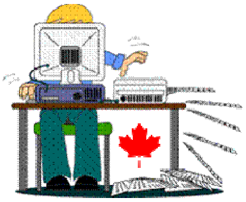
Media Watch...

*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.*

31 December 2018 Edition | Issue #595



Compiled & Annotated by Barry R. Ashpole

‘How grief camp reinforces the need for death education in elementary schools’ (p.14), in *Canadian Journal for New Scholars in Education.*

Canada

Hospice funds still fall short, Ontario doctors warn

ONTARIO | *The Catholic Register* – 18 December 2018 – Ontario’s palliative care (PC) doctors are warning that the government is not ready for “an imminent spike in the number of people facing end of life (EoL). The Ontario Medical Association (OMA) section of palliative medicine say it’s nice Queen’s Park is putting money into new hospice beds, but it’s not enough. “We were pleased to see the Ontario Government’s announcement confirming that it will fund some new residential hospices,” said the release, but the increasing number of elderly is putting pressure on EoL care. The Ministry of Health & Long-Term Care announced it was “moving forward with plans to build 193 new hospice beds across Ontario.”[1] It is investing $33.6 million for the beds, plus an additional $20.3 million in operational funding once they are open. The financing had been put in place more than a year ago by the previous Liberal government. However, new hospice beds on their own won’t close the gap on PC, said Toronto PC doctor and chair of the OMA Section of Palliative Medicine Dr. Bill Splinter. ”There’s still, unfortunately, a lot of needless suffering that’s going on that shouldn’t be going on,” he said. Palliative medicine in Ontario needs both more trained and dedicated personnel and more palliative beds, whether in hospices or hospitals, Splinter said. While 87% of Canadians could benefit from PC at EoL, only 15% are receiving it, according to a recent report by the Canadian Institute for Health Information.[2] https://goo.gl/negidy

Specialist Publications

‘Ethical issues in nursing home palliative care: A cross-national survey’ (p.11), in *BMJ Supportive & Palliative Care*.

‘Palliative care doctors raise concerns about withdrawing high-dose opioids’ (p.19), in *The Medical Post*.

‘Measuring the quality of dying and death in advanced cancer: Item characteristics and factor structure of the Quality of Dying & Death Questionnaire’ (p.20), in *Palliative Medicine*.

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1. ‘Helping more people get end-of-life care in a home-like setting,’ Ministry of Health & Long-Term Care, 10 December 2018. **Press release:** https://goo.gl/VnvWwC

Cont.

2. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. [Noted in 24 September 2018 issue of Media Watch (#582, p.1)] **Download/view (scroll down to foot of page and 'Related Links') at:** https://goo.gl/qE2smV

N.B. See 'Palliative Care at the End of Life,' Health Quality Ontario, June 2016. [Noted in 4 July 2016 issue of Media Watch (#469, p.2)]; selected articles on PC in the province also noted in this issue of the weekly report.] **Download/view at:** https://goo.gl/jTW7qa

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC ('Second Opinion') | Online – 22 December 2018 – **'Assisted dying is one "smooth" public health change.'** New data is also beginning to emerge in one of the most profound developments in Canadian healthcare. It's been almost three years since medically-assisted dying became legal in Canada and so far it's estimated that about 4,000 Canadians have had a medically assisted death."Generally it's a very smooth process with profoundly thankful patients and families, that's what I'm seeing in my practice," said Kerry Bowman [bioethicist at the University of Toronto]. "For all of us that's got to be one of the really crucial developments," said Heather MacDougall [a medical historian Heather MacDougall at the University of Waterloo]. "We're all going to die. The question is whether we do it with dignity or we get hamstrung by the rules and regulations. I think it takes a lot of social courage for a society to face that." There are still a series of unresolved issues. Right now the law does not permit advance directives -- where people can specify when they want their lives to end. And there are other questions about whether young people and people with mental health issues should be permitted to have a medically-assisted death. "The first iteration is very rarely ever entirely to everyone's satisfaction and clearly there were components of this that need to be rethought and revisited," said MacDougall. "Generally we have found our stride," said Bowman. "It's these peripheral areas that are a big challenge." https://goo.gl/RMHLfo

N.B. Extract from CBC's 'A year of change in Canadian public health.'

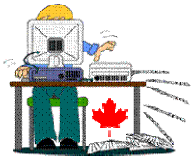
Specialist Publications

'Denying assisted dying where death is not "reasonably foresee-able": Intolerable over generalization in Canadian end-of-life law' (p.22), in *Canadian Journal of Bioethics.*

'An entrustable professional activity descriptor for medical aid in dying: a mixed-methods study' (p.23), in *CMAJ Open.*

'Marginalized Canadians may lack information about end-of-life options' (p.23), in *Canadian Medical Association Journal.*

'Wishing you won't be here: Medical assistance in dying for psychiatric patients' (p.23), in *Ethics, Medicine & Public Health.*



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

U.S.A.

Challenges faced by Asians and Latinos at end-of-life care (Part 3[1])

CALIFORNIA | The Oakland Post – 27 December 2018 – The end of life (EoL) is not easy for most Americans nearing death. The good news is that up to 90& of pain and suffering can be controlled. But the bad news is that over half of all dying Americans experience unwanted pain and suffering during their final days. And the numbers are even greater for people of color. African-Americans, Asians, and Latinos have less access to the pain medication and comfort care that hospice can provide at the EoL compared to whites. Asians, Latinos, and other ethnic minorities whose second language is English face additional challenges. Language barriers and cultural traditions can inhibit awareness of and discussions about EoL options and are often compounded by poverty and lack of education. In many traditional Latino and Asian cultures, speaking openly about death is taboo, especially when a loved one is seriously ill. Latinos and Asians are less likely than whites to discuss their EoL preferences or engage in advance care planning (ACP) – EoL conversations with family or health providers). Patients who engage in ACP are less likely to die in the hospital or to receive futile intensive care. Family members have fewer concerns and experience less emotional trauma if they have the opportunity to talk about their loved one's wishes. Family plays an important role in the EoL decision-making process in both Latino and Asian cultures. Among Latino families, a male member, usually the oldest son or uncle, is responsible for making decisions on behalf of the dying family member. The expectation is that if the elected caregiver respects and loves the dying patient, they will insist the hospital "do everything" to keep the patient alive – this can mean another round of chemotherapy or multiple emergency room visits. https://goo.gl/BKNgkm

Specialist Publications

'Empowering patients with Alzheimer's disease to void unwanted medical care: A look at the dementia care triad' (p.16), in *American Journal of Alzheimer's Disease & Other Dementias*.

'Timely referral to hospice care for oncology patients: A retrospective review' (p.8), in *American Journal of Hospice & Palliative Medicine*.

'Moving toward openness: Blackfeet Indians' perception changes regarding talking about end of life' (p.9), in *American Journal of Hospice & Palliative Medicine*.

'Current practices of live discharge from hospice: Social work perspectives' (p.15), in *Health & Social Work*.

'Overcoming barriers to growth in home-based palliative care' (p.18), in *Journal of Palliative Medicine*.

'Advance care planning outcomes in African Americans: An empirical look at the trust variable' (p.13), in *Journal of Palliative Medicine*.

'A farewell to falsity: Shifting standards in Medicare fraud enforcement' (p.21), in *Seton Hall Law Review*.

1. Part 1: https://goo.gl/vVDLgj; Part 2: https://goo.gl/rTGfjS

Related

- CALIFORNIA | *The Sacramento Bee* – 27 December 2018 – **'California's elderly increasingly choose to spend final days at home.'** The proportion of elderly Californians dying at home has jumped sharply over the last two decades, according to new figures from the U.S. Centers for Disease Control & Prevention. About 36% of California's elderly who died last year did so at home, up from less than 25% in 1999. At the same time, the proportion of inpatient deaths at medical facilities and nursing homes has fallen. California seniors are more likely to die at home today than in a nursing home or medical facilities – a new development. https://goo.gl/kdT7sd

Cont.

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

- CALIFORNIA | *Forbes* – 27 November 2018 – **'How California is changing palliative care.'** California became the first state to mandate home-based palliative care (PC) to those in its Medicaid program. Although other Medicaid programs may pay for components of PC – such as advance care planning – "California is truly leading in this regard," says Stacie Sinclair, senior policy manager for the Center to Advance Palliative Care, a national organization. Hawaii and Washington are also looking at adding home-based PC to their Medicaid benefits. Most of the Medi-Cal population is enrolled in managed care plans which in turn contract with agencies to deliver home-based PC. https://goo.gl/cDn2Uw

Virtual reality helps hospice workers see life and death through a patient's eyes

NATIONAL PUBLIC RADIO | Online – 27 December 2018 – You wait in the sterile purgatory of your oncologist's office, between your spouse and your daughter, for the doctor to give you the verdict on your latest scans. "I'm afraid it's not good news," she says quietly, hands clasped. Your lung cancer has grown despite your recent chemotherapy. Surgery, chemo and other treatments, she tells you, will likely only make you sicker. "How long?" asks your spouse. Four to six months, the doctor answers. You may feel a surge of terror, confronted so starkly with news of your own death. You may also feel a welling-up of empathy. And that's the point of the exercise – the reason you're wearing a heavy headset. You aren't really dying, but you are looking out into a virtual world through the eyes of Clay Crowder, a fictional 66-year-old man who has incurable lung cancer. The University of New England College of Osteopathic Medicine in Biddeford, Maine, and a nearby hospice are using this virtual reality simulation, developed by Embodied Labs, to help nurses, other hospice workers and students learn about and empathize with patients at the ends of their lives. "I was skeptical at first that a virtual reality tool could be so realistic," says Daryl Cady, CEO of Hospice of Southern Maine. "But once I went through it, I realized what a viable method it could be, for not only teaching but also helping people understand [the] end of life better." The "Clay" virtual reality project is now used by some schools, hospice and senior care centers, including Comfort Keepers, a large system of in-home caregivers, Ohio's Hospice of Dayton, and several locations of the Benedictine Health System's elder care communities. Researchers have discovered virtual reality simulations like this one, can make viewers more empathetic to people they virtually embody: people of different races; people with colorblindness; even an avatar of an older version of themselves. https://goo.gl/h5c41f

