

Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Dealing with a novel viral epidemic creates spiritual and psychosocial issues similar to those encountered in a palliative care (PC) practice. PC workers would do well to be aware of such issues and act proactively when such epidemics arise.

'The challenge of providing holistic care in a viral epidemic: Opportunities for palliative care' (p.4), in *Palliative Medicine*.

U.S.A.

COVID-19

Hospice, palliative care providers: Let government hear your voice during pandemic

HOSPICE NEWS | Online – 20 March 2020 – Though little is certain, direct organizational contact with state and federal agencies and legislators has the potential to move action forward that could benefit the hospice and palliative care (PC) communities during the COVID-19 pandemic... State and federal agencies are taking steps to help alleviate the burdens placed on the healthcare system by the COVID-19 pandemic. However, few of the actions so far are oriented around the specific needs of the hospice and PC communities. This could signal a lack of awareness or understanding of the needs of those providers among executive leaders and legislators, particularly at the state level. While agencies such as the U.S. Centers for Medicare & Medicaid Services routinely work with hospices, the same may not be true for many legislators or governors who are also making key decisions that could impact providers and patients. Even

under normal circumstances, hospice and PC providers are adversely impacted by a lack of awareness of the nature of their work, as well as the value and benefits they provide to patients and families, payers, as well as the healthcare system at large. Organizations must also contend with ongoing stigma associated with the very word “hospice” among much of the public. <https://bit.ly/39ag7T8>

Specialist Publications

'**Kidney supportive care: Core Curriculum 2020**' (p.5), in *American Journal of Kidney Diseases*.

'**Early impact of the 2014 World Health Assembly resolution on palliative care: A qualitative study using semi-structured interviews with key experts**' (p.11), in *Journal of Palliative Medicine*.

Cont.

Related:

- **HOSPICE NEWS** | Online – 20 March 2020 – ‘**Hospices struggle to access patients in nursing homes amid pandemic.**’ With older adults suffering from chronic or life-limiting medical conditions among those most vulnerable during the COVID-19 outbreak, nursing homes (NH) across the country are restricting access to their facilities. As a result, hospice providers have experienced difficulty accessing their patients in NH settings. NH populations are at the highest risk of being affected by the Coronavirus, according to the Centers for Disease Control & Prevention.¹ To address pandemic spread concerns, the Center for Medicare & Medicaid Services announced critical measures last week to keep nursing home residents safe from exposure to COVID-19.² <https://bit.ly/33BR3Dr>
 1. ‘Preparing for COVID-19: Long-term Care Facilities, Nursing Homes,’ Centers for Disease Control & Prevention. **Download/view at:** <https://bit.ly/3a5vw8C>
 2. ‘Guidance for Infection Control & Prevention of Coronavirus Disease 2019 (COVID-19) in Nursing Homes,’ Center for Medicare & Medicaid Services. **Download/view at:** <https://go.cms.gov/3dmB4xt>
- **HOSPICE NEWS** | Online – 19 March 2020 – ‘**States strategize to improve palliative care quality and access.**’ Palliative care (PC) providers across the nation are working with state lawmakers to reshape and streamline policies that could increase awareness of and access to their services. The very nature of interconnected services involved in PC often poses accessibility challenges. Fewer than 5% of patients with serious illnesses who stand to benefit from PC actually receive it...¹ Challenges include lack of workforce capacity, public stigmas, high healthcare costs, and state policies that prevent timely patient access. To address challenges and embed palliative services across a variety of settings, state policies need to be better woven into the overall scope of healthcare. <https://bit.ly/2J5qWSN>
 1. ‘Palliative Care: A Primer for State Policymakers,’ National Academy for State Health Policy, May 2019. **Download/view at:** <https://bit.ly/2U4luiC>
- **HOSPICE NEWS** | Online – 18 March 2020 – ‘**Hospices turn to telehealth to reach patients during COVID-19 outbreak.**’ As the COVID-19 outbreak continues to take shape, hospices are increasingly using telehealth services to limit physical contact with patients and practice social distancing. Strategies to implement this method of support to patients and their families are evolving during the worldwide health emergency. Hospices ... are working to reduce risk of exposure to the Coronavirus among their vulnerable patient populations. Increased use of telemedicine is one of the various tactics that providers are employing. While Medicare telehealth benefits gradually were expanded during the last couple years, the COVID-19 outbreak placed a critical need for change. <http://bit.ly/3b68Q8n>
- **HOSPICE NEWS** | Online – 17 March 2020 – ‘**Hospice providers will weather the COVID-19 storm.**’ While much of the nation grinds to a halt amid the COVID-19 pandemic, hospice providers remain on the move – providing essential care to suffering patients and families in their homes and communities. In observations of the hospice community, going the extra mile seems to be a matter of course for providers. In the best of times and the worst of times, hospices rise to the occasion. Hospices may be better prepared than most to respond to the current crisis, and the larger healthcare system may have much to learn from their example. The unique and multifaceted skill sets that hospice providers bring to bear are particularly relevant to the realities of this pandemic. <http://bit.ly/3ba4KMB>
- **HOSPICE NEWS** | Online – 16 March 2020 – ‘**Hospice, palliative care patients at high risk for COVID-19.**’ The hospice and palliative care patient populations are among the most vulnerable to COVID-19. Understanding the risk points can be key for providers to minimize the potential risks of COVID-19 on aging and seriously ill patients. The symptoms of COVID-19 will be considerably more severe for adults age 60 or older who acquire the virus than for members of younger demographics...¹ The same is true for patients who already have a chronic or life-limiting illness. Spread of COVID-19 is likely to have a significant impact on patients who are advanced in years or those who are terminally ill, due to both prevalence and severity of infections. <http://bit.ly/2wfaOEv>
 1. ‘How many adults are at risk of serious illness if infected with Coronavirus?’ Kaiser Family Foundation, March 2020. <http://bit.ly/3b1s7HZ>

Cont.

