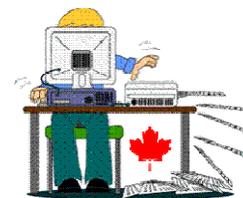


Media Watch...

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.

19 August 2019 Edition | Issue #627



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Compiled & Annotated by Barry R. Ashpole

This model ensures that palliative care is accessible early in the course of disease, provided longitudinally in collaboration with other treating healthcare teams, and based on the needs of the patient and family, rather than on prognosis.

'Team-based outpatient early palliative care: A complex cancer intervention' (p.7),
in *BMJ Supportive & Palliative Care*.

Canada

Nursing home residents with advanced dementia often face “distressing” transfers, MDs find

ONTARIO | CBC News – 16 August 2019 – If everyone was more aware of dementia, it could improve comfort in a loved one's dying days, say Canadian geriatricians who found distressing medical procedures were common among nursing home residents, especially men. The geriatric researchers published a study ... on 27,000 nursing home residents in Ontario with advanced dementia who died.¹ They focused on differences between men and women in receiving “burdensome interventions” in the last month of life. These included transfers to an emergency department to be mechanically ventilated and other invasive treatments. Dr. Nathan Stall led the research, which he hopes will guide better care for frail, vulnerable older adults with advanced dementia. “It really can be psychologically distressing for these individuals to be transferred out of their home to a foreign environment where all sorts of invasive things are happening

1. 'Sex-specific differences in end-of-life burdensome interventions and antibiotic therapy in nursing home residents with advance dementia,' *JAMA Network Open*, published online 16 August 2019. **Full text:** <http://bit.ly/2TK39Wb>

Noted in Media Watch 5 August 2019 (#625, p.5):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 August 2019 – ‘**Can persons with dementia meaningfully participate in advance care planning discussions? A mixed-methods study of SPIRIT.**’ Despite the importance of persons with dementia (PWDs) engaging in advance care planning (ACP) at a time when they are still competent to appoint a surrogate decision maker and meaningfully participate in ACP discussions, studies of ACP in PWDs are rare. SPIRIT engaged PWDs and surrogates in meaningful ACP discussions, but requires testing of efficacy and long-term outcomes. **Abstract:** <http://bit.ly/2GKHms3>

N.B. Selected articles on palliative and end-of-life care for people living with dementia noted in 29 July 2019 issue of Media Watch (#624, p.13).

Caregiving in Canada: As population ages, one-in-four Canadians over 30 are looking after loved ones

ANGUS REID INSTITUTE | Online – 12 August 2019 – Three years ago, Canada quietly crossed a critical demographic threshold. For the first time, there were officially more seniors – those 65 and over – than children – those 14 and under – in the country. As population trends skew older, a new study finds most Canadians are – or expect to be – directly involved in caregiving for their loved ones. Indeed, while one-in-four Canadians older than age 30 (26%) say they are already providing care for someone, another one-in-three (33%) expect to do so in the future. Canadians in their 40s and 50s appear to shoulder the greatest responsibility of caregiving, largely for a parent or in-law. Nearly three-in-ten (28%) currently act as caregivers, and a further four-in-ten say they anticipate becoming one in the future. Moreover, their caregiving obligations are often twofold, as about 42% of Canadian parents with children under 15 are between the ages of 40 and 59. Among those currently providing care, nearly half (47%) say they're making real sacrifices to balance their caretaking responsibilities with their day-to-day activities. This

presents an acute public policy challenge, one that could put increasing financial and emotional strain on Canadian seniors and their caregivers in the decades to come. <http://bit.ly/2YLecnS>

Specialist Publications

'Family caregivers of children and adolescents with rare diseases: A novel palliative care intervention' (p.14), in *BMJ Palliative & Supportive Care*.

'Advanced illness home care' (p.7), in *Canadian Family Physician*.

'Do caregiver experiences shape end-of-life care perceptions? Burden, benefits, and care quality assessment' (p.14), in *Journal of Pain & Symptom Management*.

'Silent voices: Family caregivers' narratives of involvement in palliative care' (p.14), in *Nursing Open*.

Noted in Media Watch 15 April 2019 (#610, p.1):

- **THE GLOBE & MAIL** | Online – 13 April 2019 – '**With a looming aging crisis, who is helping the caregivers?**' As health advances allow those with chronic illnesses to live longer, respite care remains costly and inconsistent and more patients prefer aging at home, the burden placed on family caregivers (FCGs) will only grow in this country. "Despite little to no training, they are expected to provide medical and nursing care in the home, navigate complicated health and long-term care systems, and serve as substitute decision makers," geriatrician Nathan Stall wrote in an editorial published last month in the *Canadian Medical Association Journal* that called for more robust health, workplace and financial aid for family carers.¹ As the country faces a looming aging crisis, governments have begun to signal that family carers are a priority. <https://tgam.ca/2DdLjnt>

1. 'We should care more about caregivers,' *Canadian Medical Association Journal*, 2019;191(9):E245-E246. Full text: <http://bit.ly/2Ts6E6Z>

Noted in Media Watch 27 August 2018 (#578, p.5):

- **JOURNAL OF PALLIATIVE MEDICINE** | Online – 20 August 2018 – '**Education, training, and mentorship of caregivers of Canadians experiencing a life-limiting illness.**' An Angus Reid survey results provide a starting point from which caregiver preferences are revealed. The rapid review of literature sets forth a set of findings and results specific to the resources required to ensure adequate education, training, and mentorship for caregivers of Canadians experiencing a life-limiting illness. After first introducing the burden of care, the preferences for caregiver education, and the importance of the patient-caregiver dyad, the palliative navigator approach is presented as a key role in the education, training, and mentorship of caregivers. Full text: <http://bit.ly/2lvS7jM>



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U.S.A.

Rural hospices leverage telemedicine to augment care

KANSAS | *Hospice News* – 16 August 2019 – Telemedicine is becoming increasingly important in hospice care for communities nationwide, but the technology, increasingly called “telehospice,” is making its biggest impact in rural areas where clinicians may have to travel significant distances to reach the patient. Telehospice isn’t new, but it is rapidly expanding. The University of Kansas Medical Center piloted the first telehospice service in 1998. That attempt encountered serious challenges due to costs and prevailing attitudes about technology at the time. A second project in 2017 found its footing, which the medical center launched in collaboration with Hospice Services & Palliative Care of Northwest Kansas. Between August 2017 and January

2018 Hospice Services engaged in 218 telehospice video encounters involving 917 participants, including staff and patients. The program yielded significant cost savings for the hospice, and participants reported that the program strengthens communication and relationships among staff and patients and family, according to a study on the project...¹ <http://bit.ly/2KCD6gD>

Specialist Publications

‘Digital health technology in palliative care: Friend or foe?’ (p.15), in *Progress in Palliative Care*.

