliative care among a nationally representative sample of U.S. adults

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 April 2019 – The authors identified 3,194 respondents (weighted sample size: 229,591,005) who met their inclusion criteria. About 71% (2,097) of all respondents had no knowledge of palliative care (PC) and 84.5% of Hispanic respondents had no knowledge of PC. Multivariable analyses indicated the middle-aged ... and elder population ... have a significantly better knowledge of PC than those under age 50. Common misconceptions existed in respondents, even those who had self-reported adequate knowledge of PC. Greater efforts are needed to promote PC and reduce the misconceptions of PC in the general population. **Abstract:** <http://bit.ly/2UT2Ozi>

Cont.

Noted in Media Watch 15 April 2019 (#610, p.9):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 8 April 2019 – ‘**What do family caregivers know about palliative care? Results from a national survey.**’ Despite their key role in caring for individuals with serious, chronic illness, there have been no national studies examining family caregiver (FCGs) awareness and perceptions of palliative care (PC). One-half of survey respondents had never heard of PC. Even among those who had heard of PC, the majority did not distinguish it from hospice care and death. Public messaging efforts are needed to clarify PC services in a way that is patient- and family-centered. **Abstract (w. list of references):** <http://bit.ly/215qWNf>

Noted in Media Watch 1 April 2019 (#608, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 March 2019 – ‘**Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey.**’ About 71% (2,097) of all respondents had no knowledge of palliative care (PC). Multivariable analyses indicated the middle-aged and elder population have a significantly better knowledge of PC than those under age 50. Common misconceptions existed in respondents, even those who had self-reported adequate knowledge of PC. Greater efforts are needed to promote PC and reduce the misconceptions of PC in the general population. **Abstract (w. link to references):** <http://bit.ly/2JCTeG>

Noted in Media Watch 1 January 2018 (#544, p.19):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2018;21(S1):S30-S36. ‘**The impact of public health awareness campaigns on the awareness and quality of palliative care.**’ A comprehensive public awareness campaign about palliative care should be based on clear and shared terminology, use well piloted materials, and the full range of mass media to suit different ages, cultures and religious/spiritual perspectives. There is evidence about key factors for success: targeting, networking, and use of specific, measurable, achievable, realistic time-bound objectives; continuous evaluation; and complementary to national and international policy. **Full text:** <http://bit.ly/2VxtBIZ>

#### End-of-life care in Australia

#### **Tracking end-of-life decisions: A survey**

*MEDICAL JOURNAL OF AUSTRALIA* | Online – 29 April 2019 – As the Australian population lives longer and life-sustaining technology continues to advance, decisions at the end-of-life (EoL) are becoming increasingly difficult, engaging complex medical, ethical, legal and psychosocial considerations. Causes of death have shifted away from acute infectious diseases towards chronic degenerative illnesses. Because of this shift, many patients at the end of their lives will require comfort-oriented care, including intensified alleviation of pain and symptoms or forgoing burdensome treatment. When suffering becomes intolerable, some patients may even develop a desire to hasten the end of their lives. These developments mean that there is an increasing likelihood that death will occur after a medical decision to provide, withhold or withdraw treatment. Though relatively uncommon, death can also occur following a decision by a patient to stop eating and drinking. Research from Europe suggests that medical EoL decisions are prevalent, though the incidence varies widely between countries, from between 23% of all deaths in Italy to 51% in Switzerland; other studies have found the prevalence to be as high as 58% in The Netherlands and over 74% in Switzerland. These medical EoL decisions take several forms, the most common being withholding and withdrawing life-prolonging treatment (“non-treatment” decisions), and alleviating pain with potentially life-shortening doses of opioids. Some of the international studies also reveal that the percentage of deaths that are occurring through “continuous deep sedation” are increasing. Little is known in Australia about the incidence of medical decisions that may precede a patient’s death, and the patient characteristics surrounding that death. **Full text:** <http://bit.ly/2VzY1Y7>

## Framing advance care planning in Parkinson disease: Patient and care partner perspectives

*NEUROLOGY* | Online – 26 April 2019 – In this qualitative descriptive study, four themes illustrate how patients and care partners perceive advance care planning (ACP) as part of clinical care: 1) Personal definitions of ACP vary in the context of Parkinson's disease (PD); 2) Patient, relationship, and healthcare system barriers exist to engaging in ACP; 3) Care partners play an active role in ACP; 4) A palliative care approach positively influences ACP. Taken together, the themes support clinician initiation of ACP discussions and interdisciplinary approaches to help patients and care partners overcome barriers to ACP.