Representative sample of professional resources:

- AMERICAN ACADEMY OF HOSPICE & PALLIATIVE MEDICINE | Online – Accessed 18 March 2020 – The Academy is working to ensure its colleagues providing hospice and palliative care have access to the tools and resources they need to take care of their patients and maintain their own safety and well-being during this unprecedented challenge. The Academy has compiled some resources that provide guidance and tools. **Download/view at:** <http://bit.ly/2UeV7p6>
 - PALLIMED | Online – Accessed 18 March 2020 – ‘**The voice and role of palliative care in the era of COVID-19.**’ The guidelines outlined in the recent letter co-sponsored by Pallimed and Geripal serve as important reminders of key messages for clinicians: social distancing, hand-washing, use of personal protective equipment to help flatten the curve of viral spread, adhering to protocols about screening, testing and even triaging. **Download/view at:** <https://bit.ly/2QztRk4>
1. ‘A letter of support for you and thoughts about COVID-19,’ Pallimed and Geripal, 13 March 2020. **Download/view at:** <https://bit.ly/2Qzulqo>

Earlier hospice referral a priority for bereaved families

HOSPICE NEWS | Online – 19 March 2020 – A wish among bereaved families of hospice patients is that their loved one had been referred to hospice earlier, new research has found.¹ Researchers from the Dana Farber Cancer Institute surveyed 140 bereaved family members to evaluate their experiences of the clinical care their loved one received and the perceived effect this care had on their grief. “One of the things that certainly came out – and from my experience with bereaved families – is wishing they had had an earlier hospice referral and longer length of stay,” said clinical psychologist and researcher Sue Morris, director of bereavement services at Dana-Farber Cancer Institute. Though the study didn’t assess patients’ understanding of hospice, Morris said she believes that families also need better education when it comes to understanding the role of hospices and the care they provide. <https://bit.ly/396Chpt>

1. ‘Insights from bereaved family members about end-of-life care and bereavement,’ *Journal of Palliative Medicine*, published online 10 February 2020. [Noted in 17 February 2020 issue of *Media Watch* (#653, p.14)] **Abstract:** <http://bit.ly/2SfHWV2>

Alzheimer’s affects 5.8 million people 65 and older. In 2050, that number may be close to 14 million.

THE WASHINGTON POST | Online – 16 March 2020 – Alzheimer’s disease, the most common dementia among older adults, now affects about 5.8 million U.S. residents 65 and older – 10% of that age group, according to a new report from the Alzheimer’s Association.¹ Age is considered the biggest risk factor for Alzheimer’s, with 3% of people 65 to 74, 17% of those 75 to 84, and 32% of people 85 and older – or nearly a third – having the disease. By 2050, the number of U.S. adults 65 and older with Alzheimer’s is expected to reach 13.8 million, with about half of them 85 or older. The association’s report attributes the growing number of Americans with Alzheimer’s to the projected aging of the U.S. population, with the West and Southeast regions of the country expected to experience the largest increases in the next five years. <https://wapo.st/39ZPD89>

1. ‘2020 Alzheimer’s Disease Facts & Figures,’ Alzheimer’s Association, March 2020. **Download/view at:** <http://bit.ly/33oL84F>

N.B. See ‘Use and Costs of Health Care, Long-Term Care & Hospice,’ beginning on p.45 of the Alzheimer’s Association report. Additional articles on hospice and end-of-life care for people living with dementia noted in the 9 March 2020 issue of *Media Watch* (#656, p.12).



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International

COVID-19: Doctors urge conversations about dying

U.K. | BBC News – 21 March 2020 – Palliative care (PC) doctors are urging people to have a conversation about what they would want if they, or their loved ones, became seriously unwell with Coronavirus. We should discuss all possible scenarios – even those we are not “comfortable to talk about,” they said. Medics said the virus underlined the importance of these conversations. New guidelines are being produced for PC for COVID-19 patients, the BBC understands. Dr. Iain Lawrie, president of The Association for Palliative Medicine of Great Britain & Ireland, told the BBC that PC teams around the country were working together to create the guidance. He said the impact of the virus was likely to change how PC would be delivered in future. <https://bbc.in/3blywOB>



Association for
Palliative Medicine
Of Great Britain and Ireland

Related:

- *EURONEWS* | Online – 16 March 2020 – ‘**Tough conversations about end-of-life care can no longer be avoided as COVID-19 spreads.**’ Given that we struggle to go about our daily lives without hearing death being mentioned at least once, perhaps now is the time to start thinking more closely about death and dying. The worst case scenario would be that we will know somebody who dies during this pandemic. As Europeans, we’re not particularly good at talking about death; you might argue it’s culturally unacceptable to start having conversations about death. This pandemic, however, could change this. In the coming weeks, we may start to see more families having conversations about how they will plan for a relative being in hospital, any wishes they might have when it comes to dying... <http://bit.ly/2U02Us1>

