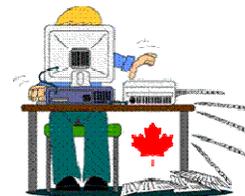


## Media Watch...

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

Human resources in end-of-life care: Scroll down to [Specialist Publications](#) and 'A few good men: It's not easy recruiting male hospice palliative care volunteers'(p.5), in *American Journal of Hospice & Palliative Medicine*.

With this issue, Media Watch begins its 12<sup>th</sup> year of publication.

## Canada

“We’re not hiding anymore.”

ONTARIO | *Architectural Record* – 12 July 2018 – Stepping through the front entrance of Casey House, the first thing you see is a hearth. The main doors of the Toronto hospital for HIV/AIDS patients open to a tall lobby, lined with rough-cut and honed limestone and centered on a fireplace. The symbolism is clear: this is, as the name suggests, a place to feel at home. That’s a rare quality in a health-care facility, but it is crucial to the care and culture here at Canada’s only independent HIV/AIDS hospital. The institution is located in Toronto’s Gay Village. Its clients ... include a sizable number of homeless people. “Our clients tend to be very much in the margin,” says Casey House CEO Joanne Simons. “Most have suffered some form of trauma in their lives. We hope within this space to empower them so that they can take care of themselves and feel compassion, dignity, and worth.” Casey House, like all hospitals in Ontario, sees its operations and capital costs largely covered by the provincial government. The remodel and addition were funded in part by an \$8 million private capital campaign. But Casey House’s design goes outside the government’s usual guidelines, in part through its adaptive reuse of a Victorian house. That building ... contains administrative offices as well as space for counseling sessions and public events. Subtle adjustments to the floor levels allow continuous barrier-free access – and visual connections – between new and old facilities. The house provides a very public front door, facing Jarvis Street—once Toronto’s best residential address and now a heavily trafficked artery. This, Simons explains, is critically important: while patients value their privacy, “we want to fight the blame and shame associated with HIV,” she says. “In the ’80s, during the HIV crisis, there was huge stigma around the virus,” says Simons. Now “we’re making a very bold statement,” she says. “We’re not hiding anymore.” <https://goo.gl/HveUhN>

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

- *CHANGE OVER TIME*, 2016;6(2):248-263. ‘Home and/or hospital: The architectures of end-of-life care.’ The architects of hospices, palliative care facilities, and the U.K.-based Maggie’s Centres strive to make their buildings look like houses to express a collective environment of caring, emphasizing quality-of-life issues over medical efficiency. This reflects larger changes in the design of therapeutic landscapes since 1980, which endeavor to normalize illness and death by engaging architecture as a tool of distraction. **Abstract:** <https://goo.gl/1bFLGg>

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## From the archives

- *AUSTRALASIAN MEDICAL JOURNAL*, 2011;4(9):495-499. **‘Spatial practices and the home as hospice.’** The suggestion, “architecture is mute” if it is in a collision with medicine, is put to the test by the potential collision between palliative medicine and palliative “space,” often resulting in the space being considered silent. What is required is further investigation into the conceptual, architectural and spatial practices that underpin hospice and palliative care, especially in the design of the home, so that the notion of space, rather than building, can make a meaningful contribution to the holistic philosophy. **Full text:** <https://goo.gl/PNaXtg>

## U.S.A.

### **National Hospice & Palliative Care Organization releases updated edition of standards of practice for hospice programs**

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 12 July 2018 – ‘Standards of Practice for Hospice Programs’ are organized around the core components of quality in hospice care, which provide a framework for developing and implementing quality assessment and performance improvement. Specific standards and practice examples are included for each component, and appendices provide additional standards for a hospice inpatient facility, nursing facility hospice care, and a hospice residential care facility. The updated edition includes compliance and quality requirements such as emergency preparedness provisions. **Download/view at:** <https://goo.gl/Wb9j72>

### Specialist Publications

**‘Update on palliative care for pediatric neurology’** (p.7), in *American Journal of Hospice & Palliative Medicine*.

**‘Socio-demographic characteristics and lengths of stay associated with acute palliative care: A 10-year national perspective’** (p.5), in *American Journal of Hospice & Palliative Medicine*.

**‘Family caregivers’ confidence caring for relatives in hospice care at home: An exploratory qualitative study’** (p.6), in *American Journal of Hospice & Palliative Medicine*.

**‘The hospice and palliative care advanced practice registered nurse workforce: Results of a national survey’** (p.10), in *Journal of Hospice & Palliative Nursing*.

### **For terminally ill cancer patients, where you live can shape end-of-life care**

PBS NEWSHOUR | Online – 9 July 2018 – If you are a terminally ill cancer patient, where you live can determine how much it will cost for you to die. The last month of life for a Medicare patient diagnosed with advanced-stage lung or colorectal cancer cost an average of \$13,663, according to a study published today...<sup>1</sup> But that cost can also vary widely, the study suggested, from \$10,131 per patient in the lowest 20% of hospital referral regions included in this study to \$19,318 in the highest 20%. What drives those price differences? A physician’s medical philosophy and practice styles propelled higher medical bills, and patients in geographic areas with fewer primary doctors and hospices *per capita* also tended to have higher end-of-life (EoL) costs, the study said. Researchers reached this conclusion after surveying physicians on what they believed, how those beliefs played out in practice and how skilled they were in delivering EoL care, along with patient and claims data. <https://goo.gl/QsDBt3>



1. ‘Factors contributing to geographic variation in end-of-life expenditures for cancer patients,’ *Health Affairs*, 2018;37(7):1136-1143. **Abstract (w. notes):** <https://goo.gl/pfCGQK>



### 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.16.

## International

### End-of-life care in Australia

#### **Palliative care resources “distressingly low” in Canberra**

AUSTRALIA (Australian Capital Territory) | *The Canberra Times* – 13 July 2018 – Staff at Clare Holland House [Hospice] are under pressure to push dying patients in and out as quickly as possible, while dealing with bottlenecks in referrals. Canberra Hospital’s palliative care (PC) service is also stretched, with a distressingly low number of specialists, a parliamentary inquiry has heard. Doctors, former politicians and peak health bodies appeared before an ACT Legislative Committee examining the end-of-life choices available to dying Canberrans... While the inquiry has dwelt on the ACT’s inability to legalise voluntary assisted dying due to Commonwealth restrictions, it has also heard evidence of shortcomings in the territory’s PC system. <https://goo.gl/9spHk2>

