

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

Palliative care specialists are used to guiding people through frightening health landscapes, but this pandemic has brought a level of uncertainty that most of us have not known in our lifetime ... and threatened many of our most fragile patients.

'Palliative care in the time of COVID-19: A visual essay' (p.2), in *Medscape*.

U.S.A.

Telehealth rules complicate opioid access for hospice, palliative patients during COVID-19

HOSPICE NEWS | Online – 6 May 2020 – Drug Enforcement Agency (DEA) telemedicine rules are complicating hospice and palliative care patients' access to necessary medications during the coronavirus pandemic. Some stakeholders have called on regulators to allow the use of audio-only telehealth for patient encounters that involve opioid prescriptions. During the COVID-19 national emergency, the DEA has waived certain requirements to allow providers to prescribe controlled substances following a telehealth encounter without a prior in-person visit in a DEA-registered facility. However, the legal definition of telemedicine specifies audio-visual communication. This has caused problems among patients who lack the necessary devices, patients in rural areas, and those with limited internet access or none at all... While the U.S. Centers for Medicare & Medicaid Services has issued several 1,135 waivers allowing providers to expand the use of audio-only telehealth for some services, at least temporarily during the crisis, the DEA requirement seems to be holding fast to the audio-visual stipulation. Close to a third of older adults live in solitude and 10% live in poverty, according to U.S. Census data...

Shelter-in-place orders have made it difficult for some families to obtain devices or secure home installations, and for many a telephone may be their sole connection to their healthcare providers for the time being. <https://bit.ly/2L7D0Nt>

COVID-19: End-of-Life Care

'Palliative care strategies offer guidance to clinicians and comfort for COVID-19 patient and families' (p.7), in *Heart & Lung*.

'Best case/Worst case: ICU (COVID-19): A tool to communicate with families of critically ill patients with COVID-19' (p.8), in *Palliative Medicine Reports*.

Specialist Publications

'Improving support for family caregivers of people with a serious illness in the U.S.: Strategic agenda and call to action' (p.11), in *Palliative Medicine Reports*.

Palliative care helped family face “the awful, awful truth”

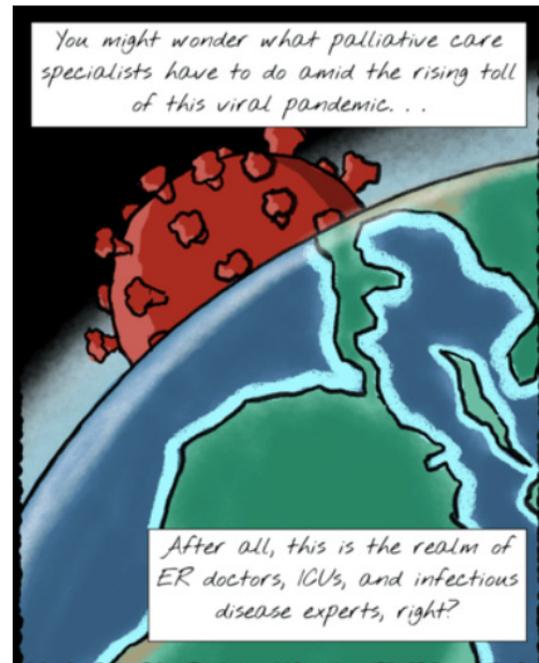
KAISER HEALTH NEWS | Online – 5 May 2020 – Clinician David Owens, like other palliative care specialists in COVID-19 hot spots around the country, has seen his professional duties transformed by the deadly coronavirus. Patients and their families face abrupt decisions about the kind of care they want, and time for sensitive deliberation is scarce. Conversations once held in person are now over the phone, with all the nuances of non-verbal communication lost. The comfort of family at the bedside of the dying is all but gone. This is the new reality for those who practice palliative medicine – a speciality focused on relieving pain and symptoms, improving quality of life, and providing support to patients and families during severe, chronic or fatal illness. Doctors and nurses trained in this branch of medicine are in high demand as hospitals treat thousands of terribly ill patients who may end up on life support with only a small chance of survival. Before the coronavirus, Owens rarely worked in the emergency room. Now he’s there regularly, called in whenever a suspected or confirmed coronavirus patient at high risk of complications comes through the doors. “It is a totally different atmosphere in an emergency room,” Owens said. “The conversations are more abbreviated than they would be because you are behind a mask, you are in a loud room, completely gowned up.” It’s a tough way to talk through sensitive and crucial questions about a patient’s chance of survival and what they want. <https://bit.ly/2L5iTiQ>

Palliative care: “The secret weapon hiding in plain sight”