From the Archives:

- *PALLIATIVE MEDICINE*, 2004;18(1):12-18. ‘**The challenge of providing holistic care in a viral epidemic: Opportunities for palliative care.**’ Disease containment [as witnessed during the 2003 SARS pandemic] resulted in isolation, where isolation meant the disruption of connectedness. This disruption of connectedness took place at multiple levels: in the patient himself, between the patient and the family, within the family, between the patient and the healthcare worker, between the patient and society, and between healthcare workers. As the nature of the disease was uncertain, prognostication was inaccurate. This created difficulties in helping patients and their families prepare for death. **Abstract (w. list of references):** <http://bit.ly/2IS8t5p>

Representative sample of professional resources:

- EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (EAPC) | Online – Accessed 19 March 2020 – ‘**COVID-19 and the palliative care response.**’ In unprecedented times, the Association knows that many of our members, supporters and colleagues are providing care in challenging circumstances. The association has set up a web page for its members to source and share important information and updates on caring for people with COVID-19. **View at:** <https://bit.ly/33xku9C>

N.B. See ‘Start thinking about palliative care in times of a pandemic...’ EAPC blog at: <https://bit.ly/2J7cxi1>

- PALLIATIVE CARE AUSTRALIA | Online – Accessed 19 March 2020 – ‘**Australian COVID-19 Palliative Care Working Group.**’ Palliative Care Australia has formed a partnership with the Australian & New Zealand Society of Palliative Medicine, Palliative Care Nurses Australia, Australasian Chapter of Palliative Medicine of the Royal College of Physicians and the End of Life Directions for Aged Care Program. **Working group website:** <http://bit.ly/3d9nw8J>
- WORLD HOSPICE PALLIATIVE CARE ALLIANCE | Online – Accessed 19 March 2020 – ‘**COVID-19 resources.**’ The Alliance strongly recommends that its members and all those caring for people with palliative care needs read and adhere to World Health Organization guidelines to control the spread of Coronavirus. The Alliance is maintains a repository of partner resources specific to COVID-19. **Download/viewed:** <http://bit.ly/2wkGtVf>

Charities set to lose £4.3 billion in funding due to COVID-19

U.K. | Press Association – 20 March 2020 – The U.K.'s charities are set to lose out on £4.3 billion of funding over the next 12 weeks, as events are cancelled and their shops are forced to close their doors in response to the Coronavirus outbreak. Many small to medium-sized organisations are facing imminent collapse unless the Government steps in with a support package, the sector has warned. The U.K. charity sector employs about 900,000 people in paid positions, and many expect to be forced to make redundancies before the COVID-19 crisis is over. As well as lost funding, many charities are facing a rise in costs as the pandemic leads to a surge in demand from the people they were set up to assist. Heidi Travis, chief executive of palliative care charity Sue Ryder, said the organisation was having to make some "incredibly difficult decisions." She said that before the pandemic, hospice charities only received enough government funding to cover about one-third of their costs, with the remainder raised through charity shops and events. <https://bit.ly/2QA5frh>

Specialist Publications

Kidney supportive care: Core Curriculum 2020

AMERICAN JOURNAL OF KIDNEY DISEASES | Online – 12 March 2020 – Kidney supportive care (KSC) is the application of palliative medicine principles and practices to patients with kidney disease. The goal is alleviation of suffering through treatment of symptoms, empathic communication, and support for psychosocial distress. KSC includes primary palliative care (PC) provided by nephrology teams, as well as referral of patients with complex distress for co-management by an interprofessional specialty PC team, when available. The team may include physicians, nurses, social workers, chaplains, and dietitians. Co-management with nephrologists offers an additional layer of support to patients and families as prognostic awareness, patient preferences, and care decisions are explored. KSC can be offered to patients experiencing acute kidney injury or chronic kidney disease, including those with kidney failure

treated by kidney replacement therapy (dialysis and transplantation). KSC includes, but is not limited to, end-of-life care. This installment of the Core Curriculum in Nephrology outlines several practical applications of KSC, with a focus on the nephrologist's approach to symptom management, active medical management of kidney failure without dialysis (also known as comprehensive conservative care), acute kidney injury in seriously ill patients, and withdrawal from dialysis. **Abstract:** <http://bit.ly/2Wit5vu>

Publishing Matters

'How Ottawa's Centre for Journalology is tackling the scourge of predatory publishers' (p.13), in *University Affairs*.

Noted in Media Watch 2 December 2019 (#642, p.6):

- *AMERICAN JOURNAL OF NEPHROLOGY* | Online – 27 November 2019 – **'Matters of life and death: Why do older patients choose conservative management?'** Although many older patients with end-stage renal disease and limited prognoses prefer conservative management (CM), it is not widely offered in the U.S. In this study, the patients' reasons for choosing CM included: poor prognoses; a wish to maintain their quality of life; their desire for a dignified life closure; and, the intention to protect family members from having to see them suffer, based on their own memory of having witnessed a relative on dialysis previously. Promoting the choice of CM will require training of clinicians in primary palliative care competencies... **Abstract (w. list of references):** <http://bit.ly/33qZy2w>

N.B. Additional articles on palliative and end-of-life care for people living with chronic kidney disease noted in 11 November 2019 issue of Media Watch (#639, p.12).

