

**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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**It was evident that for hospice staff, the care of patients with complex needs was intrinsic to their job but was not something easily described or understood.**

'What makes palliative care needs "complex"? A multi-site sequential explanatory mixed methods study of patients referred for specialist palliative care' (p.6), in *BMC Palliative Care*.

## Canada

### **Fraser Health to evict Delta Hospice Society, open new hospice beds next door**

BRITISH COLUMBIA | *Surrey Now-Leader* – 15 January 2021 – The Delta Hospice Society will have until late March to vacate the Irene Thomas Hospice, according to a statement by the health minister and the Fraser Health Authority. In February of last year, Health Minister Adrian Dix announced the Fraser Health Authority had given the society a year's notice that it would terminate its contract with the society after the board voted not to provide medical assistance in dying (MAiD) at the Irene Thomas Hospice in Ladner. The facility is located on Fraser Health property adjacent to Delta Hospital, rented to the society for \$1 a year, and the health authority provides the hospice with \$1.5 million in annual funding, which covers 94% of the 10-bed centre's operating costs. Under the terms of its agreement with the Society, Fraser Health says it will serve the society 30 days' notice to vacate the premises on 25 February 2021. The notice to vacate will apply to both the Irene Thomas Hospice and the Harold & Veronica Savage Centre for Supportive Care, as both buildings are on the same property and under the same lease. As part of its transition plan,

Fraser Health will open five hospice beds at Mountain View Manor, a Fraser Health-owned and operated long-term care facility located on the Delta Hospital campus, that same day. A further five hospice beds will open at the facility by mid-April. The Society's board said in a news release 8 January 2021 that it deeply regrets "being compelled" to take the action due to Fraser Health cancelling its contract over its refusal to comply with a provincial policy requiring hospices to provide MAiD. <http://bit.ly/3oS0SH4>

### Specialist Publications

'Hospice care provider perspectives of medical assistance in dying in a Canadian hospice that does not provide medical assistance in dying' (p.11), in *Canadian Journal of Nursing Research*.

'Conscientious objection to medical assistance in dying in rural/remote nursing' (p.11), in *Nursing Ethics*.

**N.B.** Search back issues of Media Watch (December 2019 onwards) for additional reports on the Delta Hospice Society-Fraser Health authority dispute at: <http://bit.ly/2ThijkC>

## Cultural differences affect South Asian perception of palliative care, says Osler study

ONTARIO | *CanIndia* (Oakville) – 11 January 2021 – A study from William Osler Health System and McMaster University examined awareness of palliative care (PC) in the South Asian community and found that culture plays a critical role in the perception of PC.<sup>1</sup> This perception, in turn, affects whether or not patients will be open to receiving it. The observational study is one of the few person-centered PC studies focused on the South Asian community outside India. The results showed that 70% of participants in the study had a lack of understanding of PC and 44% thought that PC went against their values and beliefs. At the same time, many of the participants agreed that when facing a life-limiting illness, they wanted to ensure that they or their family members had a better quality of life and alleviate suffering... Recent Ontario research also indicates that immigrants of South Asian origin are at a higher risk of aggressive end-of-life care that is often contrary to their wishes.<sup>2</sup> There is a strong likelihood that perceptions of PC within the South Asian populations are contributing to this. Other key findings in the study showed that participants had differing attitudes when it came to talking about death – ranging from discomfort to frank acceptance. While the study showed education is necessary to change common perceptions of PC, cultural values, faith, and spiritual beliefs didn't necessarily pose a barrier to participants accepting PC services. <http://bit.ly/35yYBJp>

1. 'Perceptions of palliative care in a South Asian community: Findings from an observational study,' *BMC Palliative Care*, published online 14 September 2020. [Noted in Media Watch 21 September 2020 (#684, p.4)] **Full text:** <https://bit.ly/2ZG1sNM>
2. 'Association between immigrant status and end-of-life care in Ontario, Canada,' *Journal of the American Medical Association*, 2017;15(318):1488-1479. [Noted in Media Watch 9 October 2017 (#533, p.2)] **Full text:** <http://bit.ly/2LhvDHe>

## U.S.A.

### New research reveals patient safety concerns and medical errors of 50% with critical end-of-life documents needed in this pandemic to protect patients

PENNSYLVANIA | Institute on Healthcare Directives – 13 January 2021 – As the nation and world are facing the COVID-19 pandemic, a pandemic producing gut-wrenching ethical challenges, placing the physician and patient relationship at odds, new ... research calls into question the tools utilized to document patient wishes for current and end-of-life care.<sup>1</sup> In this pandemic, you have heard countless times that patients need to prepare with advance directives... You have heard experts advocate to complete POLST (Physicians Orders for Life-Sustaining Treatment) documents on patients to ensure their wishes are followed so that we don't over-utilize precious resources such as ventilators or keep patients alive against their wishes, further limiting hospital capacities. The newest research ... reveals medical providers often incorrectly provide the wrong level of care and both under and over treat patients despite their documented wishes. This comes at a time when hospitals have enforced limited or zero

visitation policies. This now places vulnerable at-risk patients in situations where they have no one to advocate for them. Physicians, who are essentially medical strangers to these patients, now are left to guess patient wishes from confusing documents. <http://prn.to/2KfFm05>

#### Extract from Institute on Healthcare Directives research report

This research does not just speak to overtreatment, it graphically portrays it. Overtreatment is when we save a life that should have been allowed to die naturally. This simulation research also reveals how undertreatment quickly occurs, can cause harm and take a life that should and would have been saved. Both overtreatment and undertreatment are unspoken and under-reported medical errors.