1. ‘TeleHospice: A community-engaged model for utilizing mobile tablets to enhance rural hospice care,’ *American Journal of Hospice & Palliative Medicine*, published online 25 February 2019. [Noted in 4 March 2019 issue of *Media Watch* (#604, p.7)] **Abstract:** <http://bit.ly/2INsufU>

Noted in *Media Watch* 12 June 2017 (#516, p.8):

- *JOURNAL OF CLINICAL ONCOLOGY*, 2017;15_suppl:e6546. ‘**TeleHospice: Implementation lessons from rural hospice care with mobile tablets.**’ Technology advances and a community-centered approach have increased telehospice (TH) adoption. With decreasing budgets as well as rural hospice closures, innovative, cost-effective and community-driven approaches such as TH are needed to decrease disparities. From staff meetings alone, in this study there was observed a savings of approximately \$2,500/month, with TH staff noting increased morale, by increased team communication. **Abstract:** <http://bit.ly/2IEmzd4>

N.B. Selected articles on the provision and delivery of hospice and palliative care services in rural America noted in 28 January 2019 issue of *Media Watch* (#599, p.16).

Florida expected to take hardest hit in hospice staff shortage

FLORIDA | *Hospice News* – 13 August 2019 – Ongoing workforce shortages in the hospice space are expected to worsen, with Florida taking the biggest hit due to the size of its population older than 65. The number of hospice and palliative care (PC) physicians and members of other disciplines will drop precipitously during the next two decades, largely due to retirements and staff leaving the field due to burnout, recent research has found.¹ Among U.S. physicians, 40% are 56 or older and incoming PC and hospice specialists will not be enough to replenish the ranks. By 2045, only one physician will be available for every 808 patients, according to the same study. Florida may see the worst of the workforce short-

Specialist Publications

‘Does acculturation matter? End-of-life care planning and preference of foreign-born older immigrants in the U.S.’ (p.8), in *Innovation in Aging*.

‘Patterns of palliative care beliefs among adults in the U.S.: Analysis of a national cancer database’ (p.11), in *Journal of Pain & Symptom Management*.

‘Knowledge of and beliefs about palliative care in a nationally-representative U.S. sample’ (p.11), in *Plos One*.

Cont.

age, which will affect workers from every discipline in the hospice field. Currently, the state has a grade of “C” in the Center to Advance Palliative Care’s state-by-state rankings of access to PC.² While certainly not a “failing grade,” the rising senior population will create sizable new demand for hospice and PC. This could seriously impact patients’ access to care. <http://bit.ly/2H6wzZz>

1. ‘Policy changes key to promoting sustainability and growth of the specialty palliative care workforce,’ *Health Affairs*, 2019;38(6):910-918. [Noted in 10 June 2019 issue of Media Watch (#617, p.1)] **Full text:** <http://bit.ly/2QMAU7N>
2. ‘America’s Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation’s Hospitals,’ Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. [Noted in 5 October 2015 issue of Media Watch (#430, p.14)] **Download/view at:** <https://reportcard.capc.org/>

Noted in Media Watch 19 February 2018 (#551, p.6):

- *AMERICAN JOURNAL OF MEDICAL QUALITY* | Online – 7 February 2018 – ‘**Hospice care needs study.**’ Medical schools have attempted to integrate hospice and palliative medicine (HPM) curricula for more than 20 years... Despite these initiatives, gaps in both education and numbers of qualified providers still exist, and hospice remains largely misunderstood by patients and medical professionals alike. A task force convened by the American Academy of Hospice & Palliative Medicine found an acute shortage of HPM physicians and reported that current fellowship programs are insufficient to fill the shortage. **First page view:** <http://bit.ly/2Wn6qPO>
 1. ‘Estimate of current hospice and palliative medicine physician workforce shortage,’ *Journal of Pain & Symptom Management*, 2012;40(6):899-911. [Noted in 13 December 2010 issue of Media Watch (#179, p.9)] **Full text:** <http://bit.ly/2QNii7Q>

Noted in Media Watch 5 February 2018 (#549, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 February 2018 – ‘**The growing demand for hospice and palliative medicine physicians: Will the supply keep up?**’ The current U.S. supply of hospice and palliative medicine (HPM) specialists is 13.35 per 100,000 adults 65 and over. This ratio varies greatly across the country. Using alternate assumptions for future supply and demand, the authors project need in 2040 will range from 10,640 to almost 24,000 HPM specialist physicians. Supply will range from 8,100 to 19,000. Current training capacity is insufficient to keep up with population growth and demand for services. **Full text:** <http://bit.ly/2CRjxwO>

New law to help promote compassionate palliative treatment options

NEW JERSEY | *NJ Biz* (Somerset) – 12 August 2019 – A bill designed to ensure the public, healthcare providers and healthcare facilities receive comprehensive and accurate information and education about palliative care (PC) and terminal illness was signed into law Friday. The law – formerly bill Assembly Bill 312 – will establish a Palliative Care and Hospice Care Consumer and Professional Information and Education Program in the Department of Health (DOH) requiring all facilities identified by the Commissioner of Health to provide information about appropriate PC and hospice care services to patients and residents with a serious illness. In implementing these requirements, DOH would be required to take into account the size of the facility; access and proximity to PC and hospice care services, including the availability of hospice and PC board-certified practitioners and related workforce staff; geographic factors; and any other factors that may impact the ability of a hospital, nursing home or facility to comply. The Commissioner may also require a facility that fails to comply with the new law to provide a plan of action to bring the facility into compliance. In addition, the law establishes the Palliative Care & Hospice Care Advisory Council within DOH. <http://bit.ly/31y2kCr>



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

I'm an ICU nurse. I know I need an end-of-life directive. So why can't I bring myself to write it?