Association between Chinese or South Asian ethnicity and end-of-life care in Ontario, Canada

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2020;192(11):E266-E274. Among decedents in Ontario, people of Chinese and South Asian ethnicity were more likely than people from the general population to receive aggressive care and to die in an intensive care unit. The observed variation in end-of-life care (EoLC) by ethnicity has multiple potential explanations, including patient preferences, health literacy, communication barriers, cultural differences, clinician behaviour, use of advanced directives, and differences in service accessibility. Differences in patient and family preferences may relate to religious and cultural beliefs, practices regarding death, notions of filial responsibility, or a preference for family-centred as opposed to individual decision-making. Previous research documented an association between minority ethnicity and decreased knowledge of advanced care planning. Communication difficulties may exist between patients of Chinese and South Asian ethnicity and healthcare professionals because of differences in languages spoken, culture, beliefs about EoLC and communication styles, which may manifest as cultural insensitivity and lead to a lack of trust. Some clinical settings may have fewer healthcare professionals of minority-ethnicity backgrounds. Lastly, people of Chinese or South Asian ethnicity may have fewer financial or social resources to help them pay for or provide non-publicly funded outpatient EoLC.

Full text: <http://bit.ly/3d5ydsy>

N.B. 'Ethnicity and "aggressive" end-of-life care,' commentary on 'Association between Chinese or South Asian ethnicity and end-of-life care...', *Canadian Medical Association Journal*, 2020;192(11):E287-E288.

Full text: <http://bit.ly/39Wx3O6>

Estimating the impact of words used by physicians in advance care planning discussions: The "Do you want everything done?" effect

CRITICAL CARE EXPLORATIONS | Online – Accessed 15 March 2020 – Using a discrete choice experiment survey, the authors estimated the impact of a commonly employed and poorly understood phrase physicians may use when discussing advance care plans with patients and their substitute decision-makers on the subsequent withdraw life-sustaining therapies. This phrase is predicted to dramatically reduce the likelihood of withdraw life-sustaining therapy even in medically non-beneficial scenarios and potentially contribute to low-value end-of-life care and outcomes. Healthcare providers who engage in advance care planning discussions with patients and their substitute decision-makers (SDMs) should never use the phrase "Do you want everything done?" as part of soliciting a patient's goals-of-care and advance directives. By using this phrase, not only are they asking for informed consent to provide an intervention that does not exist, but they are also potentially exposing both the patient and their SDM to a future of needless suffering. **Full text:** <http://bit.ly/2U8Vrp3>

Related:

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 12 March 2020 – '**Comparing advance care planning in young-onset dementia in the U.S. vs. Belgium...**' Important similarities between interviewees were restricted knowledge of advance care planning (ACP), limited communication about advance directives (ADS), and their recommendation for professionals to timely initiate ACP. Major differences were attention paid to those end-of-life decisions depicted in the legislature of their respective countries, American caregivers placed higher emphasis on financial planning than their Belgian peers, and, in the case of consulting professionals for ADs, American caregivers turned to lawyers, whereas Belgian caregivers relied on physicians. **Abstract:** <http://bit.ly/2TTBrrA>
- *JOURNAL OF MEDICAL INTERNET RESEARCH*, 2020;22(3):e15578. '**The feasibility and effectiveness of web-based advance care planning programs: Scoping review.**' Web-based, interactive, and person-centered advance care planning (ACP) programs are mainly developed and evaluated in the U.S. They contained the key elements of ACP, such as discussing and documenting goals and preferences for future care. In general, studies report that Web-based ACP programs tend to be feasible. Only 13 studies measured the programs' effectiveness, and they showed significant improvement in ACP knowledge, communication, and documentation. The key outcome of ACP – concordance between preferred and received treatment and care – is yet understudied.. **Full text:** <http://bit.ly/2Qrm9bu>

Stringent control of opioids: Sound public health measures, but a step too far in palliative care?

CURRENT ONCOLOGY REPORTS | Online – 13 March 2020 – The introduction of stringent opioid prescribing restrictions has inevitably impacted upon the ability of those prescribing opioids for advanced life-limited disease to practice as previously and could limit the supply of adequate pain relief to patients with cancer. This review considers the evidence that symptom management of patients with advanced cancer contributes to the “opioid problem” and whether there is adequate recognition of the risks involved. The literature suggests that the risk of opioid abuse is low in the palliative care (PC) population as is the risk of legal consequences for doctors prescribing opioids at the end of life. However, as many patients with cancer are living longer or surviving with chronic pain, PC physicians must be cognisant not only of the risks of long term opioid use but also of the risk of opioid misuse. Adherence to evidence or consensus-based guidelines is necessary to avoid inappropriate prescribing. In PC it is appropriate not only to exercise a reasonable degree of opioid control and surveillance, primarily for the good of society, but also to ensure that the ability to treat pain in patients with advanced malignant disease is not compromised. **Abstract (w. list of references):** <http://bit.ly/2w7Ltwj>

Noted in Media Watch 30 December 2019 (#646, p.11):

- *PALLIATIVE MEDICINE* | Online – 23 December 2019 – ‘**The perception of barriers concerning opioid medicines: A survey examining differences between policy makers, healthcare professionals and other stakeholders.**’ There are significant differences in the perception of barriers between policymakers and healthcare professionals working in the field of harm reduction, pain management and palliative care... The aspects that were most frequently perceived as a major barrier or as having major impact were lack of training, lack of financial resources, and physicians’ reluctance to prescribe opioids. The responses to the knowledge and attitude questions mirror familiarity with specific professional discourses in the diverse stakeholder groups. **Full text:** <http://bit.ly/34Rx4A>