1. 'Utilizing simulation to evaluate the living will and POLST ability to achieve goal concordant care when critically ill or at end of life: The realistic interpretation of advance directives,' *Journal of Healthcare Risk Management*, published online 10 December 2020. **Abstract:** <https://bit.ly/3bCnUOA>

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**N.B.** Search back issues of Media Watch for additional articles on POLST at: <http://bit.ly/2ThiikC>

**Related:**

- CALIFORNIA | *Scope* (Stanford Medicine) – 11 January 2021 – ‘**Hospitals’ DNR orders are increasingly complex and varied.**’ A recent study from the Stanford Center for Biomedical Ethics found that ... hospitals have taken markedly different approaches to designing do not resuscitate (DNR) orders, which could result in variabilities in end-of-life (EoL) care.<sup>1</sup> DNR policies are designed to allow patients to make EoL choices that reflect their values and preferences, and to relieve loved ones of having to make those decisions. But in recent years, however, the range of choices has expanded greatly. The study found that hospitals differ dramatically in whether these additional decision points are incorporated in DNR orders. <http://stan.md/3nBut6u>
  1. ‘Variation in the design of do not resuscitate orders and other code status options: A multi-institutional qualitative study,’ *BMJ Quality & Safety*, published online 20 October 2020. [Noted in Media Watch 26 October 2020 (#689, p.7)] **Full text:** <https://bit.ly/2Hj5JAA>

**How California can fix its hospice system and reduce care inequities**

CALIFORNIA | *California Health Report* – 12 January 2021 – As hospice care has expanded in California, so have complaints of fraud and malpractice. A federal report last year identified California as leading the nation in serious complaints and inspection concerns about subpar care at hospices.<sup>1</sup> A recent *Los Angeles Times* investigation pointed to hundreds of complaints about patient mistreatment and questionable practices by hospice providers in the state.<sup>2,3,4</sup> Advocates for seniors say unscrupulous hospice providers have signed non-terminally ill patients up for end-of-life care they didn’t need, and then billed Medicare for services and equipment. Patients were often duped into enrolling in hospice with promises of “freebies” such as housekeeping help or personal protective supplies, not realizing they’d signed away their rights to receive life-saving medical care, which isn’t covered when people are in hospice. Seniors from all walks of life fall victim to these fraudulent practices, but those with limited English proficiency are especially vulnerable... More than 44% of Californians speak a language other than English at home... Some fraudsters appear to target these seniors, knowing they may be more easily duped into signing paperwork they don’t understand because it’s in English, said Morales. Hospice fraud is one of the top complaints callers report to the federally funded hotline, with more than 50 reports registered last year through September. Many more likely go unreported, she said. <http://bit.ly/3iaMBTj>

1. ‘Hospice Deficiencies Pose Risk for Medicare Beneficiaries,’ Office of the Inspector General, Department of Health & Human Services, July 2019. [Noted in Media Watch 15 July 2019 (#622, p.2)] **Download/view at:** <http://bit.ly/2XTBPJH>
2. ‘End-of-life care has boomed in California. So has fraud targeting older Americans,’ *The Los Angeles Times*, 9 November 2020. [Noted in Media Watch 14 December 2020 (#696, p.2)] <https://lat.ms/3m0gsOH>
3. ‘Dying Californians suffer harm and neglect from an industry meant to comfort them,’ *The Los Angeles Times*, 9 November 2020. [Noted in Media Watch 14 December 2020 (#696, p.3)] <https://lat.ms/2KaWfbF>
4. ‘What you need to know if you or a loved one requires end-of-life care,’ *The Los Angeles Times*, 9 November, 2020. [Noted in Media Watch 14 December 2020 (#696, p.3)] <https://lat.ms/37NvCSr>



**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>

## Specialist Publications

### Palliative care services in the Neuro-ICU: Opportunities and persisting barriers

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 January 2021 – Neurointensivists face unique challenges in providing timely supportive care to terminally ill patients expected to expire in the Neuro-ICU. This study explored the extent of effective utilization of, and recorded barriers to, palliative and hospice services in a dedicated 30-bed Neuro-ICU at a large academic medical center. Across services, 146 expired patients were never referred to palliative care (PC) or hospice services. Of those referred, over one-third were referred more than 4 days past admission to the Neuro-ICU. On average, patients were referred with less than one day before expiration. Common barriers to referral for supportive services were documented (e.g., patient expected to expire, family declined service). Despite benefits of PC and an in-hospital hospice opportunity, the authors identified lack of referral, and particularly delays in referral to services as significant barriers. Future research should solidify triggers for EOL services in this setting. **Abstract (w. list of references):** <http://bit.ly/3nykNJH>

#### Research Matters

“‘The ethics approval took 20 months on a trial which was meant to help terminally ill cancer patients. In the end we had to send the funding back’”: A survey of views on human research ethics reviews’ (p.13), in *Journal of Medical Ethics*.

‘Reflective insights from developing a palliative care children and young people’s advisory group’ (p.14), in *Palliative Medicine*.

‘Perspectives on COVID-19 and palliative care research’ (p.14), in *Palliative Medicine*.

#### Publishing Matters

‘Communicating scientific uncertainty in an age of COVID-19: An investigation into the use of pre-prints by digital media outlets’ (p.15), in *Health Communication*.

Noted in Media Watch 7 October 2019 (#634, p.11):

- *NEUROCRITICAL CARE* | Online – 29 August 2019 – ‘Palliative care in the neuro-ICU: Perceptions, practice patterns, and preferences of neurointensivists.’ The authors surveyed members of the [U.S.] Neurocritical Care Society to explore current practice patterns, perceptions, and preferences regarding integration of palliative care (PC) in the neurological ICU. PC consultations are utilized infrequently by the majority of the respondents. The most common indication for a palliative consultation was to discuss goals-of-care and make treatment decisions. A large majority either agreed or strongly agreed that PC services were utilized in the management of difficult cases apart from discussions regarding withdrawal of life-sustaining therapy. **Abstract (w. list of references):** <http://bit.ly/2mQ0zln>

#### Related:

- *EMERGENCY MEDICINE CLINICS OF NORTH AMERICA*, 2021;39(1):217-225. ‘Neuroethics and end-of-life care.’ The emergency department is where the patient and potential ethical challenges are first encountered. Patients with acute neurologic illness introduce a unique set of dilemmas related to the pressure for ultra-early prognosis in the wake of rapidly advancing treatments. Many with neurologic injury are unable to provide autonomous consent, further complicating the picture, potentially asking uncertain surrogates to make quick decisions that may result in significant disability. The emergency department physician must take these ethical quandaries into account to provide standard of care treatment. **First page preview:** <http://bit.ly/3srjXSU>



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## Cost savings associated with palliative care among older adults with advanced cancer

