

## 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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**'Unpacking "the cloud": A framework for implementing public health approaches to palliative care' (p.9), in *Health Promotion International*.**

## Canada

### **Palliative paramedic program to train thousands in end-of-life care**

*THE NATIONAL POST* | Online – 29 January 2019 – Health authorities across the country are getting funds to train thousands of paramedics to deliver palliative care (PC). The Canadian Partnership Against Cancer and the Canadian Foundation for Healthcare Improvement say they are jointly providing up to \$5.5 million over the next four years for the plan in six provinces. They expect that will support training for more than 5,000 paramedics. The two agencies say palliative paramedic services can reduce unnecessary hospital visits and give those with cancer and other life-limiting conditions access to urgent end-of-life care “when they need it, and where they want it.” The program is based on existing models in Nova Scotia, Prince Edward Island and Alberta. The funds will go to health teams including: British Columbia Emergency Health Services, Saskatchewan Health Authority Regina Area, Interlake-Eastern Regional Health Authority in Manitoba, York Region Paramedic Services in Ontario, Ottawa Hospital Research

Institute, New Brunswick Department of Health, and Eastern Health in Newfoundland and Labrador. Having paramedics able to deliver PC eases the strain on health-care resources including hospital beds and emergency departments, and cuts the total time paramedics spend on a call... <http://bit.ly/2sUKVos>

### Specialist Publications

**'Palliative and end-of-life care education in Canadian emergency medicine residency programs: A national cross-sectional survey' (p.8), in *Canadian Journal of Emergency Medicine*.**

**'How the Canadian Medical Association found a third way to support all its members on assisted dying' (p.17), in *British Medical Journal*.**

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Discontinuation by Google of its URL shortening service, effective in March, makes it necessary for Media Watch to switch to the similar service provided by Bitly. This will not effect accessing articles, reports, etc., noted in past issues of the weekly report.

Noted in Media Watch 20 August 2018 (#577, p.7)

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2018;25(3):112-115. **‘U.K. ambulance services: Collaborating to provide good end-of-life care.’** The East of England Ambulance Service National Health Service (NHS) Trust (EEAST) has undertaken a number of successful collaborations with community end-of-life care (EoLC) providers and hospices, while one of the hospices works with EEAST paramedics and the local university to provide EoLC education to paramedic students. The South East Coast Ambulance Service NHS Foundation Trust has developed an improvement project, dedicated to EoLC and focusing on education, integration and collaboration of the ambulance service with the EoLC community, and improving the access to information.

**N.B.** Access this article at the journal website: <http://bit.ly/2sU1ZuD>. Additional articles on the role of ambulance services and paramedics in palliative and end-of-life care noted in 18 June 2018 issue of Media Watch (#568, pp.11-12).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NOVA SCOTIA | *The Coast* (Halifax) – 30 January 2019 – **‘958 days without medical assistance in dying policy.’** It’s been 958 days since Bill C-14 passed federal legislation, yet Nova Scotia still lacks a program for medical assistance in dying (MAiD) as well as MAiD policy and regulation. Without policy, physicians and nurse practitioners have no way of governing MAiD, creating a series of loopholes and lack of general knowledge surrounding the subject. The Nova Scotia Health Authority, meanwhile, has published false information on its website and staff at St. Martha’s hospital in Antigonish still refuse to perform the assistance at all. Under the province’s Frequently Asked Questions website for physicians and nurse practitioners, it states that mental illness is the sole underlying medical condition excluded from the legislation for MAiD, and that’s not true. <http://bit.ly/2Uuhdm0>

**N.B.** ‘Medical Assistance in Dying: Frequently Asked Questions for Public,’ Nova Scotia Health authority, Updated 4 October 2018. **Download/view at:** <http://bit.ly/2DL1dpX>

## U.S.A.

### New York re-defines hospice prognosis for Medicaid patients

NEW YORK STATE | *Niagara Gazette* (Niagara Falls) – 2 February 2019 – Nearly two-and-a-half years ago, the eligibility regulations for hospice care for strictly Medicaid recipients underwent a dramatic change that has gone under the radar not only in the public eye, but also in the hospice community. Without much public acknowledgment, New York state amended the Public Health Law in August 2016 by re-defining “terminal illness” for patients on Medicaid from the traditional six-month prognosis to a 12-month prognosis. The revised regulation, known as the Hospice Modernization Bill, demonstrated the State’s commitment to expanding the level of service Medicaid recipients should be able to access. New York also stands out as one of the only states to define “terminal illness” for Medicaid recipients with this adopted 12-month timeline. Medicaid-only recipients in New York State who have been diagnosed with a terminal illness now have the option of choosing hospice care much sooner in their illness. Instead of waiting

for a prognosis of six months or less, patients who receive exclusively Medicaid coverage can be admitted into hospice care when they have a prognosis of 12 months or less should their illness run its natural course. <http://bit.ly/2MSlflD>

#### Specialist Publications

**‘The development of pathways in palliative medicine: Definition, models, cost and quality impact’** (p.10), in *Healthcare*.

**‘Agency and change in healthcare organizations: Workers’ attempts to navigate multiple logics in hospice care’** (p.12), in *Journal of Health & Social Behavior*.

**‘Cancer and Opioids: Patient Experiences with Stigma (COPEs)’** (p.12), in *Journal of Pain & Symptom Management*.

## Minority hospitals less likely to give end-of-life relief, study says

UNITED PRESS INTERNATIONAL | Online – 1 February 2019 – Hospitals that primarily serve people of color are less likely to provide relief from the stress of a serious illness, regardless of the person's race, a new study says.<sup>1</sup> Only about 22% of white patients with metastatic cancer received palliative care (PC), according to research... “We knew that black and Hispanic cancer patients receive PC at lower rates than white patients, but until now, we didn’t know why. Was it just that doctors were not offering these services to their black and Hispanic patients? Or is there some other factor at play?” said Alexander Cole, a researcher at the Center for Surgery & Public Health at the Brigham & Women's Hospital, in a news release. Overall, the study included more than 600,000 individuals with metastatic cancer and found that only 21.7% received PC. That includes 20.0% of black patients and 15.9% of Hispanic patients. The study focused on patients with prostate, non-small cell lung, colon and breast cancers, which are four of the deadliest cancers. <http://bit.ly/2Bhw5wV>

1. ‘Association of care at minority-serving vs. non-minority-serving hospitals with use of palliative care among racial/ethnic minorities with metastatic cancer in the U.S.,’ *JAMA Open Network*, published online 1 February 2019. **Full text:** <http://bit.ly/2Ttrpea>

**N.B.** Selected articles on ethnic and racial disparities in the provision and delivery of palliative and end-of-life care in the U.S. noted in 14 January 2019 issue of *Media Watch* (#597, p.14).