FORBES | Online – 3 May 2020 – Diane Meier wanted to talk. The renowned geriatrician, professor of medical ethics, and director of the Center to Advance Palliative Care read my article in *Forbes* and was concerned.¹ “Everyone is going to think palliative care (PC) is only for people facing the end of life,” Diane told me. “That’s not true.” I re-read my article and realized that Diane had a point. I had written my piece in order to convey that, as clinicians, we don’t always put enough emphasis on the fact that much of what we clinicians offer does not cure disease – it manages it. I believe this is especially true when it comes to older patients and those with a range of serious chronic illnesses, for whom some of our medical interventions do a lot more harm than good. Rather than chasing low yield, high risk interventions, we should help our patients learn to live well despite chronic illness, help them find enjoyment and pleasure in the things that matter most, and provide them with the knowledge they need to make informed decisions. And that is where PC comes in. <https://bit.ly/2ypBH2>

1. ‘The hidden power of palliative care,’ *Forbes*, 18 November 2019. <https://bit.ly/2zUgtRX>

Palliative care in the time of COVID-19: A visual essay



MEDSCAPE | Online – 4 May 2020 – The fact that many clinicians have been called into clinical service to provide care outside of their specialty is well recognized. Palliative care specialists, too, must be braced for the onslaught. **Download/view slide presentation at:** <https://wb.md/2SOJ2aj>



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International

More people dying at home during COVID-19 pandemic: U.K. analysis

U.K. (England, Scotland & Wales) | *The Guardian* (London) – 8 May 2020 – About 8,000 more people have died in their own homes since the start of the Coronavirus pandemic than in normal times, a *Guardian* analysis has found, as concerns grow over the number avoiding going to hospital. Of that total, 80% died of conditions unrelated to COVID-19, according to their death certificates. Doctors' leaders have warned that fears and deprioritisation of non-Coronavirus patients are taking a deadly toll. The data shows 8,196 more deaths at home in England, Wales and Scotland compared with the five-year average for this time of year, including 6,546 non-COVID deaths. It also indicates a drop in non-COVID deaths in hospital, however, leading experts to conclude that many who would ordinarily have been admitted to a ward and died there are instead dying at home. <https://bit.ly/2yEDIEI>

COVID-19

Dying surrounded by family “a fundamental right” says U.K. judge

U.K. (England) | *The Guardian* (London) – 5 May 2020 – Being allowed to die surrounded by your nearest relatives is a fundamental part “of any right to private or family life,” a senior judge has ruled. Delivered in the middle of the Coronavirus crisis, the court of protection ruling could have an immediate effect at a time when families have been deterred from saying goodbye to people dying in care homes and hospitals due to fears over spreading the infection. In her judgment, in a case involving a terminally ill woman who has since died, Mrs. Justice Lieven said: “The ability to die with one’s family and loved ones seems to me to be one of the most fundamental parts of any right to private or family life ... It would seem to me self-evident that such a decision by the state that prevents someone with a terminal disease from living with their family, must require a particularly high degree of justification.” The case was brought earlier this year by the daughter of the elderly woman, who had been living in a care home for almost 10 years. The woman was diagnosed with advanced terminal ovarian cancer and admitted to hospital in January. She later returned to her care home. The ruling comes at a time of concern over deaths linked to COVID-19 in care homes. Many homes have banned visitors due to the risk of passing on the virus. <https://bit.ly/2yB1pbz>



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>

COVID-19: End-of-Life Care

'Bereavement support on the frontline of COVID-19: Recommendations for hospital clinicians' (p.7), in *Journal of Pain & Symptom Management*.

'A dual-centre observational review of hospital based palliative care in patients dying with COVID-19' (p.7), in *Journal of Pain & Symptom Management*.

Specialist Publications

'Redefining palliative care: A new consensus-based definition' (p.6), in *Journal of Pain & Symptom Management*.

'Palliative care: What, who, when, how' (p.6), in *World Medical Journal*.

Palliative care and frailty

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE NEWSLETTER, 2020;21(5). Frailty is a common geriatric syndrome that embodies an elevated risk of catastrophic declines in health and function among older adults. It is related to the overall health state of a person, which is determined by the number of medical conditions he or she presents. Considering the rapid ageing of the population around the world, more and more health practitioners will have to manage this complex condition. Typical of frailty is a decline of physiologic reserve. This results in greater risk of poor health outcomes, including falls, delirium, and functional decline, leading to hospitali-

zation and death. Studies have shown a clear association between frailty and health care costs and use. It is an emerging global health burden with major implications for clinical practice and public health. Because frailty is progressive and irreversible, there is a clear indication for the provision of palliative or end-of-life care. **Full text:** <https://bit.ly/2yJeX4R>

[Specialist Publications](#)

'Palliative care and end-of-life considerations for the frail patient' (p.4), in *Anesthesia & Analgesia*.