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 January 2021 – There is inconsistent evidence that palliative care (PC) intervention decreases total healthcare expenditure at end-of-life for oncology patients. This inconsistent evidence may result from small sample sizes at single institution studies and disparate characterization of costs across studies. Comprehensive studies in population-based datasets are needed to fully understand the impact of PC on total healthcare costs. This study analyzed the impact of PC on total healthcare costs in a nationally representative sample of advanced cancer patients. In this study, patients who received a PC consultation experienced an average per patient cost of \$5,834 compared to \$7,784 for usual care patients... PC consultation within 7 days of death decreased healthcare costs by \$451, while PC consultation more than 4 weeks from death decreased costs by \$4,643. This study demonstrates that PC has the capacity to substantially reduce healthcare expenditure among advanced cancer patients. Earlier PC consultation results in greater cost reductions than consultation in the last week of life. **Abstract (w. list of references):** <http://bit.ly/2XxsxkC>

Noted in Media Watch 16 November 2020 (#692, p.5):

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 5 February 2020 – ‘**Economics of palliative care for cancer: Interpreting current evidence, mapping future priorities for research.**’ Early research studies on the economics of palliative care (PC) have reported a general pattern of cost savings during inpatient hospital admissions and the end-of-life phase. Recent research has demonstrated more complex dynamics, but expanding PC capacity to meet clinical guidelines and population health needs seems to save costs. Quantifying these cost savings requires additional research, because there is significant variance in estimates of the effects of treatment on costs, depending on the timing of intervention, the primary diagnosis, and the overall illness burden. **Abstract:** <http://bit.ly/3beeGW5>

## Integrating a palliative approach into the healthcare provided by the French-African Pediatric Oncology Group’s pilot units. Insights from a 3-year training program

*ARCHIVES DE PÉDIATRIE* | Online – 11 January 2021 – Working alongside local stakeholders, members of the French-African Pediatric Oncology Group developed a 3-year program to train pediatric oncology teams from 15 French-speaking countries in Africa in using analgesics and providing palliative care (PC). This program was rolled out in three phases: 1) Initial training; 2) *In situ* assessment; and, 3) Advanced training in selected topics. To access this program, multidisciplinary teams had to come up with a project to improve their existing PC and pain management practices, and commit themselves to implementing it. All the teams invited agreed to take part in the program, which explicitly broached a subject that is often avoided in oncology teaching. The first phase was rolled out in 2017, with 65 trainees from 19 units attending one of three sessions held in Dakar, Senegal, Abidjan, Côte d’Ivoire, and Rabat, Morocco. The subsequent assessment revealed that only half the teams had started to implement their projects. The advanced training phase was therefore adjusted accordingly. A collective training session held in Marseille was attended by 15 trainees from seven teams whose projects were already underway, while *in situ* mentoring was provided for six other teams, through French-African twinnings in four cases. The length and openness of the program meant that we were able to identify and share the units’ diverse realities, and fine-tune their projects accordingly, as well as plan ways of continuing the training both locally and collectively. **Abstract:** <http://bit.ly/38LNezH>

## “Imagine you have ALS”: Death education to prepare for advance treatment directives

*BEHAVIOURAL SCIENCES* | Online – 6 January 2021 – Community death education enables people to get to the heart of what it means to face a serious illness such as amyotrophic lateral sclerosis and then manage palliative care (PC) with family members. Death education (DeEd) can get ordinary people to think of death and dying before they are diagnosed with a serious illness. DeEd can help individuals to reflect on issues that they do not normally give importance and that need to be pondered instead. In fact, holding these issues in due consideration on the one hand can be useful for managing way the possibility of the

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disease in a more resilient, and on the other hand for developing more feelings of solidarity and empathy towards patients and their families. This project found that people are not sufficiently knowledgeable about either PC or the law governing advance treatment directives. Even these people have considered the experience of death education useful for becoming aware of this possibility, and this has increased their serenity. This confirms that it is possible to talk about death and the most dramatic situations of illness without creating anxiety, but reducing it. What reduces anxiety is the possibility of talking about these issues and becoming aware of how culture and society manage them, offering important answers that are usually hidden from everyday life. This study confirms the relevance of religious and spiritual discourse, which is considered particularly valuable when addressing these issues. **Full text:** <http://bit.ly/3nybmKp>

### **What makes palliative care needs “complex”? A multi-site sequential explanatory mixed methods study of patients referred for specialist palliative care**

*BMC PALLIATIVE CARE* | Online – 15 January 2021 – Uncertainty around what complex needs are and ambivalence regarding the hospice services available are features of the current system. Despite this, the authors found that “complex needs,” specifically multiple needs within and across domains, are recorded in hospice referrals, though detail is often lacking. Several steps could be taken to improve the consistency of referrals. Referrers may have a history with patients, and could draw more on this knowledge when documenting the reasons for referral to ensure that the patient and their family is directed to the service that best meets their needs. Greater consideration of the non-physical needs of patients is warranted. Across all domains, where appropriate, the use of standardised screening tools and performance measures ... as a supplement to free-text information, could provide greater clarity and enable hospices to individualize services early on. Hospices could improve the referral process by ensuring that referrers are aware of the needs addressed by each available service. Palliative care (PC) specialists could offer training and support to GPs, community nurses, care-home nurses and other staff to reach all patients in need, especially those with non-malignant disease. Structured referral forms – now normal practice in all other specialties – could contain a section on PC provided prior to referral, clarifying what PC has already been offered, when and why the person is now being referred for hospice care. Hospices are increasingly under pressure to show their “worth” to commissioning groups through tangible outputs and impacts, which may contribute to a greater emphasis on more medical aspects of PC, which downplays the psychological, social and spiritual care provided. This may partly explain the emphasis on physical symptoms found in referral documentation. Clear communication on the interventions offered by hospices to address non-physical care needs is needed to ensure that referrers and commissioners understand the range of specialist PC services available, and how these can significantly improve quality of life for those with greatest need. **Full text:** <http://bit.ly/2KnuFss>

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### **Challenges for palliative care day services: A focus group study**