Misconceptions about health costs when you're older

It's really hard to predict when someone will die

THE NEW YORK TIMES | Online – 24 December 2018 – A widely held view is that much spending is wasted on "heroic" measures taken at the end of life (EoL). Are all the resources devoted to Medicare and Medicaid really necessary? Let's get one misunderstanding out of the way. The proportion of health spending at the EoL in the U.S. is lower than in many other wealthy countries.[1] Still, it's a tempting area to look for savings. Only 5% of Medicare beneficiaries die each year, but 25% of all Medicare spending is on individuals within one year of death.[2] However, the big challenge in reducing EoL spending, highlighted by a recent study, is that it is hard to know which patients are in their final year.[3] The study used all the data available from Medicare records to make predictions: For each beneficiary, it assigned a probability of death within a year. Of those with the very highest probability of dying – the top 1% – fewer than half actually died. "This shows that it's just very hard to know in advance who will die soon with much certainty," said Amy Finkelstein, an economist and an author of the study. "That makes it infeasible to make a big dent in healthcare spending by cutting spending on patients who are almost certain to die soon." That does not mean that all the care provided to dying patients – or to any patient – is valuable. Another study finds that high EoL spending in a region is closely related to the proportion of doctors in that region who use treatments not supported by evidence – in other words, waste. https://goo.gl/DtFFCC

1. 'End-of-life medical spending in last twelve months of life is lower than previously reported,' *Health Affairs*, 2017;36(7):1211-1217. [Noted in 10 July 2017 issue of Media Watch (#520, pp.10-11)] **Full text:** https://goo.gl/3dfoJp

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2. ‘Medicare spending at the end of life: A snapshot of beneficiaries who died in 2014 and the cost of their care,’ Kaiser Family Foundation, July 2016. **Full text:** https://goo.gl/Ju81yn

3. ‘Predictive modeling of U.S. healthcare spending in late life,’ *Science*, 2018;360(6296):1462-1465. [Noted in 2 July 2018 issue of Media Watch (#570, p.3)] **Abstract:** https://goo.gl/LioPPT

Providing comfort and connection as the end draws near

THE WASHINGTON POST | Online – 23 December 2018 – In the U.S., there’s probably no better way to spoil cocktail party chatter than by introducing the subject of death, dying or the end of life (EoL). Yet, in the same way that the birth process went from a doctor-run event to a movement in which women took charge of their own pregnancies and deliveries, there is growing interest in thinking about the dying process. In part, that’s because the large population bulge of boomers is reaching a point where the end seems not that far away. But also, many people have had the experience of sitting at the bedside of a dying person without the slightest clue what to do. The growing interest in the topic is seen in death cafes, death doulas, the “death positive” movement, hospice work and even the End-of-Life University . There are special decks of card that allow families to work through EoL decisions. And increasingly, classes, seminars, and programs are available that try to help people understand how to comfort those in the last stages of life. https://goo.gl/bbw8xe

Human Rights Watch: Centers for Disease Control guideline needs revision

HUMAN RIGHTS WATCH | *Pain News Network* – 18 December 2018 – Federal and state efforts to reduce opioid prescribing have harmed pain patients across the country and caused many doctors to arbitrarily cutoff or taper patients who need opioid medication, according to a new report from Human Rights Watch.[1] The 109-page report … highlights the many unintended consequences of the 2016 Centers for Disease Control (CDC) opioid guideline, which discourages doctors from prescribing opioids for chronic pain.[2] The report recommends the CDC revise the guideline to explicitly state that patents should not be involuntarily tapered off opioids and that some patients may require higher doses. Although voluntary and only intended for primary care physicians, the CDC guideline has been widely adopted by regulators, law enforcement and insurance companies, usually with no effort made to measure its impact on pain patients and the quality of their care. One of the most surprising things Human Rights Watch learned, according to researcher Laura Mills, is how little the government knows – or is willing to say – about cutbacks in opioid prescribing. https://goo.gl/3m3HbC

Specialist Publications

‘Palliative care doctors raise concerns about withdrawing high-dose opioids’ (p.19), in *The Medical Post*.

1. ‘Not Allowed to Be Compassionate: Chronic Pain, the Overdose Crisis, and Unintended Harms in the U.S.,’ Human Rights Watch, December 2018. **Download/view at:** https://goo.gl/EDwJdZ

2. ‘CDC Guideline for Prescribing Opioids for Chronic Pain,’ Centers for Disease Control, 2016. **Download/view at:** https://goo.gl/dd6KJX

Noted in Media Watch 29 October 2018 (#587, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 October 2018 – **‘Dying on hospice in the midst of an opioid crisis: What should we do now?’** In the past year, 20.2 million Americans had a substance use disorder (SUD) and SUDs are disabling disorders that largely go untreated. In addition, the co-existence of both a mental health and SUD is very common with the use of opioids often as a means of chemical coping. Most hospice programs do not have standardized SUD policies/guidelines in place despite the increasing concerns about substance abuse within the U.S. The goal of this article is to review the literature on this topic and offer strategies on how to manage pain in patients who have active SUD or who are at risk for developing SUD in those dying on hospice. **Abstract:** https://goo.gl/GtUE1Q

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Noted in Media Watch 17 September 2018 (#581, p.8):

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 10 September 2018 – **'Ensuring and restoring balance on access to controlled substances for medical and scientific purposes: Joint statement from palliative care organizations.'** The central principle of "balance" represents the dual obligation of governments to establish a system of control that ensures the adequate availability of controlled substances for medical and scientific purposes while simultaneously preventing their non-medical use, diversion, and trafficking, two primary goals of the international control system. This report presents examples of unbalanced systems and a joint statement from global and regional palliative care organizations to promote development of balanced systems for optimal public health outcomes. **Abstract:** https://goo.gl/JhTRBM

International

Organization launched for "well-dying"

KOREA | *The Korean Times* (Seoul)– 30 December 2018 – In an aged society where longevity is not specific to an affluent group of people, what becomes important is how to live in later life and how to end life with dignity. In this context, civic group members, lawmakers, scholars and businesspeople have formed a group for "well-dying." The group is aimed at helping individuals prepare better for their later years and a beautiful ending to their lives in a super-aged society, where the elderly aged 65 or over take up over 20% of the total population. Korea has become an aged society, with more than 14% of the population being old. "Unprepared deaths can be a huge burden for friends, family members and for society," said Won Hye-young of the Democratic Party of Korea.... "All citizens should be able to end their lives respectfully and beautifully based on their own decisions, and it should settle into the culture of society," he explained as the object of the group's establishment. The group will concentrate on teaching patients how to write an advance medical directive, a document in which the person specifies, in advance, which medical treatment they wish to receive or not when he or she becomes unable to make a decision, like in a state of brain death. It can be used for deciding whether or not to give life-sustaining treatment. It will also help people put their names up for organ donations, heritage donations, and prepare for hospice facilities. https://goo.gl/5Zyddi

Specialist Publications

'Delay in commencement of palliative care service episodes provided to Indigenous and non-Indigenous patients: Cross-sectional analysis of an Australian multi-jurisdictional dataset' (p.10), in *BMC Palliative Care.*

'End-of-life care research on people with intellectual disabilities: Challenges for proactive inclusion in an Irish context' (p.12), in *British Journal of Learning Disabilities.*

'Palliative care in Solomon Islands' (p.9), in *Development Policy Centre Discussion Paper No. 74.*

'Social work in funeral homes, a unique Chinese practice?' (p.19), in *Omega – Journal of Death & Dying.*

'Perceptions of palliative care in a lower middle-income Muslim country: A qualitative study of healthcare professionals, bereaved families and communities' (p.20), in *Palliative Medicine.*

'Understanding and preventing situations of abuse in healthcare: Navigation work in a Swedish palliative care setting' (p.21), in *Social Science & Medicine.*

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Study: 36% of terminal cancer patients in Japan end their lives in pain

JAPAN | *The Japan News* (Tokyo) – 27 December 2018 – Nearly 40% of cancer patients felt some sort of physical pain in the month before they died, it has been learned from results of the first nationwide survey of its kind conducted among families of deceased patients by the National Cancer Center Japan. The results indicate the need for more palliative care, which is provided to relieve the mental and physical stress endured by people with terminal illnesses. https://goo.gl/2uqBuL

> **N.B.** See 'Integration of oncology and palliative care: Less-mentioned issues and a Japanese perspective,' *The Lancet Oncology*, 2018;19(11):e570-e571. [Noted in 22 October 2018 issue of Media Watch (#586, p.13)] **Access article at:** https://goo.gl/XGRGft

Charity finds the needs of siblings of seriously ill children are ignored by government

U.K. (England) | *Charity Today News* – 21 December 2018 – Brothers and sisters of seriously ill children risk being left with a long-term negative impact on their mental health and education unless there is more funding to support them, a report published by Rainbow Trust Children's Charity warns.[1] The report ... illustrates that demand for sibling support is increasing, and the mental health and educational attainment of brothers and sisters of seriously ill children can be affected by their situation. It calls on statutory authorities to recognise the value of sibling support and to fund it. The report includes testimonials from brothers and sisters supported by Rainbow Trust and data from children's hospices surveyed about the increasing need for sibling support. More than 70% of children's hospices, who responded to a 2018 Rainbow Trust survey of sibling support in England, said the demand for sibling support has increased over the last three years but only a third said that they can "always" meet demand. https://goo.gl/AEZEkN

1. 'See us, Hear us, Notice us: The case for supporting siblings of seriously ill children,' Rainbow Trust Children's Charity, December 2018. **Download/view at:** https://goo.gl/gdmrh6