THE WASHINGTON POST | Online – 11 August 2019 – I of all people should know how to do this. As an ICU nurse, I see every day how agonizing it is for families to make end-of-life care decisions for loved ones who have not made their wishes clearly known. I know what I want. I know what the legal options are. But when I sit down to fill out the papers, I stall. The form remains incomplete. All of my experience urges me to act. I think of the anguished adult son trying to decide whether his elderly, unconscious mother would want to live permanently connected to a ventilator. “Pray for me that she dies before I have to make a decision,” he told me. If she had made her choices known before medical calamity struck, her son would have the peace of mind of carrying out her wishes, one way or another. I think of another family, where two siblings – one of them a physician – came to blows in the hospital waiting room because they could not agree on whether to stop aggressive treatment for their father, given that his organs were shutting down, one by one. Of course I want to reduce what's called the “decisional burden” on my own family by making my choices clear in case I become too sick some day to decide for myself. I just can't bring myself to translate my well-informed preferences into a legal document such as an advance directive. I'm not alone. <https://wapo.st/2Klfaam>

N.B. Selected articles on advance directives in the U.S. healthcare system noted in 21 January 2019 issue of Media Watch (#598, pp.8-9).

International

Russian Justice Ministry proposes to set palliative care procedure for convicts

RUSSIA | Russian Legal Information Agency (Moscow) – 13 August 2019 – The Justice Ministry of Russia has developed a draft order to organize the delivery of palliative healthcare services for detainees and inmates, a ministry statement reads. The penitentiary system medical organizations would provide palliative care (PC) to convicts and detained defendants when indicated. If the restrictive measure is changed, in particular for health reasons, but a person needs the continuation of treatment or PC, peni-

tertiary doctors would give him or her a tertiary referral... <http://bit.ly/2TrYmZn>

Specialist Publications

'Using the term “palliative care”: International survey of how palliative care researchers and academics perceive the term “palliative care” (p.12), in *Journal of Palliative Medicine*.

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

Forget Me Not Children's Hospice announces closure of Grace's Place

U.K. (England) | *The Bury Times* (Bolton, Greater Manchester) – 12 August 2019 – A children's hospice has announced it will close its doors at the end of this month due to “insufficient funds.” “Rising costs of care” and inadequate funding from the National Health Service were cited as reasons behind the imminent closure of Grace's Place in Radcliffe. The hospice building in Dumers Lane will be vacated by the end of August, with a total of 11 employees and several volunteers affected by the closure. Forget Me Not Children's Hospice – the charity which oversees Grace's Place – held a staff consultation over the termination of services throughout July. However, the CEO said it was “with deep regret” that the charity has been “unable to secure enough additional funding” to keep the site running. In a statement, chief executive Luen Thompson said: “I am very sad to have to announce that Grace's Place in Bury will now close. “Despite extensive media coverage, support from local politicians and council members and generous offers of support from the community, we have not been able to secure enough additional funding to keep our doors open and continue to deliver services to local families at Grace's Place. <http://bit.ly/2MZpEoE>

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Noted in Media Watch 8 July 2019 (#621, p.2):

- U.K. (England) | *The Bury Times* (Bolton, Greater Manchester) – 2 July 2019 – ‘**Children’s hospice set to close only months after opening.**’ A children’s hospice may have to close due to a lack of funding, only six months after opening. Bosses at Grace’s Place hospice in Radcliffe say they have been left with “no choice” but to launch a consultation proposing to cease services at the facility. Rising costs have left the charity in an “unsustainable position” as it chases a £56,000 shortfall, which it has blamed on insufficient funding from the National Health Service. <http://bit.ly/306Cdlg>

Noted in Media Watch 24 June 2019 (#619, p.3):

- U.K (England) | BBC News – 19 June 2019 – ‘**Children’s hospices “to shut if National Health Service does not increase funding.”**’ Children’s hospices in England will be forced to cut services or shut unless the National Health Service increases its funding, a charity has warned. Together for Short Lives, which helps terminally ill children, highlights a “dangerous cocktail” of higher costs and a drop in state funding. Its recent report examined funding for 27 of the 34 children’s hospices in England.¹ <https://bbc.in/2WVlu6s>

1. ‘Statutory Funding for Children’s Hospice and Palliative Care Charities in England, 2018-2019,’ Together for Short Lives, June 2019. **Download/view at:** <http://bit.ly/2FIgoSu>

N.B. News media coverage in recent months on funding issues *vis-à-vis* hospices in England noted in 17 June and 8 July 2019 issues of Media Watch (#618, p.5) and 8 July 2019 (#621, p.2), respectively.

Fifty jobs under threat at Somerset hospice

U.K. (England) | Third Sector – 12 August 2019 – St. Margaret’s Hospice Care said in a statement that it was proposing to close the service at Yeovil and transform the site into a base for its community team, as well as providing day hospice facilities and outpatient services. The hospice will increase the number of beds at its other site in Taunton from 12 to 16, the statement said, but the charity has also proposed losing the 10 beds that are currently in Yeovil. The statement said it hoped to relocate those staff affected either to Taunton or the community team, but warned that up to 53 jobs could be at risk because of the changes. The hospice said that an uncertain economic climate and changes in demand for its services, particularly from Somerset’s ageing population, were behind the proposals. It added that flatlining National Health Service funding had meant an ever-increasing reliance on legacies to enable the charity to break even. The value of legacies rose by 22% to £2.9 million, the charity’s accounts for the year to 31 March 2018 show. <http://bit.ly/2H3rMrX>

Specialist Publications

Offering the best death possible: Supporting people using substances at the end of life

ADDICTION | Online – 10 August 2019 – By 2060, it is forecast that 48 million people worldwide will need, but will die without, palliative (PC) at their end of lives, an increase of 87% from 2016. Practice-based reports suggest an increasing number of these people will be using substances and there will not be enough PC services to cope. Empirical evidence to underpin practice development is scarce. A Rapid Evidence Assessment (REA) (2004-2016) on this topic found no evidence of existing practice models to support people with co-existing substance use and palliative or end of life needs despite this being the primary focus of the

search. Even with wider search parameters, only five of the 60 papers included in the REA were published in substance-focused journals. These included papers from the U.K. and Sweden

Publishing Matters

‘Scientific authors in a changing world of scholarly communication: What does the future hold?’ (p.15); in *American Journal of Medicine*.