## Oregon removes feeding tube option from end-of-life medical directive form

OREGON | Oregon Public Broadcasting (Portland) – 31 January 2019 – Oregon’s end-of-life (EoL) medical directive form [Physician Orders for Life-Sustaining Treatment], or POLST form, will no longer include the option of having a feeding tube. Doctors say they work well for patients in a coma or living with a condition like Lou Gehrig’s disease. But Dr. Susan Tolle with Oregon Health & Science University’s Center for Ethics in Health Care, said research shows the tubes can be harmful for people with dementia.<sup>1</sup> They tend to increase discomfort and agitation ... <http://bit.ly/2DNuVuF>

1. ‘It is time to remove feeding tubes from POLST forms,’ *Journal of the American Geriatrics Society*, published online 31 January 2019. **Letter to the editor:** <http://bit.ly/2G1fEZu>

## Now that right-to-try law is enacted, even supporters are wondering if they were sold false hope

KAISER HEALTH NEWS | Online – 29 January 2019 – As conservatives pushed for the right-to-try legislation, opponents of the bill were vocal in saying that it would give desperate patients false hope. Now, that those patients are trying to get experimental drugs from pharmaceutical companies, they face discouraging obstacles and frustrations. <http://bit.ly/2TgVJsh>

**N.B.** Additional articles on the issue of “right-to-try” new experimental or investigational drugs noted in 21 January 2019 issue of *Media Watch* (#598, p.3).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW MEXICO | *Albuquerque Journal* – 29 January 2019 – ‘**Committee passes “aid-in-dying” bill.**’ A bill that would allow New Mexicans diagnosed with a terminal illness to seek a physician’s help to end their lives cleared its first legislative hurdle after more than three hours of debate. Similar “aid-in-dying” legislation has prompted moral, religious and legal questions in past years and never received final approval. The bill prompted some of the same types of questions, but ultimately advanced on a party-line vote. Members of the House Health & Human Services Committee voted 4-3 to approve the legislation... Under current state law, it is illegal for a doctor to prescribe medication that might help a patient to end his or her life. The bill proposed in the House – along with a companion bill in the Senate – would sanction that practice, but only under limited circumstances. House Bill 90 now goes to the House Judiciary Committee. <http://bit.ly/2Bbvexu>

## International

### **Outdated drug policies leave millions of Africans in agony**

*THE ECONOMIST* | Online – 31 January 2019 – Anna has just hit puberty and she can barely move. She has late-stage cancer and a tumour protrudes from her neck. As a nurse walks in, Anna (not her real name) slowly covers her face with a veil. She is dying in agony in Dantec, one of Senegal's main hospitals. But the doctors don't have enough morphine to give her. In west Africa there are just 52 palliative care centres such as hospices for about 360 million people. Many of these do not have enough drugs. In Senegal the average patient who needs it gets 13 mg of morphine a year, compared with 55,704 mg in America. Across sub-Saharan Africa nine-tenths of cancer sufferers in moderate or severe pain die without the relief granted by opioids. <https://econ.st/2Tprvn0>

### **Over 35,000 patients refused life-sustaining treatment since last year**

KOREA | *The Korea Herald* (Seoul) – 30 January 2019 – More than 35,000 people have refused life-sustaining medical treatment since legislation on end-of-life care went into effect 4 February 2018, the Ministry of Health & Welfare and the Korea National Institute for Bioethics Policy report. Under the law, any individual over the age of 19 can submit a written form in advance indicating his or her intention of refusing treatment, even before receiving a diagnosis of terminal illness. Patients can also exercise the right to die naturally if two doctors certify that they they are expected to die within a few months. If the patient is incapable of expressing his or her wishes and has not submitted the form in advance, the doctor in charge can terminate life-sustaining treatment with the confirmation of another doctor and a statement from the family that the patient would not want the treatment. As of Monday, a total of 35,431 patients – 21,291 male patients and 14,140 female patients – had forgone life-prolonging medical treatment in

#### **Opioid pain relief in different countries**

**U.S.** gets 30 times more opioid pain relief medication than it needs

**Mexico** gets only 36% of what it needs

**China** gets about 16% of what it needs

**India** gets 4% of what it needs

**Nigeria** gets just 0.2% of what it needs

**Source:** *The Lancet* Commission on Global Access to Palliative Care & Pain Relief: <http://bit.ly/2Gd7oVs>

**N.B.** 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, October 2017. [Noted in 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** <http://bit.ly/2Ww8Cku>

keeping with the law. Of those patients, 14,787 had refused life-prolonging treatment within the first six months after the law took effect. Their numbers had grown to 17,830 by the seventh month, 20,742 by the eighth month, 24,331 by the ninth month and 28,256 by the 10th month. Among the 35,431 patients, only 0.8% had submitted written forms ahead of time. About 31% decided to terminate treatment only after being diagnosed as terminally ill, and in the other 67.7% of cases the families consented on behalf of patients who were unable to express their wishes. <http://bit.ly/2CYSmzk>

#### **Specialist Publications**

**'Korean physicians' perspectives on prognostication in palliative care: A qualitative study'** (p.6), in *American Journal of Hospice & Palliative Medicine*.

### **We all want increased choice in elder care – but neoliberal health policies make this difficult**

IRELAND | *The Conversation* – 29 January 2019 – With the view of reducing healthcare costs – and under the pretext of increasing choice – the U.K. and Irish governments have outsourced a great proportion of their home care services to for-profit providers. This is having several implications: no meaningful

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choice, increased loneliness among older people, a dissatisfied and sometimes exploited care work force and poor quality care. While governments pay lip service to the notion of choice, their disinvestment in public home care services means that older people and their families often have no choice but to “choose” for-profit home care providers, as these are becoming the norm for elder home care. In the past decade, there has been a change from government-operated public facilities into private, autonomous facilities and services, organised for profit. And there are further problems with this situation, beyond transformation of care into a commodity. Home care is not a typical product on a supermarket shelf. Care is a complex bundle of activities, tasks and interactions. Home care is a high involvement purchase, which requires considerable time and emotional investment. But people in need of care might not have all the necessary information, skills or time required to navigate intricate care markets. <http://bit.ly/2Ru4AoM>

### **Hospices could face closure over £30 million Tory “stealth tax” levy on owners**

U.K. | *The Daily Mirror* (London) – 28 January 2019 – Hospices could face closure as they are hit with an estimated £30 million Tory “stealth tax” over pensions. The Government is raising employers’ pension contributions in the health sector. National Health Service (NHS) Trusts will get extra cash to deal with the increase. But charity hospices, where terminally ill people are cared for in their final days, won’t get additional money to ease the transition and care homes will not get any money either. Health sector employers – including hospices – currently pay 14.3% of a worker’s pensionable pay into the NHS pension scheme. That is set to rise to 20.6% from this April under plans revealed in a consultation due to close today. Hospice UK CEO Tracey Bleakley said: “We are deeply concerned about the impact that current proposals to significantly increase employer contributions to the NHS pension scheme would have on charitable hospices across the U.K.” <http://bit.ly/2B6y8Uu>

### **Stop “fighting” cancer, and start treating it like any other illness**

U.K. | *The Guardian* (London) – 28 January 2019 – Do you have a cancer? Or are you “a brave hero fighting against the demon foe”? Have you something in your body that needs removing, or are you a heroic victim in a war you may “win or lose”? A poll by Macmillan Cancer Support has found that many people with cancer are fed up with the language of war.<sup>1</sup> They want to be treated like anyone else who is ill. They want to discuss their treatment with a doctor. It is simple as that. Anyone with experience of a cancer knows well the lugubrious looks you get. You poor thing. We are so sorry. How long have “they” given you? Be brave. Be positive. Fight back. Don’t give in and “lose.” It suggests you lacked courage and were “beaten.” Language always matters. It matters not because it affects physical wellbeing – a subject on which psychotherapists differ – but because it affects how people live with their illness and relate to those around them. The taboo that surrounds cancer is still intense. Until the middle of the last century, its apparent incurability made it the great unmentionable. That taboo still turns initial diagnosis, even of the commonest and most curable cancers such as breast, bowel, lung and prostate, into a devastating blow that can be treated as a premonition of death by family and friends. <http://bit.ly/2RVmmGC>

1. ‘Cancer clichés can leave people isolated and disempowered...,’ Macmillan Cancer Support, January 2019. **Download/view at:** <http://bit.ly/2sS1QYG>