N.B. Selected articles on palliative and end-of-life care for the frail elderly noted in 17 February 2020 issue of Media Watch (#653, pp.11-12)

[Specialist Publications](#)

Palliative care and end-of-life considerations for the frail patient

ANESTHESIA & ANALGESIA, 2020;130(6):1504-1515. Patients with frailty experience substantial physical and emotional distress related to their condition and face increased morbidity and mortality compared with their non-frail peers. Palliative care (PC) is an interdisciplinary medical specialty focused on improving quality of life (QoL) for patients with serious illness, including those with frailty, throughout their disease course. Anesthesiology providers will frequently encounter frail patients in the perioperative period and in the intensive care unit (ICU) and can contribute to improving the QoL for these patients through the provision of PC. The authors highlight the opportunities to incorporate primary PC, including basic symptom management and straightforward goals-of-care (GoC) discussions, provided by the primary clinicians, and when necessary, timely consultation by a specialty PC team to assist with complex symptom management and GoC discussions in the face of team and/or family conflict. In this review, the authors apply the principles of PC to patients with frailty and synthesize the evidence regarding methods to integrate PC into the perioperative and ICU settings. **Abstract (via PubMed):** <https://bit.ly/2LgBIQh>

Palliative care for pediatric intensive care patients and families

CURRENT OPINION IN PEDIATRICS, 2020;32(3):428-435. This article reviews current evidence and best practices for integrating palliative care (PC) into the pediatric intensive care unit (PICU), with a focus on surgical patients. PC is best integrated in a tiered approach, with primary PC provided by the PICU and surgical providers for all patients and families, including basic symptom management, high-quality communication, and end-of-life care. Secondary and tertiary levels of care involve unit or team-based "champions" with additional expertise, and subspecialty PC teams, respectively. PICU and surgical providers should be able to provide primary PC, to identify patients and families for whom a PC consult would be helpful, and should be comfortable introducing the concept of PC to families. This review provides a framework and tools to enable PICU and surgical providers to integrate PC best practices into patient and family care. **Abstract:** <https://bit.ly/35DkOoB>

N.B. Additional articles on PC in PICUs noted in 9 March 2020 issue of Media Watch (#656, p.5).

Temporal trends in place of death for end-of-life patients: Evidence from Toronto, Canada

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 4 May 2020 – Understanding the temporal trends in the place of death among patients in receipt of home-based palliative care (PC) can help direct health policies and planning of health resources. The authors assessed the temporal trends in place of death and its determinants over the past decade for patients receiving home-based PC. They also examined the impact of early referral to home-based PC services on patient's place of death. Survey data collected in a home-based end-of-life care (EoLC) program in Toronto, Canada, from 2005 to 2015 were analysed using a multivariate logistic model. The results suggest that the place of death for patients in receipt of home-based PC has changed over time, with more patients dying at home over 2006-2015 when compared to 2005. Also, early referral to home-based PC services may not increase a patient's likelihood of home death. Understanding the temporal shifts of place of death and the associated factors is essential for effective improvements in home-based PC programs and the development of EoLC policies.

Abstract: <https://bit.ly/2SPCsQT>

Living in the moment for people approaching the end of life: A concept analysis

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – 6 May 2020 – “Living in the moment” is a special concept that helps nurses to provide a dignified quality of life to their patients and to help them cope with uncertainties that arise at the end of life (EoL). The authors' analysis has identified that the concept of living in the moment – and its attributes, antecedents and consequences – can be used for nurses to gain insight into their patients' perspectives, values and preferences relating to dignified person-centred care, to develop instruments that measure the concept, and to improve theory-based applications in palliative/EoL care settings. This analysis is also important to support nursing caring to help how patients who have a life-limiting illness can live in the moment. Further research is needed to expand on the definitions of health-related outcomes with respect to living in the moment from the family perspective.

Full text: <https://bit.ly/2Wzsvld>

Patients' experiences of telehealth in palliative home care: Scoping review

JOURNAL OF MEDICAL INTERNET RESEARCH, 2020;22(5):e16218. The use of telehealth in palliative home care does not seem to add further burden to most patients. Telehealth increased and improved access to healthcare professionals at home, and it enhanced the feelings of security and safety. Furthermore, the visual features of telehealth allowed a close connectedness with healthcare professionals, which seemed to be highly valued. There were contradicting results on whether the use of telehealth improved burdensome symptoms and quality of life. The results further suggest that telehealth apps may be a positive addition to palliative home care, and patients' reports thereof are in favor. However, healthcare professionals need to individually tailor the telehealth app to enhance usability and user friendliness for patients. Technology including video was preferable to patients. To make solid inferences and suggest recommendations for practice and policy, more systematic reviews and studies highlighting the negative aspects of telehealth should be conducted. Future studies also need to address the experiences of using telehealth among patients with life-limiting illnesses other than cancer and the oldest-old patients. **Full text:** <https://bit.ly/2SiGaeP>

N.B. Selected articles on telehealth in palliative care noted in 27 April 2020 issue of Media Watch (#663, pp.1-2).