Cont.

focussing on changing patterns of illness or causes of death among drug users, definitions of U.K. drug-related mortality and, as with the majority of papers in the REA, North American research focussing on “opioid abuse” in cancer patients or “drug diversion.” Since the REA there has only been one further paper from Italy, but it focussed on the incidence of “alcoholism” in two cohorts of patients with advanced cancer. There is, therefore, an indisputable gap in the evidence base to guide the practice responses of substance use professionals meaning it is the role of front-line substance use services to develop their own models for policy and practice. **Full text (click on pdf icon:** <http://bit.ly/2yQI9Vp>

Noted in Media Watch 5 August 2019 (#625, p.12):

- *NURSING ETHICS* | In press – Accessed 28 July 2019 – “‘It’s just drug seeking behaviour isn’t it?’: Troubling the narratives surrounding substance use and pain management at the end of life.’ The authors examine narrative positioning related to pain management for people who use substances at the end of life (EoL). They explore how dominant narrative genres associated with biomedicine, such as “restitution” and narratives common within the context of drug services such as “recovery” can hinder effective pain management within this population. The authors argue that these discourses can marginalise the ethical self-identity of patients who use substances at the EoL. It can also trouble health and social care professionals in supporting patients and generating counter-narratives that challenge those often associated with substance use. **Abstract:** <http://bit.ly/2MnppDQ>

N.B. Selected articles on terminal ill patients with drug and alcohol addictions noted in 15 July 2019 issue of Media Watch (#622, pp.9-10).

Team-based outpatient early palliative care: A complex cancer intervention

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 12 August 2019 – The authors describe the essential principles and domains of care, as well as key tasks, of an early team-based outpatient PC intervention for patients with advanced cancer. This model ensures that PC is accessible early in the course of disease, provided longitudinally in collaboration with other treating healthcare teams, and based on the needs of the patient and family, rather than on prognosis. This proactive approach to care is consistent with the contemporary definition of PC, which is to improve quality of life (QoL) by prevention as well as relief of symptoms and other problems. This intervention was developed at a comprehensive cancer centre, and its structures and personnel may not be available in other settings. Early PC is of increasing relevance for patients with advanced cancer and other diseases, for whom prolonging and improving QoL are simultaneous goals. The description of the intervention may assist researchers wishing to replicate or build on it for use in other trials. In addition, this intervention may serve as a template for PC teams to develop outpatient services, provide education and standardise care. Lastly, oncologists and family physicians may find this information useful to inform their own practice when treating patients with advanced cancer and their families. **Full text:** <http://bit.ly/33qOiVb>

Advanced illness home care

CANADIAN FAMILY PHYSICIAN, 2019;65(8):534-535. Palliative care (PC) has moved from historically focusing on dying patients to focusing on palliation any time in illness, suggesting PC can be appropriate for almost everyone entering their last years. In 2017, the Framework on Palliative Care in Canada Act was passed, which mandates that in the subsequent 5 years, the Canadian government must define PC – its teaching, data collection, funding, and access. Such an expansion of PC requires us to reconsider its provision – the character of this sort of PC, and the fact that some of this care needs to be provided to homebound patients. Increasing numbers of family physicians will be required as members of teams providing such care, which the authors have here called advanced illness home care (AIHC). So far, suggestions to address this need have focused mainly on training family physicians in clinical aspects of PC. While this training is beginning to be provided, the authors propose additional ways to develop AIHC in Canada. PC is expanding to include a wider scope of patients living with chronic disease and aging. Some of this care includes AIHC, and the complexity of such care requires teams that include family physicians with particular training and skills. Some of this training is already beginning to be provided, but some is lacking. The authors propose that resources be devoted to the clinical and practical requirements of developing AIHC practices. **Full text:** <http://bit.ly/2N7cs1d>

End-of-life decision-making for ICU patients with limited English proficiency: A qualitative study of healthcare team insights

CRITICAL CARE MEDICINE | Online – 9 August 2019 – Research indicates that the increasing population of over 25 million people in the U.S. who have limited English proficiency (LEP) experience differences in decision-making and subsequent care at end of life (EoL) in the ICU when compared with the general population. The authors identified six key differences in EoL decision-making for patients with LEP compared with patients without LEP: 1) Clinician communication is modified and less frequent; 2) Clinician ability to assess patient and family understanding is impaired; 3) Relationship building is impaired; 4) Patient and family understanding of decision-making concepts (e.g., palliative care) is impaired; 5) Treatment limitations are often perceived to be unacceptable due to faith-based and cultural beliefs; and, 6) Patient and family decision-making styles are different. Facilitators of high-quality decision-making in patients with LEP included: 1) Pre-meeting between clinician and interpreter; 2) Interpretation that communicates empathy and caring; 3) Bidirectional communication of cultural perspectives; 4) Interpre-

tation that improves messaging including appropriate word choice; and, 5) Clinician cultural humility. Awareness of these factors can facilitate interventions to improve high-quality, compassionate, and culturally sensitive decision-making for patients and families with LEP. **Abstract:** <http://bit.ly/2ORUr9L>

Does acculturation matter? End-of-life care planning and preference of foreign-born older immigrants in the U.S.

INNOVATION IN AGING, 2019;3(2). It is important for health service providers and future research serving older immigrants to consider socioeconomic and institutional determinants, which have accrued throughout the lifespan and would affect their end-of-life care planning and preference. Adding to the culturally competent approach, assessing multidimensional needs and enabling factors and accelerating positive family dynamics may help older immigrants, especially those from racially minority groups, be more aware of and engage in advance care planning. **Full text:** <http://bit.ly/2H2AgiN>

Noted in Media Watch 17 September 2018 (#581, p.3):

- REUTERS HEALTH | Online – 11 September 2018 – ‘**Limited English may mean less-gentle death in ICU.**’ Death for patients in U.S. intensive care units (ICUs) may look a lot different for people with limited English proficiency (LED) than for native speakers.¹ About 8.5% of U.S. adults don’t speak English as their primary language. While communication is crucial for decision-making at the end of life, it’s not been clear how language skills might influence the type of care dying patients receive. Researchers examined data on 27,523 patients admitted to ICUs in a large academic hospital over a 3-year period. Among patients who died in the ICU, those with LED were 62% less likely to have orders for comfort care before they died and they took an average of 19 days longer to transition from active treatment to only measures designed to ease pain and suffering. <https://reut.rs/2YNrrVe>