Noted in Media Watch 13 August 2018 (#576, p.8):

- *CRITICAL APPROACHES TO DISCOURSE ANALYSIS ACROSS DISCIPLINES*, 2018;10(1):1-16. “**It is completely ok to give up a little sometimes**”: **Metaphors and normality in Swedish cancer talk.** The clichéd conceptualization of cancer illness as a battle, which the patient can either win or lose, can be problematic. For patients referred to palliative care it can cause feelings of guilt and failure. This framing of cancer, referred to as “the battle script,” has been questioned in previous research, and there seems to be awareness among health practitioners that battle metaphors should be avoided. **Abstract:** <http://bit.ly/2SaqKkp>

**N.B.** English language article. Click on pdf icon to access full text. Selected articles on the use of metaphors in relation to life-limiting or life-threatening illness noted in 21 May and 29 January 2018 issues of Media Watch (#564, p.5 and #548, p.15, respectively).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Times* (London) – 1 February 2019 – **‘Bitter split on assisted dying hits Royal College of Physicians.’** Doctors are in open revolt against their professional body amid claims that the Royal College of Physicians has been captured by lobbyists for assisted dying. A former official has threatened legal action over a new vote on the issue that he called a “sham poll.” The college opposes allowing doctors to help terminally ill patients to end their lives, but plans to poll its members and fellows again. Unless there is a 60% majority for or against assisted dying, it will adopt a neutral position. Opponents of the new poll argue that a neutral stance would amount to “tacit support for assisted suicide.” <http://bit.ly/2TqohzL>

## Specialist Publications

### **Korean physicians’ perspectives on prognostication in palliative care: A qualitative study**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 January 2019 – Semi-structured interviews were conducted in Korea with 11 palliative care (PC) physicians. Participants on average had 6.4 years of hospice and PC experience. The authors identified 4 main themes about prognostication: 1) The importance of prognostication (to help patients and their families prepare for death, to determine the appropriate time of transition to hospice care, to facilitate appropriate decision making, and to facilitate communication with patients and their families); 2) Difficulties of prognostication (discomfort estimating the exact date of death); 3) Basis of prognostication (clinical prediction of survival as well as prognostic scores); and 4) Areas for further research (need for a simpler scoring system or parameters to predict survival with greater certainty). PC physicians in Korea reported similar perceptions about the role and challenges inherent in prognostication compared to clinicians in Western cultures. However, they emphasize the need to predict final days to keep families with dying patients, reflecting family-centered aspects of Asian culture. They reported frustrations with inaccurate prognostication schemas and called for the development of simpler, more accurate predictors as a focus of future research. **Abstract:** <http://bit.ly/2B4DT4Q>

### Publishing Matters

**‘Evaluating research and researchers by the journal impact factor: Is it better than coin flipping?’** (p.17), in *Journal of Informetrics*.

**‘Why do researchers decide to publish in questionable journals? A review of the literature’** (p.18), *Learned Publishing*.

**‘Is journal peer-review now just a game?’** (p.18), in *MedPage Today*.

**‘Development and validation of search filters to find articles on palliative care in bibliographic databases’** (p.18), in *Palliative Medicine*

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### Resources

**‘How not to publish in an undesirable journal’** (p.19), Canadian Association of Research Libraries.

**‘Identifying appropriate journals for publication’** (p.19), University of Alberta.

## **Effects of a personalized web-based decision aid for surrogate decision makers of patients with prolonged mechanical ventilation: A randomized clinical trial**

*ANNALS OF INTERNAL MEDICINE* | Online – 29 January 2019 – Every year, the families of more than 400,000 patients on prolonged life support in intensive care units across the U.S. face weighty decisions about their loved one's recovery and whether to end life-sustaining care. The patients can't speak for themselves and often haven't made their end-of-life wishes known, leaving these heavy choices to families. Using a computer-based guide to personalize these decisions can help families feel less conflicted, according to research at Duke University. However, the treatment guide – a tool commonly called a “decision aid” in health care – did not ease symptoms of depression, anxiety or post-traumatic stress for the decision-makers as they oversaw their loved one's care, researchers found. The randomized clinical trial included 416 decision-makers for 277 patients who had been on life support at least 10 days. **Abstract:** <http://bit.ly/2FVVAI2>

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

## **Timing of palliative care referral and aggressive cancer care toward the end-of-life in pancreatic cancer: A retrospective, single-center observational study**

*BMC PALLIATIVE CARE* | Online – 28 January 2019 – The authors' findings mirror the results of a small number of international studies and reaffirm the benefits of early referral to palliative care (PC) for pancreatic cancer patients to avoid futile treatment and inappropriate care toward the end of life (EoL). They however question the current benchmarks for aggressive cancer care at the EoL, based on their findings that patients with significant symptoms and whose caregivers lack support appropriately require acute hospital service utilization or care in a supported environment. The authors suggest that in modern cancer care there can sometimes be a need to reconsider the use of the term “aggressive cancer care” at the EoL when the care is appropriately based on an individual patient's presenting physical and psychosocial need. For pancreatic cancer patients, the wide spectrum of significant symptomology experienced and the condensed time frame associated with the diagnosis may appropriately justify the use of acute services and treatments at this point of life. Ironically, the widespread use of what is traditionally described as aggressive treatments in the final month of life may paradoxically rise with PC integration earlier in the disease trajectory and into the acute setting, as symptom burden is appropriately managed, unless outreach community services develop alternate solutions to reduce hospital presentations and maintain care in the community. The debate must thus continue as to how we best achieve and benchmark outcomes that are compatible with patient and family needs, informed views, experiences and healthcare priorities.

**Full text:** <http://bit.ly/2UrUyXw>

**N.B.** Additional articles on palliative and end-of-life care for people living with pancreatic cancer noted in 12 November 2018 issue of Media Watch (#589, p.15).

## **Understanding care when cure is not likely for young adults who face cancer: A realist analysis of data from patients, families and healthcare professionals**

*BMJ OPEN* | Online – 28 January 2019 – In response to the lack of empirical research, policy and expert practice to inform delivery of optimal care for young adults when cure of their cancer is not likely, the authors collected data directly from patients with incurable cancer, and their nominated family carers and healthcare professionals. They used realist evaluation to seek the underlying mechanisms in their data and how these influenced outcomes. People with blood cancers and those aged between 16 and 24 years were difficult to recruit and may have unrecognised specific needs. Although analysis of this unique data set has highlighted specific challenges for young adults, their families and healthcare professionals in the delivery of end-of-life care, additional work is needed to make changes to practice that will improve experience and outcomes. **Full text:** <http://bit.ly/2HMTkEC>



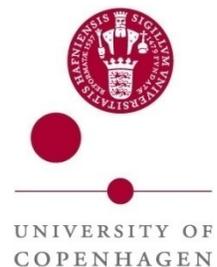
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## Palliative and end-of-life care education in Canadian emergency medicine residency programs: A national cross-sectional survey

*CANADIAN JOURNAL OF EMERGENCY MEDICINE* | Online – 30 January 2019 – There are no generally agreed upon competencies for Canadian emergency medicine (EM) residents with regard to palliative and end-of-life care (P&EoLC) in the emergency department (ED). The authors conducted a cross-sectional study of Canadian EM residency programs to measure the existing curricula in P&EoLC. Preliminary analysis [of study findings] shows that few Canadian post-graduate EM programs have a structured educational program pertaining to P&EoLC. Current barriers to education that can be addressed in future curricular initiatives include lack of time, curriculum development, and instructor availability. **Abstract (w. list of references):** <http://bit.ly/2FYFzRr>