### End-of-life care in Nigeria

#### **Terminal illness: Lack of facilities takes toll on patients, families**

AFRICA (Nigeria) | *The Daily Trust* (Abuja) – 11 July 2018 – Terminally ill patients and their families experience untold hardships in the country due to absence of requisite facilities, financial burden as well as ignorance on how to take care of the patients. *The Daily Trust* findings revealed that in spite of the huge amounts of money required to care for terminally-ill persons, the patients and their families pay from their pockets as government does not pay or subsidise the healthcare services for them. The National Health Insurance Scheme also does not cover most terminal illnesses. Findings also revealed that aside the absence of special centers for treatment of terminally ill persons, many hospitals lack required equipment for the treatment of terminal illnesses such as radiotherapy and dialysis machines. <https://goo.gl/k2cZ36>

Noted in Media Watch 16 November 2015 (#436, p.8):

- KENYA | *The Mail & Guardian* (Nairobi) – 9 November 2015 – **‘Morbid but fascinating: The Quality of Death Index, where South Africa and Uganda lead, and Nigeria trails.’** The index highlights the advances that countries are making in taking care of their citizens at the end of life, as well as the remaining challenges and gaps in policy and infrastructure.<sup>1</sup> It’s morbid, but important stuff. The need for long-term, palliative care is set to rise significantly. <https://goo.gl/KzyOkf>

1. Nigeria was ranked 77th of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit, October 2015. [Noted in the 12 October 2015 issue of Media Watch (#431, p.6)] <https://goo.gl/zXrmiA>

**N.B.** Selected articles on the development of palliative care in Africa noted in the 21 May 2018 issue of Media Watch (#564, pp.10-11).

## Specialist Publications

**‘Home healthcare and hospice: A Pacific Islands perspective’** (p.8), in *Home Healthcare Now*.

**‘Text network analysis of newspaper articles on life-sustaining treatments’** (p.10), in *Journal of the Korean Academy of Community Health Nursing*.

**‘How do experienced professors teach palliative medicine in European universities? A cross-case analysis of eight undergraduate educational programs’** (p.11), in *Journal of Palliative Medicine*.

**‘Medical Oncology Group of Australia position statement and membership survey on voluntary assisted dying’** (p.13), in *Internal Medicine Journal*.

**‘A phronetic inquiry into the Australian euthanasia experience: Challenging paternalistic medical culture and unrepresentative health policy’** (p.14), in *Journal of Law & Medicine*.

## 6,000 people “missing out” on palliative care every year

U.K. (Wales) | ITV News (Cardiff) – 11 July 2018 – At least 6,000 of the 23,000 people with life-limiting and terminal conditions in Wales are not receiving the expert care they would benefit from, members of the National Assembly of Wales have warned. Particularly those with dementia, heart failure, and neurological conditions face many barriers accessing hospice and palliative care (PC) – with provisions of care varying across Wales. A report by a cross-party group of Assembly Members says people's diagnoses, age, and where they live lead to unequal access.<sup>1</sup> It says children and adults are missing out on care delivered at home or in the community because of GP, community paediatric and district nurse shortages. Mark Isherwood AM, Chair of the Cross Party Group, says collaboration between the National Health Service and voluntary sector organisations is needed to overcome the significant challenges. The report calls on the Welsh Government to deliver a “robust” action plan to address medical staff shortages, and for health boards to ensure comprehensive out-of-hours coverage for people's end-of-life care. It also recommends hospice and PC providers educate colleagues about the role of PC and the range of services available to people. The Welsh Government welcomed the report, but “strongly refuted” the number of people affected. <https://goo.gl/K74mZT>

Cynulliad  
Cenedlaethol  
Cymru

National  
Assembly for  
Wales



1. 'Inequalities in access to hospice and palliative care,' Cross Party Group Hospices & Palliative Care, July 2018. **Download/view at (scroll down to 'Inquiry Report 2018')**: <https://goo.gl/qVA7sS>

Noted in Media Watch 1 January 2018 (#544, p.5):

- U.K. (Wales) | National Health Service Wales – 20 December 2017 – '**End-of-life care: Annual statement of progress.**' More people are accessing appropriate end-of-life care, according to a report published by the Welsh Government.<sup>1</sup> The report details the achievements made against the End-of-Life Care Delivery Plan. Healthcare professionals have received training on guidance to implement the care decisions of patients, and utilising advance care plans to support people to die in their preferred place. This has helped to increase of the number of people registered on the palliative care (PC) register, which has increased by 69% since 2011-2012. <https://goo.gl/wbSTsQ>

1. 'End-of-life care: Annual statement of progress,' National Health Service Wales, December 2017. **Download/view at:** <https://goo.gl/a8fU3S>

**N.B.** Additional articles on palliative and end-of-life care in Wales noted in the 18 December 2017 issue of Media Watch (#543, p.12)

## Pay rise for National Health Service staff could add £100 million to hospice bill, charity says

U.K. (England) | National Health Executive – 10 July 2018 – Recent pay rises for National Health Service (NHS) could have a “damaging impact” on charitable hospices around England and put vital services at risk, a major hospice charity has said. Hospice UK estimates that changes resulting from the NHS pay deal – secured in early June where over a million NHS workers were to receive a 6.5% pay increase – that its 200-member hospices will have to spend an extra £100 million over the next three years ... as much as 2% of the extra government funding set aside for the NHS staff pay increase... A recent Written Ministerial Statement outlined by the government stated how it intends to address the impact of the pay award on non-NHS providers, including hospices. The Government will allow non-NHS providers – that are providing NHS services and that employ staff on an Agenda for Change contract – to access part of the £800 million that is being made available to the NHS this year for staff pay. Only those organisations that match Agenda for Change terms and conditions will be able to access the extra funding. Most hospices use Agenda for Change terms and conditions as a guide to their local pay policies for clinical staff – rather than matching the terms and conditions exactly – so it looks likely that the majority of hospices would not be able to access this funding. <https://goo.gl/BGwFhV>

**N.B.** Hospice UK press release, 'Charities warn that National Health Service pay award could hit hospices hard,' 10 July 2018. <https://goo.gl/PYPZW2>

## Specialist Publications

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

#### **Socio-demographic characteristics and lengths of stay associated with acute palliative care: A 10-year national perspective**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 July 2018 – Patient demographics and characteristics are essential components associated with length of stay in hospice. Race, age, gender, health insurance status, income level, and location of hospice care services are indicators that are associated with differing lengths of stay. Hospice care demand is on the rise, and with 70 million boomers retiring in the next few decades, demand is expected to increase. It is because of demand that exploring the factors that affect a patient's length of stay is essential for understanding beneficiary care and family experience. These insights are key for medical and clinical practitioners in providing hospice patients and their families with the intended benefits and care of the Medicare Hospice Program. This study uses Medicare hospice services data from 2006 to 2014 to examine how race, age, gender, health insurance status, income level, and location before entering acute care are associated with acute care lengths of stay. Overall, this study found that race, age, gender, health insurance status, and income level have a statistically significant association with whether a patient was from home-based or from facility-based hospice. **Abstract:** <https://goo.gl/r1DDmS>

**N.B.** Additional articles on racial disparities in the provision and delivery of hospice and palliative care in the U.S. noted in the 29 January 2018 issue of Media Watch (#548, pp.6-7).