Australians want to die at home but struggle to get access to end-of-life care

AUSTRALIA (South Australia) | ABC News (Adelaide) – 20 December 2018 – Australians "are not dying well" with only one in four people able to access palliative care (PC), a national advocacy body has warned. Palliative Care Australia claims every state and territory is falling to adequately fund end-of-life (EoL) care. Its views are supported by a scathing new review of a South Australian plan to reform PC services, which found the former state government and current health system have failed to improve EoL care for almost a decade.[1] The South Australian review found that of the 32 initiatives the former Labor state government pledged in 2009, only three had been implemented. "The lack of action has had real and significant impacts," the report found. "[People] still cannot be assured of living and dying well at the EoL stage." The Health Performance Council's review found less community-based care was created than was promised, the state had seen higher levels of hospitalisation and acute care treatments, there was more pressure on carers, more disruption for consumers and greater delays in receiving care. It also found a PC unit promised for Aboriginal people in Port Augusta had not been built, there were high levels of staff turnover and burnout, a state-wide grief and loss service had not been implemented and there was no evidence any work had been done to better meet the needs of culturally and linguistically diverse groups. During that time, consumer complaints about PC also skyrocketed. https://goo.gl/kExU18

1. 'Revisit review of South Australia's Palliative Care Services Plan 2009-2016,' Health Performance Council, Government of South Australia, November 2018. **Download/view at:** https://goo.gl/sTN8f7

Updated 12.21.2018

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.25.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | *Community Care Review* – 17 December 2018 – **'Legalising assisted dying "may advance" palliative care.'** The nation's peak palliative care (PC) body is reviewing its position on euthanasia and physician-assisted dying after it became legal in Victoria, and has released two key reports on assisted dying around the world.[1] Victoria became the first Australian state to allow assisted dying with the passage of the Voluntary Assisted Dying Act in 2017. Victorians who meet eligibility criteria will be to able request voluntary assisted dying from June 2019. The reports by Palliative Care Australia found that while legalising assisted dying is likely to raise difficult issues for healthcare workers, there is no evidence to suggest the sector will suffer as a result. On the contrary, the reports conclude that the introduction of euthanasia may even have benefits for PC. **Full text:** https://goo.gl/LCwdK8

    1. 'Assisted dying's impact on palliative care explored in new reports,' Palliative Care Australia, 10 December 2018. [Noted in 17 December 2018 (#594, p.5)] **Download/view at:** https://goo.gl/UVpGbm

Specialist Publications

Timely referral to hospice care for oncology patients: A retrospective review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 December 2018 – Although oncologic benchmarks suggest patients should be enrolled in hospice 3 months prior to death, studies show that most hospice referrals are being made too late. These shorter stays in hospice result in increased cost of care especially at the end of life (EoL) with most patients dying on aggressive treatments in the hospital. Thus, identifying barriers to hospice placement is critical in improving the referral process and enhancing the quality of EoL care. This [U.S.] study found that the demographics between hospice and non-hospice patients were not significantly different. Hospice patients spent a median of 10 days in hospice and 71% of patients were in hospice 30 days or less. Additionally, 56% of patients were in hospice 10 days or less. Increased education for patients and care providers along with better utilization of palliative care services and incorporating a nurse navigator to help with transitioning patients to hospice would improve earlier referral to hospice care and enhance patients' quality of life. **Abstract:** https://goo.gl/z7pU77

Publishing Matters

'Open access medical journals: Promise, perils, and pitfalls' (p.24), in *Academic Medicine.*

'Being a deliberate prey of a predator: Researchers' thoughts after having published in predatory journal' (p.24), in *LIBER Quarterly*.

N.B. The Retraction Watch Database launched (p.25),

Related

- *BMC CANCER* | Online – 22 December 2018 – **'Characteristics and impact of the most-cited palliative oncology studies from 1995 to 2016.'** Palliative oncology care is increasingly being delivered as a distinct service, ushering in a new era of research questions. A unique billing code for palliative care (PC) [in the U.S.] will allow investigators to study questions related to adoption of PC and its effect on healthcare utilization/cost of care using electronic medical record data and large datasets of medical claims. Oncology practices are now integrating patient reported outcomes into routine clinical care. This will provide a rich source of relevant, patient centric data where palliative oncology-specific quality metrics can be developed and tailored to individual cancer type and clinical setting (e.g., urban vs. rural, academic vs. community). **Full text:** https://goo.gl/HNaEa1

Moving toward openness: Blackfeet Indians' perception changes regarding talking about end of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 16 December 2018 – In the past, a taboo perception of Blackfeet traditional belief in end-of-life (EoL) discussion was identified as a core barrier for hospice use. However, a recent anecdotal increase in hospice interest triggered the research team to investigate community-wide interest as well as traditional appropriateness of hospice introduction. The authors interviewed 10 tribally recognized Elders and surveyed 102 tribal members who were over 18 years old using a modified Duke End-of-Life Care Survey. The elders' statements were divided into two, saying that an EoL discussion was not against tradition and that sickness and death would break the living spirit, thus no such discussion. Despite, the importance of a family gathering and the need for knowledge about EoL care were confirmed. The survey showed that 90% of the respondents thought dying was a normal part of life and 76% felt comfortable talking about death. There was a shift in the Blackfeet Indians' attitude toward EoL discussion from reluctance to at ease. Recommendations specific to the Blackfeet-related entities are presented. **Abstract:** https://goo.gl/2HmiB3

Noted in Media Watch 18 December 2017 (#543, p.4):

- U.S. | National Public Radio – 12 December 2017 – **'Native Americans feel invisible in U.S. healthcare system.'** The life expectancy of Native Americans in some states is 20 years shorter than the national average. There are many reasons why: health programs for American Indians are chronically underfunded by Congress. And, about a quarter of Native Americans reported experiencing discrimination when going to a doctor or health clinic, according to a poll by National Public Radio, the Robert Wood Johnson Foundation, and Harvard T.H. Chan School of Public Health. https://goo.gl/H1bKvM

Noted in Media Watch 31 July 2017 (#523, p.11):

- *JOURNAL OF TRANSCULTURAL NURSING* | Online – 22 July 2017 – **'Culturally relevant palliative and end-of-life care for U.S. indigenous populations...'** American Indians/Alaska Natives have higher rates of chronic illness and lack access to end-of-life care (EoLC). Four themes emerged in this review: 1) Communication; 2) Cultural awareness/sensitivity; 3) Community guidance for EoLC programs; 4) Barriers. Two sub-themes: 1) Trust/respect; and, 2) Mistrust. Limitations are lack of research funding, geographic isolation, and stringent government requirements. **Abstract:** https://goo.gl/yegFi2

Can hospitalists turn the tide of aggressive end-of-life hospital care?

ANNALS OF INTERNAL MEDICINE | Online – 18 December 2018 – Ms. S, a 61-year-old woman with refractory, progressive metastatic hepatocellular carcinoma, was admitted with acute liver failure. After hearing her diagnosis, she understood that she was approaching the end of her life. She expressed a desire to return home to her family, agreeing to stay in the hospital only if there was a meaningful intervention to be offered. The hepatology consult team requested a cadre of tests to investigate the cause of her progression. As the hospitalist overseeing her care, the author attributed her presentation to the advanced cancer and felt certain that she would not improve with any intervention. Her oncologist agreed. However, the hepatology team persisted in their recommendations for additional testing. Unfortunately, the patient grew more lethargic, her condition deteriorated, and she ultimately died in the hospital. **Abstract:** https://goo.gl/qjjzka

Palliative care in Solomon Islands

AUSTRALIAN NATIONAL UNIVERSITY (Development Policy Centre) | *Development Policy Centre Discussion Paper No. 74* – 12 December 2018 – This is the first published exploration of palliative care (PC) in Solomon Islands. Following a literature review, data collection involved documentary analysis and interviews with policymakers, health professionals, and other community stakeholders. All interviewees agreed that there is a need to pay more attention to PC in Solomon Islands. Key areas for future action include: supporting health professionals to have difficult conversations with people about their prognosis

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and what to expect during the dying process; training for health professionals in pain assessment and management; improving systems and guidelines, particularly referral systems and access to morphine; and expanding support for families caring for loved ones dying at home. Future research opportunities exist in understanding: families' and patients' needs; cultural approaches to caregiving, pain and death; the role of traditional healers; how to increase health literacy; the costs and savings associated with PC provision; and, the knowledge, attitudes and behaviours of health professionals. An examination of the opiate analgesic system is a pressing research priority. The authors conclude with recommendations for donors regarding how they could support future action and research. **Abstract:** https://goo.gl/TttXXi

> **N.B.** Click on pdf icon to access full text. See 'Health closer to home: Transforming care in the Solomon Islands,' World Health Organization, March 2017. https://goo.gl/4vXDvY

Delay in commencement of palliative care service episodes provided to Indigenous and non-Indigenous patients: Cross-sectional analysis of an Australian multi-jurisdictional dataset

BMC PALLIATIVE CARE | Online – 22 December 2018 – This is the first quantitative multi-jurisdictional investigation of health service quality for Indigenous Australians in palliative care (PC). The dual vulnerability experienced by socially disadvantaged persons with a life-limiting illness underscores the importance of investigating equity of PC service provision. The authors findings provide reassurance that timeliness of episode-by-episode care provision to Indigenous Australians within the majority of specialist PC services nationwide that provide data to Palliative Care Outcomes Collaboration [an Australian Commonwealth Government-funded program established in 2005] has met the established benchmark overall, while suggesting modest disparities affecting this population. However, these findings do not elucidate between-service heterogeneity in performance and under-represent Indigenous Australians, especially those who reside in the most remote communities nationwide and are thereby likely to be both particularly vulnerable to inequity of health service provision and among the most likely to require end-of-life care. **Full text:** https://goo.gl/pD9nb9

> **N.B.** Additional articles on palliative and end-of-life care for Indigenous peoples in Australia noted in 29 October 2018 (#587, p.3).

Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: A qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention

BMC PALLIATIVE CARE | Online – 20 December 2018 – This study has distinguished key aspects of facilitation of evidence-based practice in relation to carer assessment and support. Essential characteristics of the facilitator role for successful implementation are identified in terms of "leverage" within the implementation team, style and skills in communication and providing support to peers. It has also evidenced the interacting contextual factors that help and hinder the facilitation process, including the specific challenges of facilitating implementation of carer support interventions as opposed to patient interventions. Though the focus of this study was implementation of carer assessment and support, these understandings are likely to be applicable for implementation of other practice interventions, particularly those that are person-centred. In the field of carer support in palliative and end-of-life care, taken together these findings broaden the knowledge base for training that tends to focus on training of individuals, extending it to understandings of organisational structures and processes necessary for its successful implementation in practice. In terms of translation of research into practice, these findings on facilitation and contextual factors have been taken forward and used to inform components of The CSNAT Approach Training and Implementation Toolkit. This toolkit will enable training of individual practitioners, and ensure that organisations wishing to implement a comprehensive person-centred approach to assessment and support for carers have access to structured implementation guidance. **Full text:** https://goo.gl/arJH6d

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Noted in Media Watch 19 June 2017 (#517, p.9):

- *PLOS ONE* | Online – 16 June 2017 – **'Factors influencing practitioner adoption of carer-led assessment in palliative homecare: A qualitative study of the use of the Carer Support Needs Assessment Tool (CSNAT).'** Not all practitioners appreciated that using the CSNAT required a shift towards a more person-centred approach to assessment; consequently they tagged the tool onto their existing practitioner-led practice. Practitioners who did use the CSNAT as intended were able to act as role models and support colleagues in making this transition. **Full text:** https://goo.gl/oYrpFV

Noted in Media Watch 16 May 2016 (#462, p.8):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 13 May 2016 – **'Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool (CSNAT).'** 24 caregivers participated in this study and identified the highest support priorities as "knowing what to expect in the future," "knowing who to contact if concerned," and "equipment to help care." The majority found this assessment process adequately addressed their needs and gave them a sense of validation, reassurance, and empowerment. **Abstract (w. list of references):** http://goo.gl/FUhMSl

Ethical issues in nursing home palliative care: A cross-national survey

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 18 December 2018 – With an increased dependency on nursing homes to provide care to the ageing population, it is likely that ethical issues will also increase. This study aimed to identify the type of ethical issues and level of associated distress experienced by nurses providing palliative care in nursing homes in the U.K. and Canada, and pilot the Ethical issues in Palliative Care for Nursing Homes (EPiCNH) instrument in Canada. Frequent ethical issues include upholding resident autonomy, managing family distress, lack of staff communication and lack of time in both countries. Higher levels of distress resulted from poor communication, insufficient training, lack of time and family disagreements. Nurses in Canada experienced a greater frequency of ethical issues; however, there was no statistical difference in reported distress levels. The survey was positively rated for ease of completion, relevance and comprehensiveness. These findings have implications on the practice of care in nursing homes, including how care is organised as well as capacity of staff to care for residents at the end of life. Training staff to take account of patient and family values during decision-making may address many ethical issues, in line with global policy recommendations. The EPiCNH instrument has demonstrated international relevance and applicability. **Abstract:** https://goo.gl/Ur32Mi

Noted in Media Watch 9 July 2018 (#571, p.15):

- *NURSING ETHICS* | Online – 26 June 2018 – **'Ethical issues experienced during palliative care provision in nursing homes.'** In this study, the 'Ethical Issues in Palliative Care for Nursing Homes' instrument was used to measure the frequency and level of distress arising from ethical issues through a cross-sectional survey... Interviews revealed three themes: 1) Ethical issues in practice; 2) Relational issues; and, 3) Organisational issues. Relational issues, primarily issues with residents and families, occurred most frequently and caused greater distress. **Abstract:** https://goo.gl/ytnEnM

Assistant practitioners in palliative care: Doing things differently

BRITISH JOURNAL OF HEALTHCARE ASSISTANTS | Online – 12 December 2018 – The acute hospital palliative care (PC) team at London North West University Healthcare National Health Trust provides specialist PC advice and supports end-of-life care (EoLC) across the trust. The Trust has experienced a year-on-year increase in demand for services and have previously managed this by recruiting more clinical nurse specialists. The appointment of two assistant practitioners to support EoLC has allowed the Trust to look at a different model of care and new ways of working to meet increasing demands on service. **Abstract:** https://goo.gl/nK3wqg

End-of-life care research on people with intellectual disabilities:
Challenges for proactive inclusion in an Irish context

BRITISH JOURNAL OF LEARNING DISABILITIES | Online – 17 December 2018 – In recent times, people with intellectual disabilities are increasingly included in research studies; however, their participation in sensitive research such as palliative and end-of-life care is less frequent. The reasons for not including people with intellectual disabilities in these kinds of research studies are issues in relation to obtaining consent, difficulty of recruiting, and engaging and collecting relevant information. Participants with intellectual disabilities were recruited by establishing a close relationship with service providers. Capacity to consent and informed consent were fostered by carefully explaining the research process through easy-to-read information, and the data collection process was successfully completed by having a person-centred approach. People with intellectual disabilities can be successfully included in research. This is possible when their diverse needs are carefully considered, and appropriately developed protocols which meet their needs in relation to their capacities and abilities are utilised. This approach requires a flexible and inclusive research process. **Abstract:** https://goo.gl/ZPJpzV

Best supportive care in advanced lung cancer – more than a label?

BRITISH MEDICAL JOURNAL | Online – 27 December 2018 – Cancer multidisciplinary team meetings are standard clinical practice in the U.K. and seek to confirm diagnoses and propose appropriate treatment plans through expert consensus. Patients who are too frail for cancer treatment or who choose not to have it are recorded as being "for best supportive care." In reality though, this plan often serves only as a label and fails to translate into anything meaningful for the patient. The team may agree on who should receive best supportive care (SC) but there is little consensus about what it constitutes in practice and who should be accountable for its delivery. The terms best SC and palliative care are often used interchangeably but are synonymous only in certain clinical contexts. PC is defined as an approach that improves the quality of life for people, and their families, facing the problems associated with life-threatening illness. It may be integrated alongside disease modifying treatments or be a plan of care in its own right when such treatment is not possible, so called best SC. A key tenet of quality improvement thinking is that "every system is perfectly designed to get the results it gets." In the context of best SC, the absence of a defined standard leads to unwarranted variation in the quality of care that patients receive. Individuals may miss out on the benefits of this care or receive care that is inappropriately medicalised in their last weeks of life. At a system level, this generates inefficiency and, at times, redundancy in the use of healthcare resources. **Introductory paragraphs:** https://goo.gl/zX3AxQ

Advance directives and code status information exchange:
A consensus proposal for a minimum set of attributes

CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS, 2019;28(1):178-185. The use of advance directives and code status remains low and only a few organizations maintain code status in electronic form. Members of the American Medical Informatics Association's Ethics Committee identified a need for a patient's end of life care (EoLC) wishes to be documented correctly and communicated easily through the electronic health record (HER) using a minimum data set for the storage and exchange of code status information. After conducting an environmental scan that produced multiple resources, ethics committee members used multiple conference calls and a shared document to arrive at consensus on the proposed minimum data set. Ethics Committee members developed a minimum required data set with links to the HL7 C_CDA Advance Directives Module. Data categories include information on the organization obtaining the code status information, the patient, any supporting documentation, and finally the desired code status information including mandatory, optional, and conditional elements. The "minimum set of attributes" to exchange advance directive/code status data described in this manuscript enables communication of patient wishes across multiple providers and healthcare settings. The data elements described serve as a starting point for a dialog among informatics professionals, physicians experienced in EoLC, and EHR vendors, with the goal of developing standards for incorporating this functionality into the EHR systems. **Abstract (w. list of references):** https://goo.gl/4AHgVv

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Related

- *JOURNAL OF MEDICAL ETHICS* | Online – 21 December 2018 – '**Authority without identity: Defending advance directives via posthumous rights over one's body.**' Many have assumed that advance directives (ADs) would lack moral authority if dementia truly produced a complete discontinuity in personal identity, such that the pre-dementia individual is a separate individual from the post-dementia individual. The author argues that even if dementia were to undermine personal identity, the continuity of the body and the pre-dementia individual's rights over that body can support the moral authority of ADs. The author proposes that the pre-dementia individual retains posthumous rights over her body that she acquired through historical embodiment in that body, and further argues that claims grounded in historical embodiment can sometimes override or exclude moral claims grounded in current embodiment. **Abstract:** https://goo.gl/vCsngw

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 December 2018 – '**Advance directives, medical conditions, and preferences for end-of-life care among physicians: 12-year follow-up of the Johns Hopkins Precursors Study.**' End-of-life preferences grouped into three classes, most aggressive (wanting most interventions; 14% of physicians); least aggressive (declining most interventions; 61%); and an intermediate class (declining most interventions except intravenous fluids and antibiotics; 25%). Physicians without an advance directive were more likely to desire more treatment, and were less likely to transition out the most aggressive class. Transition probabilities from class to class did not vary over time. Persons with cancer expressed preference for the least aggressive treatment while persons with cardiovascular disease and depression had preferences for more aggressive treatment. **Abstract (inc. link to references):** https://goo.gl/NATmRT

- *PLOS ONE* | Online – 18 December 2018 – '**Ability of end-of-life preferences in relation to health status and life-events: A cohort study with a 6-year follow-up among holders of an advance directive.**' The results of this study make an important contribution to disputing the criticism concerning the usability of advance directives (ADs) due to a lack of stability of preferences of their owners. Whereas a change in health status and the experience of other life-events were not related to instability of general self-reported preferences about the end of life (EoL), they did increase the odds of communication about ADs. Yet, communication remains an issue of concern. In order to translate general preferences about EoL put down in ADs to specific decisions in practice, communication is vital. The authors show that possession of an AD does not necessarily lead to frequent discussions between patients and caregivers. **Full text**: https://goo.gl/8A2jeu