## Advanced care planning five years on: An observational study of multi-centred service development for children with life-limiting conditions

*CHILD: CARE, HEALTH & DEVELOPMENT* | Online – 29 January 2019 – Documented advanced care planning (ACP) was measured against published children's palliative care standards. The first review (R1) included 48 patients with 114 health care records... The follow-up review (R2) included 47 patients, with 80 health care records... The proportion of records containing evidence of a prognostic discussion had risen from 73% (R1) to 91% (R2). The proportion of health care records with ACP was consistent between R1 and R2 (75% and 72%, respectively). An ACP tool was found to be in regular use in R2 compared to no examples in R1. The acute hospital trust plans were more detailed in R2 than R1. The proportion of cases where preferred location of death matched actual location was stable, around half. Challenges remain in engaging children and young people in advanced planning. **Abstract:** <http://bit.ly/2Wu2c5b>



### Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 January 2019 – ‘**Patients’ perspectives on approaches to facilitate completion of advance directives.**’ Although a majority of participants [in this study] with advance directives (ADs) had used lawyers, participants were ambivalent about the benefits of lawyer facilitation. Most valued both the medical perspective of a health-care professional and a lawyer’s attention to legal requirements for AD validity. Trust emerged as an overarching theme, and participants valued legal regulation of ADs to ensure document authenticity and delivery of preference-concordant care. **Abstract:** <http://bit.ly/2HNFzpo>
- *AUSTRALIAN JOURNAL OF RURAL HEALTH* | Online – 30 January 2019 – ‘**Project to improve storage, access and incorporation of advance care plans in a regional Australian hospital.**’ Interventions over 18 months addressed: 1) Medical records processes for receiving and processing advance care planning (ACP) documents; 2) Information technology solutions for electronic storage and alerts; 3) Clerical staff duties in regards ACP documents; and, 4) Clinician education. There was a 12-fold increase in ACP documents stored electronically and 100% of audited notes had correct filing of ACP documents with an alert in place at follow-up audit. **Abstract:** <http://bit.ly/2RxWDPO>
- *CURRENT GERIATRICS REPORTS* | Online – 24 January 2019 – ‘**Disease-specific advance care planning interventions for older adults.**’ The authors highlight 13 studies within the last 5 years focusing on advance care planning (ACP) models in older adults with the above diseases. Useful interventions include incorporation of non-physician facilitators, varying platforms of ACP delivery, surrogate participation, and written communication of patient preferences to other providers. Several existing models were applicable across disease types. Further research comparing ACP models in older adults is warranted. **Abstract (w. list of references):** <http://bit.ly/2sOUS6J>



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

## Nursing care at the end of life: Optimizing care of the family in the hospital setting

*CLINICAL JOURNAL OF ONCOLOGY NURSING*, 2019;23(1):13-17. An initiative was undertaken to create a blueprint for operationalizing research findings that identified family preferences for nursing support during the peri-death experience of a loved one within acute care. Seven components of an acute bereavement support protocol were delineated: 1) Developing room signage; 2) Assessing family prioritization parameters of support measures; 3) Offering advice on saying goodbye; 4) Performing an honoring ceremony; 5) Creating a memory keepsake; 6) Escorting the family out of the hospital; and, 7) Sending a sympathy card following the loved one's death. **Abstract:** <http://bit.ly/2DFgKrB>

## On heartbreak in oncology

*CURRENT ONCOLOGY REPORTS* | Online – 24 January 2019 – The many successes cancer medicine has witnessed over the past two decades have dramatically escalated the burden of care that oncologists are expected to provide. The availability of multiple treatment lines for diseases previously approached with therapeutic nihilism coupled with significant improvements in outcomes has been a boon to all those affected by cancer. These same achievements have also dramatically increased patient and societal expectations and have impacted the burden of care while blurring the lines between previously stark transitions from active to palliative or hospice care beyond recognition. The prolongation of active treatment times for almost all disease subtypes has resulted in a significant increase in the number of clinical stress points within an oncologist-patient relationship. **Abstract (w. list of references):** <http://bit.ly/2UseNnX>

## Unpacking “the cloud”: A framework for implementing public health approaches to palliative care

*HEALTH PROMOTION INTERNATIONAL* | Online – 27 January 2019 – Designing and implementing population-based systems of care that address the social determinants of health, take action on multiple levels, and are guided by evidence-based principles is a pressing priority, and an international challenge. Aging persons are a priority demographic whose health needs span physical, psychosocial and existential care domains, increase in the last year of life, are often poorly coordinated and therefore remain unmet. Compassionate communities (CCs) are an example of a public health approach that fully addresses the holistic healthcare needs of those who are aging and nearing end of life. The sharing of resources, tools, and innovations among implementers of CCs is occurring globally. Although this can increase impact, it also generates complexity that can complicate robust evaluation. When initiating population health level projects, it is important to clearly define and organize concepts and processes that are proposed to influence the health outcomes. The Health Impact Change Model (HICM) was developed to unpack the complexities associated with the implementation and evaluation of a Canadian CC intervention. The HICM offers utility for citizens, leaders and decision-makers who are engaged in the implementation of population health level strategies or other social approach-

es to care, such as compassionate cities and age or dementia-friendly communities. The HICM's concepts can be adapted to address a community's healthcare context, needs, and goals for change. The authors share examples of how the model's major concepts have been applied in the development, evaluation and spread of a complex CC approach. **Abstract:** <http://bit.ly/2RrPpgd>

### “We are all in this together”: Building capacity for a community-centred approach to caring, dying and grieving in Australia

*EUROPEAN JOURNAL FOR PERSON CENTRED HEALTHCARE*, 2018;6(4):685-692. “Compassionate communities” is emerging as an international strategy for implementing the public health palliative care approach to end-of-life (EoL). It is a community-centred approach which places people and their naturally occurring networks at the centre of care, death and grief, thus extending the concept of person-centred care to network-centred care. This article describes the first steps in the development of a Compassionate Community in the South West of Western Australia. **Abstract (w. list of references):** <http://bit.ly/2RuPq2T>

**N.B.** Noted in the 11 December 2018 issue of Media Watch (#593, p.11).

Cont.

Noted in Media Watch 2 July 2018 (#570, p.5):

- *BMC PALLIATIVE CARE* | Online – 29 June 2018 – ‘Towards a public health approach for palliative care: An action-research study focused on engaging a local community and educating teenagers.’ The education program about palliative care (PC) was deemed to be excellent, exciting and enlightening by the teenagers to whom it was specifically designed. Positive feedback was given by the teenagers, parents and other participants. The findings of this action-research study show that the education program and education-intervention contributed to create awareness about PC among the participant teenagers, who ended the program with a positive message about PC. **Full text:** <http://bit.ly/2HNgsTg>

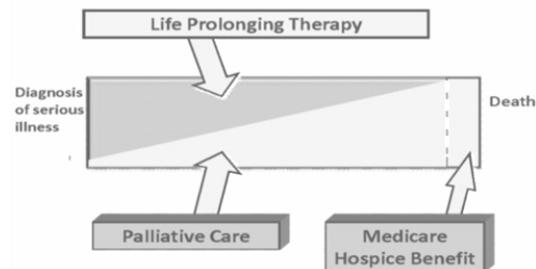
Noted in Media Watch 13 June 2016 (#466, p.14):