#### **A few good men: It's not easy recruiting male hospice palliative care volunteers**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 July 2018 – Four male HPC volunteers were interviewed in Study 1. They agreed that a direct approach is best when it comes to recruiting male volunteers, especially a personal story or testimonial. Two different volunteer position descriptions were created for Study 2: one description was similar to what might appear on a community-based hospice palliative care (HPC) program's web site or in a newspaper advertisement looking for visiting HPC volunteers; the other description was in the form of a personal testimonial ostensibly written by a male HPC volunteer describing his role through examples of interactions he has had with patients and patients' family members. Twenty-five males responded to each description. Both of the descriptions generated low and non-significantly different levels of interest in becoming a HPC volunteer. Believing this work to be too emotionally demanding and not having enough time for volunteering were the two most commonly given reasons for not wanting to become a HPC volunteer. Suggestions for future recruitment efforts are discussed. **Abstract:** <https://goo.gl/ZrAkZH>

## Journal Watch

'What are "predatory" academic journals?' (p.14), in *The Economist*.

'A rising number of journals that claim to review submissions do not bother to do so' (p.15), in *The Economist*.



*European Journal of Palliative Care*, the official review journal of European Association of Palliative Care, is ceasing publication. The final issue is expected to be published in the next week or so. **Journal home page:** <https://goo.gl/YvRTJ3>



13 October 2018

<https://goo.gl/sxz85U>

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Noted in Media Watch 22 November 2010 (#176, p.8)

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 17 November 2010 – ‘**Supporting the volunteer career of male hospice-palliative care volunteers.**’ The authors invited men to discuss their volunteer careers with hospice-palliative care (HPC) to better understand how to recruit and train, retain and support, and then successfully end their volunteer experience. They described a complex interplay of individual characteristics with the unique roles available to HPC volunteers. The men’s recruitment experiences coalesced around both individually based and organizationally based themes. Results pertaining to retention revealed the interchange between their personalities, the perks and pitfalls of the unique experiences of an HPC volunteer, and the value of the organization’s support for these volunteers. **Abstract:** <http://goo.gl/8XS2mv>

### “It’s better to have three brains working instead of one”: A qualitative study of building therapeutic alliance with family members of critically ill patients

*BMC HEALTH SERVICES RESEARCH* | Online – 9 July 2018 – The four dimensions of therapeutic alliance prove analytically useful to highlight current strength in ICU provider-family relationships [see sidebar]. The authors identified several opportunities to improve these relationships in the areas of family integration and empowerment. In our center, we have implemented a comprehensive informational website for families, an initiative that aligns with the Society of Critical Care Medicine’s family-centered care guideline for family education. The authors sought to expand on the guideline’s recommendations on family-centered communication training for ICU clinicians by implementing role-playing exercises for critical care trainees to highlight the importance of informal family interactions that target family empowerment. Future efforts to build therapeutic alliance should also consider educational activities that enable physicians and other providers to reflect on the norms and practices that produce inequality across the provider-family dyad. Further research is necessary to understand the best ways to integrate families into rounds, how to build on the com-

plementary roles and practices of physicians and nurses, and how informal interactions shape and constrain family-provider relationships. Multiple interventions are likely needed to continually foster positive relationships, mitigate identified barriers and transform the ICU into a more inter-professional and family-centered therapeutic environment to enhance patient and family outcomes. **Full text:** <https://goo.gl/gB9kkn>

#### Extract from *BMC Health Services Research* article

Therapeutic alliance is an ideal relationship that emerges between patients (or families as surrogates) and providers when conditions of these four distinct dimensions are met: 1) Effective information exchange and empathetic communication; 2) Integration of families into the care team through equalization of power by providers; 3) Collaboration between families and providers in establishing mutually agreed goals; and, 4) Empowerment of families by providers to partner in decision-making.

#### Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 July 2018 – ‘**Family caregivers’ confidence caring for relatives in hospice care at home: An exploratory qualitative study.**’ Evidence shows that caregivers of hospice patients do not feel confident or prepared to care for relatives or friends who die at home. Four storylines running longitudinally through interviews [with family caregivers] were identified as shaping, giving meaning to, and contextualizing caregivers’ confidence: 1) Values/relationships; 2) Stories of terminal illness; 3) Needs; and, 4) Support. Caregivers’ confidence is shaped by the terminal illness of the person for whom they care and caregivers’ values and relationships. It is also influenced by their needs and the sources and strength of support they receive. **Abstract:** <https://goo.gl/EnzKg2>
- *BMC FAMILY PRACTICE* | Online – 13 July 2018 – ‘**Challenges in supporting lay carers of patients at the end of life: Results from focus group discussions with primary healthcare providers.**’ Healthcare providers in general practice identified many relational challenges in daily primary palliative

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care. Based on the authors findings, strategies to resolve these may concern the dimensions knowledge, professional attitude, and skills which could be further supported and developed as part mixed interventions with educational and organisational elements. The results of this study indicate that it is insufficient to demand a support network; existing structures need to be recognized and included into the care in general practices. **Full text:** <https://goo.gl/5bRNYX>

- *SCANDINAVIAN JOURNAL OF OCCUPATIONAL THERAPY* | Online – 13 July 2018 – ‘**Occupational balance among family members of people in palliative care.**’ In this study, the authors found that being a family member to a person in palliative care changes roles and can cause occupational imbalance. To a large extent it affects daily routines, habits and everyday occupations, and may even lead to ill health. Their findings may suggest that family members could benefit from strategies to maintain valued roles and occupations. The Swedish healthcare system currently seems to neglect the needs of the family members, just taking the patient into consideration. Accordingly, developing new ways to organize the provision of palliative care that also takes the family members into consideration, as well as their occupational needs might help to close these gaps. **Full text:** <https://goo.gl/p4xiMy>