1. ‘Differences in code status and end-of-life decision making in patients with limited English proficiency in the intensive care unit,’ *Mayo Clinic Proceedings*, published online 9 August 2018. [Noted in 13 August 2018 issue of Media Watch (#576, p.11)] **Abstract (w. link to references):** <https://mayocl.in/31AtkS4>

Cont. next page



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>

Noted in Media Watch 17 September 2018 (#581, p.12):

- *JOURNAL OF IMMIGRANT & MINORITY HEALTH* | Online – 10 September 2018 – ‘**Exploring the “patient experience” of individuals with limited English proficiency: A scoping review.**’ This review mapped the literature on the patient experience of individuals with limited English proficiency (LEP). The authors reviewed sixty qualitative and mixed-methods studies published between 2007 and 2017. They identified four major themes: 1) Communication, language barriers, and health literacy; 2) Relationships with healthcare professionals; 3) Discrimination and intersection with other dimensions of identity; and, 4) Cultural safety. The authors also identified factors that may improve LEP patient experience, including: mitigating language barriers through interpretation or language-concordant providers, offering translated patient resources, and educating healthcare professionals about cultural safety. **Abstract (inc. list of references):** <http://bit.ly/33EbfV0>

N.B. Selected articles on patients with LEP in the context of end-of-life care noted in 20 August 2018 issue of Media Watch (#577, p.2).

Emotions in the room: Common emotional reactions to discussions of poor prognosis and tools to address them

EXPERT REVIEW OF ANTICANCER THERAPY | Online – 10 August 2019 – Advanced cancer patients often want prognostic information, and discussions of prognosis have been shown to enhance patient understanding of their illness. Such discussions can lead to high-quality, value-consistent care at the end of life (EoL), yet they are also often emotionally challenging. Despite how common and normal it is for patients to experience transient emotional distress when receiving “bad news” about prognosis, emotional responses have been under-addressed in existing literature on prognostic discussions. Drawing upon psychology research, principles of skilled clinical communication, and published approaches to discussions of serious illness, the authors summarize patients’ common emotional reactions and coping strategies. They then provide suggestions for how to respond to them in clinic. Ultimately, effective management of emotional reactions to bad news may lead to earlier, more frequent, and more transparent discussions of prognosis, thus promoting cancer patients’ understanding of, and adjustment to, their illness and improving the quality of their EoL care. **Abstract (w. article highlights):** <http://bit.ly/31tmIEQ>

Related

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 15 August 2019 – ‘**Communication strategies for sharing prognostic information with patients: Beyond survival statistics.**’ High-quality communication for people living with serious illness includes sharing information using patient-centered approaches. Reconceptualizing prognosis beyond just survival provides a more comprehensive (and perhaps more acceptable) frame for planning and decision-making that empowers patients with serious illness and families to adjust to changes in their lives. Sharing prognosis can also close the distance that is created when a clinician has prognostic estimates that are not shared with the patient, even if the intention is protective. **Full text:** <http://bit.ly/2OYtfGg>

“You helped me keep my head above water”: Experience of bereavement research after loss of a loved one in the ICU – Insights from the ARREVE study

INTENSIVE CARE MEDICINE | Online – 12 August 2019 – Bereavement research has helped to improve end-of-life practices in the ICU. However, few studies have explored bereaved relatives experience of research participation in this context. Three themes were derived from the thematic analysis: 1) Struggling (reactivation of emotional distress associated with the ICU experience and the loss is frequent, specifically during the 1st follow-up call); 2) Resilience (as time goes by, research participation becomes increasingly positive; the calls are a help both in giving meaning to the relatives’ experience and in accepting the loss); and, 3) Recognition (research calls can compensate for the absence of support during bereavement). Although some emotional difficulties must be acknowledged, bereavement research is overall associated with benefits, by facilitating emotional adjustments, meaning-making and resilience. Lack of support and social isolation during bereavement are frequent experiences, revealing that support strategies for bereaved relatives should be developed after the loss of a loved one in the ICU. **Abstract (w. list of references):** <http://bit.ly/2Z3o3AD>

Quality improvement in hospice settings: Perceptions of leaders

INTERNATIONAL JOURNAL OF HEALTH CARE QUALITY ASSURANCE, 2019;32(7):1098-1112. Seven leaders participated in interviews. Five themes were developed from data analysis: 1) Patient-centered care; 2) Continuous quality improvement (QI); 3) Leadership involvement and commitment; 4) Communication as a foundation for QI; and, 5) Perceived barriers. Data analysis suggests that use of QI approach in palliative and hospice care enhances the quality of care provided for patients, and can help improve patient satisfaction. Because there is a paucity of research on implementation of QI strategies in hospice and palliative care settings, this research can have wide practical implications. This research can provide useful practical tips to leaders as they work on implementing QI projects in their organization. This manuscript can be of value to leaders, administrators and academicians who are interested in applying QI principles to healthcare processes especially in palliative and hospice care settings. Ability to work with others, solid communication and involvement of employees from all levels can help in streamlining current systems of care. **Abstract:** <http://bit.ly/2Mjn5y6>

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

Documentation of palliative and end-of-life care process measures among young adults who died of cancer: A natural language processing approach

JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY | Online – 14 August 2019 – Few studies have investigated palliative and end-of-life care processes among young adults (YAs), aged 18-34 years, who died of cancer. This retrospective study used a natural language processing algorithm to identify documentation and timing of four process measures in YA cancer decedents' medical records: palliative care involvement, discussions of goals-of-care, code status, and hospice. Among YAs, 138 had a recorded date of death. In this group, 54.3% had at least one process measure documented early (31-180 days before death), 18.0% had only late documentation of process measures (0-30 days), and 27.5% had none documented. **Abstract:** <http://bit.ly/2OTamEy>

Burden and causes of hospital admissions in heart failure during the last year of life

JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY: HEART FAILURE, 2019;7(7):561-570. Congestive heart failure (CHF) is a chronic medical condition with a high morbidity and mortality. Despite increases in multidisciplinary team approaches for heart failure management, care of patients towards the end of life (EoL) is often not prioritized. Efforts to improve care for heart failure patients at the EoL will need to understand the common issues faced by this patient population. This study sought to evaluate the causes of medical decompensation in patients with heart failure in the last year of life. The retrospective analysis found that heart failure and cardiovascular disease were common reasons for hospital admission, but the majority of admissions were for non-cardiac issues. While hospitalization frequency increased towards the time of death, the proportion of admissions for cardiac and non-cardiac causes remained unchanged. The findings of this study underscore the importance of recognizing non-cardiac issues in patients with end-stage CHF. The main strength of this study is the large cohort of heart failure patients in their final year of life. The limitations of the study include the lack of information on functional class, ejection fraction, and reliance on diagnostic codes for establishing cause of admission. **Study run-down:** <http://bit.ly/2YRwBi9>

N.B. Selected articles on palliative care for patients living with heart failure noted in 12 August 2019 issue of Media Watch (#626, pp.7-8).