- *PROGRESS IN PALLIATIVE CARE* | Online – 9 June 2016 – ‘Which public health approach to palliative care? An integrative literature review.’ Public health (PH) and palliative care (PC) are both broad disciplines with blurred boundaries. There is growing support for an alignment of PC to PH. Given the novel nature of this alignment and the ambiguity of the parent definitions, there is an understandable lack of clarity around this merged model. The aim of this study is to describe the theoretical features of the PH approach to PC as articulated in the current research literature. **Abstract (w. link to list of references):** <http://bit.ly/2WrRqMV>

**N.B.** Additional articles on a public health approach to end-of-life care noted in this issue of Media Watch.

### The development of pathways in palliative medicine: Definition, models, cost and quality impact

*HEALTHCARE* | Online – 1 February 2019 – The field of palliative medicine (PM) has moved significantly upstream to include the care of any patient with a serious illness. PM and care pathways are impacting professional practice, patient outcomes, quality of care, length of stay and hospital costs. The future of PM should include the development of primary and integrated care pathways for inpatient-, outpatient- and community-based serious illness care, to standardize referral patterns and demonstrate its impact on resource utilization. Just as end-of-life care pathways standardized symptom management at the time of death, similar care pathways should be developed for early PM consultations to address symptom control and cohesive disease management as part of multidisciplinary teams. Care pathway development should also involve support patterns for caregivers and management of the bereaved after hospice enrollment. Outcomes research involving integrated care pathways in PM is completely lacking and should be considered a prime area of future research efforts to support the management of PM programs and further demonstrate the specialty’s positive impacts on patient quality and cost of care. **Full text:** <http://bit.ly/2HNoUC7>



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### Last Aid Course. An education for all citizens and an ingredient of compassionate communities

*HEALTHCARE* | Online – 28 January 2019 – Knowledge in palliative care (PC) is very limited or totally absent in most communities, and information about the effects of educational procedures in teaching non-professionals in basic PC is sparse. In the Last Aid courses, the public knowledge approach and the initial experiences from the implementation process are described. In addition, a review of the literature on educational efforts regarding PC for non-professionals and the existing literature on courses is provided. An international working group has established a curriculum for Last Aid courses based on four teaching hours (45 minutes each). The feasibility of these courses for the public has been tested in pilot courses. The experiences in different countries are overall very positive. The courses are well-attended. The evaluation of questionnaires in a German pilot study has shown a favorable response. Last Aid courses may form the educational basis of compassionate communities, and are well-suited to inform the public about PC and end-of-life care. **Full text:** <http://bit.ly/2Bem43h>

## Conspiracy of silence in palliative care: A concept analysis

*INDIAN JOURNAL OF PALLIATIVE CARE*, 2019;25(1):24-29. The conspiracy of silence in palliative care (PC) is a common phenomenon that affects patients, their families, and health-care teams. Silence can occur in two forms: as a conspiracy and as a pact. The conspiracy of silence generally involves family members and healthcare teams who withhold full or partial information from the patient. On the contrary, in the pact of silence, both patient and family members, and even the health-care team, agree not to talk about patient's disease process, in spite of having this information. In either case, the agreements can be explicit or implicit. The conspiracy of silence occurs due to communication failures caused by contradictions between what is expected and what actually occurs, unrealistic expectations, system of beliefs about illness and death, scarce or ambiguous information, fear of losing the loved one, poor caregiving skills, lack of training in communication skills, stress, overburden, and prognosis uncertainty. The conspiracy of silence in PC has negative consequences for patients, mainly for their autonomy, decision-making skills, and quality of life. It also affects family functioning and coping and humanization of health care provided by health-care teams. Scales to measure the concept of "conspiracy of silence" in PC were not found. Studies on this concept have been conducted using scales that tangentially assess "conspiracy of silence" by measuring communication skills. It is necessary to develop scales that allow assessing this concept. **Full text:** <http://bit.ly/2Uy9rHv>

## Recognising and managing dying patients in the acute hospital setting: Can we do better?

*INTERNAL MEDICINE* | Online – 24 January 2019 – Healthcare professionals have limited formal end-of-life care training despite the large proportion of hospital deaths. A retrospective review of 201 acute hospital deaths revealed 166 (82.6%) had documentation to suggest the patient was dying, but this was performed late with a median time between documentation and death of 0.84 days. Furthermore, 132 (66%) patients received an intervention in the final 48 hours of life. This highlights the need to improve the recognition and management of dying patients in acute hospitals. **Abstract:** <http://bit.ly/2sTa56G>

Noted in Media Watch 3 December 2018 (#592, p.9):

- *BMJ OPEN* | Online – 25 November 2018 – ‘How do palliative care doctors recognise imminently dying patients? A judgement analysis.’ The National Institute for Health & Care Excellence guideline on end-of-life care describes the recognition of imminent death as an essential first step towards improving care for dying patients.<sup>1</sup> However, the guideline does not clearly explain how doctors are expected to identify such patients, nor how novice doctors can be expected to learn or improve this clinical skill. **Full text:** <http://bit.ly/2RR5XmC>

1. ‘Care of dying adults in the last days of life,’ National Institute for Health & Care Excellence, December 2015. [Noted in 21 December 2015 issue of Media Watch (#441, p.7)] **Download/view at:** <http://bit.ly/2Tj0xxD>

**N.B.** Selected articles on awareness of imminent or impending death noted in 25 June 2018 issue of Media Watch (569, p.10).



### [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>

## Hospice in the U.S.

### **Agency and change in healthcare organizations: Workers' attempts to navigate multiple logics in hospice care**

*JOURNAL OF HEALTH & SOCIAL BEHAVIOR* | Online – 29 January 2019 – There is no doubt that the organization of healthcare is currently shifting, partly in response to changing macro-level policies. Studies of healthcare policies often do not consider healthcare workers' experiences of policy change, thus limiting understanding of when and how policies work. This article uses longitudinal qualitative data, including participant observation and semi-structured interviews with workers within hospice care as their organizations shifted in response to a Medicare policy change. Prior to the policy change, she found that the main innovation of hospice – the interdisciplinary team – is able to resist logics from the larger medical institution. However, when organizational pressures increase, managers and workers adjust in ways that reinforce medical logics and undermine the interdisciplinary team. These practices illustrate processes by which rationalization of healthcare affects workers' experiences and the type of care available to patients. **Abstract:** <http://bit.ly/2UnGCgQ>

### **Cancer and Opioids: Patient Experiences with Stigma (COPES)**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 January 2019 – This study, to the authors' knowledge, provides the first evidence of opioid stigma and its consequences in cancer patients and offers potential targets for interventions aimed at reducing stigma and encouraging safe, effective opioid use. Participants were 125 adults undergoing active cancer treatment being seen at the Moffitt Supportive Care Medicine Clinic [headquartered in Tampa, Florida]. Patients were primarily women (65%) aged 45-64 years (49%), most commonly diagnosed with breast (23%) and hematologic (15%) cancer. Among patients who reported opioid use, the most common reason for use was pain relief (94%), followed by improved sleep (25%). A sub-set of patients reported using less (13%) or more (8%) opioid medication than advised. Opioid stigma was endorsed by 59/97 patients prescribed opioids (61%), including fear of addiction (36%), difficulty filling prescriptions (22%), and awkwardness communicating with providers (15%). Stigma-related behaviors were endorsed by 28 (29%) of respondents prescribed opioids, with "taking less opioid medication than needed" as the most commonly endorsed behavior (20%). **Abstract:** <http://bit.ly/2MEv726>

**N.B.** Additional articles on opioid use in the context of palliative and end-of-life care noted in 28 January 2019 and 31 December 2018 issues of Media Watch (#599, p.10 and #595, pp.5,19, respectively).

