

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.

5 October 2020 Edition | Issue #686



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In times of uncertainty and complexity, palliative care should stand shoulder-to-shoulder with patients, caregiver, clinicians, and health systems to contribute to hoping for the best, and planning for the rest.

'Compassion in a crisis: The role of palliative care during the COVID-19 pandemic' (p.9), in *Mayo Clinic Proceedings*.

U.S.A.

New Executive Order may put palliative care for newborns at risk

FORBES | Online – 1 October 2020 – Progress in medical management gets blurred when one speaks of palliative care (PC) for newborns, where the decision is made to forego invasive medical interventions, letting the newborn pass away in the setting of receiving multiple modalities of comfort care. In some instances, this decision is discussed after birth, either in the days and hours subsequent to delivery, or even months later, when no medical intervention can be instituted to improve the dismal outcome for the child. In other cases, this decision might be discussed during pregnancy, when prenatal testing reveals multiple severe abnormalities that would preclude viability. Usually such devastating anomalies can be discovered early in pregnancy, in the first 12 to 18 weeks, but some may not be found until the third trimester, after 26 weeks of pregnancy. In still other situations, pediatric PC may be discussed for older infants and children, where a devastating illness or injury may lead to consideration for end-of-life discussions. PC is typically thought of as an option for end-stage illnesses in

adults, palliation for children, and, yes, newborns is a critical part of pediatric medicine. According to an article published in 2018 from the University of Missouri-Kansas City School of Medicine, "There remains a need to integrate PC with intensive care rather than await its application solely at the terminal phase of a young infant's life – when s/he is imminently dying. Future considerations for applying neonatal PC include its integration into fetal diagnostic management, the developing era of genomic medicine, and expanding research into PC models and practices in the neonatal intensive care unit."¹ <https://bit.ly/33pVBhP>

Specialist Publications

'Exploring the impact of the Coronavirus pandemic on pediatric palliative care clinician personal and professional well-being: A qualitative analysis of U.S. survey data' (p.7), in *Journal of Pain & Symptom Management*.

1. 'Pediatric palliative care in infants and neonates,' *Children*, published online 7 February 2018. [Noted in Media Watch 12 February 2018 (#550, p.9)] Full text: <https://bit.ly/34eL73S>

Cont.

Noted in Media Watch 10 August 2015 (#422, p.8):

- *AMERICAN JOURNAL OF MATERNAL CHILD NURSING*, 2015;40(1):44-50. ‘**Clinician perspectives of barriers in perinatal palliative care.**’ Physicians and nurses [i.e., study participants] differ significantly in the barriers that they report. Nurses expressed more obstacles at the healthcare systems level reporting difficulty in their ability to garner interdisciplinary support and gain administrative backing. Physicians were more confident in their ability to counsel patients than nurses. Members of both disciplines expressed similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. The study participants also reported a lack of societal support and understanding about perinatal palliative care. **Abstract:** <https://bit.ly/3e3Gpu4>

Noted in Media Watch 18 May 2020 (#666, p.6):

- *ADVANCES IN NEONATAL CARE* | Online – 6 May 2020 – ‘**Conceptually redefining neonatal palliative care.**’ The purpose of this article is to suggest a conceptual definition of neonatal palliative care (NPC) that encompasses all the essential concepts as a way of moving NPC forward by having a consistent approach. Following a review of the NPC literature, a thematic analysis as a method for identifying, analyzing, and interpreting patterns of meaning in the definitions (“themes”) within the literature was undertaken. The major themes identified included philosophies of care, support, culture and spirituality, the team, and clinical management. At the heart of NPC is the primacy of maintaining quality of life, while providing ethical and humane care that supports a “good death.” **Abstract:** <https://bit.ly/2LsFvKJ>

Physicians misjudge a terminal patient’s life span: Is it fraud?