Redefining palliative care: A new consensus-based definition

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 6 May 2020 – The International Association for Hospice & Palliative Care (IAHPC) developed a consensus-based definition of palliative care (PC) that focuses on the relief of serious health related suffering, a concept put forward by *The Lancet* Commission Global Access to Palliative Care & Pain Relief. Developing a consensus-based definition of PC required extensive deliberation, rigorous examination and thorough testing. It was challenging to find common ground among individuals with longstanding experience in the field of PC who had firmly held positions. Although the consensus-based definition is not perfect, it creates practice and policy value beyond its intended purpose of defining PC comprehensively and clearly. It provides an opportunity to examine international developments in the conceptualization and practice of PC and to achieve an explicit and shared understanding of that practice across the global community. The new definition is inclusive, encompasses health-system advances, and reflects the opinions and perceptions among a global community of professional health care providers. The new definition is aligned with the recommendations of *The Lancet* Commission, allowing for future synergy with efforts to implement the recommendations of its report and future implementation activities.¹ Future research is needed to evaluate the uptake, benefits and challenges faced by those who use this new definition. This consensus-based definition must be open to critical discussion that includes patients and caregivers as well as providers. To this end, the IAHPC continues to collate all feedback in what will be a continuous process of adapting the definition of PC to the ever-changing realities of patient needs.
Full text: <https://bit.ly/3dtSyHp>



1. 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage: *The Lancet* Commission report,' *The Lancet*, published online 7 October 2017. [Noted in 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** <http://bit.ly/2Ww8Cku>

N.B. 'Palliative care definition,' International Association for Hospice & Palliative Care. [Noted in 14 June 2019 issue of Media Watch (#597, p.4)] **Download/view at:** <https://bit.ly/2zgLyis>

Noted in Media Watch 17 February 2020 (#653, p.9):

- *CURRENT TREATMENT OPTIONS IN ONCOLOGY* | Online – 11 February 2020 – '**Evolving definitions of palliative care: Upstream migration or confusion?**' Palliative care (PC) has evolved over the decades from its roots in the hospice movement to a much wider approach in which early intervention further "upstream" in the illness is encouraged to improve quality of life for patients and their families. This new definition has a strong evidence base in cancer trials and is supported by major national and international organizations. However, it has proven difficult to convince patients, the public, and even healthcare providers, of this upstream migration of PC, with many continuing to associate PC exclusively with end-of-life care. **Abstract:** <http://bit.ly/2OSWQ1m>

Related:

- *WORLD MEDICAL JOURNAL*, 2020;66(2):25-28. '**Palliative care: What, who, when, how.**' Regrettably, there are many factors that work against the provision and delivery of palliative care... There will always be the need to contend with the "distaste" many health professionals feel when confronted with end-stage disease, and a reluctance to change the focus of care from disease control to comfort. Linked with this is the inability of many professionals to engage sensitively and skillfully in discussions about impending death. Further, the underlying values of most healthcare systems are incompatible with compassion and caring. The values of the system tend to be competition, rationalization, productivity, efficiency, and even profit. **Full text:** <https://bit.ly/3dfYHHI>

N.B. Link is to a pdf of the complete, February edition of the journal. Scroll down to the relevant pages.



Would the articles on this page be of interest to a colleague?

Bereavement support on the frontline of COVID-19: Recommendations for hospital clinicians

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 3 May 2020 – Deaths due to COVID-19 are associated with risk factors which can lead to prolonged grief disorder, post-traumatic stress and other poor bereavement outcomes among relatives, as well as moral injury and distress in frontline staff. The authors of this article review relevant research evidence, and provide evidence-based recommendations and resources for hospital clinicians to mitigate poor bereavement outcomes and support staff. For relatives, bereavement risk factors include dying in an intensive care unit, severe breathlessness, patient isolation or restricted access, significant patient and family emotional distress, and disruption to relatives' social support networks. Recommendations include advance care planning; proactive, sensitive and regular communication with family members alongside accurate information provision; enabling family members to say goodbye in person where possible; supporting virtual communication; providing excellent symptom management and emotional and spiritual support; and providing and/or signposting to bereavement services. To mitigate effects of this emotionally challenging work on

staff, the authors recommend an organisational and systemic approach which includes access to informal and professional support. **Full text:** <https://bit.ly/3fhSrAM>

Caring for bereaved family members during the COVID-19 pandemic: Before and after the death of a patient

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 May 2020 – Bereavement care is an integral component of quality end-of-life care. However, few hospitals and other health care institutions offer universal bereavement care to all families of deceased patients. Given the current COVID-19 pandemic, there is an urgency from a public health perspective to expand bereavement services in an attempt to mitigate poor bereavement outcomes, including prolonged grief disorder and other psychiatric disorders. The authors recommend that all hospitals implement basic bereavement outreach, utilizing palliative care tools and psychological strategies to prepare families for the death of their loved ones and to support them afterwards in the initial months of their bereavement. **Full text:** <https://bit.ly/2Wd5ETG>