*BMC PALLIATIVE CARE* | Online – 12 January 2021 – Palliative care (PC) day services reflect the holistic nature of PC, in aiming to improve the quality of life of patients and their family caregivers complementing mainstream PC...<sup>1</sup> The challenge is to recognise needs that may be addressed via day-services and then to refer patients immediately and integrate day-services into care plans early, even alongside other models of curative intent or life-prolonging treatment. The lack of standardisation of day services has resulted in variations in function, delivery, model of care and staffing, confirming previous research. Research indicates a lack of consensus on the model and variable outcome measures makes replication or application to specific patient groups challenging. Participants noted that the origins of day-service stemmed from a social model of care that has evolved to combine both social and medical services. The hybrid model was viewed as advantageous as it enabled patients’ physical, and psychosocial needs to be met in line with the holistic nature of PC, so having the potential to reduce demand on other healthcare services. The lack of evidence about the impact of day services on patient outcomes makes it difficult to quantify such beneficial effects and indeed to understand the specific nature of the contribution of PC day services. There is a need for the model of day-service and the implications of this upon other services, to be investigated. **Full text:** <http://bit.ly/38CMuNt>

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1. 'The strengths and challenges of palliative day-care centers: Qualitative study with the professionals involved,' *Journal of Palliative Care*, published online 3 October 2017. [Noted in Media Watch 9 October 2017 (#533, p.13)] **Abstract (w. list of references):** <http://bit.ly/3nxldis>

### **Gaining insight into the views of outpatients with Huntington's disease regarding their future and the way they deal with their poor prognosis: A qualitative study**

*BMC PALLIATIVE CARE* | Online – 12 January 2021 – Three strategies emerged for facing a future with Huntington's disease (HD). Participants saw the future: 1) As a period that you have to prepare for; 2) As a period that you would rather not think about; and, 3) As a period that you do not have to worry about yet. Participants could adopt more than one strategy at a time. Even though participants realized that they would deteriorate and would need more care in the future, they tried to keep this knowledge "at a distance." with the motivation of keeping daily life as manageable as possible. This interview study has provided valuable insight into the views of HD patients regarding their future and planning future care, and how patients deal with the prognosis of HD. A contrast seems to exist between the advance care planning recommendation to discuss goals and wishes for the future and the tendency of patients to keep the future at a distance. Healthcare providers may consider starting conversations in the present as well by exploring current everyday struggles and victories, personal values and life goals. From there, conversations may continue about the future and preferences for future care. **Full text:** <http://bit.ly/2MSHdst>

Noted in Media Watch 23 October 2017 (#535, p.12):

- *NEUROLOGY ADVISOR* | Online – 19 October 2017 – '**Defining unique needs for palliative and hospice care in Huntington disease.**' The course of Huntington disease (HD) can take decades to fully evolve from the early hallmarks of chorea, mood disturbances, and mild cognitive impairment to end-stage disease in which patients often die from complications of dementia and/or significant decline in motor function. Palliative and hospice care play an important role in the long-term management of HD, including ongoing symptom relief measures, caregiver support, and end-of-life care. Services offered by palliative care and hospice often overlap significantly, particularly in imminently terminal conditions such as cancer and heart disease... **Full text:** <http://bit.ly/2XwG1Nt>

### **Chinese medical teachers' cultural attitudes influence palliative care education: A qualitative study**

*BMC PALLIATIVE CARE* | Online – 12 January 2021 – China holds one fifth of the world's population and faces a rapidly aging society. In its ambition to reach a healthcare standard comparable to developed countries by 2030, the implementation of palliative care (PC) gains special importance. PC education in China is limited and disparate. The prevailing culture promotes ambivalent perceptions of PC among medical teachers and the wider society. A pragmatic general understanding of teaching works as a further barrier for PC education, which is elsewhere characterized by holistic approaches, communication, and reflection. However, developing research is challenging the cultural orthodoxy and highlighting the value of rethinking end-of-life (EoL) culture, reducing harm not through withholding diagnosis and prognosis, but by enabling high quality EoL care through a more open communication. Approaches, such as train the trainer sessions, to change medical teachers' views on PC and PC education and their cultural attitudes towards death and dying are crucial to further promote the implementation of PC in China. **Full text:** <http://bit.ly/2LoaQl2>

**N.B.** Additional articles on palliative and EoL care in China noted in Media Watch 3 August 2020 (#677, p.8).

### **Spiritual care practices in hospices in the Western Cape, South Africa: The challenge of diversity**

*BMC PALLIATIVE CARE* | Online – 10 January 2021 – Two prominent themes emerged in this study: 1) The challenges of providing relevant spiritual care (SC) services in a religiously, culturally, linguistically and racially diverse setting; and, 2) The organisational context impacting such a SC service. Participants agreed that SC is an important service and that it plays a significant role within the inter-disciplinary team. Partici-

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pants recognised the need for SC training and skills development, alongside the financial costs of employing dedicated SC workers. In spite of the diversities and resource constraints, the approach of individual hospices to providing SC remained robust. It emerged quite clearly from this study that rendering SC services within a diverse palliative care setting ... was both essential and challenging. Hospice staff need to be in possession of a broad range of critical skills, knowledge and expertise in order to provide quality SC services against the backdrop of deeply entrenched external constraints such as racial prejudices, religious difference, and social and cultural segregation. **Full text:** <http://bit.ly/35LSEcn>

#### Related:

- *BRITISH JOURNAL OF NURSING* | Online – 12 January 2021 – ‘**The importance and meaning of prayer rituals at the end of life.**’ This article explores the meaning of ritual, how rituals are structured and how prayer rituals are used at the end of life from a cross-cultural perspective. Facing death can be a challenge to a person’s sense of identity and their understanding of their world around them, beginning a process of spiritual suffering. Prayer rituals can help maintain a sense of control and identity during this time of crisis, offering comfort, meaning and structure. Prayer rituals from different cultures follow similar structures that can be deconstructed, allowing nurses to decipher their meaning and deepen the quality of care they provide to the dying person and those left behind. **Abstract:** <https://bit.ly/38CDtUA>

#### **Palliative care needs and integration of palliative care support in chronic obstructive pulmonary disease (COPD): A qualitative study**

*CHEST* | Online – 9 January 2021 – A multi-centre qualitative study was undertaken in COPD services and specialist palliative care (PC) in the U.K., involving patients with severe COPD, their carers and health professionals (HPs). Four themes were generated from interviews with 20 patients, six carers and 25 HPs: 1) Management of exacerbations; 2) PC needs; 3) Access to PC and pathways; and, 4) Integration of PC support. Uncertainty and fear were common in patients and carers, with identified needs for reassurance, rapid medical access, home care and finance advice. Timely PC was perceived as important by HPs. PC was integrated into COPD services although models of working varied across regions. Reliable screening tools and needs assessment, embedded psychological care and enhanced training in PC and communication skills were perceived important by HPs for timely PC referrals and optimised management. PC is increasingly being implemented for non-malignant diseases including COPD throughout the U.K. although models of working vary. A theoretical model is developed to illustrate the concept and pathway of the integration of PC support. A standardised screening and needs assessment tool is required to improve timely PC and address the significant needs of this population. **Abstract:** <https://bit.ly/2MWHWJf>