KAISER HEALTH NEWS | Online – 30 September 2020 – Can physicians always tell when a patient has less than 6 months to live? And if they misjudge, is that fraud? A registered nurse and three non-clinicians filed a federal False Claims Act (FCA) lawsuit against Care Alternatives, a for-profit hospice in Cranford, New Jersey, claiming the hospice illegally admitted at least 16 patients who were not in their last 6 months of life and so did not qualify for Medicare hospice coverage. The whistleblowers’ medical expert ... testified that the patients’ medical records did not back up the hospice medical director’s prognosis of imminent death and thus did not support a certification of need for hospice care. The hospice’s medical expert disagreed, testifying that a physician could reasonably have determined that the life expectancy of each of those patients was 6 months or

less. The whistleblowers were all former staffers. A federal district judge held that a “mere difference of opinion between physicians, without more, is not enough” to show that the hospice filed false claims to Medicare under the law. But in March, the 3rd U.S. Circuit Court of Appeals reversed that ruling, finding that “a difference of medical opinion is enough evidence to create a triable dispute of fact regarding FCA falsity.” <https://wb.md/2ESFcJm>

[Specialist Publications](#)

‘Palliative, hospice, and end-of-life care and Omnibus Budget & Reconciliation Act regulations’ (p.5), in *Caring for the Ages*.

Is death the great equalizer?

MASSACHUSETTS | *The Boston Globe* – 25 September 2020 – In 2019, *The Boston Globe* Spotlight team set out to research death in Massachusetts, to determine the effect of wealth and race on how long people live and how and where they die. This investigation involved an unprecedented statistical review of the information contained on 1.2 million death certificates, covering every Massachusetts death back to 1999. The Spotlight team surveyed by mail more than 450 families that had recently lost a loved one, asking specific questions about the end-of-life (EoL) care their loved one received. And the team collaborated with Suffolk University on an unusual survey, polling public opinion on issues related to death and dying. The findings were stark and striking. Here, in a progressive state that boasts some of the world’s greatest hospitals, poor people live shorter lives, much shorter, than those with money. Black and Latino



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patients get less hospice care, die with more pain, and suffer more early deaths than do white and Asian people. People who are Black, Latino, or poor die more often inside sterile hospitals, while the wealthier have long had better access to residential-like alternatives. The team found that in addition to a lack of good options for everyone, there is often a lack of trust; for Black patients, especially, EoL planning to avoid an overly medicalized death raises suspicions about not getting enough care. <https://bit.ly/3mY2xdB>

N.B. This article is the first in a three-part series. Selected articles on disparities in the provision and delivery of hospice and palliative care for racial/ethnic minorities in the U.S. noted in Media Watch 31 August 2020 (#681, p.3).

International

Concern over lack of clarity in guardian awareness of do-not-resuscitate forms

U.K. (Scotland) | *Evening Express* (Aberdeen) – 30 September 2020 – New figures published by the Mental Welfare Commission ..suggest it is unclear if guardians had been told about the do-not-attempt CPR (DNACPR) form in 67% of such cases. Guardianship orders are used to safeguard those who lack the capacity to make their own decisions, with 15,973 orders in place in Scotland as of this March. It marks the highest figure ever recorded – up from more than 6,400 people in 2012, with 3,199 orders granted in 2019-2020... The majority (74%) of granted guardianship orders last year were private, from relatives or friends, with the remainder from local authorities. As well as a lack of clarity over DNACPR, the commission also found just 76% of individuals and guardians had received a visit from a supervising officer in the past six months. The same figure (76%) had the correct medical certification from doctors for their medical treatment, which suggests just under a quarter do not have the proper paperwork. <https://bit.ly/3n6oZBv>



Global palliative care database

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE | Online – 29 September 2020 – The association has announced a joint collaboration project with the Federación Médica de Buenos Aires, Argentina, to develop a Global Palliative Care Database from palliative care (PC) services from around the world. The objectives of this project are to: 1) Provide demographic, epidemiological information of patients at the time of the first consult with a PC service; 2) Identify the prevalent symptoms at the time of the initial PC consultation; 3) Identify the therapeutic interventions recommended for the treatment and management of the symptoms identified in the consultation; and, 4) Analyze the similarities and differences among and prepare a report for publication. The database will show the similarities and differences among reasons for referral and time of referral to PC services, as well as pre-

scribed therapeutic interventions and referrals to other disciplines. The system registers items adapted from 'An essential package of PC and pain relief health services,' in *The Lancet Commission on Global Access to Palliative Care & Pain Relief Report*.¹ <https://bit.ly/3cKbRxI>

Specialist Publications

'Estimating the number of patients receiving specialized palliative care globally in 2017' (p.7), in *Journal of Pain & Symptom Management*.