Noted in Media Watch 10 June 2019 (#617, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2019;22(6):612-614. ‘**That was then, this is now: Using palliative care principles to guide opioid prescribing.**’ Palliative care (PC) providers ... do not want to contribute to the growing problem of opioid misuse, overdose, and accidental death. So the question becomes how do we balance the important goal of reducing suffering with our equally compelling desire to act as responsible providers. Consensus-based PC principles may serve as a clinically useful guide to the decision-making process about whether or not to prescribe opioids. The approach using these familiar core principles is probably best illustrated by the following two patients ... and their complex pain management issues. **Full text:** <http://bit.ly/2KnWQVL>

Grief literacy: A call to action for compassionate communities

DEATH STUDIES | Online – 19 March 2020 – The compassionate communities movement challenges the notion that death and dying should be housed within clinical and institutional contexts, and works to normalize conversations about death and dying by promoting death literacy and dialogue in public spaces. Community-based practices and conversations about grief remain marginal in this agenda. The authors theorize how grief could be better conceptualized and operationalized within the compassionate communities movement. They develop the concept of *Grief Literacy* and present vignettes to illustrate a grief literate society. Grief literacy augments the concept of death literacy, thereby further enhancing the potential of the compassionate communities approach. **Abstract:** <http://bit.ly/2vyvsiN>

Related:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 16 March 2020 – ‘**“I want to go home”:** How location at death influences caregiver well-being in bereavement.’ Congruence between a dying person’s preferred and actual locations at death has been considered good care and may influence the quality of bereavement. Yet, the preferred location for end-of-life care may be unaddressed. There has been little focus on the reciprocity between caregiver-patient wishes. Discussing preferences about the place of end-stage care may not make location congruence possible, but it can foster shared understanding and support for caregivers’ sense of coherence and well-being in bereavement. **Abstract (w. list of references):** <http://bit.ly/2vZtV5D>

Towards advance care planning in pediatrics: A qualitative study on envisioning the future as parents of a seriously ill child

EUROPEAN JOURNAL OF PEDIATRICS | Online – 19 March 2020 – Parents prefer open and honest information about their child’s illness and prognosis and they value the concept of advance care planning (ACP), while they emphasize the need for an individualized approach. Healthcare professionals, however, see parental factors like unease and emotional burden as key barriers for ACP. When envisioning the future of their seriously ill child, parents tended to stay close to the near future initially, with a focus on disease-related, practical themes. In this interpretive qualitative study, ongoing conversations uncovered deeper, value-based elaborations towards the future. To engage parents in ACP, the future needs to be discussed in relation to the present and the past. There is “no sharing without caring.” Parents who felt cared for and acknowledged in their challenging context by clinicians, were open to share their perspectives on the future of their seriously ill child. To share deeper motives and values underlying goals and preferences for future care and treatment, parents need a stimulating attitude of listening and encouragement from clinicians to express their feelings. **Full text:** <https://bit.ly/3bjTbIN>

“If only I could turn back time”: Regret in bereaved parents

PEDIATRIC & BLOOD CANCER | Online – 20 March 2020 – Regret about loss is one of the most intense types of regret experienced in life. Little is known about the bereavement regret of parents whose child has died of cancer. Although knowledge about parents’ experiences after their child’s death is vital for supporting these families, parents’ regret is mostly hidden from the treating clinical staff. This study aimed to explore these parents’ regret themes and their impact on their future lives. Regret seems to be a general phenomenon among bereaved parents and strongly influences the grieving process, in the sense of reflecting on past experiences to reorient for future actions. As this study was explorative, it is significant toward deepening the understanding of bereavement regret in future. These insights are crucial when working with affected families to help them decide important issues they can care about now and will not regret later. **Full text:** <https://bit.ly/2U6zuIE>

Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 March 2020 – ‘**Location of clinician-family communication at the end of life in the pediatric intensive care unit and clinician perception of communication quality.**’ Clinicians reported that the majority of communication occurred at the bedside, and less commonly family conferences and rounds. Quality of care (QoC) was rated higher when the majority of conversations occurred during family conferences and lower for patients of non-white race. QoC decreased when 8 of the 10 barriers to care were reported. This has important implications for future ICU communication research as the majority of previous research and education has focused on family care conferences. **Abstract:** <http://bit.ly/2TZ0nht>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 13 March 2020 – ‘**Emergencies in pediatric palliative care: A survey of ambulance officers to understand the interface between families and ambulance services.**’ Most ambulance officers did not easily identify patients as receiving palliative care (PC). Many felt these cases were challenging, confidence levels varied, and staff counselling services were felt to be relevant. They were most likely to use correspondence provided by the family from their usual team as a guide for emergency management. Half felt patients receiving PC should have a “not for resuscitation” order. Respondents suggested officer support could be improved through increased patient documentation and promotion of existing officer supports. **Abstract:** <http://bit.ly/33p06aD>

Psychological interventions for patients with advanced disease: Implications for oncology and palliative care