Media Watch Online

Updated 08.12.2019

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.16.

Triaging the terminally ill

Development of the Responding to Urgency of Need in Palliative Care (RUN-PC) triage tool

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 14 August 2019 – Evidence-based resource allocation is receiving increasing attention as we strive for equity, transparency and cost-effectiveness across healthcare. In the context of finite resources, which of our patients with terminal illness should be prioritised for urgent palliative care (PC)? This study found physical suffering was the most important determinant of urgency, followed by imminent dying, psychological suffering, caregiver distress, discrepancy between care needs and care arrangements, mismatch between current and desired site of care, and unmet communication needs. PC triage, which is complex and contextual has been made more transparent through this discrete choice experiment. The RUN-PC Triage Tool provides an important step towards evidence-based assessment of priority for PC. Further research is underway to determine the validity of the tool in clinical practice and its impact on patient and caregiver outcomes. **Abstract (w. link to references):** <http://bit.ly/33HpwAm>

Patterns of palliative care beliefs among adults in the U.S.: Analysis of a national cancer database

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 10 August 2019 – Despite growing recognition of the need for public advocacy and involvement, data on public perception of palliative care (PC) is limited. The authors sought to examine patterns of beliefs, socio-demographic differences, and the impact of information source on perceptions of PC. Data were analyzed from the 2018 Health Information National Trends Survey, a representative sample of public knowledge on cancer-related information. Overall, 42.5% automatically thought of death when thinking about PC, and 31.7% equate PC with hospice care. Lower proportions perceived PC as incompatible with curative medical therapy: 15.1% believed PC means giving up, and 14.5% believed PC requires the discontinuation of other treatments. Perceptions varied by age, race, education attainment, income, and marital status. Six in every 10 American adults knowledgeable about PC have at least one documented misperception, with differential beliefs by socio-demographic groups. Source of information had little impact on PC beliefs. These findings may help focus future measures to educate the public about the role of PC in healthcare and address gaps in knowledge. **Abstract (w. link to references):** <http://bit.ly/2MVEHjc>

Related

- *PLOS ONE* | Online – 15 August 2019 – ‘**Knowledge of and beliefs about palliative care in a nationally-representative U.S. sample.**’ Nearly three-quarters (71.6%) [of survey respondents] had never heard of palliative care (PC). Consistent with similar analyses of these and other data, among those who had heard of PC, between 90-95% expressed accurate knowledge that the goals of PC include managing pain and other physical symptoms, offering social and emotional support, and helping friends and family cope. Further, accuracy was lower for other aspects of PC knowledge: about one-third endorsed the inaccurate belief that PC is the same as hospice care, and one-third either agreed with or did not know whether accepting PC requires stopping other treatments. Negative beliefs about PC were common: in particular, over 40% of participants associated PC with death. **Full text:** <http://bit.ly/2TAbSKF>

Noted in Media Watch 12 August 2019 (#626, p.1):

- CENTER TO ADVANCE PALLIATIVE CARE | Online – 8 August 2019 – ‘**Palliative care still relatively unknown among the general public: Shows education for consumers and physicians necessary to make a difference.**’ New opinion research confirms that once educated with the correct definition of palliative care (PC), understanding and favorability greatly increase among consumers and physicians. “All organizations and clinicians must proactively align themselves in defining PC correctly,” said Diane E. Meier, the Center’s director. “With an aging population increasing exponentially, it is more important than ever that both the field of PC and the referring clinicians evolve their rhetoric. The point must always be made that PC is based on need, not prognosis.” <http://bit.ly/2ZXaHXK>

Seven types of uncertainty when clinicians care for pediatric patients with advanced cancer

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 16 August 2019 – Clinicians deciding whether to refer a patient or family to specialty palliative care (PC) report facing high levels of uncertainty. Most research on medical uncertainty has focused on prognostic uncertainty. In a phenomenological qualitative analysis of “uncertainty” as experienced and described by interdisciplinary pediatric oncology team members the authors found that clinicians caring for patients with advanced cancer confront seven broad categories of uncertainty: 1) Prognostic; 2) Informational; 3) Individual; 4) Communication; 5) Relational; 6) Collegial; and, 7) Inter-institutional. Each of these kinds of uncertainty can contribute to delays in referring patients to PC. To manage these forms of uncertainty, providers need to develop strategies and techniques to handle professionally challenging situations, communicate bad news, manage difficult interactions with families and colleagues, and collaborate with other organizations. **Abstract (w. link to references):** <http://bit.ly/2YZgq2Y>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 9 August 2019 – ‘**Impact of specialized pediatric palliative care: A systematic review.**’ Specialized pediatric palliative care (SPPC) is increasingly involved in the care of seriously ill children, yet the evidence on its impact has not been comprehensively reviewed. Studies analyzed 46 domains, operationalized as 136 distinct outcomes. SPPC was associated with better child quality of life (QoL) scores in all four studies that assessed this outcome. The paucity and low certainty of the evidence precluded any firm recommendations about SPPC practice. Larger collaborative networks and greater consensus regarding SPPC research standards are needed. **Abstract (w. link to references):** <http://bit.ly/2z4xipA>

Noted in Media Watch 1 July 2019 (#620, p.11):

- *PATIENT EDUCATION & COUNSELING*, 2019;102(8):1404-1412. ‘**Impact of specialized pediatric palliative care programs on communication and decision-making.**’ Study quality was poor in 58% of included papers. Specialized pediatric palliative care (SPPC) programs generally support and improve communication and decision-making for children with life-threatening conditions, their families and associated healthcare professionals (HCPs). Families referred to an SPPC program had more discussions with HCPs on a broad variety of topics. However, data on communication with children, siblings, and other family members was scarce and of poor quality. **Abstract:** <http://bit.ly/2FuWGZq>