**Abstract:** <http://bit.ly/2Lc4KU2>

**N.B.** Additional articles on palliative and end-of-life care for patients living with Parkinson's disease noted in 17 September 2018 (#581, p.13).

## A study to understand the impact of bereavement grief on the workplace

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 25 April 2019 – Although most employees and business owners or operators will likely experience the death of one or more loved ones over their work lives, attention has not focused on how bereavement grief impacts the workplace. A study was conducted for foundational information. Data on the annual incidence of bereavement leaves and related matters were collected from a relatively representative sample of small, medium, and large Canadian organizations. Two of every three organizations had 1+ employees take a bereavement leave last year, with 3.2% of all employees taking a bereavement leave consisting of 2.5 days on average and often with additional travel and accommodation days. The findings suggest that more should be done by organizations to prepare for bereavement leaves and assisted work returns. This preparation is essential for the tsunami of bereavement grief in the years ahead as deaths increase rapidly in number with population aging. **Abstract:** <http://bit.ly/2ZHVVEA>

Noted in Media Watch 18 March 2019 (#606, p.4):

- U.K. | *HuffPost* – 12 March 2019 – ‘**Should offices have bereavement first aiders to help with grief at work?**’ Bereavement first aiders should be trained by employers to help people in the workplace struggling with grief, according to the Sue Ryder charity.<sup>1</sup> The majority of U.K. adults are not getting any formal support after the loss of a loved one. Around seven in 10 U.K. adults have been bereaved at least once in the last five years. Sue Ryder suggests a number of measures to improve support for the bereaved, including a call for employers to consider training “bereavement first aiders” in the workplace, to give people the skills to help colleagues who want to return to work. <http://bit.ly/2HfOrD6>

1. ‘A Better Grief,’ Sue Ryder, March 2019. **Download/view at:** <http://bit.ly/2Hh9x3G>

Noted in Media Watch 22 December 2014 (#389, p.16):

- *BEREAVEMENT CARE*, 2014;33(3):111-112. ‘**Handling bereavement in the workplace – a guide for employers.**’ Grief cannot be left at the door by staff when they come to work, and how they are treated by their employers at this vulnerable time will have important consequences for both. If bereavement is handled well in the workplace the employer will always be remembered – if it is handled badly it will never be forgotten. The authors discuss the recently published Advisory, Conciliation & Arbitration Service guidance for employers on handling bereavement in the workplace.<sup>1</sup> **First page view (w. link to references):** <http://bit.ly/2XRzmeV>

1. ‘Managing bereavement in the workplace: A good practice guide,’ Advisory, Conciliation & Arbitration Service, U.K., 2014 (noted in 22 September 2014 issue of Media Watch, #376, p.15). **Download/view at:** <http://bit.ly/2UZ57pz>

## **“It all depends!”: A qualitative study of preferences for place of care and place of death in terminally ill patients and their family caregivers**

*PALLIATIVE MEDICINE* | Online – 3 May 2019 – It is often suggested that terminally ill patients favour end-of-life (EoL) care at home. Yet, it is unclear how these preferences are formed, if the process is similar for patients and family caregivers, and if there are discrepancies between preferences for place of care and place of death. Understanding these nuances is essential to support people in their decision-making and ultimately provide better care at the EoL. A total of 17 participants (8 patients and 9 caregivers) were recruited from an acute palliative care hospital ward, a sub-acute hospice unit, and a palliative home care organisation in Melbourne, Australia. The process of forming location preferences was shaped by uncertainty relating to the illness, the caregiver and the services. Patients and caregivers dealt with this uncertainty on a level of thoughts, emotions, and actions. At the end of this process, patients and caregivers expressed their choices as contextual, personal, relational, conditional and flexible preferences. These findings suggest that in many cases EoL decision-making does not conclude with a clear and stable choice. **Abstract:** <http://bit.ly/2IWKALQ>