JOURNAL OF CLINICAL ONCOLOGY | Online – 5 February 2020 – A growing body of research demonstrates the feasibility and efficacy of psychological interventions for adult patients with advanced cancer. The authors consider these interventions according to three broad phases in which they are most commonly applied: soon after diagnosis of advanced cancer, when living with the disease, and at or near the end of life (EoL). Cumulative evidence from well-designed studies demonstrates the efficacy of psychosocial interventions for patients with advanced disease to relieve and prevent depression, anxiety, and distress related to dying and death, as well as to enhance the sense of meaning and preparation for EoL. Individual and couple-based interventions have been proven to be most feasible, and the development and use of tailored and validated measures has enhanced the rigor of research and clinical care. Palliative care (PC) nurses and physicians can be trained to deliver many such interventions, but a core of psychosocial clinicians, including social workers, psychologists, and psychiatrists, is usually required to train other health professionals in their delivery and to ensure their quality. Few of the interventions for which there is evidence of effectiveness have been routinely incorporated into oncology or PC. Advocacy on the basis of this evidence is required to build psychosocial resources in cancer treatment settings and to ensure that psychological care receives the same priority as other aspects of PC in oncology. **Abstract:** <http://bit.ly/38NjDCJ>

Related:

- *QUALITATIVE HEALTH RESEARCH* | Online – 19 March 2020 – ‘**How primary care physicians elicit sensitive health information from patients: Describing access to psychosocial information.**’ Multiple communication models describe factors that influence disclosure of sensitive health information. However, these models do not address the receiver’s perspective of health-related information, nor do they address how the receiver promotes disclosure. In the primary care chronic disease visit, the patient must disclose sensitive health-related psychosocial information to the primary care physician (PCP) for the PCP to understand potential barriers to care and make treatment decisions (e.g., referral to social work). **Abstract (w. list of references):** <https://bit.ly/3dknF9s>

Death attitudes, palliative care self-efficacy, and attitudes toward care of the dying among hospice nurses

JOURNAL OF CLINICAL PSYCHOLOGY IN MEDICAL SETTINGS | Online – 13 March 2020 – Research has linked death attitudes, palliative care self-efficacy, and attitudes toward care of the dying among nursing students and other nursing samples, but not among hospice nurses. This study investigated these relationships among hospice nurses. More positive attitudes toward care of the dying were associated with lower fear of death and death avoidance as well as higher neutral acceptance and escape acceptance, but not with approach acceptance. More positive attitudes toward care of the dying was associated with perceived capability to answer end-of-life (EoL) concerns, but not with perceived capability to respond to EoL symptoms. Clinical interventions seeking to improve attitudes toward care of the dying among hospice nurses may be most effective by targeting death attitudes and improving self-efficacy in the area of discussing EoL concerns with patients. **Abstract (w. list of references):** <http://bit.ly/3d1oALG>

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>

Related:

- *JOURNAL OF NURSING SCHOLARSHIP* | Online – 19 March 2020 – ‘Nursing professionals’ attitudes, strategies, and care practices towards death: A systematic review of qualitative studies.’ Thirteen categories emerged, grouped into three themes: 1) Meanings and feelings during the dying process; 2) Coping strategies in the face of death; and, 3) The importance of training, experience, and providing a dignified death. In the different accounts of the participants, it was found death had a large negative emotional impact on them, that the participants complained about the lack of previous training in the care of dying patients, and that avoiding these complex situations was one of the strategies most commonly used by professionals to face the death of a patient. **Abstract:** <http://bit.ly/2U31r3Z>

The association of increasing hospice use with decreasing hospital mortality: An analysis of the National Inpatient Sample

JOURNAL OF HEALTHCARE MANAGEMENT, 2020;65(2):107-120. The primary finding in this study was that at least part of the decrease in in-hospital mortality for six major hospital diagnoses (i.e., heart failure, chronic obstructive pulmonary disease, acute myocardial infarction, acute myocardial infarction with cardiogenic shock, septic shock, and lung neoplasm) could be explained by increases in discharge to hospice for these patient groups. Hospice usage converts an in-hospital death to a hospice death and does not show up on reported hospital mortality data. The authors doubt that this is the primary motivating factor for the increased usage of hospice, although there is a secondary benefit to a hospital when reporting hospital mortality data. The finding could be another motivating factor for capturing the primary benefits of hospice, such as bringing experts on pain control, emotional and spiritual support for patients, and support for the patients’ loved ones. In addition, because considerable resources are used for the care of patients in the terminal stages of disease, hospice decreases health system costs. **Full text:** <http://bit.ly/2vyAE6h>



Free to choose: A moral defense of the right-to-try movement

JOURNAL OF MEDICINE & PHILOSOPHY, 2020;45(1):61-85. The claim that individuals legitimately differ with respect to their values seems to be uncontroversial among bioethicists, yet many bioethicists nevertheless oppose right-to-try laws. This seems to be due in part to a failure to recognize that such laws are intended primarily to be political, not legal, instruments. The right-to-try movement seeks to build political support for increasing access to newly developed drugs outside of clinical trials. Opponents of right-to-try laws claim that increasing access outside of clinical trials would undermine evidence-based medicine. They seek to maximize overall gains to patients by protecting them from adverse drug reactions and ensuring that drugs are more effective on average. In contrast, right-to-try activists have a point that regulatory judgments of drug safety and effectiveness impose one set of trade-offs on all individuals, regardless of their different values. That might be acceptable if determinations of safety and effectiveness were black and white, but that does not seem to be the case. This article argues that judgments of safety and effectiveness are in an important respect normative and reflect the perceived value of those ends relative to others. Such judgments, when universally imposed, harm patients who would readily make do with less knowledge of drug safety and effectiveness in exchange for more time and self-determination. The relevant moral principle is that of respect for individual autonomy. Just as that principle should lead one to substitute collective decisions for individual ones to regulate a natural monopoly, the same principle should lead one to substitute individual decisions for collective ones to avoid a government monopoly on access to newly developed drugs. It is argued that reforms should increase the number of treatment options available to patients outside of clinical trials. The final section of the article discusses ways in which current regulations might be reformed so as to provide more treatment options outside of clinical trials, without undermining evidence-based medicine. **Abstract:** <http://bit.ly/2QhE6tg>