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 December 2018 – '**Advance care planning outcomes in African Americans: An empirical look at the trust variable.**' Racial disparities in rates of hospice use, a marker of quality of end-of-life (EoL) care, have been a long-standing problem. Although distrust has been cited as a main reason for the preference of intensive EoL care among African Americans, the role of trust has not been closely analyzed in predicting EoL care in the context of advance care planning (ACP) outcomes. The authors identified nine quantitative studies that measured and evaluated trust as a predictor or correlate of ACP preferences. Three studies were designated as low quality, and six studies were of moderate quality. The majority of studies found no significant differences in trust between African Americans and their White counterparts. Further, we found that trust was not associated with ACP outcomes in the majority of studies. **Abstract:** https://goo.gl/DmBP2N

- *JOURNAL OF PSYCHOSOCIAL ONCOLOGY* | Online – 26 December 2018 – '**"I think it's a bit early for now": Impact of psychological factors on drafting advance directives among cancer patients.**' A large majority of the sample surveyed reported having no knowledge about advance directives (ADs). Of the patients who initially agreed to participate, two-thirds declined after the presentation of the theme of the study. The reasons of patients who declined to participate related to avoidance of the issue of death, a focus on present time perspective, or an ambivalence between the AD proposal and recovery plans. This study provides further evidence of the difficulties for patients to express their willingness to engage in AD discussions or research. The extent of the psychological issues experienced by patients and the level of avoidance they expressed raise many questions about the ethical issues and the spread of ADs used in oncology settings. **Abstract:** https://goo.gl/R7KxRL

How grief camp reinforces the need for death education in elementary schools

CANADIAN JOURNAL FOR NEW SCHOLARS IN EDUCATION, 2018;9(2):90-99. Established to help normalize the grieving process, grief camps are traditionally for children and adolescents who have experienced a death-related loss. These camps take children and adolescents out of their daily environment, inviting them to express their grief in innovative and developmentally appropriate ways. The author is a volunteer at two grief camps in Manitoba and it is apparent that these camps not only fill a gap in the bereavement experiences of children and adolescents, but also highlight the need for more preparation in terms of dying, death, and loss. Pupils in Ontario spend almost 6,000 hours in elementary school, yet there is no curriculum that directly addresses death. As a microcosm, grief camp reinforces the need for death education on a macro level in elementary schools. **Abstract:** https://goo.gl/35yfrL

> **N.B.** Click on pdf icon to access full text: Selected articles on including the topic of dying and death in the school curriculum noted in 10 December 2018 issue of Media Watch (#593, p.6).

Communication skills training for healthcare professionals in oncology over the past decade

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 17 December 2018 – Effective communication in cancer care requires complex communication skills of healthcare professionals (HCPs), which can be advanced by communication skills training (CST). The number of empirical studies on CST has grown steadily over the last decade. However, controversies on CST abound. The aim of this review of reviews is to summarize evidence for the effectiveness of CST in oncology as well as for effective CST features (intensity, format and content) and to synthesize the current opinion on CST. The evidence synthesized from multiple reviews supported the effect of CST on HCPs' communication skills. Yet, the certainty of evidence was limited as studies were diverse and effects heterogeneous. Furthermore, limited evidence was found for effective CST intensity, format and content. Authors of the reviews advocated further high-quality research with robust outcome measurement to establish the most essential features of CST and recommended implementation of CST in the standard training of HCPs with continuous supervision. CST can probably improve some aspects of HCPs' communication skills. Despite the uncertain evidence, implementation of CST into clinical practice is widely advocated and specific recommendations regarding intensity and format are provided. Evidence to justify and substantiate implementation efforts is needed. **Abstract:** https://goo.gl/YqjJqc

Brain death at fifty: Exploring consensus, controversy, and contexts

THE HASTINGS REPORT, 2018;48(S4):S2-S5. This special report is published in commemoration of the fiftieth anniversary of the 'Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death,' a landmark document that proposed a new way to define death, with implications that advanced the field of organ transplantation. This remarkable success notwithstanding, the concept has raised lasting questions about what it means to be dead. Is death defined in terms of the biological failure of the organism to maintain integrated functioning? Can death be declared on the basis of severe neurological injury even when biological functions remain intact? Is death essentially a social construct that can be defined in different ways, based on human judgment? These issues … are discussed and debated in this report by leading experts in the field, many of whom have been engaged with this topic for decades. **Abstract:** https://goo.gl/7z41oz

THE HASTINGS CENTER REPORT

Journal contents page: https://goo.gl/MoKc7w

> **N.B.** Additional articles on defining "brain death" noted in 17 December 2018 issue of Media Watch (#594, pp.1-2).

Current practices of live discharge from hospice: Social work perspectives

HEALTH & SOCIAL WORK | Online – 15 December 2018 – Hospice provides holistic support for individuals living with terminal illness and to their caregivers during the bereavement period. However, some individuals who enroll in hospice services are decertified as they do not experience a decline in health as quickly as required by current regulations, a practice referred to as a live discharge. The interruption in care can affect the physical and psychosocial care needs for individuals and caregivers and leave hospice clinicians with questions about how to best support them. However, there are no formal guidelines to support this process. This qualitative study explored the current practices of hospice social workers across the U.S. engaged in the live discharge process. Results from this study emphasize the need to bridge the gaps between policy and practice. Specifically, results highlight the challenges hospice social workers face to replicate or supplement the holistic support and unique services hospice provides for individuals discharged alive, and suggest further research to develop live discharge guidelines to identify appropriate support for patients and their caregivers who no longer meet hospice eligibility requirements. **Abstract:** https://goo.gl/o1ayNE

Noted in Media Watch 11 August 2014 (#370, p.4):

- *THE WASHINGTON POST* | Online – 6 August 2014 – **'Rising rates of hospice discharge in U.S. raise questions about quality of care.'** At hundreds of U.S. hospices, more than one in three patients are dropping the service before dying, research shows, a sign of trouble in an industry supposed to care for patients until death.[1] When that many patients are leaving a hospice alive, experts said, the agencies are likely to be either driving them away with inadequate care or enrolling patients who aren't really dying in order to pad profits. https://goo.gl/pwkLbk

    1. 'A national study of live discharges from hospice,' *Journal of Palliative Medicine*, 7 August 2014. **Abstract:** https://goo.gl/snwrzm

Critical explorations of marginalized grief

ILLNESS, CRISIS & LOSS, 2019;27(1):3-5. Following some initial collaborative writing on two articles for this journal exploring relationships between crisis, illness, loss, and well-being, and then more specifically considerations for the *Handbook of the Sociology of Death*, *Grief and Bereavement* (NY: Routledge, 2017) and 'Disenfranchised Grief' in *Handbook of the Sociology of Death, Grief, and Bereavement: A Guide to Theory and Practice* (NY: Routledge, 2017), the idea was formulated for a collection of focused inquiries into disenfranchised grief [published in this special issue of *Illness, Crisis & Loss*]. The initial starting point was the desire to extend opportunity and writing about some of the important, but marginalized, realms of these topics. To this end, a range of authors was commissioned to make potential contributions. The first focus was explicitly disenfranchised grief... In this regard, the editors were keen to develop understanding of the diversity of difficult experiences which, by their inherent nature, are particularly hidden from social acknowledgment. They had after this two very distinct additional aims. The second was to try to provide an opportunity to support new authors … to get published. The third was to invite a diversity of approaches, methods, topics, and client considerations to be included. This edition offers four different, but applied, explorations of disenfranchised grief. **Full text:** https://goo.gl/eD7ZKo

N.B. Journal contents page: https://goo.gl/7cdKm

Related

- *JOURNAL OF FAMILY NURSING* | Online – 17 December 2018 – **'How grandparents experience the death of a grandchild with a life-limiting condition.'** Traditionally, family-focused care extends to parents and siblings of children with life-limiting conditions. Only a few studies have focused on the needs of grandparents, who play an important role in the families of children with illness and with life-limiting conditions, in particular. The findings of this study about the unique footprint of grandparent grief suggest development of family nursing practice to better understand and support grandparents during the illness of a grandchild, in addition to bereavement support. **Abstract:** https://goo.gl/o92sbc

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N.B. See 'A voice unheard: Grandparents' grief over children who died of cancer,' *Mortality*, 2007;12(1):66-78. [Noted in 20 January 2014 issue of Media Watch (#341, p.17, under 'Worth Repeating')] **Abstract:** https://goo.gl/dkBwsc ; and, 'Forgotten grievers: An exploration of the grief experiences of bereaved grandparents,' *International Journal of Palliative Nursing*, 2011;17(4):170-176. [Noted in 25 April 2011 issue of the weekly report (#198, p.4)] **Abstract:** https://goo.gl/2tEc7i

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 18 December 2018 – **'The phenomenon of bereaved parenting: An integrative review of literature.'** Results revealed 3 influential contexts: 1) The general of parental grief and bereavement, described as traumatic and life-changing experiences; 2) The personal of the resulting parental changes and coping strategies; and, 3) The relational of the subsequent parenting of surviving children, an experience characterized by periodic conflict between personal and children's needs, emotional fluctuations, challenges with levels of protectiveness and control, and a heightened sense of responsibility within the parental role. **Abstract:** https://goo.gl/Av3MDC

The role of the memory service in helping carers to prepare for end of life: A mixed methods study

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY | Online – 15 November 2018 – The authors explore current memory service practice in helping carers prepare for end of life. Most clinicians [surveyed] agreed that discussions of these topics were appropriate for their role. However, there was considerable variability in practice. Informing people with dementia and family about the progressive nature of dementia and providing written information about legal issues were routine, as was emphasising to carers the importance of accessing support from their social network. However, discussing the implications of loss of capacity, advance care planning and legal arrangements only occurred in two-thirds of services, 37% of services would tell the person with dementia that it was terminal, and only 11% discussed spirituality or the meaning of death. When these conversations occurred, clinicians usually provided written information, consistent with the Memory Services National accreditation programme audit.[1] The authors found stronger endorsement for National Institute for Health & Care Excellence than European Association for Palliative Care guidelines, which may be expected given the latter are not mandatory and are relatively new.[2,3] **Full text:** https://goo.gl/Ch4cM9