Related:

- *HEART & LUNG* | Online – 7 April 2020 – ‘**Palliative care strategies offer guidance to clinicians and comfort for COVID-19 patient and families.**’ As the medical care of patients with COVID-19 evolves, palliative care (PC) has a role in the treatment of these patients and their families. Not all patients may need or be able to see specialist PC clinicians; however, PC strategies can be adapted for use by non-palliative specialist clinicians during this pandemic. PC principles can support clinicians navigating unfamiliar and distressing decision-making during these uncharted times and may help bring comfort to COVID-19 patients and their families. The authors discuss applying core PC principles as well as targeted strategies to support patients and families. **Full text:** <https://bit.ly/2YGdOWq>
- *JAMA ONCOLOGY* | Online – 7 May 2020 – ‘**Palliative care for patients with cancer in the COVID-19 era.**’ With early studies suggesting that patients with active cancer are particularly susceptible to COVID-19, the current pandemic is forcing palliative care (PC) health care professionals to better define our identity as a field. With social distancing requirements, should we minimize patient contact to keep our patients and ourselves safe? As a relatively new specialty, are PC consults a luxury that we can hold off on to avoid overburdening the medical system? Even in this pandemic, PC is not a luxury; it is a necessity. In these troubling times when we have to be cognizant of our patients' and our safety, we should not hold back on providing PC services. **Full text:** <https://bit.ly/3dpErmC>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 5 May 2020 – ‘**A dual-centre observational review of hospital based palliative care in patients dying with COVID-19.**’ This case series collected data from two acute hospitals examining the management of patients diagnosed with COVID-19 who subsequently died and compared this to national and local end-of-life audit data for all other deaths. This brief report suggests a spectrum of mode of dying and provides clinicians with a contemporaneous overview of the authors' experience, knowledge and pattern recognition when caring for people with COVID-19 and highlights the value of proactive identification of patients and risk of deterioration and palliation. **Abstract (w. link to references):** <https://bit.ly/2xFKleP>

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 May 2020 – ‘**COVID-19: A time for creative compassion.**’ The COVID-19 pandemic has changed our world in almost every aspect, but it does not get to change the fact that patients deserve – and healthcare workers want to deliver – compassionate care. As it is unlikely that things will “go back to normal” for the foreseeable future, compassion, creativity, and solidarity will be essential for creating new ways to provide patient-centered care. For end-of-life care, the range of our capabilities has become restricted, but with a little effort and a lot of heart, we can still perform the small acts of kindness that we already know make a big difference. **Full text:** <https://bit.ly/2zIEJfH>
- *PALLIATIVE MEDICINE REPORTS* | Online – 30 April 2020 – ‘**Best case/Worst case: ICU (COVID-19): A tool to communicate with families of critically ill patients with COVID-19.**’ During the COVID-19 pandemic, critically ill patients have been hospitalized and strictly isolated. In March 2020, palliative care clinicians at the University of Wisconsin were asked to bridge a gap in communication between patients' families and critical care teams, as bedside demands overwhelmed the critical care team's capacity to provide consistent communication with family. In response, the authors adapted an established intervention ... to support daily conversations between hospital-based clinicians and out-of-hospital family. **Full text:** <https://bit.ly/2W3sVrk>

The first steps taken to implement palliative care in advanced heart disease: A position statement from Denmark

JOURNAL OF PALLIATIVE MEDICINE | Online – 7 May 2020 – The aim of the article was to generate a national position statement as the first step in implementing palliative care (PC) in severe heart disease with focus on advanced heart failure, including tools to identify the need for and timing of PC and how PC could be organized in Denmark. A task force was formed in the Danish Society of Cardiology Heart Failure Working Group, and the position statement was prepared in collaboration with members from a broad group of specialties, including palliative medicine. Because of major gaps in evidence, the position statement was based on small and low-quality studies and clinical practice statements. This position statement was aligned with the European Society of Cardiology recommendation, focusing on relieving suffering from the early disease stages parallel to standard care and supplementing life-prolonging treatment. The statement delivers practical guidance on clinical aspects and managing symptoms during the three stages of advanced heart disease. Furthermore, the statement describes the importance of communication and topics to be broached, including deactivating implantable cardioverter defibrillators. The statement recommends a targeted effort on organizational strategies using high-quality assessment tools and emphasizes multidisciplinary and inter-sectoral collaboration. Danish cardiologists supported by allied professionals acknowledge the importance of PC in advanced heart disease. This national position statement intended to inform and influence policy and practice and can hopefully inspire other countries to take action toward implementing PC in advanced heart disease. **Abstract:** <https://bit.ly/3bdb05S>

Exploring patients' experience with clinicians who recognize their unmet palliative needs: An inpatient study