## **Residents’ and family members’ perceptions of care quality and self-determination in palliative phase in residential care**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 29 April 2019 – Dependency on others can compromise self-determination for older persons in the palliative phase in residential care. Family members can support the residents’ self-determination but may also jeopardize it. Quality of care (QoC) is linked to respecting the autonomy of the residents and providing opportunities to participate in decision-making. The aim of the study was to provide knowledge about residents’ and family members’ perceptions of QoC and self-determination and to detect possible differences between their experiences. In this cross-sectional study QoC was perceived as lower than preferred in the majority of items and there was a high level of agreement between residents and family members. Lowest mean values in QoC were found in: support when feeling lonely; support when feeling worry, anxiety or fear; and staff’s time to talk to the residents. Decision-making in everyday life and in life-changing situations showed that neither residents nor family members trusted staff to know about the residents’ preferences. Broad improvements are needed, especially in psychosocial care. Several of the negative outcomes on QoC and self-determination seem to derive from a focus on practical tasks and the lack of trustful relationships between residents and staff. An early implementation of palliative care, with a focus on what brings quality to each resident’s life, could facilitate QoC and self-determination, in both everyday life and at the end of life. **Abstract (w. references):** <http://bit.ly/2DAF11m>

Noted in Media Watch 19 November 2018 (#590, p.9):

- *AUSTRALIAN JOURNAL OF PRIMARY HEALTH* | Online – 14 November 2018 – ‘**Identifying palliative care needs in residential care.**’ The aim of this study is to determine the accuracy, feasibility and acceptability of the surprise question (SQ) in combination with the Supportive & Palliative Care Indicator Tool (SPICT) in identifying residents who have palliative care (PC) needs in residential aged care facilities. The SPICT marginally increased the ability to identify residents in need of proactive end-of-life planning. A combination of the SQ and the SPICT is effective in predicting PC needs and may trigger timely care planning. **Abstract (w. list of references):** <http://bit.ly/2ZFDxw9>

Noted in Media Watch 9 October 2017 (#533, p.5):

- AUSTRALIA (Australian Capital Territory) | *Australian Ageing Agenda* (Canberra) – 4 October 2017 – ‘**A new palliative approach for residential aged care.**’ The Palliative Care Needs Rounds Checklist is undergoing a second trial in 12 facilities after a pilot at four sites in 2014-2015 showed the benefits of taking a proactive integrated approach to providing specialist palliative care within aged care facilities. Benefits of the tool include improved skills and knowledge of the care team, cost-effectiveness for the acute sector, and an increased possibility for residents to die in their preferred place with pain and suffering well managed, according to the study.<sup>1</sup> <http://bit.ly/2GHQBbl>

1. ‘Improving specialist palliative care in residential care for older people: A checklist to guide practice,’ *BMJ Supportive & Palliative Care*, published online 2 August 2017 (noted in 7 August 2017 issue of Media Watch, #524, p.8). **Abstract:** <http://bit.ly/2GP8AOE>

## Spiritual assessment and spiritual care offerings as a standard of care in pediatric oncology: A recommendation informed by a systematic review of the literature

*PEDIATRIC BLOOD & CANCER* | Online – 29 April 2019 – Children with cancer and their families experience shifts in spiritual wellness from diagnosis through treatment and survivorship or bereavement. An interdisciplinary team conducted a systematic review of quantitative and qualitative research on spiritual assessments, interventions, and outcomes in childhood cancer... Thirty-nine well-designed studies were included in the final analysis. The findings from this systematic review indicate the need for early spiritual assessment with offering of continued support for the spiritual functioning of children with cancer and their families as a standard of care. **Abstract:** <http://bit.ly/2IQ86Kw>