'Gaps in end-of-life care and lack of support for family carers in Poland and Central Eastern Europe' (p.7), in *Palliative Care & Social Practice*.

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 Media Watch 16 October 2017 (#534, p.14)] **Full text:** <http://bit.ly/2Ww8Cku>

Cont.

Noted in Media Watch 28 September 2020 (#685, p.13):

- *PALLIATIVE MEDICINE REPORTS* | Online – 15 September 2020 – ‘**Palliative care in public policy: Results from a global survey.**’ National policy recognition for palliative care (PC) is far from universal and is generally (though not exclusively) confined to high-income countries. There is some evidence, however, that a significant number of others, including low- and middle-income countries, are making progress in this direction. A 2015 World Health Organization survey reported that 37% of countries had an operational national policy for non-communicable diseases that included PC.¹ This is a higher figure than the authors report for the number of countries with a stand-alone policy. Two factors may explain the difference. **Full text:** <https://bit.ly/2G44pAw>

1. ‘National palliative care capacities around the world: Results from the World Health Organization Non-communicable Disease Country Capacity Survey,’ *Palliative Medicine*, 2018;32(1):106-113. [Noted in Media Watch 10 July 2017 (#520, p.15)]. **Abstract (w. list of references):** <https://bit.ly/3cnVbv3>

Noted in Media Watch 29 June 2020 (#672, p.5):

- *HEALTH POLICY & PLANNING* | Online – 24 June 2020 – ‘**Strategies used to establish palliative care in rural low- and middle-income countries...**’ Despite the inclusion of palliative care (PC) in national health policy in some countries, implementation in the community is often reliant on advocacy and financial support from non-government organizations. Networking to coordinate care and medication availability near-patient homes are essential features of implementation. Training, role play, education and mentorship are strategies used to support health providers and volunteers. PC services for rural low- and middle-income countries communities may best be delivered using a networked service among health professionals, community volunteers, religious leaders and technology. **Abstract:** <https://bit.ly/383nT2j>

Noted in Media Watch 1 June 2020 (#668, p.19):

- *WELLCOME OPEN RESEARCH* | Online – 20 May 2020 – ‘**Global development of children’s palliative care: The picture in 2017.**’ The authors identified 21 countries in the highest categories of development for children’s palliative care (PC)... In addition, 778 million children live in 55 countries with only isolated and patchy provision. Meanwhile, 610 million children live in 77 countries that only have capacity building activity in place. A further 265 million children live in 106 countries where no known children’s PC activity is taking place, or it has proved impossible to gather any evidence on it. An even greater number, 646 million children, live in 29 countries where the available evidence on the level of children’s PC development is contradictory. **Full text:** <https://bit.ly/3ggncq5>

N.B. Additional articles on global PC development in this issue of Media Watch.

Portable designs to temporarily convert subacute hospital rooms into palliative care rooms

AUSTRALIA (Victoria) | *Lens* (Monash University, Melbourne) – 17 September 2020 – In 2016 there were 77,369 palliative care (PC) related hospitalisations in Australia. Australia has 673 public acute hospitals, but only 133 have dedicated hospice units – about a third of which are located in New South Wales. Average length of stay for PC patients is 10.7 days, compared to 5.6 days for other hospitalisations. Due to this lasting mismatch in demand and supply, in 2011, only 34% of palliative patients received care in a designated PC room, while 27% were managed in acute or subacute hospital rooms. The proposed design concepts can fulfil a lasting need with the rapid and temporary conversion of subacute hospital rooms into PC rooms. Consisting of a guest bed that folds out of a cabinet and a digital

connectivity module, the system allows the PC patient to have family stay overnight and allows for the personalisation of the hospital room. The digital connectivity module can be used to display iPads or electronic communications devices, enabling patients to digitally spend time with family, beyond the hospital. <https://bit.ly/3imwO2u>

[Specialist Publications](#)

‘**The impact of introducing palliative care needs rounds into rural residential aged care: A quasi-experimental study**’ (p.5), in *Australian Journal of Rural Health*.