### **Pediatric palliative care**

#### **The “liaison” in consultation-liaison psychiatry: Helping medical staff cope with pediatric death**

*CHILD & ADOLESCENT PSYCHIATRIC CLINICS* | Online – 4 July 2018 – Pediatric consultation-liaison clinicians are well positioned to provide support, guidance, and systemic recommendations about how to help medical clinicians cope with the stresses of working with dying children. Interventions to support sustainability in this work need to occur at the institutional and team-based levels as well as in individual practice. Shared clinical work around challenging cases provides opportunities to engage with medical clinicians about their difficult experiences and provide reflection and support. Psychiatry services may also be in a role of advocating for institutionally based interventions that can help their medical colleagues. **Abstract:** <https://goo.gl/Vj7xfM>

### **Related**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 July 2018 – ‘**Update on palliative care for pediatric neurology.**’ It has long been recognized that patients with neurological conditions, and particularly pediatric neurology patients, are well suited for palliative care (PC) because they frequently have a high symptom burden and variable prognoses. In 1996, the American Academy of Neurology formally recognized a need for neurologists to “understand and apply the principles of palliative medicine.” Subsequently, some reviews have proposed a simultaneous care model in which PC is integrated for all neurology patients from the time of diagnosis. **Abstract:** <https://goo.gl/P3JMCp>
- *BMC PALLIATIVE CARE* | Online – 13 July 2018 – ‘**A qualitative study of health care professionals’ views and experiences of paediatric advance care planning.**’ The value of conducting the planning process in stages and considering the environment where the conversation is held being important. These factors were identified as helping the process both for the health care professional, but also for families. Clearly timely advance care planning, with involvement of the appropriate team from specialist palliative care or a children’s hospice for parallel planning, suggest that this will avoid families having difficult conversations at a crisis time. **Full text:** <https://goo.gl/X3brTA>

#### **Communication matters: Pitfalls and promise of high-tech communication devices in palliative care of severely physically disabled patients with amyotrophic lateral sclerosis**

*FRONTIERS IN NEUROLOGY* | Online – 6 July 2018 – Amyotrophic lateral sclerosis (ALS) is the most common motor neuron disease, leading to progressive paralysis, dysarthria, dysphagia and respiratory disabilities. Therapy is mostly focused on palliative interventions. During the course of the disease, verbal as well as non-verbal communicative abilities become more and more impaired. In this light, communication has been argued to be “the essence of human life” and crucial for patients’ quality of life. High-tech augmentative and alternative communication (HT-AAC) technologies such as eye-tracking based com-

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puter devices and brain-computer-interfaces provide the possibility to maintain caregiver-independent communication and environmental control even in the advanced disease state of ALS. Thus, they enable patients to preserve social participation and to independently communicate end-of-life-decisions. In accordance with these functions of HT-AAC, their use is reported to strengthen self-determination, increase patients' quality of life and reduce caregiver burden. Therefore, HT-AAC should be considered as standard of (palliative) care for people with ALS. On the other hand, the supply with individually tailored HT-AAC technologies is limited by external and patient-inherent variables. This review aims to provide an overview of the possibilities and limitations of HT-AAC technologies and discuss their role in the palliative care for patients with ALS. **Abstract:** <https://goo.gl/tzgdWk>

### **Home healthcare and hospice: A Pacific Islands perspective**

*HOME HEALTHCARE NOW*, 2018;36(4):252-257. The Pacific Islands Geriatric Education Center of the University of Hawaii conducted situational assessments of caregivers, older adults, and healthcare professionals in the Republic of Palau. The findings revealed an urgent need for a solution to the identified crisis of an aging population, increasing chronic diseases and their corresponding impact on caregivers and society. In 2010, the National Healthcare Financing Act was signed into law, becoming Palau's first step in helping residents and workers in Palau pay for medical expenses. This program is referred to as the Health Care Fund and consists of two parts: National Health Insurance & Medical Savings Account. Advocacy and promotion of home healthcare services in Palau was facilitated by the Pacific Islands Geriatric Education Center. Because of these efforts, systems changed to establish home healthcare services and expand the Health Care Fund with a proposed Home Health Insurance Benefit from the National Health Insurance. This is a huge leap forward to improve access to care for older adults and the home-bound in Palau. **Abstract:** <https://goo.gl/RHXqsR>

### **Social and organizational practices that influence hospice utilization in nursing homes**

*JOURNAL OF AGING STUDIES*, 2018;46(9):76-81. This article shows how staff beliefs and work routines influenced hospice utilization in two nursing homes. In one, 76% of residents died on hospice and in the other 24% did. Staff identified barriers to hospice including families who saw hospice as giving up and gaps in the reimbursement system. At the high-hospice nursing home, staff said hospice care extended beyond what they provided on their own. At the low-hospice nursing home, an influential group said hospice was essentially the same as their own end-of-life care and therefore needlessly duplicative. Staff at the high-hospice nursing home proactively approached families about hospice, whereas staff at the low-hospice nursing home took a reactive approach, getting hospice when families asked for it. Findings demonstrate how staff beliefs and practices regarding hospice shape end-of-life care in nursing homes. **Abstract:** <https://goo.gl/XatZ1X>

### **Managing clinical uncertainty: An ethnographic study of the impact of critical care outreach on end-of-life transitions in ward-based critically ill patients with a life-limiting illness**

*JOURNAL OF CLINICAL NURSING* | Online – 10 July 2018 – Rapid response teams, such as critical care outreach teams, have prominent roles in managing end-of-life (EoL) transitions in critical illness, often questioning appropriateness of treatment escalation. Clinical uncertainty presents clinicians with dilemmas in how and when to escalate or de-escalate treatment. A study across two hospitals observed transition points and decisions to de-escalate treatment, through the lens of critical care outreach. Three main themes emerged: 1) Early decision-making and the role of critical care outreach; 2) Communicating EoL transitions; and, 3) EoL care and the input of critical care outreach. Findings suggest there is a negotiation to achieve smooth transitions for individual patients, between critical care outreach, and parent or ward medical teams. This process of negotiation is subject to many factors that either hinder or facilitate timely transitions. There needs to be a cultural shift towards early and open discussion of treatment goals and limitations of medical treatment, particularly when facing serious illness. With training and competencies, outreach nurses are well placed to facilitate these discussions. **Abstract:** <https://goo.gl/NsrgdQ>