### **Interprofessional work in serious illness communication in primary care: A qualitative study**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 January 2019 – Evidence demonstrates that discussion between clinicians and seriously ill patients about their goals and preferences, or serious illness communication, is a high-value intervention, resulting in growing demand for improvement in this area. Promising efforts address this demand utilizing interprofessional teams; yet, we lack insight into how different professions work together to deliver better serious illness communication. The authors derived primary themes and sub-themes from participant descriptions of program implementation: the importance and value of interprofessional teams, nurses, and individual initiative; the role of preparation and structure in enabling high-quality communication; and, the ways in which attempts to improve serious illness communication reveal other problems that can limit program effectiveness or be perceived as program failures. The authors derived a conceptual model that illustrates the relationships between interprofessional team interactions, workflows, and perceived program outcomes. **Abstract:** <http://bit.ly/2UjSPmO>



Discontinuation by Google of its URL shortening service, effective in March, makes it necessary for Media Watch to switch to the similar service provided by Bitly. This will not effect accessing articles, reports, etc., noted in past issues of the weekly report.

## Palliative sedation and terminal sedation

*MÉDECINE PALLIATIVE* | Online – 30 January 2019 – End-of-life situations where pharmacological sedation can be considered are first of all important relational issues between patient, relatives and caregivers. The respect of these issues shapes practice. Two forms of sedation can therefore be distinguished. Palliative sedation is part of the relational anthropology of palliative care. It aims for the relief of symptoms and is part of a dynamic that it seeks to support and not to oust. To do this, it respects the ethical principles of medicine, starting with the principle of proportionality of care for illness and symptoms. From this point of view, sedation is a valuable therapeutic tool for palliative comprehensive and socialized care, and the caring relationship is always part of the therapeutic alliance. Conversely, terminal sedation is part of the technical perspective and the conceptual framework of euthanasia. It aims for the suspension of consciousness and precipitates a relational break, if not death. Sedation then becomes a simple procedure of disconnection, an anticipation of death. Proportionality of care is no longer respected. A will of control and absolute efficiency underlies the practice, this at the cost of the isolation and the reification of the people – from the depersonalization of the patient to the instrumentalization of caregivers. **Abstract:** <http://bit.ly/2WnZK06>

**N.B.** French language article. Additional articles on PS noted in the 14 January issue of Media Watch (597, pp.6-7).

## No matter the species

### U.S. and U.K. veterinary medicine schools: Emphasis on end-of-life issues

*MORTALITY*, 2019;24(1):61-71. Data were obtained via a mailed questionnaire (80% U.S., and 86% U.K. return rates). Results revealed that over 96% of schools have offerings related to end-of-life (EoL) issues, with nearly 100% of students exposed to these offerings. The average number of hours spent on EoL issues is 7 (U.S.) and 21 (U.K.). Topics covered most often are “euthanasia,” “analgesics for chronic pain,” and “communication with owners of dying animals.” Veterinary schools overwhelmingly note that dying, death and bereavement are important topics. It might be helpful to veterinary medicine students if their own feelings regarding dying and death were addressed early in the curriculum and throughout class activities and clinical work. **Abstract (inc. link to references):** <http://bit.ly/2MAtO4e>

#### Never say die?

A palliative care physician and a veterinarian compare notes on “dying well.” **EAPC Blog:** <http://bit.ly/2BaMGiH>

**N.B.** Additional articles on the parallels to be drawn between palliative and veterinary medicine noted in 8 May 2017 issue of Media Watch (#511, p.9).

Noted in Media Watch 17 October 2016 (#483, p.15):

- *PALLIATIVE MEDICINE* | Online – 7 October 2016 – ‘**Palliative care education for medical students: Differences in course evolution, organisation, evaluation and funding: A survey of all U.K. medical schools.**’ Information is limited regarding the current organisation of palliative care (PC) teaching across U.K. medical schools. Development, organisation, course evaluation and funding for PC teaching at U.K. medical schools are variable. An academic department of palliative medicine existed in 12/30 medical schools. **Abstract:** <http://bit.ly/2DCT2vS>

Noted in Media Watch 14 March 2016 (#453, p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 2016;34(6):559-565. ‘**A 40-year history of end-of-life offerings in U.S. medical schools: 1975-2015.**’ At 5-year intervals, U.S. medical schools were surveyed via a questionnaire. The inclusion of end-of-life topics has expanded over the 40-year period as findings reveal that U.S. undergraduate medical students are currently exposed in over 90% of programs to death and dying, palliative care and geriatric medicine, with the emphasis on these topics varying with the medical programs. **Abstract:** <http://bit.ly/2FR70fU>

## Palliative care in gynecologic oncology

*OBSTETRICS & GYNECOLOGY CLINICS OF NORTH AMERICA*, 2019;46(1):179-197. The integration of palliative care (PC) and hospice into standard gynecologic oncology care is associated with cost-savings, longer survival, lower symptom burden, and better quality of life for patients and caregivers. Consequently, this comprehensive approach is formally recognized and endorsed by the Society of Gynecologic Oncology, the National Comprehensive Cancer Network, and the American Society of Clinical Oncology. This article reviews the background, benefits, barriers, and most practical delivery models of PC. It also discusses management of common symptoms experienced by gynecologic oncology patients. **First page view:** <http://bit.ly/2G4Q5Gd>

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

- *GYNECOLOGIC & OBSTETRIC INVESTIGATION* | Online – 10 August 2018 – ‘**Gynecologic oncologists’ perceptions of palliative care and associated barriers: A survey of the Society of Gynecologic Oncology.** Members of the Society of Gynecologic Oncology were invited to participate in an anonymous online survey. A total of 174 (16%) gynecologic oncologists completed the survey. The majority (75%) agreed or strongly agreed that palliative care (PC) should be integrated into cancer care at diagnosis of advanced or metastatic cancer. The most frequently perceived PC barriers included patients’ unrealistic expectations (54%), limited access to specialty PC (25%), poor reimbursement (25%), time constraints (22%), and concern of reducing hope or trust (21%). **Abstract (w. list of references):** <http://bit.ly/2RUZR4L>

## A palliative care model and conceptual approach suited to clinical malignant haematology

*PALLIATIVE MEDICINE* | Online – 28 January 2019 – People with a haematological malignancy often experience episodes of sudden and acute deterioration related to the treatment or the underlying disease. However, it is not uncommon for these patients to recover from episodes of “near-to-death” deterioration. This erratic illness trajectory makes predicting survival near the end of life (EoL) difficult for clinicians. Hence, people with a haematological malignancy often experience a swift change in their goals of care, leaving little time for planning and preparing for death. A growing body of evidence highlights that people with a haematological malignancy often receive sub-optimal standards of palliative care (PC). Challenges integrating PC in the haematology setting have largely been attributed to the unpredictable illness trajectory these patients often experience and lack of knowledge and understanding of PC among health care professionals. Although PC is recommended to be integrated (and known to lead to benefits) early in the illness trajectory for people with a life-threatening illness, many haematologists still perceive PC as EoL care. PC is integrated later and less often for people with a haematological malignancy compared to those with other types of cancer. There is a gap in knowledge and variation in practice around how

and when to provide best practice PC for people with a haematological malignancy. The authors discuss a PC model and conceptual approach that are well suited to clinical malignant haematology and can lead to best practice palliative and EoL care for this unique population. **Full text:** <http://bit.ly/2sT70Ug>

### Space for intuition – the “surprise” question in haemato-oncology: Qualitative analysis of experiences and perceptions of haemato-oncologists

*PALLIATIVE MEDICINE* | Online – 28 January 2019 – Thematic analysis identified 4 themes and 11 sub-themes: 1) Meaning and relevance of the “surprise” question; 2) Feasibility; 3) The concept of “surprise”; and, 4) Personal aspects of prognostication. A key function of the “surprise” question was to stimulate intuition and promote patient-centred goals of care by initiating a process of pause → reflection → change of perspective. It was easy and quick to use, but required time and communication skills to act on. Participants’ training in palliative care enhanced their willingness to use the “surprise” question. **Abstract:** <http://bit.ly/2MC9DD3>

**N.B.** Additional articles on the “surprise” question noted in 24 September 2018 issue of Media Watch (#582, p.9).

Cont.