JOURNAL OF PALLIATIVE MEDICINE | Online – 4 May 2020 – Given the national shortage of palliative care (PC) specialists relative to the need for their services, engaging non-specialists is important to ensure patients with serious illness have an opportunity to share their goals and values with their providers. Hospital medicine clinicians are well positioned to conduct these conversations given they care for many medically complex patients. Yet, little is known about the patient experience of inpatient goals and values conversations led by hospitalist teams. An automated screening tool was used to identify patients at increased risk for unmet palliative needs. The multidisciplinary team was informed of the screen's results on the intervention units but not on the control units. Intervention unit clinicians were asked to consider talking with patients about their goals and values. The intervention patients reported improved quality of communication and fewer anxiety and depression symptoms compared with the control patients. Hospice utilization in addition to emergency department visits and hospital readmissions did not differ between the two groups. This study suggests that informing the care team regarding their patients' potential unmet PC needs is associated with patients reporting improved experience of their care without adverse effects on their mood. **Abstract:** <https://bit.ly/2L4lhGE>

Patients with haematological malignancies should not have to choose between transfusions and hospice care

THE LANCET HAEMATOLOGY, 2020;7(5):e418-e424. Despite the clear benefits of hospice care, patients with haematological malignancies [in the U.S.] have the lowest rates of enrolment among patients with any tumour sub-type. Furthermore, when patients with haematological disorders do enroll into hospice care, they are more likely to do so within 3 days of death than are patients with non-haematological malignancies. Although reasons for low and late hospice use in this population are multifactorial, a key barrier is limited access to blood transfusions in hospice programmes. In this Viewpoint, the authors discuss the relationship between transfusion dependence and hospice use for patients with blood cancers. They suggest that rather than constraining patients into either transfusion or hospice models, policies that promote combining palliative transfusions with hospice services are likely to optimise end-of-life care for patients with haematological malignancies. **Summary:** <https://bit.ly/3f7quLl>

Noted in Media Watch 4 March 2020 (#604, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 26 February 2019 – ‘**Haematologists and palliative care: A multi-centric qualitative study.**’ This study identifies haematologists’ perceptions of palliative care (PC). This study highlights four key themes: 1) The aim of PC was clearly identified as alleviating severe suffering; 2) PC was identified as a separate specialty, and participants expressed the need for collaboration; 3) Early intervention was perceived as beneficial to avoid certain situations such as hospitalisation or emergency department visits at the end of life (EoL); 4) The main barrier to PC referral remained the negative connotations associated with the term “palliative,” which was overwhelmingly associated with the EoL... **Abstract:** <http://bit.ly/2H5PTH2>

The more who die, the less we care: Confronting the deadly arithmetic of compassion

MEDICAL DECISION MAKING | Online – 6 May 2020 – We are inconsistent and sometimes incoherent in our valuation of human life. We value individual lives greatly, but these lives lose their value when they become part of larger crisis. As a result, we do too little to protect human lives in the face of catastrophic threats from violence, natural disasters, and other causes. In medicine, this may pose difficult choices when treating individual patients with expensive therapies that keep hope alive but are not cost effective for the population, for example with end-of-life care. Lifesaving judgments and decisions are highly context-dependent, subject to many forms of response mode and framing effects and affective biases. This has implications for risk communication and the concept of shared decision-making. Slower, more introspective decision-making, as in the cleft palate example, may reduce some of the affective biases associated with fast, intuitive decisions. But slow thinking can also induce serious biases as can occur with the prominence effect. **Full text:** <https://bit.ly/2WJAT8e>

“Empty chairs at empty tables.”: Disenfranchisement by association

OMEGA – JOURNAL OF DEATH & DYING | Online – 7 May 2020 – The rise in research publications over the last few decades about disenfranchised grief has deepened our understanding of this field. Importantly, it raises awareness and validates human experiences of bereavement, which are often socially ignored, muted, and stigmatized. However, while researchers in the field actively engage in the task of “enfranchisement,” as they present their work at scientific conferences, they might experience what we term *disenfranchisement by association* in the academic sphere. Based on our own experience, this article will demonstrate the parallel pathways between disenfranchisement of bereaved individuals and disenfranchisement of disenfranchised grief researchers, as it emerges in three main expressions of disenfranchisement: reluctance to listen, shame and guilt inflicting, and demand for euphemism. A conclusive note on how to address this kind of disenfranchisement is suggested. **Abstract:** <https://bit.ly/2Lber2b>



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

A mixed-methods pilot study of ‘LIFEView’ audiovisual technology: Virtual travel to support well-being and quality of life in palliative and end-of-life care patients