### End-of-life care in Poland

## Sobering reality of palliative care provision for patients with advanced chronic obstructive pulmonary disease

*POLISH ARCHIVES OF INTERNAL MEDICINE*, 2019;129(4):222-224. With the growing interest and studies demonstrating the benefits of palliative care (PC) for nonmalignant diseases, there is a need to train both pulmonologists and other healthcare professionals to deliver integrated PC in hospital and home settings with the roles of multidisciplinary team including pharmacist, local priest, physical therapist, PC specialist, PC nurse and psychologist, psychiatrist, social worker, and community based caregiver volunteers. The author applauds the Polish Pulmonary Society for developing the guideline for PC in patients with advanced chronic obstructive pulmonary disease (COPD). The next step is to address the challenges identified by Brożek *et al* to develop practical strategies and address educational training needs for clinicians.<sup>1</sup> Thus, it is paramount to employ effective end-of-life communication to develop trust between patients and physicians, which is a step forward in the right direction to achieve PC goals. **Download/view full text at:** <http://bit.ly/2Wcq8cS>

1. 'End-of-life care for patients with advanced lung cancer and chronic obstructive pulmonary disease: survey among Polish pulmonologists,' *Polish Archives of Internal Medicine*, 2019;129(4):222-224. **Abstract:** <http://bit.ly/2vyoWop>

**N.B.** English language articles.

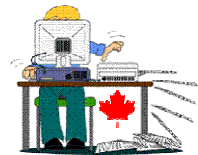
Noted in Media Watch 11 February 2019 (#601, p.7):

- *COPD: JOURNAL OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE* | Online – 4 February 2019 – '**Palliative care provision for patients with advanced chronic obstructive pulmonary disease: A systematic integrative literature review.**' Experiences about advanced chronic obstructive pulmonary disease (COPD), palliative care (PC) timing, service delivery and PC integration emerged as main themes, defining a developing taxonomy for PC provision in advanced COPD. This taxonomy involves different levels of care provision and integrated care is the last step of this dynamic process. Furthermore, PC involvement, holistic needs' assessment and management and advance care planning have been identified as elements of integrated care. **Abstract:** <http://bit.ly/2Sd99ck>

**N.B.** Additional articles on PC for people living with COPD noted in this issue of Media Watch.

### 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>



## No matter the species

### **Overcoming obstacles to palliative care: Lessons from our physician counterparts**

*VETERINARY CLINICS: SMALL ANIMAL PRACTICE*, 2019;49,(3):387-397. In the past 40 years, the field of palliative care (PC) for people faced many of the same obstacles in development and expansion that veterinary PC now confronts. A series of interviews with pioneers in human PC revealed what those early obstacles were professionally, personally, and institutionally. Many of the hurdles are strikingly similar to what veterinary professionals are currently facing in their attempts to grow PC as both an independent subspecialty and an integrated part of general practice [such as negative connotations to the phrase “palliative care”]. Veterinarians can translate their experiences and successes to help veterinary PC flourish. **First page view:** <http://bit.ly/2WprVLF>



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

Representative sample of recent journal articles:

- *BMJ OPEN* | Online – 1 May 2019 – ‘**Canadian French and English newspapers’ portrayals of physicians’ role and medical assistance in dying (MAiD) from 1972 to 2016: A qualitative textual analysis.**’ Canadian events defined five eras. From 1972 to 1990, newspapers portrayed physician’s MAiD role as a social issue by reporting supportive public opinion polls and revealing it was already occurring in secret. From 1991 to 1995, newspapers discussed legal aspects of physicians’ MAiD role including Rodriguez’ Supreme Court of Canada appeal and Federal government Bills. From 1996 to 2004, journalists discussed professional aspects of physicians’ MAiD role and the growing split between palliative care and physicians who supported MAiD. They also reported on court cases against Canadian physicians, Dr Kevorkian and suffering patients who could not receive MAiD. From 2005 to 2013, newspapers described political aspects including the tabling of MAiD legislation to change physicians’ role. Lastly, from 2014 to 2016, newspapers again portrayed legal aspects of physicians’ role as the Supreme Court of Canada was anticipated to legalise MAiD and the Québec government passed its own legislation. Remarkably, newspapers kept attention to MAiD over 44 years before it became legal. Articles generally reflected Canadians’ acceptance of MAiD and physicians were typically portrayed as opposing it, but not all did. Newspaper portrayals of physicians’ MAiD role discussed public opinion, politicians’ activities and professional and legal aspects. Portrayals followed the issue-attention cycle through three of five stages: 1) Pre-problem; 2) Alarmed discovery and euphoric enthusiasm; and, 3) Realising the cost of significant progress. **Full text:** <http://bit.ly/2ZNESRD>
- *CANADIAN JOURNAL ON AGEING* | Online – 3 May 2019 – ‘**Medical assistance in dying: Alberta approach and policy analysis.**’ The legalization of medical assistance in dying (MAiD) in Canada has presented an opportunity for physicians, policy makers, and patients to rethink end-of-life care. This article reviews the key features of the Alberta MAiD framework and puts it in the context of other provinces and their MAiD programs. The authors also compared policies and MAiD practices in different provinces/ territories of Canada. In addition, they used the Alberta MAiD database to provide the current state of patient demographics and access to MAiD services in Alberta in 2017-2018. Significant differences were identified between provincial/territorial MAiD program processes and practices. Alberta, Ontario, and Quebec have more comprehensive frameworks. Alberta has dedicated resources

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to the support of MAiD. The median age of those who received MAiD service in Alberta from July 2017 to April 2018 was 70 years; a higher proportion were males (55%) and the majority included patients with a cancer diagnosis (70%). Approximately 39% of MAiD events happened in a hospital setting, and 38% occurred in patients' homes. The authors present some recommendations on MAiD program development, implementation, and review based on Alberta's experience with MAiD over the past two years. **Abstract (w. list of references):** <http://bit.ly/2LIBcnb>

- *INTERNATIONAL JOURNAL OF CANADIAN STUDIES* | Online – 25 April 2019 – '**Morality politics of physician-assisted suicide: Comparing Canada and the U.S.**' In contrast to the European tendency toward parliamentary enactment of euthanasia reforms, policies on physician-assisted suicide (PAS) in both Canada and the U.S. were promulgated by high court rulings. These rulings were very different, however: the Supreme Court of Canada upheld a constitutional right to assisted-suicide while the Supreme Court of the U.S. denied that any constitutional right exists. This comparative analysis of public opinion, media coverage, federalism, interest groups, and jurisprudence argues that the key variable explaining these divergent policy outcomes was the one-sided debate over PAS in the U.S., while a two-sided debate occurred in Canada. **Abstract:** <http://bit.ly/2ZMjsV4>
- *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 29 April 2019 – '**Comparing the attitudes of four groups of stakeholders from Quebec, Canada, toward extending medical aid in dying to incompetent patients with dementia.**' The Canadian province of Quebec has recently legalized medical assistance in dying (MAiD) for competent patients who satisfy strictly defined criteria. The province is considering extending the practice to incompetent patients. We compared the attitudes of four groups of stakeholders toward extending MAiD to incompetent patients with dementia. Response to a province-wide postal survey responses ranged from 25% for physicians to 69% for informal caregivers. In all four groups, the proportion of respondents who felt it was acceptable to extend MAiD to an incompetent patient with dementia was highest when the patient was at the terminal stage, showed signs of distress, and had written a MAiD request prior to losing capacity. In those circumstances, this proportion ranged from 71% among physicians to 91% among informal caregivers. **Abstract:** <http://bit.ly/2ULQ4us>
- *JAMA NEUROLOGY* | Online – 29 April 2019 – '**Attitudes toward physician-assisted death from individuals who learn they have an Alzheimer disease biomarker.**' A minority of participants in this study with elevated amyloid- $\beta$  expressed a desire for physician-assisted death (PAD) should they experience cognitive decline. This mirrors relative desire for PAD among other terminally ill populations. Interviewees with participants were relatively more likely to report future planning, suggesting that they, similar to those seeking PAD now, may be particularly motivated by loss of autonomy. The authors' findings suggest that learning one's amyloid imaging result does not change baseline attitudes regarding the acceptability of PAD. However, among those who indicate a personal openness to PAD, an elevated amyloid imaging result and the associated risk of cognitive decline are viewed as relevant to PAD-related decision making. The authors did not ask about other end-of-life preferences or perceived quality of life of persons with dementia, which may have added nuance to their findings. Consistent with evidence that people with mild cognitive impairment and early dementia are at risk for suicidal behavior, several interviewees stated they would consider suicide if they developed cognitive impairment. **Abstract:** <http://bit.ly/2GHidOi>