N.B. Additional articles on “right-to-try” laws noted in 20 January 2020 issue of *Media Watch* (#649, pp.11-12).

Understanding the outcomes of supplementary support services in palliative care for older people: A scoping review and mapping exercise

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 19 March 2020 – When older people and other key stakeholders talk about what matters to those receiving supplementary or volunteer services or interventions towards the end of life they talk about four main concepts: enriching relationships, greater autonomy and perceived control, knowing more, and improved mental health. These are not concepts exclusive to supplementary support services, but are clearly benefits from such care. These are not, however, necessarily the concepts assessed as outcomes in commonly used outcome measurement tools with older people and those towards the end of their lives. Example outcome measurement tools, when assessed against these concepts, often have high numbers of redundant items, or do not assess against each of these concepts. Measuring the outcomes of supplementary support services therefore, using most existing tools risks increasing respondent burden with redundant items, or measuring inappropriate concepts. **Full text:** <https://bit.ly/2xejafK>

Early impact of the 2014 World Health Assembly resolution on palliative care: A qualitative study using semi-structured interviews with key experts

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 March 2020 – In 2014, the World Health Assembly (WHA) approved the Resolution “Strengthening of palliative care (PC) as a component of comprehensive care throughout the life course” (WHA67.19), urging national governments to carry out actions to develop PC. Although we lack a set of indicators to assess the global impact of Resolution WHA67.19, the authors identified several efforts made to explore and to describe cognate actions carried out at different levels. In 2015, the World Health Organization (WHO) Non-Communicable Disease Country Capacity Survey showed that a minority of countries include PC in their national policy for non-communicable diseases, and reported that PC is least likely to have funding, compared with other non-communicable disease services. In 2016, a civil society report pointed out that donor countries had not yet given adequate provision to facilitate the implementation process for the Resolution, although examples of progress on the integration of PC into the health policy were cited (India, Colombia, Romania); progress in PC education was illustrated (Jordan, Panama, Morocco); and improvements in drug availability (Mexico) and in rolling out PC services (Ethiopia) were presented. Also in 2016, the WHO Secretariat reported a range of actions by Member States, the WHO headquarters, and regional and country office focused on access to oral morphine and essential medicines; the integration of PC into global disease control and health system plans; and information about guidance, tools, and training programs on PC. The same year, the WHO published a practical manual on how to plan and implement PC services integrated into existing healthcare services. In 2017, an edited collection *Building Integrated Palliative Care Programs & Services* was published by a group of activists aiming to assist governments and providers to build and strengthen PC provision. However, a global survey of PC in 2017 concluded that a mere 14% of the world population has access to the highest levels of PC provision, while 53% live in countries where PC delivery is localized to a significant degree and lacks sufficient integration with the wider health and social care system to achieve high coverage. Since the approval of the Resolution, PC has been integrated in subsequent WHO or WHA resolutions, but these are non-binding in character, making for difficulties in global implementation and in the assessment of impact on national policies. **Full text:** <https://bit.ly/3a7rZH0>

Barriers and solutions to advance care planning among homeless-experienced older adults

JOURNAL OF PALLIATIVE MEDICINE | Online – 17 March 2020 – Study participants considered advance care planning (ACP) important, reflecting on deaths of people in their networks who had died. Participant-identified barriers to ACP included poor ACP knowledge, lack of familial ties and social isolation, competing priorities, avoidance and lack of readiness, fatalism and mistrust, and lack of ACP training for clinical and non-clinical staff. They identified solutions that included framing ACP as a way to provide meaning and assert choice, providing easy-to-read written documents focused on the populations’ unique needs, tailoring content and delivery, initiating ACP in non-clinical settings, such as permanent supportive housing, and providing incentives. **Abstract:** <http://bit.ly/33sAEB7>

Cont.

Noted in Media Watch 22 July 2019 (#623, p.6):

- *JOURNAL OF AGING & HEALTH* | Online – 15 July 2019 – ‘**Feasibility of advance care planning in primary care for homeless adults.**’ The authors implemented an advance care planning (ACP) project to discuss and document advance care plans with all patients aged 45 and older who received primary care at their adult homeless program clinics. Over 14 months, ACP was discussed with 48% of the population and healthcare proxy (HCP) appointment with 91% of these patients. Most appointed a HCP from personal relationships, though a significant minority could not and were considered “surrogate-less.” End-of-life preferences varied. Approximately 20% of patients wanted to defer to a surrogate for each decision. **Abstract:** <http://bit.ly/2LIB1aB>

Noted in Media Watch 24 June 2019 (#619, p.10):