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Noted in Media Watch 9 July 2018 (#571, p.11):

- *JOINT COMMISSION JOURNAL ON QUALITY & PATIENT SAFETY* | Online – 27 June 2018 – ‘**Who benefits from aggressive rapid response system treatments near the end of life? A retrospective cohort study.**’ Many patients near the end of life (EoL) are subject to rapid response system (RRS) calls. A study was conducted in a large teaching hospital to identify a cut-off point that defines non-beneficial treatment for older hospital patients receiving an RRS call, describe interventions administered, and measure the cost of hospitalization. Overall, 8.9% of the 733 patients studied had a pre-existing not-for-resuscitation (NFR) or not-for-RRS order; none of those patients survived to three months. By contrast, patients without an NFR or not-for-RRS order had three-month survival probability of 71%. **Abstract:** <https://goo.gl/18otCA>

### **Palliative care: The “miracle drug” still missing in many clinical pathways**

*JOURNAL OF CLINICAL PATHWAYS* | Online – Accessed 14 July 2018 – Palliative care (PC) focuses on relieving the stress, pain, and symptoms of serious illness at any point along patients’ care trajectory. Most physicians and patients think PC is only for patients at the end of life (EoL) or that it is an “extra” or unnecessary service, yet evidence demonstrates that PC saves money while improving lives when added to routine care. As the U.S. health care system moves toward more value-based care delivery models, much needs to be done to reshape how physicians and patients think of PC. If PC were a drug, we would be holding hearings on Capitol Hill right now, demanding to know why everyone does not have access to its benefits. We would be writing think pieces, positing ways to bring down PC costs; we would be pushing the Food & Drug Administration for fast-track approval. We would be writing of the ways in which we should be incorporating PC into clinical pathways. Instead, when most patients hear “palliative care,” they either do not know what it is, or they think it means care for the dying. Likewise, clinicians often associate PC with the EoL or “what to do when there is nothing left to do.” **Full text:** <https://goo.gl/St9k3t>

### **Content validity of a conceptual model of a palliative approach**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 July 2018 – The term “palliative approach” has emerged to connote healthcare activities provided consistent with the philosophy of palliative care (PC), but not limited to specialized care providers or settings. A rigorous understanding of the palliative approach requires a conceptual model, which links the philosophy of PC to specific actions of practitioners, and is applicable to patients with any life-threatening illness, at any point on the disease trajectory, and provided by any care provider in any setting. The authors propose a conceptual model asserting that a palliative approach exists when care simultaneously addresses whole-person needs, enhances quality of life, and acknowledges mortality. Nineteen definitions are identified [in a literature search]. The three domains were represented in the majority: 1) Whole-person care (17/19); 2) Quality-of-life focus (17/19); and, 3) Mortality acknowledgement (15/19). Published definitions also included other concepts, but only one of these (family within the unit of care) appeared in more than a few definitions. The proposed conceptual model bridges philosophical definitions and clinician behavior and has potential to inform broad implementation of a palliative approach, at both clinic and system levels. **Abstract:** <https://goo.gl/JBrDH1>



### **Barry R. Ashpole**

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>

## The hospice and palliative care advanced practice registered nurse workforce: Results of a national survey [in the U.S.]

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2018;20(4):349-357. One barrier to continued growth of palliative care (PC) is the shortage of qualified hospice and PC clinicians. Advanced practice registered nurses are an important part of the interdisciplinary PC team, and strengthening this workforce can help alleviate the shortage of clinicians and improve access to quality PC. However, there is a dearth of information about this workforce. The authors distributed an online survey between October 2016 and January 2017 and received 556 responses. Sixty-three percent had more than 20 years of experience as a registered nurse yet were newer to practice as a hospice and PC advanced practice nurse, with 53.8% having 0 to 5 years of experience in this role. Forty-one percent indicated that their traditional graduate educational preparation was insufficient in preparing them for their specialty role. Most indicated that they did not experience barriers to practice in their current position, but 7.3% identified significant issues. These results can inform future professional, educational, and regulatory efforts to support and develop the PC advanced practice registered nurse workforce. **Abstract:** <https://goo.gl/cvZZRz>

Noted in Media Watch 2 July 2018 (#570, p.11):

- *JOURNAL OF PALLIATIVE CARE* | Online – 29 June 2018 – ‘Nurse practitioners as disruptive innovators in palliative medicine.’ There are not enough physicians available to care for the growing number of patients... The authors believe that nurse practitioners (NPs) are well positioned to meet this demand. They use the concept of disruptive innovations to provide support for their belief that NPs can, and should, take a larger role in palliative medicine. **Abstract:** <https://goo.gl/Dg5D6y>

**N.B.** Additional articles on the palliative care workforce in the U.S. noted in the 14 May 2018 issue of Media Watch (#563, p.7).

## Text network analysis of newspaper articles on life-sustaining treatments

*JOURNAL OF THE KOREAN ACADEMY OF COMMUNITY HEALTH NURSING*, 2018;29(2):244-256. In the general daily and healthcare newspapers [in Korea], the top eight core keywords were common: “patients,” “death,” “LST (life-sustaining treatments),” “hospice palliative care” (HPC), “hospitals,” “family,” “opinion,” and “withdrawal.” There were also common subtopics shared by the general daily and healthcare newspapers: withdrawal of LST, HPC, National Bioethics Review Committee, and self-determination and proxy decision of patients and family. Additionally, the general daily newspapers included diverse social interest or events like well-dying, euthanasia, and the death of farmer Baek Nam-ki,<sup>1</sup> whereas the healthcare newspapers discussed problems of the relevant laws, and insufficient infrastructure and low reimbursement for HPC. The discourse that withdrawal of futile LST should be allowed according to the patient’s will was consistent in the newspapers. Given that newspaper articles influence knowledge and attitudes of the public, registered nurses are recommended to participate actively in public communication on LST. **Abstract (w. list of figures and references):** <https://goo.gl/e9oDk2>



**Korean Academy of  
Community Health Nursing**

1. ‘Why the death of one rice farmer has captivated South Korea,’ *The South China Morning Post*, published online 1 October 2016. <https://goo.gl/dESUqe>

**N.B.** Korean language journal article. To access full text click on pdf icon.

Noted in Media Watch 9 April 2018 (#558, p.4):