Noted in Media Watch 4 May 2020 (#664, p.8):

- *JAMA INTERNAL MEDICINE* | Online – 27 April 2020 – ‘**Proactive integration of geriatrics and palliative care principles into practice for chronic obstructive pulmonary disease.**’ Half of adults with chronic obstructive pulmonary disease (COPD) in the U.S. will be 75 years or older by 2030. Patients with COPD often have years of debilitating symptoms that accelerate their loss of independence and well-being. COPD is progressive and incurable; many patients are frail and socially isolated and struggle with long lists of medications. Their care is often chaotic and fragmented, with frequent emergency department visits and hospitalizations. Clinicians who routinely care for patients with COPD should proactively integrate geriatrics and palliative care principles into their daily practice. **Abstract:** <https://bit.ly/2S9Fb7h>

Noted in Media Watch 4 November 2019 (#638, p.16):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 October 2019 – ‘**Early palliative care in chronic obstructive pulmonary disease.**’ Guidelines recommend that pulmonary clinicians involve palliative care (PC) in chronic obstructive pulmonary disease (COPD); however, integration before advanced stage, that is, early PC, is rare. Pulmonary and PC clinicians [i.e., study participants] agreed that early PC could add value to disease-focused COPD care. Perspectives on many barriers and facilitators were shared between specialties along broad educational, clinical, and operational categories. Pulmonary and PC clinicians shared concerns about the misconception that PC was synonymous to end-of-life care. **Abstract:** <http://bit.ly/36cebtj>

## The first Czech perinatal hospice: Joint venture or competitive field?

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 13 January 2021 – There is no legally established perinatal hospice in the Czech Republic. Several initiatives work towards launching an institution to support parents in the event of a fatal prenatal diagnosis or life-limiting condition in their unborn baby. Parents use the label perinatal hospice as they subvert and transform the narrow legal and strictly medical framework for such institutions. Hospice care became a legitimate sector of care provision only recently. This study analyses four initiatives that strive to establish and formalise perinatal hospices in the Czech Republic, with a focus on the strategies these initiatives engage in to achieve change. A sociological qualitative empirical study ... informs the findings. Initiatives vary in approach from cooperation to competition in being recognised as 'the first perinatal hospice'. This study shows how such rhetoric is adopted to attract the funding required for sustainability. **Abstract:** <https://bit.ly/39AAaMG>

## Racial/ethnic disparities in nursing home end-of-life care: A systematic review

*JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 8 January 2021 – Health disparities are pervasive in nursing homes (NHs) [in the U.S.], but disparities in NH end-of-life (EoL) care – i.e., hospital transfers, place of death, hospice use, palliative care (PC), advance care planning (ACP) – have not been comprehensively synthesized. Eighteen articles were included, most were good quality and most used data through 2010. Studies varied in definitions and grouping of racial/ethnic minority residents. Four outcomes were identified: 1) ACP; 2) Hospice; 3) EoL hospitalizations; and, 4) Pain management. Differences in EoL care were most apparent among NHs with higher proportions of Black residents. Racial/ethnic minority residents were less likely to complete advance directives. Although hospice use was mixed, Black residents were consistently less likely to use hospice before death. Hispanic and Black residents were more likely to experience an EoL hospitalization compared with non-Hispanic White residents. Racial/ethnic minority residents experienced worse pain and symptom management at the EoL; however, no articles studied specifics of PC (e.g., spiritual care). Research is needed that uses recent data, reflective of current NH demographic trends. To help reduce EoL disparities, language services and cultural competency training for staff should be available in NHs with higher pro-

portions of racial/ethnic minorities. **Abstract (w. list of references):** <https://bit.ly/2K7rMf3>

### Socio-demographic disparities in access to hospice and palliative care: An integrative review

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 January 2021 – The objective of this review was to synthesize current literature on disparities in access to hospice and palliative care, highlight the range of socio-demographic groups affected by these inequities, characterize the domains of access addressed, and outline implications for research, policy, and clinical practice. Of the articles included, 80% employed non-experimental study designs. Study measures varied, but 70% of studies described differences in outcomes by race, ethnicity, or socio-economic status. Others revealed disparate access based on variables such as age, gender, and geographic location. Overall synthesis highlighted evidence of disparities spanning five domains of access: 1) Approachability; 2) Acceptability; 3) Availability; 4) Affordability; and, 4) Appropriateness. Sixty percent of studies primarily emphasized acceptability, affordability, and appropriateness. This integrative review highlights the need to consider various stakeholder perspectives and attitudes at the individual, provider, and system levels going forward, to target and address access issues spanning all domains. **Abstract (w. list of references):** <http://bit.ly/3oBiKG3>

Noted in Media Watch 14 December 2020 (#696), p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 December 2020 – ‘**Disparities in palliative and hospice care and completion of advance care planning and directives among non-Hispanic blacks: A scoping review of recent literature.**’ It is well-established that disparities in diversity, equity and inclusivity are widespread in American society and in the U.S. healthcare system. Receiving palliative care for people with serious illness, and hospice services for people approaching the end of life (EoL) is no exception. It is urgent that we understand and eliminate both disparities in serious illness care and disparities in EoL care. The story about race and palliative and hospice care in U.S. is very much the same story of racism in healthcare. **Full text:** <https://bit.ly/37Juxv0>

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Noted in Media Watch 26 October 2020 (#689, p.10):

- *JOURNAL OF RACIAL & ETHNIC HEALTH DISPARITIES* | Online – 19 October 2020 – ‘**End-of-life wishes among non-Hispanic, Black and White middle-aged and older adults.**’ Although some research has been done on end-of-life (EoL) preferences and wishes, knowledge of racial differences in the EoL wishes of non-Hispanic White and non-Hispanic Black middle-aged and older adults is limited. Previous studies exploring such racial differences have focused mainly on EoL decision-making as reflected in advance healthcare directives concerning life-sustaining medical treatment. This study focuses on racial differences in non-decision-based aspects of EoL care, that is, EoL care that incorporates patients’ beliefs, culture, or religion. **Abstract (w. list of references):** <https://bit.ly/2TlekFf>