1. 'World Alzheimer Report: The Global Impact of Dementia,' Alzheimer's Disease International, 2015. **Download/view at:** https://goo.gl/ED4AVu

2. 'Dementia: Assessment, management and support for people living with dementia and their carers,' National Institute for Health & Care Excellence, 2018. **Download/view at:** https://goo.gl/g2Tw7u

3. 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, published online 4 July 2013. [Noted in 8 July 2013 issue of Media Watch (#313, p.10)] **Full text:** https://goo.gl/xkAyq2

Related

- *AMERICAN JOURNAL OF ALZHEIMER'S DISEASE & OTHER DEMENTIAS* | Online – 13 December 2018 – **'Empowering patients with Alzheimer's disease to void unwanted medical care: A look at the dementia care triad.'** The authors examine the role of each member of the dementia care triad and how to empower the patient to participate in planning future medical care. Physicians have the same professional disclosure obligations to dementia patients as they do to all other capable patients with terminal illnesses. Because there is little consensus about what facts should be included in a diagnostic disclosure, the authors offer a proposal to empower newly diagnosed patients with dementia with capacity to plan for their future medical care. **Abstract:** https://goo.gl/Kgr33S

Closing the Gap Between Knowledge & Technology
http://goo.gl/OTpc8I

Shared decision making in managing multiple sclerosis: Revisiting the research agenda

INTERNATIONAL JOURNAL OF MS CARE, 2018:20(6):v-vi. This theme issue of the journal deals with patient involvement in managing multiple sclerosis (MS), specifically regarding so-called disease-modifying drugs in MS. Shared decision making (SDM) is increasingly recognized as the preferred healthcare approach. Patients' autonomy is the bioethical principle behind SDM and has recently been emphasized as one of the main principles of the Revised Declaration of Geneva. However, while SDM is a bioethical principle, it is less clear if it leads to better health outcomes. In addition, health economic savings have been claimed, but still with little evidence. Even without proof of these benefits, SDM is a bioethical must and a quality-of-care indicator by itself. The articles in this issue add to understanding of the topic in the MS field. **Full text:** https://goo.gl/qYVvof

Extract from *International Journal of MS Care* article

Palliative care (PC) is substantially under investigated in multiple sclerosis (MS). Research about PC is also hampered by it being mentally connected to the idea of terminal illness, and thus considered a taboo topic. The European Academy of Neurology is currently working on a clinical guideline about PC in MS, which will presumably show substantial knowledge gaps. However, SDM has been studied in PC in oncology, which possibly best represents the area in medicine where care without patient centeredness is virtually impossible.

N.B. Journal contents page: https://goo.gl/KdzNwe

Noted in Media Watch 10 December 2018 (#593, p.12):

- *JOURNAL OF CLINICAL NEUROSCIENCE*, 2018;58:13-19. **'Ten-year trends of palliative care utilization associated with multiple sclerosis patients in the U.S. from 2005 to 2014.'** The national trends of palliative care (PC) utilization in multiple sclerosis (MS) patients increased by 120 times from 0.2% to 6.1% during 2005-2014, particularly with the dramatic single-year increase between 2010 (1.5%) and 2011 (4.5%). Moreover, the proportion of receiving PC in in-hospital death gradually increased from 7.7% in 2005 to 58.8% in 2014. PC in MS inpatients may affect hospital utilization and charges in different ways. **Abstract (inc. link to references):** https://goo.gl/T78dxv

N.B. Selected articles on PC for people living with MS – and in neurology in general – noted in this issue of Media Watch.

Condition-specific pamphlets to improve end-of-life communication in long-term care: Staff perceptions on usability and use

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 21 December 2018 – This article reports findings on the usability and staff use of 5 condition- specific pamphlets of high prevalence in long-term care (LTC): dementia, heart failure, chronic obstructive pulmonary disease, renal failure, and frailty. The pamphlets were created in response to residents', families', and staff's recommendations for activating early reflections and communication about end-of-life care (EoLC). The pamphlets were reportedly accurate, relevant, and easy to understand. Following 6 months of availability, most staff in LTC had read the pamphlets, found the information useful, and planned to share them. However, half of the staff questioned their role in pamphlet distribution and most had not distributed them. Regulated staff (i.e., staff affiliated with a regulated profession) expressed more comfort sharing the pamphlets than care aides and support staff. Condition-specific pamphlets appear to hold promise in providing residents and families with relevant information that may activate early reflections and conversations about EoLC. However, structured implementation strategies, training, and discussions are required to improve staff comfort with distribution and explore roles in distribution and follow-up. **Abstract (inc. link to references):** https://goo.gl/RdtvmC

Exploring an integrated palliative care model for older people: An integrative review

JOURNAL OF INTEGRATED CARE | Inprint – Accessed 18 December 2018 – Due to an international ageing population, global health organisations have recognised challenges arising from fragmented interaction between health and social sectors in end-of-life care (EoLC). The authors explore existing literature on integrative palliative care (PC) services for older people. Nine studies fitted the inclusion criteria and three themes were identified: person-centred care, coordination of care, and education and training. The review identifies that integrated PC requires coordinated techniques that focus upon quality of life, individual needs and awareness of vulnerability rather than fixation on inevitable mortality. The emerging presence of the need for integrated PC requires further research in order to develop coherent models of integrated PC which can be incorporated into practice. This review identifies themes relevant to emerging issues in the global health sector of EoLC. The literature suggests that the optimised use of an integrated care approach to a palliative model of care is required and in need of further investigation. **Abstract:** https://goo.gl/UR5e2m

Overcoming barriers to growth in home-based palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 27 December 2018 – Home-based palliative care (PC) fills a critical gap between acute care (during crises) and hospice care for seriously ill patients. As of 2018, home-based PC capacity in the U.S. has not scaled to meet patient needs. The Center to Advance Palliative Care conducted a needs assessment to catalog and analyze barriers to growth in the field of home-based PC. Home-based PC program leaders cited their major challenges as being: a lack of clarity on the applicability of national standards to home-based programs, a lack of sustainable financing methods for home-based PC, and lack of awareness of existing support resources for program design and leadership development. Home-based PC programs will benefit from improved professional awareness of national quality standards and existing technical assistance. New prospects for alternative payment models that allow for sustainable interdisciplinary home-based care represent a promising opportunity for the field. **Abstract:** https://goo.gl/sAkkGh

Top ten tips palliative care clinicians should know about spinal tumors

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 December 2018 – Nearly 20% of cancer patients develop symptomatic spine metastases. Metastatic spine tumors are most commonly extradural tumors that grow quickly and often cause persistent pain, weakness, paresthesias, urinary/bowel dysfunction, and/or paralysis. Surgical intervention aims to achieve more effective pain management, preserve/restore neurological function, provide local tumor control, and stabilize the spinal column. The desired result of treatment is ultimately to improve a patient's quality of life (QoL). Neurosurgeons employ multiple decision frameworks and grading scales to assess the need and effectiveness of a variety of surgical interventions ranging from minimally to maximally invasive. Likewise, palliative care (PC) offers an array of treatment options that allows the best, individualized plan to be determined for a given patient. Therefore, cross-functional collaboration between PC, radiation oncology, medical oncology, and neurosurgery is crucial both in the maximization of available treatment options and optimization of QoL for patients. **Abstract:** https://goo.gl/HqxtDM

Back Issues of Media Watch
http://goo.gl/frPgZ5

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

Palliative care doctors raise concerns about withdrawing high-dose opioids

THE MEDICAL POST | Online – 18 December 2018 – Many of Canada's palliative care doctors are concerned about a recent proposal to ban high-dose opioids, saying it could have patient safety implications. In a recent *Canadian Medical Association Journal* (*CMAJ*) editorial, Dr. David Juurlink of Toronto, a physician and toxicologist, and Matthew Herder, an expert in health law from Halifax, argued for a ministerial recall of high-strength opioids (100 mg morphine equivalent or above) – the inappropriate prescribing of which have significantly worsened the opioid crisis which has killed thousands of Canadians.[1] This "ministerial recall" would be made possible by legislation passed in 2014 [i.e., the Protecting Canadians from Unsafe Drugs Act] … While the law has never been used before, Herder and Dr. Juurlink argue that the harms associated with high-strength opioids warrant invoking this recall power. But the Canadian Society of Palliative Care Physicians (CSPCP) suggest that such a recall could have unintended consequences, particularly for cancer patients. In a response to the *CMAJ*, Dr. Leonie Herx, president of the society, wrote that these patients sometimes require doses well above the 200 mg oral morphine equivalent (the recommended daily maximum for chronic non-cancer pain patients).[2] **Full text:** https://goo.gl/PyCsJp

1. 'High-strength opioid formulations: the case for a ministerial recall,' *Canadian Medical Association Journal*, 2018;190(48):E1404-E1405. **Access options at:** https://goo.gl/k6t7K9

2. 'CSPCP response to Herder & Juurlink's High-strength opioid formulations...,' *Canadian Medical Association Journal*, published online 7 December 2018. **Letter to the editor:** https://goo.gl/HVNXzv

N.B. CSPCP position statement on access to opioids for patient requiring palliative care. **Download/view at:** https://goo.gl/srKt4c

Social work in funeral homes, a unique Chinese practice?