- *JOURNAL OF URBAN HEALTH* | Online – 7 June 2019 – ‘**Utilization of advance care planning for homeless adults: Case studies.**’ The authors examined the feasibility and outcomes of advance care planning (ACP) in primary care for patients who have experienced homelessness. They found that such efforts had significant impacts on patients’ hospital care and allowed their wishes to be honored when they lost capacity for medical decision-making, particularly at the end of life. Six case studies demonstrate the outcomes of ACP in primary care for homeless adults and highlight lessons learned. To their knowledge, this is the first case series showing how ACP for homeless adults in primary care has been utilized during hospital care. **Abstract (w. list of references):** <http://bit.ly/2WOeaWe>

Top ten tips palliative care clinicians should know about integrating population health principles into practice

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 March 2020 – The field of palliative care (PC) has spent the past decade demonstrating that it improves outcomes for patients, clinicians, and health systems. Forward-thinking organizations preparing for a reimbursement system rooted in value have built robust inpatient PC programs and are rapidly moving toward the outpatient and community settings as well. As PC programs get larger and are increasingly tasked with leading a wide variety of diverse initiatives, population health principles can help to focus programs on high-value activities. This article, written by population health researchers and PC clinicians, seeks to provide PC teams nationally with a variety of population health strategies and tools to guide PC delivery throughout the health system and beyond. **Abstract:** <http://bit.ly/3b3iZm8>

Ethical and research governance approval across Europe: Experiences from three European palliative care studies

PALLIATIVE MEDICINE | Online – 18 March 2020 – Research requires high-quality ethical and governance scrutiny and approval. However, when research is conducted across different countries, this can cause challenges due to the differing ethico-legal framework requirements of ethical boards. There is no specific guidance for research which does not involve non-medicinal products. Eighteen principal investigators in 11 countries conducting one of three European-funded studies participated in this study. There was variation in practice including whether ethical approval was required. The time to gain full approvals differed with the U.K. having governance procedures that took the longest time. Written consent was not required in all countries nor were data safety monitoring committees for trials. There were additional differences in relation to other data management issues. Researchers need to take the differences in research approval procedures into account when planning studies. Future research is needed to establish European-wide recommendations for policy and practice that dovetail ethical procedures and enhance transnational research collaborations. **Abstract (w. list of references):** <http://bit.ly/3d61dk6>



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

Emotionally reflexive labour in end-of-life communication

SOCIAL SCIENCE & MEDICINE | Online – 14 March 2020 – Within palliative care, clear and open communication about death is encouraged. Euphemisms are discouraged as threats to promoting clear understanding of the prognosis; to opening communication about what a good death means to individual patients and families; and, to fostering collaborative planning aimed at achieving this “good death.” Principles of patient-centred and culturally competent care, however, which reflect trends of individualisation, plurality and multiculturalism that are characteristic of late modernity, encourage respect for and support of patients’ and families’ preferences. These may include wishes to avoid open communication, preferences for euphemisms, and definitions of a “good death” that vary from the practitioner’s, and within families. The aim of this study was to examine how physicians navigate these competing priorities. Findings show that synonyms familiar to clinicians are often used to communicate prognoses in multidisciplinary meetings. In communication with patients and families, doctors rely on emotional and cultural cues to decipher the preferred terminology and response. Drawing on a late modern re-imagining of emotion management, the authors conceptualise the work performed in this context as emotionally reflexive labour. These findings suggest that blanket protocols for direct communication overlook the complexity of end-of-life communication in an era where a “good death” is understood to be culturally relative. **Abstract:** <http://bit.ly/2WeuvqN>

[Publishing Matters](#)

How Ottawa’s Centre for Journalology is tackling the scourge of predatory publishers

UNIVERSITY AFFAIRS | Online – 20 March 2020 – Predatory journals deviate from accepted editorial procedures (by not doing peer reviews, for example) and engage in unethical practices (such as neglecting to archive studies). To bring attention to the problem, Dr. Kelly Cobey and her colleagues at the centre recently published a definition of predatory journals,¹ and kicked off a series of initiatives that will make publishers and academics’ published research more transparent, ethical and open. In a world where predatory or deceptive journals likely outnumber legitimate journals, scholars will need all the support they can get: worldwide, there are about 13,000 deceptive journals – and that number is rising. Based in the clinical epidemiology program at the Ottawa Hospital Research Institute, the Centre for Journalology was started in 2014 by David Moher, the centre’s director. “I was aware of the substantial problems with the quality of biomedical research,” says Dr. Moher, who is also an associate professor in the school of epidemiology and public health at the University of Ottawa, where he holds a university research chair. “I wondered why researchers were able to advance their careers when it was clear that they weren’t practising best publication practices, or their institutions weren’t asking for best practices. I wondered whether this had anything to do with the perverse incentives in place at institutions to promote the careers of researchers.” Journalology, a relatively new field of research, is the scholarly study of academic publication practices – and it cuts to heart of some of these “perverse incentives,” including a publish-or-perish culture in universities. **Full text:** <https://bit.ly/2J6pMzy>



1. ‘Defining predatory journals and responding to the threat they pose: A modified Delphi consensus process,’ *BMJ Open*, published online 9 February 2020. [Noted in 17 February 2020 issue of *Media Watch* (#653, p.17)] **Full text:** <http://bit.ly/2SdQaNr>

N.B. Centre for Journalology: <http://bit.ly/36Hxw5B>



Would this article be of interest to a colleague?

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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.

Updated 03.18.2020

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