**N.B.** Search back issues of Media Watch for additional articles on disparities in the provision and delivery of hospice and PC for racial/ethnic minorities in the U.S. at: <http://bit.ly/2ThijkC>

### **Advance care planning in Asia: A systematic narrative review of healthcare professionals’ knowledge, attitude, and experience**

*JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 6 January 2021 – The results of this study show that the current Western-oriented advance care planning (ACP) may not always easily be transferable to other cultures, including Asian ones. Its uptake in Asia may be improved by adapting the current ACP models to acknowledge the deep importance traditionally attached to the role of the family. If policy and standard system are established for ACP, healthcare professionals (HCPs) may be empowered to deliver it. Similarly, its rate of delivery may be improved by training to HCPs and cultural shift. The authors’ findings may also be relevant to the practice of ACP in Western countries. HCPs who engage in ACP with patients of Asian origin should pay particular attention to the potentially essential role of family in ACP. Given that ACP is at an early stage of development in Asia, Asian patients and families living in another country may benefit from clear explanations of the legal and standard systems related to ACP specific to the country. **Full text:** <https://bit.ly/2LceZJ0>

#### **Related:**

- *BMC MEDICAL ETHICS* | Online – 13 January 2021 – ‘**Grounds for surrogate decision-making in Japanese clinical practice: A qualitative survey.**’ In the coming years, surrogate decision-making is expected to become highly prevalent in Japanese clinical practice. Further, there has been a recent increase in activities promoting advance care planning, which potentially affects the manner in which judgments are made by surrogate decision-makers. This study revealed the current state of surrogate decision-making in Japan. When making decisions on important aspects related to a patient’s life, surrogate decision-makers based their decisions on not only the preferences and best interests of the patient but also their own and their family’s preferences. **Full text:** <http://bit.ly/38GneFT>

Noted in Media Watch 10 August 2020 (#678, p.13):

- *JAPANESE JOURNAL OF CLINICAL ONCOLOGY* | Online – 6 August 2020 – ‘**Advance care planning in Asian culture.**’ Ageing has been recognized as one of the most critically important healthcare issues worldwide. It is relevant to Asia, where the increasing number of older populations has drawn attention to the paramount need for healthcare investment, particularly in end-of-life care. The advocacy of advance care planning is a means to honor patient autonomy. Since most East Asian countries are influenced by Confucianism and the concept of “filial piety,” patient autonomy is consequently subordinate to family values and physician authority. The dominance from family members and physicians during a patient’s EoL decision-making is recognized as a cultural feature in Asia. **Abstract:** <https://bit.ly/3fDI0aK>



#### **Media Watch: Access Online**

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

## Improving family access to dying patients during the COVID-19 pandemic

*THE LANCET: RESPIRATORY MEDICINE* | Online – 12 January 2021 – In response to the COVID-19 pandemic, most healthcare organisations have implemented policies to restrict visitor access. Although there are exceptions to some of these policies, including limited visiting for patients nearing the end of life (EoL), they still have profound effects on the dying and their family members. We are still in the midst of the pandemic, but there are compelling reasons to expand access of family members to their loved ones as they near the EoL, despite the risk of infection. Hospital visitor policies represent an attempt to balance two competing priorities. Restrictions reduce the chance of harm from infection, but increase the chance of harm from isolation or separation. Exemptions can reduce isolation and allow for a more compassionate response to patients nearing the EoL, but they potentially increase the risk of COVID-19 transmission. It is too early to assess the burden of complex grief of family members who endure the loss of a loved one during the pandemic, and we have little bereavement data from previous pandemics. We know that restrictive visitor policies are associated with a higher frequency of delirium and anxiety in patients. We also know that separation from the patient, the absence of normal death rites, and the disruption of social support networks are risk factors for poor bereavement outcomes. **Full text:** <https://bit.ly/3nM8OZq>

## Conscientious objection to medical assistance in dying in rural/remote nursing

*NURSING ETHICS* | Online – 11 January 2021 – In 2016, the Supreme Court of Canada legalized medical assistance in dying (MAiD) in Canada. Similar to jurisdictions where this has been a more long-standing option for end-of-life care, the Supreme Court's decision in Canada included a caveat that no healthcare provider could be compelled to participate in MAiD. The Canadian Nurses Association, in alignment with numerous ethical guidelines for healthcare providers around the globe, maintains that nurses may opt out of participation in MAiD if they conscientiously object to this procedure. The realities of implementing MAiD are still unfolding. One area that has received little attention in the literature thus far is the ability of nurses who aid with, rather than administer, MAiD to conscientiously object. This is particularly significant in rural and remote areas of Canada where geographic dispersion and limited numbers of nursing staff create conditions that limit the ability to transfer care or call on a designated team. Exercising conscientious objection to MAiD in rural and remote areas, by way of policies developed with an urban focus, is one example of how the needs of rural nurses and patients may not be met, leading to issues of patient access to MAiD and retention of nursing staff. To illustrate the complexities of nurses' conscientious objection to MAiD in a rural setting, the authors apply an ethical decision-making framework to a hypothetical case scenario and discuss the potential consequences and implications for future policy. Realizing that conscientious objection may not be a viable option in a rural or remote

context has implications for not only MAiD, but other ethically sensitive healthcare services as well. These considerations have implications for policy in other jurisdictions allowing or considering medically assisted deaths, as well as other rural and remote areas where nurses may face ethical dilemmas. **Full text:** <http://bit.ly/3oyByG2>

### **Hospice care provider perspectives of medical assistance in dying in a Canadian hospice that does not provide medical assistance in dying**

*CANADIAN JOURNAL OF NURSING RESEARCH* | Online – 12 January 2021 – Participants in this study included hospice administrators, nurses, staff and volunteers who provide care at an in-patient hospice facility in a geographically isolated medium sized city ... in a western Canadian province. Introduction of medical assistance in dying (MAiD) challenged and disrupted care practices, for example, situating MAiD within hospice and palliative care, caring for patients undergoing MAiD within a non-provider facility, and balancing interpersonal dynamics in an interdisciplinary team environment. Themes were underpinned by participants' attempts to reconcile MAiD within personal beliefs and work environment. Caring for patients who chose MAiD changed the dynamic of care. Participants focused on providing patient-centred care while attempting to normalize the MAiD process. Educational resources to support patient-centred care for patients who undergo MAiD off-site, address care provider self-care, and to facilitate safe and effective interdisciplinary communication are needed. **Abstract (w. list of references):** <http://bit.ly/3qr09x7>