- SOUTH KOREA | KBS World Radio (Seoul) – 6 April 2018 – ‘Thousands suspend life-sustaining treatment after well-dying law implemented.’ More than three-thousand patients have forgone life-prolonging treatment since the Hospice, Palliative Care & Life-sustaining Treatment Decision-making Act, commonly known as the well-dying law, went into effect two months ago. According to the Ministry of Health & Welfare and the Korea National Institute for Bioethics Policy, a total of 3,274 terminally ill patients withheld or suspended life-sustaining treatment between 4 February, when the well-dying law took effect, and 3 April. <https://goo.gl/BQdBYd>

## **Fair, just and compassionate: A pilot for making allocation decisions for patients requesting experimental drugs outside of clinical trials**

*JOURNAL OF MEDICAL ETHICS* | Online – 7 July 2018 – Patients have received experimental pharmaceuticals outside of clinical trials for decades. There are no industry-wide best practices, and many companies that have granted compassionate use, or “preapproval,” access to their investigational products have done so without fanfare and without divulging the process or grounds on which decisions were made. The number of compassionate use requests has increased over time. Driving the demand are new treatments for serious unmet medical needs; patient advocacy groups pressing for access to emerging treatments; internet platforms enabling broad awareness of compelling cases or novel drugs and a lack of trust among some that the pharmaceutical industry and/or the Food & Drug Administration have patients’ best interests in mind. High-profile cases in the media have highlighted the gap between patient expectations for compassionate use and company utilisation of fair processes to adjudicate requests. With many pharmaceutical manufacturers, patient groups, healthcare providers and policy analysts unhappy with the inequities of the status quo, fairer and more ethical management of compassionate use requests was needed. This paper reports on a novel collaboration between a pharmaceutical company and an academic medical ethics department that led to the formation of the Compassionate Use Advisory Committee (CompAC). Comprising medical experts, bioethicists and patient representatives, CompAC established an ethical framework for the allocation of a scarce investigational oncology agent to single patients requesting non-trial access. **Abstract:** <https://goo.gl/Eg2gXN>

**N.B.** Selected articles on the issue of “right-to-try” new experimental or investigational drugs noted in the 11 June 2018 issue of Media Watch (#567, p.12).

## **How do experienced professors teach palliative medicine in European universities? A cross-case analysis of eight undergraduate educational programs**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 July 2018 – In Europe in recent decades, university teaching of palliative medicine (PM) has evolved. In some countries it has been introduced as a compulsory subject in all medical schools, but in a majority of countries it remains an isolated subject at few universities. An intentional sample of eight university professors from Spain, France, U.K., Italy, Hungary, Sweden, Germany, and Poland was chosen. The introduction of PM in the universities depends on the existence of a favorable social and political context in relation to palliative care and the initiative of pioneers, trusted by students, to push this education forward. A PM curriculum frequently starts as an optional subject and becomes mandatory in a short period. In the reported universities, PM uses a wide variety of teaching methods, such as lectures, workshops, role-plays, and discussions. PM assessment included tests, discussions, reflections, portfolios, and research works. According to respondents’ opinions, lack of recognition, funding, and accredited teachers, along with competition from other curricula, are the main barriers for PM teaching development at universities. The described cases may shed light on other medical schools to develop PM *curricula*. **Abstract:** <https://goo.gl/TvaiT8>

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

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 26 May 2015 – ‘**Palliative care medical education in European universities: A descriptive study and numerical scoring system proposal for assessing educational development.**’ Forty-three countries provided the requested information. In 13 countries, a palliative medicine (PM) course is taught in all medical schools, being compulsory in six of them. In 15 countries, PM is taught in at least one university. In 14 countries, PM is not taught within medical curricula. A full professor of PM was identified in 40% of countries. Three indicators were developed to construct a scale of educational development: 1) Proportion of medical schools that teach PM; 2) Proportion of medical schools that offer PM as a compulsory subject; 3) Total number of PM professors. The highest level of PM educational development was found in Israel, Norway, the U.K., Belgium, France, Austria, Germany and Ireland. **Abstract (w. link to references):** <https://goo.gl/PvPNYn>

## “Fighting” cancer may detract men from palliative care

*MEDICALXPRESS* | Online – 9 July 2018 – Men with advanced cancer are 30% less likely than women to consider palliative care (PC), according to a University of Rochester Medical Center study.<sup>1</sup> “There is an ethos of ‘fight, fight, fight,’ and there is nothing wrong with that,” said Timothy E. Quill, an internationally recognized pioneer in PC. “But if all you do is fight and you ignore the emotional and spiritual aspects of what’s happening, it’s a missed opportunity to look at life in a different way.” Scientists analyzed data from 383 individuals with advanced cancer between the ages of 22 and 90, who had been asked about their preferences for PC. Response options were: definitely no, possibly no, unsure, possibly yes, and definitely yes. The analysis accounted for other factors such as aggressiveness of the cancer, age, race, and financial status, but gender was the only factor that significantly influenced preference for PC, according to the study... The research is consistent with other studies showing that men also are less likely to sign do-not-resuscitate orders at the end of life... For this study, PC was defined as “comfort care, focusing on quality of life.” All of the patients had advanced cancer. **Full text:** <https://goo.gl/wr8YJS>

1. ‘Preference for palliative care in cancer patients: Are men and women alike?’ *Journal of Pain & Symptom Management*, 2018;56(1):1-6. **Abstract (w. link to list of references):** <https://goo.gl/onQoVD>

Noted in Media Watch 21 May 2018 (#564, p.4):

- U.K. (England, Northern Ireland, Scotland & Wales) / *The Guardian* (London) – 15 May 2018 – ‘**Pressure to stay positive may be a negative for cancer patients...**’ The perceived need to “fight” cancer and remain positive is having a negative effect on people living with the disease, especially those with a terminal diagnosis who are not getting the right support for the end of life. Research by Macmillan Cancer Support shows that there are a number of barriers preventing honest conversations about dying.<sup>1</sup> One of the biggest barriers is the pressure to stay positive, even when patients received a terminal diagnosis. <https://goo.gl/GzUWiq>

1. “‘Fighting talk’ can leave cancer patients unable to talk about death and dying,” Macmillan Cancer Support, May 2018. **Download/view at:** <https://goo.gl/LRxCMc>