OMEGA – JOURNAL OF DEATH & DYING | Online – 21 December 2018 – Social workers were introduced to funeral homes in China amid the transition and expansion of both the funeral home industry and the social work profession and are proving to play a valuable, though under-researched role in serving not just clients but also communities and funeral home staff. Funeral home social work fills gaps in after-death care and mental health and is distinct from palliative, hospice, end-of-life, and bereavement social work. Based on the experiences of funeral homes that employ social workers, this article argues that this innovation may bring new ideas to bridge some of the service gaps in after-death care in China and globally. The authors outline the support that will be needed from funeral homes, social work service agencies, and educational and research institutes to facilitate further development of funeral home mental health and social services and to promote the professionalization of funeral home social workers in China. **Abstract:** https://goo.gl/Q49t7F

Examining the complex relation among religion, morality, and death anxiety: Religion can be a source of comfort and concern regarding fears of death

OMEGA – JOURNAL OF DEATH & DYING | Online – 20 December 2018 – Students … completed measures of fear of death, frequency of immoral behavior, discrepancy between ideal and actual religious practices, strength of religious beliefs, views of God as punishing or forgiving, and behavior efficacy (the extent to which fate in the afterlife was perceived to be determined by behavior in this life). Frequency of immoral behavior was not related to fears of death, but both strength of religious views and behavior efficacy were negatively correlated with fears of death. In contrast, perceived failure to live up to religious standards was associated with more death anxiety, especially among those with punishing views of God. These findings support the idea that some aspects of religion can help protect people from death anxiety, whereas other aspects of religion can exacerbate fears of death. **Abstract:** https://goo.gl/xNZd6o

Measuring the quality of dying and death in advanced cancer: Item characteristics and factor structure of the Quality of Dying & Death Questionnaire

PALLIATIVE MEDICINE | Online – 18 December 2018 – Ensuring a good death in individuals with advanced disease is a fundamental goal of palliative care. However, the lack of a validated patient-centered measure of quality of dying and death in advanced cancer has limited quality assessments of PC interventions and outcomes. Caregivers of deceased advanced-cancer patients, pooled from three studies involving urban hospitals, a hospice, and a community care access center in Ontario, Canada, completed the Quality of Dying & Death Questionnaire 8-10 months after patient death. Psychosocial and practical item ratings demonstrated negative skewness, suggesting positive perceptions; ratings of symptoms and function were poorer. Of four models evaluated using confirmatory factor analyses, a 20-item, four-factor model, derived through exploratory factor analysis and comprising symptoms and functioning, preparation for death, spiritual activities, and acceptance of dying, demonstrated good fit and internally consistent factors. Multiple regression analyses indicated that quality of dying was most strongly associated with Symptoms & Functioning and that quality of death was most strongly associated with Preparation for Death. A new four-factor model best characterized quality of dying and death in advanced cancer as measured by the Quality of Dying & Death Questionnaire. Future research should examine the value of adding a connectedness factor and evaluate the sensitivity of the scale to detect intervention effects across factors. **Abstracts:** https://goo.gl/XhswYn

Related

- *POSTGRADUATE MEDICAL JOURNAL* | Online – 17 December 2018 – **'How are you hoping to die?'** The taboo on discussing death appears to be lessening. 'Death cafés' have arrived in the U.S. and western Europe so that anyone can find a place to talk about their hopes and fears of what will happen when their time arrives. Articles and books about dying seem to be coming out every month. Much recent writing about the subject concerns the issues of medicalisation, over-diagnosis and over-treatment, and how we avoid accepting the fact that life is "actually brief and universally precarious." **Full text:** https://goo.gl/ALa5Nw

Perceptions of palliative care in a lower middle-income Muslim country: A qualitative study of healthcare professionals, bereaved families and communities

PALLIATIVE MEDICINE | Online – 17 December 2018 – The compatibility of Islamic theology with the principles of palliative care (PC) has been established at a conceptual level. This study describes its compatibility in a particular Muslim context, in which the perceptions of PC have been constructed through an amalgamation of Islamic theology and the fragility of life in a low-resource setting. The authors demonstrate how faith is combined with certain cultural-specific traits to construct a response to some of the principles of PC. The process of introducing PC at a national level in Mauritania is underway, and this research informs the future integration of PC within the health services. Advocacy is in tune with the cultural paradigm and is better able to unite policy makers, families, patients, religious leaders and health professionals to agree on the importance and need of PC for Mauritania. **Full text:** https://goo.gl/vK8MMH

Extract from *Palliative Medicine* article

Three major themes were identified. First, there is a perceived lack of congruency between an illness which limits life and the strong belief in destiny. The second theme describes the perceived barriers to communication of issues relating to PC. Finally, a good death is described, framed within the interplay of religious faith and cultural practices.

N.B. Additional articles on the Islamic perspective on end-of-life and end-of-life care noted in 5 & 12 February 2018 issues of Media Watch (#549, p.8 and #550, p.14, respectively).

A farewell to falsity: Shifting standards in Medicare fraud enforcement

SETON HALL LAW REVIEW, 2019;59(1):1-50. For the better part of a decade, Americans have had a front-row seat to a fervent and turbulent debate over the future of their healthcare system. The passage of the Patient Protection & Affordable Care Act of 2010 (ACA), the most comprehensive health reform effort since the mid-1960s, ushered in a new era in health law and policy, granting millions of Americans access to healthcare. After multiple legal challenges and congressional efforts that ultimately failed to slay the law, the ACA had become entrenched by the end of the Obama administration, even though pieces of the law had failed to work exactly as planned. Now, with the surprising election of President Donald Trump, re-energized Republicans are targeting the law once more, and it suddenly appears more vulnerable than ever. Dynamic uncertainty again permeates the national debate. Although most powerful protections of the ACA may evaporate – no small event, to be sure – the value-based era which it unleashed seems here to stay. Indeed, this era – focused on efficiency, standardization, and quality within American medicine – has just begun to bear fruit. Illustrated prominently by recent changes to Medicare that alter how the program pays its doctors for services they provide to its beneficiaries, America is moving away from the old strictures of fee-for-service medicine. At the same time, traditional legal tools, and particularly the federal government's most prominent anti-fraud tool, the civil federal False Claims Act, seem to be facing new limits. This has been recently evident in medical necessity-based fraud cases, and particularly highly publicized fights that have targeted the burgeoning industry of hospice care. This article tracks this development, ultimately arguing that the move to "reimbursement-based regulation" may be a positive step in finally reining in the worst excesses of American healthcare. But it also cautions against the deceptive simplicity of allowing medical heterogeneity and clinical complexity to prevent application of America's most powerful anti-fraud tools to its medical industry. Just because reimbursement policy has shifted to shoulder some of the regulatory burden of overtreatment does not mean that healthcare fraud – like fee-for-service medicine – should be confined to the past. In the end – and regardless of whatever legislation the national debate surrounding American healthcare produces – American medicine must adequately address its susceptibility to overtreatment, its incentives toward financial excess and waste, and its inability to push providers and entities into adopting more efficient practices. Medicare is finally moving quickly to bring about effective changes, and the program is seeking clarity in the midst of a period of tremendous uncertainty for American healthcare. **Abstract (via PubMed):** https://goo.gl/cc6uv7

> **N.B.** See 'Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity...,' Office of Inspector General, U.S. Department of Health & Human Services, July 2018. [Noted in the 6 August 2018 issue of Media Watch (#575, pp.3-4)] **Download/view at:** https://goo.gl/DPTmw9

Understanding and preventing situations of abuse in healthcare:
Navigation work in a Swedish palliative care setting

SOCIAL SCIENCE & MEDICINE | Online – 24 December 2018 – This article analyzes how health professionals conceptualize abusive situations, and how they develop collective learning and explore preventive strategies. It is based on an interactive research collaboration with a hospice and palliative care clinic in Sweden during 2016-2017. The empirical material consists of group discussions and participant observations collected during interactive drama workshops for all clinic staff. Based on three types of challenges in the material, identified through thematic analysis, the authors establish the concept of navigation work to show how health professionals prevent or find ways out of challenging and potentially abusive situations. First, the navigation of care landscapes shows how staff navigate the different territories of the home and the ward, reflecting how spatial settings construct the scope of care and what professionals consider to be potentially abusive situations. Second, the negotiation of collective navigations addresses the professionals' shared efforts to protect patients through the use of physical and relational boundaries, or mediating disrupted relationships. Third, the navigation of tensions in care highlights professionals' strategies in the confined action space between coercing and neglecting patients who oppose necessary care procedures. Theoretically, the concept of navigation work draws upon work on care in practice, and sheds light on the particular kind of work care professionals do, and reflect on doing, in order to navigate the challenges of potentially abusive situations. By providing a perspective and shared vocabulary, the concept may also elicit ways in which this work can be verbalized, shared, and developed in clinical practice. **Abstract:** https://goo.gl/4gVCyV

The operations of the prison service towards the social inclusion of convicts: The cooperation with palliative care institutions

SOCIAL STUDIES: THEORY & PRACTICE, 2018;4(1):31-43. The author is a practitioner who has been working in the prison service [in Poland] for over 20 years. Among his professional experiences, a special place is occupied by those connected with the issue of hospice voluntary service of persons deprived of their liberty. He presents a bold idea carried out in Polish prisons, consisting of preparing and directing prisoners to help the terminally ill pass away in a dignified manner. The implementation of this program is very difficult and involves great responsibility. However, many years of experience-hospice staff, employees of prisons, members of patients' families and firstly, patients-confirm that this is a very good direction for activating convicts who have an opportunity to experience their humanity on a daily basis. Hospice, contact with other people, contact with patients-all this transforms their thinking, behavior, allows it to verify the hierarchy of personal values. An added value is also the opportunity reintegrate people who are not related to penitentiary isolation into the community. This experience is powerful for the prisoners and therefore very moving and transformative.

N.B. Polish language article. Scroll down journal contents page and click on article title to access full text at: https://goo.gl/omefqp.