## **Timely identification of patients in need of palliative care using the Double Surprise Question: A prospective study on outpatients with cancer**

*PALLIATIVE MEDICINE* | Online – 11 January 2021 – The Surprise Question (“Would I be surprised if this patient were to die within the next 12 months?”) is widely used to identify palliative patients, though with low predictive value. To improve timely identification of palliative care (PC) needs, the authors propose an additional Surprise Question (“Would I be surprised if this patient is still alive after 12 months?”) if the original Surprise Question is answered with “no.” The Double Surprise Question performs better than the original Surprise Question alone when identifying patients with cancer at risk of dying during the next year. Adding the second Surprise Question makes it possible to divide the patients for whom the original Surprise Question is answered with “no” into two groups: a small group to focus proactive PC on, and a larger group to monitor less intensively. Thus, the Double Surprise Question can help professionals to carefully balance between the timely identification of more patients with cancer who have unmet PC needs, without overburdening limited professional resources. However, more scientific evidence is needed to support this hypothesis. Further research should examine whether the application of the Double Surprise Question contributes to more timely PC. Additionally, future studies should validate the Double Surprise Question in different settings and different patient groups. Moreover, to minimize the risk of missing patients in need of PC, studies need to reveal how often the Double Surprise Question should be used as an identification tool. Finally, the authors recommend studying whether the Double Surprise Question is a cost-effective way to identify patients in need of PC. **Full text:** <http://bit.ly/35uqv9A>

Noted in Media Watch 4 January 2021 (#698, p.8):

- *SUPPORTIVE CARE IN CANCER* | Online – 22 December 2020 – ‘**Treatment goals and changes over time in older patients with non-curable cancer.**’ The findings of this study suggests that patients’ goals become less stable when they enter the late phase of their disease. In practice, it is a challenge for healthcare providers to determine when patients have entered this phase. The surprise question (“Would I be surprised if this patient died in the next year?”) has been shown to be a simple and effective tool for identifying patients with cancer who have a greatly increased 1-year mortality risk. Recently, it was suggested that a double surprise question, adding “Would it surprise me if this patient is still alive after 12 months?” had even better predictive values. **Full text:** <https://bit.ly/3aDUSgQ>

## **“Cold bedrooms” and other cooling facilities in U.K. children’s hospices, how they are used and why they are offered: A mixed methods study**

*PALLIATIVE MEDICINE* | Online – 11 January 2021 – The death of a child is acutely distressing. Evidence on the benefits and value to parents of spending time with their dead child have now been integrated into routine practice and is regarded as a bereavement support intervention. U.K. children’s hospices have a tradition of using “cooling facilities” (cold bedrooms, cooled blanket/mattress) to extend this period of time by slowing deterioration of the body. 41/52 hospices completed a cross-sectional survey and 13 directors of care were interviewed. All hospices [i.e., survey respondents] had cooling facilities. Some offered use of portable cooling facilities at home, though take-up appears low. Hospices differed in approaches to managing care and duration of use. Views on whether parents should observe deterioration informed the latter. Directors of care believed they provide families with time to say “goodbye” and process their loss. Challenges for staff were reported. Cooling facilities are a core element of U.K. children’s hospice provision. The views of directors of care that cooling facilities may support early grieving processes align with existing studies and grief theories. Further research is required to further understand the ways cooling facilities may affect early grieving processes (including differences of experience), and how hospices’ cooling facility-related practices and care may impact on this. The second stage of this research, a multi-site qualitative investigation of bereaved parents’ experiences of using cooling facilities, addresses these evidence gaps. **Full text:** <http://bit.ly/39rLsmu>

## **Palliative and end-of-life care for people living with dementia in rural areas: A scoping review**

*PLOS ONE* | Online – 14 January 2021 – The literature synthesized in this review provided an understanding and overview of the experiences, needs, and shortfalls of dementia-related palliative and end-of-life (EoL) care services and supports in rural areas. Key themes were identified and main areas for improvement were discussed. Although there was a paucity of research regarding rural palliative and EoL care for people with dementia, several areas were highlighted within the existing literature including the importance of extending further knowledge about dementia, having early conversations about advanced care and treatment options to allow for informed decision-making, and providing a person-centered approach to allow for individuals to remain cared for in their preferred care settings. The potential for using technological solutions to help address rural issues with access to services and supports was also discussed. These findings can be used to inform future research and policy and the development of services, supports, and intervention strategies to improve the lives of people living with dementia and further research is recommended. **Full text:** <https://bit.ly/3stZiOf>

**N.B.** Search back issues of Media Watch for additional articles on palliative and EoL care for people living with dementia at: <http://bit.ly/2ThijkC>

## **Developing a paramedic approach to palliative emergencies**

*PROGRESS IN PALLIATIVE CARE* | Online – 11 January 2021 – Emergency health services have experienced a steady increase in demand from palliative patients accessing 9-1-1 during times of acute crisis, although the majority of these patients do not wish for conveyance to hospital following paramedic treatment. To address this demand, and to provide patients with the right care, the first time, the British Columbia Emergency Health Service (BCEHS) introduced the province's first Assess, See, Treat & Refer (ASTaR) Clinical Pathway. This alternative model of care is intended to improve patient-oriented care by providing care for patients in their own home and reducing the requirement for conveyance to the emergency department, thus reducing the requirement for hospitalization. Launched in June 2019, the ASTaR Pathway includes the early recognition of patients with palliative needs accessing 9-1-1, the use of secondary triage services and the automatic notification and referral of non-conveyed patients to primary healthcare teams for patient follow-up. This commentary outlines the early integration of the ASTaR Palliative Clinical Pathway into the BCEHS paramedic approach to palliative patient care. **Abstract:** <https://bit.ly/3qbaE7C>

**N.B.** Additional articles on the role of paramedics in palliative and end-of-life care noted in Media Watch 23 November 2020 (#693, p.14).