## “Caregrieving” in palliative care: Opportunities to improve bereavement services

*PALLIATIVE MEDICINE* | Online – 6 July 2018 – Traditionally, bereavement follow-up is provided to the caregivers following the death of a patient. However, there has been recognition that preparing family caregivers in advance of an impending death of a loved one may ameliorate the post-loss distress and dislocation. It may also be a way to identify caregivers who are at risk for future maladjustment to the loss. Palliative care’s ability to provide continuity of care from pre- to post- loss may help to prepare the caregiver for their loved one’s approaching death and provide a sense that they have not been abandoned or forgotten by the service after the patient dies. The lack of an evidence-based, standardized protocol for screening caregivers at risk of a difficult bereavement adjustment has impeded progress in the delivery of bereavement care. There also is a concern that bereavement interventions not inadvertently inflict psychological harm on the bereaved survivor. Despite the exponential growth in technological applications in the realm of detection and intervention, hospitals and hospices have done remarkably little to capitalize on the potential usefulness of these technologies for improving bereavement diagnosis, support, resources, and care. There is a need for palliative care services to pay closer attention to the psychological needs of family caregivers, and to “caregrieving,” both while the patient is alive, as well as after the patient has died. **Full text:** <https://goo.gl/McvtpL>



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

## Creating space to discuss end-of-life issues in cancer care

*PATIENT EDUCATION & COUNSELING* | Online – 6 July 2018 – When oncologists break the bad news that a patient’s treatment is no longer effective, they often use a conversational device called an “exhausted current treatment” (ECT) statement, which avoids discussing prognosis in favor of further discussing treatment options. Analysis suggests that improving and prioritizing patient-centered care and shared decision making is possible if we first understand the social organization of clinical visits. ECT statements and their movement towards discussing treatment options means that opportunities are bypassed for patients and caregivers to process or discuss scan results, and their prognostic implications. When oncologists and patients, by fixating on treatment options, bypass opportunities to discuss the meaning of scan results, they fail to realize other goals associated with prognostic awareness. Talking about what scans mean may add minutes to that part of the clinic visit, but can create efficiencies that conserve overall time. The authors recommend that oncologists, after delivering scan news, ask, “Would you like discuss what this means?” **Abstract:** <https://goo.gl/tU648c>

### Related

- *JAMA INTERNAL MEDICINE*, 2018;178(7):930-940. ‘**Effect of a patient and clinician communication-priming intervention on patient-reported goals-of-care discussions between patients with serious illness and clinicians: A randomized clinical trial.**’ In this multicenter cluster-randomized trial of 132 clinicians and 537 patients, the Jumpstart-Tips intervention resulted in a significant increase in patient-reported goals-of-care conversations during routine outpatient clinic visits, from 31% in the usual care group compared with 74% in the intervention group. The intervention also increased the patient-reported quality of these discussions. **Abstract:** <https://goo.gl/C6pbNh>

## Ageing and dying in the contemporary neoliberal prison system: Exploring the “double burden” for older prisoners

*SOCIAL SCIENCE & MEDICINE* | Online – 9 July 2018 – The authors propose that older prisoners face a “double burden” when incarcerated. This double burden means that as well as being deprived of their liberty, older people experience additional suffering by not having their health and wellbeing needs met. For some, this double burden includes a “*de facto* life sentence,” whereby because of their advanced age and the likelihood that they will die in prison, they effectively receive a life sentence for a crime that would not normally carry a life sentence. There has been little popular or academic debate concerning the ethical and justice questions that this double burden raises. The authors proposes that these changes are best understood as unplanned, but reasonably foreseeable consequences of neoliberal penal policies. Although the authors focus on the U.K. (which by comparison with other European countries has high rates of imprisonment), many of the challenges discussed are emerging in other countries across the world. The article illustrates starkly how neoliberal policies and discourses have shaped the expansion and composition of the prison population with its consequent implications for health and justice. **Abstract:** <https://goo.gl/KZSLaf>

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 May 2018) can be downloaded/viewed at: <https://goo.gl/YLckx6>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *INTERNAL MEDICINE JOURNAL*, 2018;48(7):774-779. ‘**Medical Oncology Group of Australia position statement and membership survey on voluntary assisted dying.**’ Majority views expressed in the survey will form the basis of a Medical Oncology Group of Australia (MOGA) position statement on voluntary assisted dying (VAD). A total of 362 members completed the questionnaire, representing 55% of the membership; 47% of respondents disagreed with VAD; 36% agreed with VAD and the re-

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maining members (17%) were “neutral.” A clear majority position was not established. Only 14% agreed that physicians involved in VAD should be required personally to administer the lethal medication; 94% supported conscientious objection of physicians to the VAD process; 95% agreed that a palliative care physician consultation should be required and 86% agreed with the need for the involvement of specialist psychiatry medical services before a patient can be deemed as suitable for VAD. The MOGA membership expressed a range of views on the topic of VAD. A clear majority-held view to support a MOGA position that either supports or opposes VAD was not established. The position statement that flows from the survey encourages informed debate on this topic and brings into focus important considerations. **Full text:** <https://goo.gl/rPPC5B>

- *INTERNAL MEDICINE JOURNAL* | Online – 8 July 2018 – ‘**Perspectives of cancer treatment providers regarding voluntary assisted dying in Victoria.**’ A survey of cancer treatment providers exploring their perspectives regarding voluntary assisted dying in Victoria and the imminent legislation showed that while almost all were aware of the Bill (92%), reported knowledge and understanding of it was much less (38%). As many clinicians supported the Bill as opposed it (28%); 44% were uncertain of their stance. Most were unwilling to directly provide voluntary assisted dying; if they did, would refer to palliative care services for ongoing support. **Abstract:** <https://goo.gl/s2MrD1>
- *JOURNAL OF LAW & MEDICINE* | Online – Accessed 12 July 2018 – ‘**A phronetic inquiry into the Australian euthanasia experience: Challenging paternalistic medical culture and unrepresentative health policy.**’ Australia’s intermittent attempts to legalise euthanasia are typically fraught with brief, polarised, and often sensationalised, public debate. Yet beyond the sensitive arguments in favour and in opposition of reform, the practical antecedents of change that may determine Australia’s genuine aptitude to enact reforms have been largely neglected. Phronetic legal inquiry thus offers insights into the euthanasia law reform experience, using Australian and international case comparisons to examine covert power dynamics, cultural discourses, and social and institutional structures that affect the practices of the legislature. On this basis, it is argued that Australia’s medical profession, and particularly its dominant providers of palliative care, are hampered by an entrenched culture of medicalisation and paternalism, within which patient autonomy provides only a veneer of self-determination. This can be strikingly contrasted with the Dutch approach of patient-centred care, which seeks to produce collaborative, respectful dialogue between physician and patient and to integrate the principles of autonomy and beneficence. Furthermore, these contrasting medical cultures represent issues in the broader policymaking context, as Australia’s health policy remains unduly subject to the pressure of unrepresentative yet influential conservative interest groups, most prominently including the Australian Medical Association. This pressure serves to suppress public opinion on the issue of euthanasia in a parliamentary climate that remains stifled by bipartisan alliances and political inertia. It is therefore argued that Australia’s prospects for successful voluntary euthanasia law reform rest on the dual pillars of developing a more patient-centred medical culture and challenging the prevailing paternalistic approach to health policymaking in Australia’s currently unrepresentative political landscape. **Abstract:** <https://goo.gl/qwUPK4>
- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 12 July 2018 – ‘**Amyotrophic lateral sclerosis and a “death with dignity.”**’ The Oregon “Death With Dignity” (DWD) Act allows a terminally ill patient with six months to live to ask a physician for medication to end their life. To receive the medication, the Act requires the patient to verbally request the prescription twice 2 weeks apart as well as in writing. Patients with amyotrophic lateral sclerosis (ALS) have three main barriers to using DWD: 1) The ability to communicate their informed consent as the disease progresses further; 2) The possibility of dementia which may affect their decisional capacity; and, 3) Given the nature and speed of ALS, limited time is available for patients to self-administer the prescription and may rush the time line for the death. **Abstract:** <https://goo.gl/WCsQmm>