PALLIATIVE MEDICINE | Online – 8 May 2020 – This pilot study provides evidence that ‘LIFEView’ technology is feasible to integrate into existing care practices as a reminiscence and virtual travel programme for adults receiving inpatient and community palliative care (PC) services. For most participants, use of ‘LIFEView’ videos and accompanying music yielded extensive conversation, reminiscence and meaning-making during sessions and interviews. Correspondingly, previous studies using reminiscence or life review interventions in PC contexts demonstrated reminiscence as an effective method of finding meaning in one’s life experiences and also found associated reductions in psychosocial and spiritual distress. Future research with ‘LIFEView’ should encourage family participation, as individuals with pre-existing relationships to participants may increase instances of reminiscence and meaning-making, and thus potential improvements in well-being. **Full text:** <https://bit.ly/3beEsse>

Specialist paediatric palliative care for children and young people with cancer: A mixed-methods systematic review

PALLIATIVE MEDICINE | Online – 2 May 2020 – An evidence base of mainly low- and moderate-quality studies shows that accessing specialist paediatric palliative care (PC) is associated with less intensive care at the end of life (EoL), more advance care planning, and fewer in-hospital deaths. Current evidence cannot tell us whether these services improve children’s symptom burden or quality of life (QoL). Nine studies reporting provider or family views identified uncertainties about what specialist paediatric PC offers, concerns about involving a new team, association of PC with EoL, and indecision about when to introduce PC as important barriers to access. There was evidence that children with haematological malignancies are less likely to access these services. Current evidence suggests that children and young people with cancer receiving specialist PC are cared for differently. However, little is understood about children’s views, and research is needed to determine whether specialist input improves QoL. **Abstract (w. list of references):** <https://bit.ly/2WmO5zt>

Noted in Media Watch 19 August 2019 (#627, p.11):

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

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 May 2020 – ‘**Supporting pediatric patients and their families at the end of life: Perspectives from bereaved parents.**’ This study asked bereaved parents to reflect on their child’s end-of-life care to identify which components of decision-making, supportive services, and communication were helpful, not helpful, or lacking. Most reported a desire for shared decision-making... There was a statistically significant association between how well death went and whether the parental perception of actual decision-making aligned with desired decision-making. Families did not utilize many of the supportive services that are available including psychology and psychiatry. **Abstract (w. list of references):** <https://bit.ly/2W9pejZ>
- *CHILDREN* | Online – 1 May 2020 – ‘**Grief and bereavement in parents after the death of a child in low- and middle-income countries.**’ A core component of high-quality pediatric palliative care that has been relatively neglected in low- and middle-income countries (LMICs) is grief and bereavement support for parents after the death of their child. The authors review the current literature on parental grief and bereavement in LMICs. This includes describing bereavement research in high-income countries, including its definition, adverse effect upon parents, and supportive interventions, followed by a review of the literature on health-related grief and bereavement in LMICs... **Full text (click on pdf icon):** <https://bit.ly/2zcY15u>

Improving support for family caregivers of people with a serious illness in the U.S.: Strategic agenda and call to action

PALLIATIVE MEDICINE REPORTS | Online – 30 April 2020 – The urgent need for a systematic approach to comprehensively improve support for family caregivers (FCGs) of people with serious illness in the U.S. is clear, given the current state that has recently been highlighted as a public health crisis. The economic implications should not be understated given the large societal burden resulting from reduced work productivity and increased use of healthcare resources by caregivers. Progressing the strategic directions developed in this plan will require a commitment from federal and state governments to implement and monitor progress toward the vision of improved quality of life for caregivers. The success of this strategy will depend upon leaders from key stakeholder groups working collaboratively to reach consensus on priorities and a willingness to accept responsibility for completing tasks effectively. The markers of a transformed system will result in a society in which FCGs have their own health and well-being considered, together with their rights and protections. They would also have access to evidence-based health information and support when they need it. Providers would have the competencies to provide high-quality (best practice), culturally appropriate, and family-centered services. **Full text:** <https://bit.ly/2Yz5QhE>

“Everybody in this community is at risk of dying.”: An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner-city settings

PALLIATIVE & SUPPORTIVE CARE | Online – 7 May 2020 – At the end of life, the need for care increases. Yet, for structurally vulnerable populations (i.e., people experiencing homelessness and poverty, racism, criminalization of illicit drug use, stigma associated with mental health), access to care remains highly inaccessible. Emerging research suggests that enhancing access to palliative care (PC) for these populations requires moving care from traditional settings, such as the hospital, into community settings, like shelters and onto the street. Thus, inner-city workers (ICWs) (e.g., housing support and community outreach) have the potential to play pivotal roles in improving access to care by integrating a “palliative approach to care” in their work. Findings of this study reveal three themes: 1) Approaches, awareness, and training; 2) Workplace policies and filling in the gaps; and, 3) Grief, bereavement, and access to supports. In brief, ICWs who draw upon harm reduction strategies strongly parallel palliative approaches to care, although more knowledge/training on palliative approaches was desired. In their continuous work with structurally vulnerable clients, ICWs have the opportunity to build trusting relationships, and over time, are able to identify those in need and assist in providing palliative support. However, despite death and dying is an everyday reality of ICWs, many described a lack of formal acknowledgement by employers and workplace support as limitations. These findings contribute promising practices for enhancing equitable access to PC for society’s most vulnerable populations by prioritizing front-line workers’ perspectives on how best to integrate a palliative approach to care where structurally vulnerable populations live and die. **Abstract (w. list of references):** <https://bit.ly/2WddSv6>