## **Research Matters**

**“The ethics approval took 20 months on a trial which was meant to help terminally ill cancer patients. In the end we had to send the funding back”: A survey of views on human research ethics reviews**

*JOURNAL OF MEDICAL ETHICS* | Online – 11 January 2021 – The authors conducted a survey to identify what types of health/medical research could be exempt from research ethics reviews in Australia. They surveyed Australian health/medical researchers and Human Research Ethics Committee (HREC) members. The survey asked whether respondents had previously changed or abandoned a project anticipating difficulties obtaining ethics approval, and presented eight research scenarios, asking whether these scenarios should or should not be exempt from ethics review, and to provide (optional) comments. Forty-three per cent of (514) respondents to whom the question applied, reported changing projects in anticipation of obstacles from the ethics review process; 25% reported abandoning projects for this reason. Research scenarios asking professional staff to provide views in their area of expertise were most commonly exempted from ethics review (to prioritise systematic review topics 84%, on software strengths/weaknesses

Cont.

85%); scenarios involving surplus samples (82%) and N-of-1 (single case) studies (76%) were most commonly required to undergo ethics review. HREC members were 26% more likely than researchers to require ethics review. Need for independent oversight, and low risk, were most frequently cited in support of decisions to require or exempt from ethics review, respectively. Considerable differences exist between researchers and HREC members, about when to exempt from review the research that ultimately serves the interests of patients and the public. It is widely accepted that evaluative research should be used to reduce clinical uncertainties – the same principle should apply to ethics reviews. **Abstract:** <http://bit.ly/35AEllb>

### **Reflective insights from developing a palliative care children and young people’s advisory group**

*PALLIATIVE MEDICINE* | Online – 12 January 2021 – The importance of actively involving patient and public members throughout the different stages of palliative care (PC) and health research projects is widely acknowledged, however patient and public involvement work rarely considers insight from children and young people. Although this is becoming increasingly recognised in other areas of research, there is currently no structured guidance on how to best involve children and young people in PC research. Attending an after-school ‘Health & Social Research Methods Club’ for 11 weeks benefitted children and researchers. Children were taught about data collection methods, data analysis and ethics in health research and used these skills to provide valuable feedback which has been implemented in current PC research projects. Children took part in considered discussions around PC topics and enjoyed attending the group. This project has equipped researchers with skills and provided a structured template for future young people’s advisory groups, ensuring the unique voices of children and young people are considered and valued in future PC research. **Full text:** <http://bit.ly/39r7mWZ>



#### **Editorial**

### **Perspectives on COVID-19 and palliative care research**

*PALLIATIVE MEDICINE* | Online – 10 January 2021 – This is a moment for palliative care (PC) research to be visible and important, and we need to ensure that it remains relevant and robustly conducted. What are the key research questions that face us now and for the medium-term future? Questions that require attention are likely to include a consideration of when, to whom, and by which services PC should be offered. Effective approaches to symptom management and palliation, including palliative rehabilitation, for those with COVID-19 need to be further studied. We need a greater understanding of “long COVID” and how this might affect, if at all, the patients that we provide care for. We need to understand the longer-term impact of some of the service changes that we have had to adopt such as remote working, a shift to home care, and teleconsultation for all patients, whether with COVID-19 or not. What is impact of changes in provision on family carers both during care and in to bereavement. A focus on community and primary care settings may be particularly important given we know that there appear to be excess home deaths, and many patients may be reluctant to access in-patient care. In particular the experiences and voices of our patients have been challenging to understand in the short term, but need to be an integral part of research going forwards. For all research areas the author believes that we need to focus on coordinated, joined up efforts. Much COVID-19 PC research to date has been small and local in scale and scope. This is not to denigrate this important research, and how teams responded rapidly, but large team or multi-national research may reap greater benefits for the future in terms of transferrable knowledge that can influence practice. **Full text:** <http://bit.ly/3idVifR>



Media Watch: Behind the Scenes  
<http://bit.ly/2MwRRAU>

## Publishing Matters

### **Communicating scientific uncertainty in an age of COVID-19: An investigation into the use of preprints by digital media outlets**

*HEALTH COMMUNICATION* | Online – 3 January 2021 – The authors investigated the surge in use of COVID-19-related preprints by media outlets. Journalists are a main source of reliable public health information during crises and, until recently, journalists have been reluctant to cover preprints because of the associated scientific uncertainty. Yet, uploads of COVID-19 preprints and their uptake by online media have outstripped that of preprints about any other topic. Using an innovative approach combining altmetrics methods with content analysis, the authors identified a diversity of outlets covering COVID-19-related preprints during the early months of the pandemic, including specialist medical news outlets, traditional news media outlets, and aggregators. They found a ubiquity of hyperlinks as citations and a multiplicity of framing devices for highlighting the scientific uncertainty associated with COVID-19 preprints. These devices were rarely used consistently (e.g., mentioning that the study

was a preprint, unreviewed, preliminary, and/or in need of verification). About half of the stories the authors analyzed contained framing devices emphasizing uncertainty. Outlets ... were much less likely to identify the research they mentioned as preprint research, compared to identifying it as simply “research.” **Full text:** <https://bit.ly/3nOzrg9>

#### **Extract from *Health Communication* article**

This work has significant implications for public health communication within the changing media landscape. While current best practices in public health risk communication promote identifying and promoting trustworthy sources of information, the uptake of preprint research by online media presents new challenges. At the same time, it provides new opportunities for fostering greater awareness of the scientific uncertainty associated with health research findings.

### **Media Watch: Editorial Practice**

EACH LISTING IN MEDIA WATCH represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

#### **Distribution**

MEDIA WATCH IS DISTRIBUTED AT NO COST to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

#### **Links to Sources**

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

IF YOU ARE AWARE OF A CURRENT REPORT, ARTICLE, ETC., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

### Media Watch: Access on Online

#### International



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

[Scroll down to 'Media Watch']

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

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

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

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

#### Asia



Asia Pacific  
Hospice Palliative  
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ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2SWdYWP>

[Scroll down to 'Media Watch']

#### Australia

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

#### Canada



CSPCP SCMSP  
Canadian Society of  
Palliative Care Physicians  
Société canadienne des  
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CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

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

#### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTPS://BIT.LY/3EPKUAC>

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

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

#### South America

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

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