## Journal Watch

### What are “predatory” academic journals?

*THE ECONOMIST* | Online – 10 July 2018 – To get ahead in academia, not much beats publishing lots of papers that have been vetted by independent experts, a process of quality control known as peer review. In recent years, however, this practice of appraising researchers by counting their publications has be-

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come problematic. This is because an astonishing number of journals that bill themselves as “peer-reviewed” do not, in fact, take the trouble to be so. A tally of journals that an American analytics firm, Cabells,<sup>1</sup> believes to falsely claim to peer-review submissions, amounted, on a recent day, to 8,699 – more than double the number of a year ago. A blacklist compiled by other experts is even longer. Fuelling the boom is a change in the way many journals make money. In the past decade or so, many have ceased selling subscriptions. Instead, they now charge authors to publish their papers. This “open-access” business model allows anyone to read papers online for free, but there’s a big drawback. A journal that need not induce readers to pay can publish rubbish, as long as authors will pay for the presumed prestige, says Elizabeth Wager, a British consultant on academic publishing and editor of *Research Integrity & Peer Review*, a journal. The result has been a flood of “atrocious” papers, note researchers at the Ottawa Hospital Research Institute, who last year completed a study of 3,702 biomedical articles from 185 suspect publishers.<sup>2</sup> These journals have come to be called “predatory” for their exploitation of earnest but duped authors. Some authors are no doubt tricked – a number of bogus journals have taken the same name as a prestigious one, a tactic known as “hijacking.” But the “predatory” label has proven broadly misleading. Authors typically know what’s up, or at least should when visiting journal websites rife with glaring errors of language and wild claims, such as rigorous peer reviews that can be completed in a jiffy. Most authors who publish in dodgy journals probably reckon the benefits of an apparently impressive résumé outweigh the risk of being caught, in which case, anyway, one could always claim ignorance. The fakery also seems to be paying off for many institutions, which may prefer highlighting their supposed prestige to casting light on missteps. A study last year by Derek Pyne, an economist at Thompson Rivers University’s business school, in British Columbia, found that publishing in bogus journals benefited many of the school’s professors and administrators.<sup>3</sup> <https://goo.gl/n4tVCM>

#### Relevant articles noted in past issues of Media Watch:

1. ‘Cabells’ journal whitelist and blacklist: Intelligent data for informed journal evaluations,’ *Learned Publishing*, published online 19 April 2018. [Noted in the 30 April 2018 issue (#561, p.15)] **Abstract:** <https://goo.gl/qjoWFh>
2. ‘Stop this waste of people, animals and money,’ *Nature*, published online 6 September 2017. [Noted in the 9 October 2017 issue (#533, p.1)] **Full text:** <https://goo.gl/CXLDMC>
3. ‘The rewards of predatory publications at a small business school,’ *Journal of Scholarly Publishing*, 2017;48(3):137-160. [Noted in the 15 May 2017 issue (#512, p.9)] **Abstract:** <https://goo.gl/a56XiU>

#### Related

- *THE ECONOMIST* | Online – 23 June 2018 – ‘**A rising number of journals that claim to review submissions do not bother to do so.**’ Experts debate how many journals falsely claim to engage in peer review. Cabells, an analytics firm in Texas, has compiled a blacklist of those which it believes are guilty.<sup>1</sup> According to Kathleen Berryman, who is in charge of this list, the firm employs 65 criteria to determine whether a journal should go on it – though she is reluctant to go into details. Cabells’ list now totals around 8,700 journals, up from a bit over 4,000 a year ago. Another list, which grew to around 12,000 journals, was compiled until recently by Jeffrey Beall, a librarian at the University of Colorado. Using Mr.Beall’s list, Bo-Christer Bjork, an information scientist at the Hanken School of Economics, in Helsinki, estimates that the number of articles published in questionable journals has ballooned from about 53,000 a year in 2010 to more than 400,000 today.<sup>2,3</sup> He estimates that 6% of academic papers by researchers in America appear in such journals. <https://goo.gl/4YovY6>
1. ‘Cabells’ journal whitelist and blacklist: Intelligent data for informed journal evaluations,’ *Learned Publishing*, published online 19 April 2018. [Noted in the 30 April 2018 issue of Media Watch (#561, p.15). **Abstract:** <https://goo.gl/qjoWFh>
  2. Beall’s list of predatory journals and publishers: <https://goo.gl/kM2FYQ>
  3. “Predatory” open access: A longitudinal study of article volumes and market characteristics,’ *BMC Medicine*, published online 1 October 2015. **Full text:** <https://goo.gl/pVNtSb>

## 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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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.
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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.

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INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/T2tCWF>

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

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

### **Asia**

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

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

### **Australia**

PALLIATIVE CARE WESTERN AUSTRALIA: <https://goo.gl/fCzNTL>

[Scroll down to 'International Websites']

Cont.

## Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: <https://goo.gl/qw5ti8>

[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']



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

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

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

[Scroll down to 'Additional Resources']

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>

[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

SASKATCHEWAN | Saskatchewan Medical Association: <https://goo.gl/5cftPV>

[Scroll down to 'Palliative Care Network Community']

## Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/KjrR6F>

[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population with poor access to palliative care.')]

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

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

## South America



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

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