Noted in Media Watch 7 May 2018 (#562, p.8):

- *ANNALS OF PALLIATIVE MEDICINE*, 2018;7(Suppl 2):109-117. '**Solidarity and compassion: Prisoners as hospice volunteers in Poland.**' Over many years the project of hospice volunteering of prisoners in Poland has helped to break down stereotyping and the perceptions of prisoners, starting with the Gdansk experience, where they gradually became full members of a care team. Over 600 prisoners have passed through the hospice in Gdansk in over 10 years of cooperation. Convicts, who are mostly doing time on charges of burglary, non-payment of alimony and petty crime, see working in the hospice as a chance to change their attitudes. **Full text:** https://goo.gl/khZpqN

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 26 December 2018 – '**"No one wants to die alone": Incarcerated patients' knowledge and attitudes about early medical release.**' Many medically complex incarcerated patients in this study did not demonstrate sufficient knowledge to apply for early medical release suggesting that patient education may help expand access to these policies. Moreover, seriously ill patients with knowledge of early medical release may benefit from enhanced psychosocial support given their disproportionate burdens of anxiety and loneliness. The authors' findings highlight the pressing need for larger studies to assess whether improved patient education and support can expand access to early medical release. **Abstract:** https://goo.gl/FX1YvC

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 can be downloaded/viewed on the Palliative Care Network website at: https://goo.gl/dqwNBA

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN JOURNAL OF BIOETHICS* | Online – 14 December 2018 – '**Denying assisted dying where death is not "reasonably foreseeable": Intolerable over generalization in Canadian end-of-life law.**' The change in Canadian law to allow access to medical assistance in dying (MAiD) restricts eligibility, among its other criteria, to those for whom "natural death has become reasonably foreseeable." A review of certain aspects of the law examined the evidence pertaining to extending access to assisted dying in three particular request situations currently denied: requests by mature minors, advance requests, and requests where mental illness is the sole underlying medical condition.[1] The requirement for this review was included in the legislation that introduced MAiD in Canada. Both

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the original change in the law and the review itself neglected to consider those with intolerable suffering for whom natural death is not reasonably foreseeable. This paper explores the possibility that access to assisted dying should be extended by removing this limiting criterion. It also considers the ethical challenges this might present for those who work in rehabilitation. **Abstract:** https://goo.gl/pqobf1

1. 'Medical Assistance in Dying,' Expert Panel on Medical Assistance in Dying, Council of Canadian Academies, December 2018. [Noted in 17 December 2018 issue of Media Watch (#594, p.2)] **Download/view at:** https://goo.gl/3oJCEa

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 17 December 2018 – **'Marginalized Canadians may lack information about end-of-life options.'** Providers of medical aid in dying (MAiD) approve most requests for the service, but marginalized Canadians may be unaware it's an option... Members of the Canadian Association of MAID Assessors & Providers were surveyed about 742 requests they handled in 2017 that resulted in 410 deaths, or more than 20% of assisted deaths in Canada that year. The study isn't representative … as most of the cases were from Ontario, Manitoba and British Columbia, but it still provides insight about overlooked aspects of MAiD. For example, "no one was looking at refusals other than Quebec," or tracking patients' reasons for requesting assisted death. The providers in the survey approved most patients for MAiD, refusing only 107 cases, or less than 15% of requests. In most refused cases, patients lacked the capacity to make the decision (39.3%) or natural death was not foreseeable (36.3%). Mental health was a factor in 10% of refusals. More people sought assisted death because of a loss of ability (30.5%) than because of suffering related to illness (28.2%) or a desire for autonomy (17.8%). Among those who received MAiD, nearly half died at home and most had health professionals and family by their side. **Full text:** https://goo.gl/KMw3gk

  N.B. MAiD stands for medical assistance in dying: https://goo.gl/oRmAhc

- *CMAJ OPEN* | Online – 21 December 2018 – **'An entrustable professional activity descriptor for medical aid in dying: a mixed-methods study.'** In jurisdictions where medical aid in dying (MAiD) is legal, there is an obligation to ensure the competence of those who assess eligibility and provide MAiD to patients. Entrustable professional activities (EPAs) are one framework for incorporating competency-based training and assessment into the workplace. The authors convened a group of experienced MAiD providers to develop an EPA descriptor for MAiD. The focus group divided MAiD into 3 components: assessment, preparation, and provision of MAiD. Participants identified key knowledge, skills and attitudes for each component. They also suggested teaching approaches, potential sources of information to evaluate progress and a potential basis for evaluating progress and entrustment. Respondents agreed on all key points except for the conditions of entrustment; these were modified based on feedback and sent back to the respondents for a second Delphi round, where agreement was achieved. The authors achieved a high degree of agreement on a competency-based descriptor of MAiD in the form of an EPA.. **Full text:** https://goo.gl/Ls4uFe

  N.B. MAiD stands for medical assistance in dying: https://goo.gl/oRmAhc

- *ETHICS, MEDICINE & PUBLIC HEALTH*, 2019;8(1):1-10. **'Wishing you won't be here: Medical assistance in dying for psychiatric patients.'** The Canadian Supreme Court's decision in Carter v. Canada conceivably allows depressed psychiatric patients without a terminal physical illness to claim that they meet the criteria for physician-assisted death. Bill C-14, *aka* the Medical Assistance in Dying Act (MAiD), conceivably does not: patients suffering from mental illness are supposedly not facing an impending death from their disorder that is reasonably foreseeable. Specific concerns have been raised about major depression as hopelessness and suicidal thinking are symptoms. If psychiatric patients are candidates for MAiD, then concerns about incurability, appreciation, and voluntariness could be met by a "conservative" oversight regime that requires extra safeguards and sufficient evidence to offset them. It should require: 1) Substantive clinical evidence that treatments have failed; and, 2) Substantive narrative evidence of how patients evaluate the risk of premature death. As per 1), it is argued that treatment refusal will not by itself determine incurability. An approach for 2) is proposed that uses methods derived from narrative psychotherapy. This narrative approach uses therapeutic techniques to inform assessments of suicidal risk, but in collaborative ways that can sustain hope. Aside from adding first-person evidence to the clinical file, it might better enable patients to articulate the extent to which they appreciate the risk of premature death. It might also enable patients to re-evaluate their wish for MAiD. More to the point, it affords patients who profess a wish to die an opportunity to express themselves and be listened to that many of them claim they want to have. **Full text:** https://goo.gl/aEDXtY

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- *JOURNAL OF JEWISH ETHICS*, 2018;4(2):163-197. **'Quality of life at end of life: The evolution of key concepts.'** By tracing the understanding of suicide texts of the biblical, rabbinic, medieval, and modern periods, this article frames a fresh approach to assisted suicide that grows out of Jewish values, halakhic evolution and consideration of developments in contemporary medical treatment. **First page view:** https://goo.gl/Q1A29B

- *MEDPAGE TODAY* | Online – 21 December 2018 – **'Physician-assisted suicide: The American Medical Association's latest quandary.'** The American Medical Association (AMA), and the entire profession of medicine in the U.S., stand at a crucial ethical crossroads. For two years the AMA has been considering the question of physician-assisted suicide (PAS): shall physician assistance with patient suicide now be considered permissible, or shall physicians hold fast to the ethic that a physician's duty is to "to cure sometimes, to relieve often, and to comfort always," but never to kill? In 2016, AMA delegates from Oregon brought a resolution to the AMA House of Delegates (HOD), its policy-making body, to request that the AMA consider dropping its longstanding opposition to physician-assisted suicide in favor of a position of neutrality. The AMA's ethical body, the Council on Ethical & Judicial Affairs (CEJA), spent 2 years of intensive study of the practice of PAS, gathering information from physicians, ethicists, U.S. states and foreign countries on the practice and implications of PAS, in an exhaustive, open and transparent process. In June of 2018 CEJA offered its report and recommendations to the AMA HOD for its consideration. **Full text:** https://goo.gl/Fbfzfx

Publishing Matters

Open access medical journals: Promise, perils, and pitfalls

ACADEMIC MEDICINE | Online – 18 December 2018 – The number of both print and open access (OA) journals has increased dramatically. While electronic availability of information on the Internet may offer greater potential for information sharing, it also gives rise to "predatory" journals and deceptive publishers. The authors describe both the opportunities and potential perils that come with OA publications. Definitions for four models of legitimate OA are provided: 1) The gold model; 2) The green model; 3) The platinum model; and, 4) The hybrid model. Benefits and risks of each model are discussed. The authors also distinguish between legitimate OA journals and predatory journals, highlighting several existing tools and resources for distinguishing between the two. They provide a checklist to help authors evaluate the policies and processes of journals and thereby avoid predatory publications. **Abstract:** https://goo.gl/SUwXLg

N.B. Click on pdf icon to access full text.

Being a deliberate prey of a predator: Researchers' thoughts after having published in predatory journal

LIBER QUARTERLY | Online – Accessed 20 December 2018 – A central question concerning scientific publishing is how researchers select journals to which they submit their work, since the choice of publication channel can make or break researchers. The gold-digger mentality developed by some publishers created the so-called predatory journals that accept manuscripts for a fee with little peer review. The literature claims that mainly researchers from low-ranked universities in developing countries publish in predatory journals. The authors decided to challenge this claim using the University of Southern Denmark as a case. They ran the Beall's List against their research registration database and identified 31 possibly predatory publications from a set of 6,851 publications within 2015-2016. A qualitative research interview revealed that experienced researchers from the developed world publish in predatory journals mainly for the same reasons as do researchers from developing countries: lack of awareness, speed and ease of the publication process, and a chance to get elsewhere rejected work published. However, the authors' findings indicate that the open access potential and a larger readership outreach were also motives for publishing in open access journals with quick acceptance rates. **Full text:** https://goo.gl/yw4G8P

The Retraction Watch Database has launched

As a number of studies have demonstrated, retracted papers continue to be cited as if they had never been retracted. That's a problem, because it suggests there's far more wasted effort going into dead ends than there needs to be. And it's a fixable problem, because one hopes scientists wouldn't knowingly reference retracted papers. That's where the database comes in. Many publishers aren't very good about marking papers as retracted, nor about alerting databases about retractions. By including all retractions, including those that aren't well-marked on publishers' sites, or in databases, access to the Retraction Watch Database will make it difficult, if not impossible, to read a paper without knowing whether it was retracted. https://goo.gl/yv5YLC

N.B. 'See 'More science than you think is retracted. Even more should be,' *The Washington Post*, 27 December 2018. https://goo.gl/SA2oQx

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

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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): https://goo.gl/SyTuQ7

<<< Addition

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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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