Noted in Media Watch 4 May 2020 (#664, p.13):

- *PALLIATIVE MEDICINE* | Online – 27 April 2020 – ‘**Caregiving at the margins: An ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end of life.**’ Research suggests strategies for enhancing access to palliative care for structurally vulnerable populations by meeting them “where they are at,” not only geographically in shelters, on the streets, and in housing units that may be traditionally deemed “unsafe” by the formal healthcare sector, but also socially to ensure they feel safe and are surrounded by care providers capable of providing them with comfort. Family caregivers have the potential to play a pivotal role, yet they must first be recognized as valuable members of the care team. **Full text:** <https://bit.ly/3eS7uRg>



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 beginning on p.13.

Managing death: Navigating divergent logics in end-of-life care

SOCIOLOGY OF HEALTH & ILLNESS | Online – 6 May 2020 – This article illuminates complex and ambiguous ethical questions relevant to the attempt to deliver choice-led end-of-life care (EoLC). How these questions are interpreted and acted upon by individual practitioners is shaped by organisational and professional logics, and three in particular: 1) Financial; 2) Patient choice; and, 3) Professional authority, which reflect meta-logics of finance, market and profession. These logics are interconnected in practice and the interplay of these logics is complex, variegated and unpredictable in the extent to which they might limit or afford particular actions by particular individuals. The dominant philosophy in EoLC, embedded in policy and practice, seeks to privilege patient choice and encourage what is seen as more cost effective, out-of-hospital activity. However, analysing the logics at play in this field shows how patient choice is structured by the actions of different health and care professionals, and that hierarchies of authority within health and care influence these actions. This is not a predictable situation of medical authority superseding non-medical, or doctor versus nurse, however – these dynamics are present, but influence is also mobilised by being familiar with patients and their families, by the physical location of the patient within different organisations (care home, hospital, etc.) and by the alignment of professional values with current conceptions of a “good death,” that is, at home or out of hospital, avoiding unnecessary intervention, lower cost and (at the same time) in line with the wishes of the patient him/herself. The values that practitioners bring and are able to enact within EoLC therefore might have a significant impact on outcomes. **Full text:** <https://bit.ly/3bcrYRF>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *WORLD MEDICAL JOURNAL*, 2020;66(2):28-37. ‘**The “normalization” of euthanasia in Canada: The cautionary tale continues.**’ In June 2016, Canada legalized euthanasia and assisted suicide, which legislators referred to collectively as medical assistance in dying” (MAiD). The authors aim to balance recent portrayals in the popular and medical media that imply only a positive impact as a result of the introduction of euthanasia into Canada’s health system. Evidence is presented to demonstrate that there are significant negative and dangerous consequences of this radical shift for medicine, and particularly for palliative medicine. These include the widening and loosening of already ambiguous eligibility criteria, the lack of adequate and appropriate safeguards, the erosion of conscience protection for healthcare professionals, and the failure of adequate oversight, review and prosecution for non-compliance with the legislation. Indeed, what has been seen over the past four years is that “the slope has in fact proved every bit as slippery as the critics had warned.” The authors also seek to reaffirm the vision of the physician’s role “to cure sometimes, to relieve often and to comfort always.” **Full text:** <https://bit.ly/3dfYHHI>

N.B. Link is to a pdf of the February edition of the journal. Scroll down to the relevant pages.

Publishing Matters

Scientific research on the Coronavirus is being released in a torrent: Will that change how science is published?

THE ECONOMIST | Online – 7 May 2020 – Exponential increases are a hallmark of pandemics. The spread of SARS-CoV-2 around the world has followed such a curve inexorably. But so, too, has the research effort to understand and control the virus. More than 7,000 papers on the pandemic – covering everything from virology to epidemiology – have appeared in the past three months... A fifth of them have come out in the past week alone. This is astonishingly fast. Researchers usually take years to design experiments, collect data and check results. Scientific journals, the self-appointed keepers of the gate between those researchers and the rest of the world, can easily take six months, often a year, to grind through the various steps of their procedure, including editing and the process of checking by anonymous outside experts, known as peer review. The current public health emergency has, however, turbocharged all this. **Full text:** <https://econ.st/2zmvk7i>

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.

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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.

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Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/2YJZzQt>

[Scroll down to 'Media Watch']

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

Australia

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

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

Cont.

Canada



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

[Scroll down to 'Are you aware of Media Watch?']

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

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTP://BIT.LY/300WMRT>

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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