Noted in Media Watch 26 February 2018 (#552, p.6):

- *BMC PALLIATIVE CARE* | Online – 21 February 2018 – ‘**Palliative care specialists’ perceptions concerning referral of haematology patients to their services: Findings from a qualitative study.**’ Participants identified a range of barriers and facilitators influencing the referral of patients with haematological malignancies to palliative care (PC): characteristics and pathways of haematological malignancies; the close patient/haematology team relationship; lack of role clarity; late end-of-life discussions and PC referrals; policy issues; and, organisational issues. **Full text:** <http://bit.ly/2UoQ9Va>

Noted in Media Watch 5 June 2017 (#515, p.15):

- *MÉDECINE PALLIATIVE* | Online – 31 May 2017 – ‘**Haematologists’ perceptions about end-of-life discussion: A qualitative study.**’ Haematological patients have half as much access to palliative care (PC) than their counterparts with solid malignancies. The main objective of the study was to understand what makes an end-of-life discussion easy or difficult at the time of relapse of an aggressive haematologic malignancy. A side issue was to explore the consequences of such discussions on integration of PC in haematology. **Abstract:** <http://bit.ly/2ThrDoB>

**N.B.** French language article.

#### Related

- *PALLIATIVE MEDICINE* | Online – 30 January 2019 – ‘**Perspectives of bereaved relatives of patients with haematological malignancies concerning preferred place of care and death: A qualitative study.**’ Although most people expressed a preference for home death, not all attained this. The influencing factors include disease characteristics, the occurrence and timing of discussions, family networks and resource availability. Preferences were described as changing over time and some family members retrospectively came to consider hospital as the “right” place for the patient to have died. Others shared strong preferences with patients for home death and acted to ensure this was achieved. No patients died in a hospice, and relatives identified barriers to death in this setting. **Full text:** <http://bit.ly/2TIFRoH>

#### **The clinical evaluation of the wish to hasten death is not upsetting for advanced cancer patients: A cross-sectional study**

*PALLIATIVE MEDICINE* | Online – 28 January 2019 – An important concern of healthcare professionals when exploring the wish to hasten death with patients is the risk of causing them some type of distress. The authors assessed 193 advanced cancer patients admitted to an oncology ward for the wish to hasten death using a semi-structured clinical interview. After the assessment the participants were surveyed to determine whether they found the interview upsetting and, if so to what extent, and also their opinion regarding the assessment’s importance. The wish to hasten death was reported by 46 (23.8%) patients. The majority (94.8%) did not find talking about the wish to hasten death to be upsetting, regardless of whether they presented it or not. The majority (79.3%) considered that it was either quite or extremely important for the clinician to proactively assess the wish to hasten death and discuss this topic, regardless of whether they experienced it. These findings suggest that healthcare professionals can explore the wish to hasten death proactively in routine clinical practice without fear of upsetting patients. **Abstract:** <http://bit.ly/2G5Z21N>



WHO COLLABORATING CENTRE  
PUBLIC HEALTH PALLIATIVE  
CARE PROGRAMMES

Noted in Media Watch 26 March 2018 (#556, p.9):

- *FRONTIERS IN PHARMACOLOGY* | Online – 14 March 2018 – ‘**Ethical challenges for an understanding of suffering: Voluntary stopping of eating and drinking and the wish to hasten death in advanced patients.**’ The authors analyze the data reported in some studies in relation to primary care patients who died as a result of voluntarily stopping eating and drinking (VSED) and examine their results in light of the qualitative findings of patients that expressed a wish to die. In their view, VSED can be understood as a response to physical/psychological/spiritual suffering, as an expression of a loss of self, a desire to live but not in this way, a way of ending suffering, and as a kind of control over one’s life. **Full text:** <http://bit.ly/2HBf4mW>

**N.B.** Additional articles on the wish to hasten death noted in this issue of Media Watch.

## Postgraduate palliative care education for all healthcare providers in Europe: Results from an European Association for Palliative Care survey

*PALLIATIVE & SUPPORTIVE CARE* | Online – 26 January 2019 – Palliative care (PC) training at basic, intermediate, and specialist levels, recommended by the World Health Organization (WHO), is challenging to access in resource-poor countries and regions. Providing support in this regard would seem a moral imperative for all countries with established PC education systems and a strong resource base. In collaboration with WHO European Office and European Association for Palliative Care (EAPC), this paper looks into the educational requirements in PC at postgraduate level within Europe. A survey was specifically designed to gather opinions and comments on elements of PC education from European experts. Participants were invited to assess the EAPC core competencies on a five-item scale and to define essential learning goals. The statistical analysis revealed a high agreement regarding the key elements of PC education. The thematic analysis indicated that at postgraduate level all healthcare providers need to: 1) Comprehend the PC philosophy; 2) Be able to demonstrate the complex symptom assessment and management competencies; 3) Be able to design care plans based on patients and families wishes integrating multi-professional and interdisciplinary approaches; and, 4) Be able to listen and self-reflect. This paper contains a new and comprehensive list of learning goals essential for multidisciplinary postgraduate PC education. **Abstract (w. list of references):** <http://bit.ly/2RIH51v>



Noted in Media Watch 8 October 2018 (#584, p.15):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 October 2018 – ‘**A systematic review of training in symptom management in palliative care within postgraduate medical curriculums.**’ Pain management, use of opioids and their side effects were most frequently covered. Most studies used self-reported, original or modified evaluation instruments, though psychometric properties were seldom reported. Despite methodological considerations, all educational methods improved trainees’ learning outcomes. The effects on trainees’ behaviour and patient-related outcomes were not evaluated. **Full text:** <http://bit.ly/2Hz0NH7>

### Palliative care in maternity units

*SOINS PÉDIATRIE*, 2019;40(306);19-21. Over recent years, palliative care (PC) in maternity units has developed considerably. This is due to the evolution of legislation, medicine and requests from many parents, faced with a fatal prenatal diagnosis, to continue with the pregnancy and support their baby at birth. In parallel, the neonatal intensive care of extremely premature babies has improved significantly. Different situations can be concerned by the setting up of PC in maternity units. **Abstract:** <http://bit.ly/2FT3wtr>

**N.B.** French language article.

Noted in Media Watch 3 October 2016 (#482, p.14):

- *MÉDECINE PALLIATIVE* | Online – 29 September 2016 – ‘**Palliative care practices in maternity wards...**’ For 90% of of survey respondents palliative care is part of the mission of working in the delivery room. The majority of end-of life practices are similar in most maternity wards – put the babies in parent’s arms or in “skin to skin” contact... Those using a protocol differ on pain assessment and consideration of the newborn’s environment among other things. **Abstract:** <http://bit.ly/2FUvPb6>

**N.B.** French language article.

Noted in Media Watch 2 May 2016, #460 (p.4):