Using the term “palliative care”: International survey of how palliative care researchers and academics perceive the term “palliative care”

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 August 2019 – The term “palliative care” (PC) has often been found to have a negative connotation leading some to suggest rebranding and some services to change their name. Perceptions of the PC community about the term remain largely unexplored. This is a cross-sectional survey of attendees to the 10th World Research Congress of the European association for Palliative Care. For 40% [of survey respondents], the term hindered the positioning of PC, 28% worried about using the term, and 55% did not discuss these difficulties. The authors found significant differences between responses and several demographics (e.g., younger age and higher likelihood of worrying about the term). They identified that the term is widely in use, and that its limitations are seen as a cultural by-product, and not as something that a name change would solve. Senior PC academics, researchers, and clinicians have an onus to ensure that colleagues with limited PC experience have the opportunity to discuss and explore the impact of the term on the practice of research. Regarding the term itself, the community’s views are conclusive: although using the term will remain a difficult task, the field’s identity is in the name. **Abstract:** <http://bit.ly/2P8K011>

Cont. next page



Would this article be of interest to a colleague?

Noted in Media Watch 4 March 2019 (#604, p.8):

- **BRITISH MEDICAL JOURNAL** | Online – 28 February 2019 – ‘**Changing perceptions is more important than changing names.**’ Nearly 30 years after the World Health Organization first defined “palliative care,” we are no closer to agreeing what the term means. Palliative care (PC) has driven major improvements in the care of people with life limiting illnesses and fostered more open public discourse about death and dying. National and international policies advocate better access to PC for everyone who needs it. *The Lancet* Commission goes further, describing it as a basic human right in the face of unrelieved suffering affecting millions worldwide.¹ The 2018 Astana Declaration endorses PC as an essential component of primary healthcare worldwide...² Yet, stigmatisation of the term among patients, professionals, and the public continues to counter positive messages about its benefits. **Introductory paragraph:** <http://bit.ly/2NzLBsA>

1. ‘Alleviating the access abyss in PC and pain relief: An imperative of universal health coverage,’ *The Lancet*, October 2017. [Noted in 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** <http://bit.ly/2Ww8CKu>

2. ‘Declaration on Primary Health Care,’ Global Conference on Primary Health Care, Astana, Kazakhstan, World Health Organization, October 2018. **Download/view at:** <http://bit.ly/2GOorVAR>

N.B. Selected articles on defining palliative and end-of-life care noted in this issue of Media Watch.

Racial and ethnic differences in parental decision-making roles in pediatric oncology

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 August 2019 – Prior work in adult oncology suggests minority patients are less involved in decision making than preferred. However, few studies have explored decision-making experiences of minority parents in pediatric oncology. In this study, most parents preferred shared decision making, whereas 23% preferred parent-led decision making and 13% preferred oncologist-led decision making. Parental decision-making preferences did not differ by race/ethnicity. However, the actual role parents played in decision making differed by parental race/ethnicity, with 25% of white parents reporting parent-led decision making, versus 37% of black parents, 48% of Hispanic parents, and 56% of Asian/other parents. Oncologists accurately predicted parental preferences for decision making 49% of the time, but accuracy also differed by race and ethnicity. Oncologists accurately predicted parental preferences for 53% of white parents, 23% of black parents, 37% of Hispanic parents, and 43% of Asian/other race parents. Minority parents held more active roles than white parents, and oncologists had more difficulty predicting decisional preferences for minority parents relative to white parents. These findings suggest that minority parents are at risk of inferior decision-making experiences. **Abstract:** <http://bit.ly/2KKwmwf>

Spiritual distress in family members of critically ill patients: Perceptions and experiences

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 August 2019 – Spiritual distress among family members of patients in the intensive care unit (ICU) has not been well characterized. This limits clinicians’ understanding of how to best offer support. The experience of spiritual distress was variably described [in this study] by all three groups [interviewed] through concepts, modulators, expressions and manifestations, and ways in which spiritual distress was addressed. Concepts included loss of meaning, purpose and connection, tension in beliefs, and interconnected distress. Modulators were related to the patient and family context, the ICU context, and the relational context. Expressions and manifestations were unique and individual, involving verbal expressions of thoughts and emotions, as well as behavioral manifestations of coping. Clinical strategies for addressing spiritual distress were described through general principles, specific strategies for discussing spiritual distress, and ways in which spiritual support can be offered. This study provides a rich description of how spiritual distress is experienced by family members of ICU patients, and how spiritual health practitioners and clinicians recognize spiritual distress and offer support. These findings will help inform clinician education and initiatives to better support families of critically ill patients. **Abstract:** <http://bit.ly/2YOBjxX>

N.B. Selected articles on spiritual care in palliative and end-of-life care noted in 12 August 2019 issue of Media Watch (#626, p.9).

Deep brain stimulation at end of life: Clinical and ethical considerations

JOURNAL OF PALLIATIVE MEDICINE | Online – 12 August 2019 – Deep brain stimulation (DBS) is an implanted neurological device effective in treating motor symptoms of Parkinson disease (PD), such as tremor, rigidity, and bradykinesia. More than 150,000 patients worldwide have been implanted with DBS devices. Questions arise at the end of life (EoL) concerning how to provide best care for patients with DBS, including its continued benefit or potential complications, yet no published articles provide guidance for hospice providers regarding the management of DBS devices in EoL care. With contributions from hospice physicians, a neurosurgeon, and ethicists, this article provides recommendations to address clinical and ethical challenges in optimizing DBS for patients with PD nearing the EoL. **Abstract:** <http://bit.ly/2YPMkPC>

N.B. Selected articles on the EoL care for patients living with PD noted in 15 July 2019 issue of Media Watch (#622, p.9).