## [Publishing Matters](#)

### **Editors should declare conflicts of interest**

*JOURNAL OF BIOETHICAL INQUIRY* | Online – 23 April 2019 – Editors have increasing pressure as scholarly publishing tries to shore up trust and reassure academics and the public that traditional peer review is robust, fail-safe, and corrective. Hidden conflicts of interest (Col) may skew the fairness of the publishing process because they could allow the status of personal or professional relationships to positively influence the outcome of peer review or reduce the processing period of this process. Not all authors have such privileged relationships. In academic journals, editors usually have very specialized skills and are selected as agents of trust, entrusted with the responsibility of serving as quality control gate-

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keepers during peer review. In many cases, editors form extensive networks, either with other professionals, industry, academic bodies, journals, or publishers. Such networks and relationships may influence their decisions or even their subjectivity towards a set of submitting authors, paper, or institute, ultimately influencing the peer review process. These positions and relationships are not simply aspects of a curriculum, they are potential Col. Thus, on the editorial board of all academic journals, editors should carry a Col statement that reflects their past history, as well as actual relationships and positions that they have, as these may influence their editorial functions. **Abstracts:** <http://bit.ly/2DFKqo2>

### **Cabell's predatory journal blacklist: An updated review**

*THE SCHOLARLY KITCHEN* | Online – 1 May 2019 – A very quick summary for those who may – against all odds – still be blissfully unaware of what terms like “predatory publishing or “deceptive publishing” refer to: what are commonly called predatory publishers are those who lie about their business practices for the purpose of attracting paying authors. These journals misrepresent themselves with regard to, for example, editorial board members (claiming people as editors without permission), peer review practices (falsely claiming to provide meaningful peer review), impact metrics (mostly by lying about their Journal Impact Factor), organizational affiliations (usually claiming a relationship with a nonexistent organization), etc. The common feature of all such journals is that instead of rigorously evaluating and vetting submitted articles, they will instead publish anything submitted as long as the author is willing to pay an article processing charge. By injecting non-vetted content into the scholarly and scientific marketplace and misrepresenting it as peer-reviewed science, these journals contaminate and undermine both the legitimacy and the trustworthiness of scholarly discourse. Thus, the introduction of Cabell's Blacklist in 2017 was a welcome development. It promised a tool that can be used by authors needing help deciding where to publish, by academics and other employers seeking to check the legitimacy of job applicants' claimed applications or editorial board memberships, or anyone else interested in monitoring the behavior of deceptive publishers. And for those who question the necessity of such a tool, it's worth noting that Cabell's Blacklist currently includes almost 12,000 journals – and its list of titles under consideration for inclusion in the Blacklist comes to over 1,000 more. **Full text:** <http://bit.ly/2Veimqz>

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### **The crisis of predatory publishers sucking the blood of science**

AUSTRALIA (New South Wales) | ABC News (Sydney) – 5 May 2019 – Science journalist John Bohannon was shocked by the results of his sting operation to expose predatory publishers. Academic librarian Jeffrey Beall found himself threatened with a billion-dollar lawsuit and much more when he published a black list of predatory journals. He believes they're the “biggest threat to science since the Inquisition.” But what tactics do predatory journals use to entice scientists and why are they dangerous? Why has the U.S. Federal Court issued one of the biggest publishers, Omics Group Inc, a \$50 million U.S. fine? Where there's profit to be made, shonky operators are waiting in the wings ready to pounce. And they have science in their sights. <https://ab.co/2vDhbh0>

#### **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

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

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

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**Barry R. Ashpole, Ontario CANADA**

**e-mail: [barryashpole@bell.net](mailto:barryashpole@bell.net)**