- *ZEITSCHRIFT FÜR GEBURTSHILFE UND NEONATOLOGIE*, 2016;220(2):53-57. ‘**Palliative care in the delivery room.**’ Basic background information of palliative care (PC) of newborns in the delivery room are presented. Recommendations are given focusing on: 1) Non-pharmacological and pharmacological ways of symptom control in PC of dying newborns; and, 2) Meeting the individual psychological, emotional and spiritual needs of the parents. **Abstract:** <http://bit.ly/2sU3dWR>

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

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH MEDICAL JOURNAL* | Online – 30 January 2019 – ‘**How the Canadian Medical Association found a third way to support all its members on assisted dying.**’ For many years, the Canadian Medical Association (CMA) has followed the public debate in Canada on assisted dying and voluntary euthanasia. Both subjects are extremely controversial and divisive, particularly for an organisation like the CMA. It represents almost 90,000 physicians, who hold wide ranging views on assisted dying. The CMA’s initial policy was that assisted dying and euthanasia were illegal in Canada and that physicians should not participate. To participate fully in the public debate, the CMA adopted a position of neutrality, advocating for all its members who held divergent views on a change in the law. **Introductory paragraphs:** <http://bit.ly/2Rpl7dW>
- *PALLIATIVE MEDICINE* | Online – 28 January 2019 – ‘**Common dedication to facilitating good dying experiences: Qualitative study of end-of-life care professionals’ attitudes towards voluntary assisted dying.**’ Given health professionals’ role in caring for patients at the end of life (EoL), their stance towards assisting a person with dying can have implications for policy development and implementation in jurisdictions where law changes are being considered. Participants reported two overarching positions grounded in differing moral philosophies with compelling arguments both for and against legalization of voluntary assisted dying. A third and common line of argument emerged from areas of shared concern and uncertainty about the practical consequences of introducing voluntary assisted dying. While a diversity of opinion was evident, all participants advocated for more public education and funding into EoL care services to make high-quality care equitable and widely available. Common dedication to reducing suffering and facilitating good dying experiences exists among experts despite their divergent views on voluntary assisted dying. **Abstract:** <http://bit.ly/2TkbbE6>

## Publishing Matters

### Evaluating research and researchers by the journal impact factor: Is it better than coin flipping?

*JOURNAL OF INFORMETRICS*, 2019;13(1):314-324. The journal impact factor (JIF) is the average of the number of citations of the papers published in a journal, calculated according to a specific formula; it is extensively used for the evaluation of research and researchers. The method assumes that all papers in a journal have the same scientific merit, which is measured by the JIF of the publishing journal. This implies that the number of citations measures scientific merits but the JIF does not evaluate each individual paper by its own number of citations. Therefore, in the comparative evaluation of two papers, the use of the JIF implies a risk of failure, which occurs when a paper in the journal with the lower JIF is compared to another with fewer citations in the journal with the higher JIF. To quantify this risk of failure, this study calculates the failure probabilities, taking advantage of the lognormal distribution of citations. In two journals whose JIFs are ten-fold different, the failure probability is low. However, in most cases when two papers are compared, the JIFs of the journals are not so different. Then, the failure probability can be close to 0.5, which is equivalent to evaluating by coin flipping. **Full text:** <http://bit.ly/2GejEFi>



Photo: Lori Waselchuk. Philadelphia, PA

### Prison Hospice: Backgrounder

Updated 02.01.2019

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 can be downloaded/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>

## Why do researchers decide to publish in questionable journals? A review of the literature

*LEARNED PUBLISHING*, 2019;32(1):57-62. The author provides an overview of the existing literature on why researchers decide to publish in questionable journals, specifically whether or not they search for a low-barrier way to getting published while being aware that the chosen journal probably does not adhere to acceptable academic standards. The choice of a publication outlet can be seen as a submission tree that consists of various incentives, and explaining why authors publish in deceptive journals may thus consist of a combination of awareness and motivational factors. Awareness and motivation of diligent authors is very different from that of unethical authors. Unethical authors may use a lack of awareness to excuse their actions, but they may actively search for a low-barrier way to getting published. As there are different types of authors who publish in deceptive journals, we need different approaches to solve the problem.

**Full text:** <http://bit.ly/2RngwZB>

### Key points

**THE CRITERIA** for selecting publication outlets may be manipulated by deceptive journals to entrap some researchers and encourage others.

**PRESSURE TO PUBLISH** has been blamed for the rise in deceptive journals, but may not be the only reason for their proliferation.

**CALLING JOURNALS PREDATORY** ignores the fact that some authors actively seek publication in them as an easy route to career progression.

**THERE ARE AT LEAST TWO DIFFERENT TYPES OF AUTHORS** who publish in deceptive journals: the unethical and the uninformed; so, at least two different approaches to the problem are required.

## Is journal peer-review now just a game?

*MEDPAGE TODAY* | Online – 31 January 2019 – Many believe that there is something sacred about the process by which manuscripts undergo peer-review by journals. A rigorous study described in a thoughtful paper is sent out to leading experts, who read it carefully and provide unbiased feedback. The process is conducted with honor and in a timely manner. It sounds nice, but most of the time, it does not happen that way. Editors receive an enormous number of papers. Top journals receive dozens of manuscripts each day. The editors perform an initial cursory review, and reject many papers in an electronic instant. More than half of the submissions do not survive the screening process. The authors are notified quickly about the bad news, but they receive no feedback. Many relatively unknown authors believe this process is biased against them. If the paper passes the initial hurdle, the editor sends it out for "peer-review" by external experts. But who are these peers? It is nearly impossible to find experts who are knowledgeable and insightful and who are also willing to take the time to perform a thorough and thoughtful review. Luminaries routinely decline most invitations to review manuscripts. Their busy schedules do not afford the opportunity to do a good job, and many believe that there is little return for their investment of time and effort. **Full text:** <http://bit.ly/2t0yyaw>

## Development and validation of search filters to find articles on palliative care in bibliographic databases

*PALLIATIVE MEDICINE* | Online – 28 January 2019 – The authors have created search filters for articles related to palliative care that perform well enough to find questions to clinical questions when time is limited (45% of the articles retrieved by the specific filter are relevant, while 93.7% of relevant articles are retrieved) and for systematic reviews (the sensitive filter retrieves 99.6% of all relevant articles, with a precision of 5%). Within our gold standard validation set, the filters had an equal or higher specificity and higher sensitivity. Hence, the authors' filters significantly reduce the number of articles that researchers and physicians need to read, without having to fear they miss important articles. The sensitive filter contains some terms that might be considered too general in a search. For instance, the term "inpatient" might cause too much noise. In the "gold standard," this resulted in the retrieval of some relevant papers that might otherwise have been missed, but it is up to the end-users to decide which terms they ultimately want to include in their searches. **Full text:** <http://bit.ly/2FTU1dG>

## Resources

- CANADIAN ASSOCIATION OF RESEARCH LIBRARIES (CARL) | Online – Accessed 21 January 2019 – ‘**How not to publish in an undesirable journal.**’ CARL has produced an infographic that provides tips for avoiding publishing in what the association describes as “undesirable journals.” **Download/view at:** <http://bit.ly/2MAyBTf>
- UNIVERSITY OF ALBERTA (Libraries) | Online – Accessed 21 January 2019 – ‘**Identifying appropriate journals for publication.**’ The University has developed a worksheet that authors can work through to determine if a journal is predatory or not. **Download/view at:** <http://bit.ly/2MxfSYC>

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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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#### International



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

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

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

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

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

#### **Asia**

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

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

#### **Canada**



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

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

#### **Europe**



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

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

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

#### **South America**

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

#### **United States**

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

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

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