Exploring and managing the impostor phenomenon in palliative care: A case series

JOURNAL OF PALLIATIVE MEDICINE | Online – 12 August 2019 – The impostor phenomenon (IP) describes the experience of questioning one's abilities and fearing exposure as an intellectual fraud, despite objective evidence of success. The IP has been identified in high-achieving professionals across a variety of disciplines, including clinical medicine, and can be associated with significant anxiety and psychological distress. The authors present three authentic cases that demonstrate how the IP may manifest in palliative care (PC) practice. Acknowledging the current emphasis on clinician wellness and burnout, they suggest that the IP may be one important source of distress for many early-career clinicians in PC. With the physician as the focus of each case, the authors explore the difficult emotions faced and highlight how PC clinicians may be uniquely vulnerable to the IP. They then identify concrete strategies to help clinicians manage feelings of IP and enhance their professional well-being. **Abstract:** <http://bit.ly/33AZLRQ>

Silent voices: Family caregivers' narratives of involvement in palliative care

NURSING OPEN | Online – 10 August 2019 – Health authorities recommend that patients receiving palliative care (PC) should have the opportunity to spend more time at home at the end of their lives. This entails increased responsibility for family caregivers (FCGs). This study demonstrated that FCGs experience limited involvement in planning PC. Their voices seem to be silent and the involvement of FCGs is not in proportion to their responsibilities. Consequently, the needs of FCGs in the PC trajectory must be addressed to successfully provide home-based care. FCGs' involvement in PC should be a topic in nursing education and continuing education for nurses. **Full text:** <http://bit.ly/31KLvVh>

Related

- *BMJ PALLIATIVE & SUPPORTIVE CARE* | Online – 17 August 2019 – **'Family caregivers of children and adolescents with rare diseases: A novel palliative care intervention.'** A novel palliative care intervention developed at Children's National Health System for caregivers of children and adolescents with rare diseases has shown preliminary success at helping families talk about potentially challenging medical decisions before a crisis occurs. **Abstract:** <http://bit.ly/2z447mF>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 August 2019 – **'Do caregiver experiences shape end-of-life care perceptions? Burden, benefits, and care quality assessment.'** Caregiver burden and benefit operate alongside one another regarding two end-of-life care (EoLC) evaluations, even when years elapse between caregiver experience reports and care recipient death. This suggests that caregiver interventions reducing burden and bolstering benefits may have a positive and lasting impact on EoLC assessments. **Abstract:** <http://bit.ly/2KwrdsB>

Digital health technology in palliative care: Friend or foe?

PROGRESS IN PALLIATIVE CARE, 2019;27(4):145-146. The artificial divide between high-tech and high-touch care must be bridged if palliative care (PC) is to meet changing consumer needs and expectations. Too often, it seems, a false dichotomy is postulated: clinical care is either high-tech or high-touch, with each of these considered antithetical to the other. This is perhaps owing to aspects of technology that, on one hand we embrace with fervour; and yet on the other hand, at times feel a need for avoidance. In the midst of this ambivalence, there is a case to strive for impeccable PC that is both high-touch and high-tech; where this is appropriate, safe, and aligned with person-centred care goals. In digital health, we now have a contemporary field of health-focused technological innovation with the potential to transform our approaches to quality of life, and digitally enhance the ways we provide humanistic care for those living with dying. **Full text:** <http://bit.ly/309ollh>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BIOETHICS* | Online – 13 August 2019 – ‘**Deciding with dignity: The account of human dignity as an attitude and its implications for assisted suicide.**’ Discussions about assisted suicide have hitherto been based on accounts of dignity conceived only as an inherent value or as a status; accounts of dignity in which it appears as a (contingent) attitude, by contrast, have been neglected. Yet there are two good reasons to consider dignity to be an attitude. First, this concept of dignity best allows us to grasp a crucial aspect of everyday language: people often express fears of losing their dignity – and it is not possible to explain this with an account in which dignity is inherent. Second, such a concept allows us to adduce new argumentation where the argument based on status ends. Dignity considered as a status provides grounds to argue for the moral permissibility of assisted suicide, in the sense that in such an account individuals possess the normative power to waive their right to life. But the question then remains of how to decide what counts as a good reason for assisted suicide – and this is where an argument based on dignity as an attitude can provide illumination. **Abstract:** <http://bit.ly/2zekc9D>
- *JOURNAL OF PALLIATIVE CARE* | Online – 14 August 2019 – ‘**Hospice palliative care and medical assistance in dying: Results from a Canada-wide survey.**’ With the legalization of medical assistance in dying (MAiD) in Canada, physicians and nurse practitioners now have another option within their scope of practice to consider alongside hospice palliative care (HPC) to support the patient and family regardless of their choice toward natural or medically assisted death. To elucidate insights and experiences with MAiD since its inception and to help adjust to this new end-of-life care environment, the membership of the Canadian Hospice Palliative Care Association (CHPCA) was surveyed. From across Canada, 452 responses were received (response rate: 15%). The majority of individuals worked as nurses (33%), administrators (16%), volunteers (16%) and physicians (11%). Almost 75% of all respondents indicated that they had experienced a patient in their program who had requested MAiD. Participants expressed dissatisfaction with the current psychological and professional support being provided by their healthcare organization and Ministry of Health – during and after the MAiD procedure. The new complexities of MAiD present unique challenges to those working in the healthcare field. There needs to be an increased focus on educating/training providers as without proper support, healthcare workers will be unable to perform to their full potential/scope of practice while also providing patients with holistic and accessible care. **Abstract:** <http://bit.ly/2KJZfsd>

Publishing Matters

Scientific authors in a changing world of scholarly communication: What does the future hold?

AMERICAN JOURNAL OF MEDICINE | Online – 15 August 2019 – Scholarly communication in science, technology and medicine has been organized around journal-based scientific publishing for the past 350 years. Scientific publishing has unique business models and includes stakeholders with conflicting interests – publishers, funders, libraries, and scholars who create, curate, and consume the literature. Mas-

Cont.

sive growth and change in scholarly communication, coinciding with digitalization, have amplified stresses inherent in traditional scientific publishing as evidenced by overwhelmed editors and reviewers, increased retraction rates, emergence of pseudo-journals, strained library budgets, and debates about the metrics of academic recognition for scholarly achievements. Simultaneously, several open access models are gaining traction and online technologies offer opportunities to augment traditional tasks of scientific publishing, develop integrated discovery services, and establish global and equitable scholarly communication through crowd-sourcing, software development, big data management and machine learning. These rapidly evolving developments raise financial, legal and ethical dilemmas that require solutions while successful strategies are difficult to predict. Key challenges and trends are reviewed from the authors' perspective about how to engage the scholarly community in this multifaceted process. **Abstract:** <http://bit.ly/2THga2W>

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