Specialist Publications

Caring for Native Americans

AMA JOURNAL OF ETHICS, 2020;22(10):E831-E905. Inequity in health status and in access to health services are pervasive, largely unrecognized, and poorly addressed in American Indian and Alaska Native communities. Understanding the origins of historically entrenched patterns of oppression and relationships between present-day practices and policies governing tribal health sites can inform the nature and scope of clinicians' individual and collective obligations. Innovating health professions education and research partnerships with Native communities can also motivate equity. This theme issue considers ethical, social, and cultural complexities of what it means to deliver just care to Native patients living on sovereign tribal land and everywhere in the U.S. **Contents page:** <https://bit.ly/30plzQv>

Noted in Media Watch 30 July 2018 (#574, p.9):

- *CANCER HEALTH DISPARITIES* | Online – 21 July 2018 – ‘**The evolution of palliative care within the American Indian Health System.**’ Palliative care (PC) is now considered an important quality component within cancer care and essential to the continuum of cancer care programs nationwide. American Indian and Alaska Native patients have significant differences in mortality from various cancers, and therefore PC is very important while working in parallel towards improved survival overall. In fact, PC has in some circumstances even contributed to improved survival. This article recounts the efforts made over many years to institute quality PC programs that are culturally acceptable to native populations and outlines “next steps.” **Abstract:** <http://bit.ly/2DXy2dZ>

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

The impact of introducing palliative care needs rounds into rural residential aged care: A quasi-experimental study

AUSTRALIAN JOURNAL OF RURAL HEALTH | Online – 27 September 2020 – This study was conducted at two residential aged care facilities in one rural town in the Snowy Monaro region of New South Wales, Australia. Palliative care (PC) needs rounds are monthly onsite triage/risk stratification meetings where case-based education and staff support help to identify residents most at risk of dying without an adequate plan in place. They are attended by residential aged care staff and led by a palliative medicine physician. Eleven PC needs rounds were conducted between April and September 2018. The number of documented advance care plans increased. There were no statistically significant changes in hospitalisations or in-hospital deaths. Further studies are required to explore the rural influence on outcomes including hospital transfers and preferred place of death. **Abstract:** <https://bit.ly/2Grn2i3>

Palliative, hospice, and end-of-life care and [the U.S.] Omnibus Budget & Reconciliation Act regulations

CARING FOR THE AGES, 2020;21(7):16-17. The regulations and surveyor guidance expect the facility and the resident's attending physician/practitioner, to the extent possible, to identify a prognosis and the basis for that prognosis, and initiate discussions/considerations regarding advance care planning and resident choices to clarify goals and preferences regarding treatment including pain management and symptom control, treatment of acute illness, and choices regarding hospitalization. Hospice services are not mandated, but facilities are expected to help residents gain access to hospice services, if desired. If hospice services are used, the regulations require close coordination between the facility and the hospice to ensure adequate communication and safe and effective patient management. The surveyor guidance points out areas where hospice may (but does not automatically) retain primary responsibility: for example, providing medical direction and management of the resident; assigning a hospice aide as needed to support the resident's ongoing care; counseling (including spiritual, dietary, and bereavement); and durable medical equipment. There are expectations for timely communication and close coordination between the hospice and the nursing home regarding the care plan and mutual resolution of any related issues. On paper, this all sounds good. However, tightly coordinated, safe, and effective hospice care only happens sometimes.

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

The palliative care needs of lung transplant candidates

CLINICAL TRANSPLANTATION | Online – 25 September 2020 – Little is known about the palliative care (PC) needs of patients awaiting lung transplantation. Among the 111 study participants, 83.5% were white, 60.0% were female, and almost three-quarters had either restrictive or obstructive lung disease. The greatest PC needs included difficulty being physically active, physical symptoms, missing work due to illness, and concerns that life might end. Participants reported that religious/spiritual beliefs contribute to their sense of purpose, but had few unmet needs in this area. Only 6.4% of study participants reported seeing a PC specialist and 48.2% were unsure what a PC specialist is. The authors conclude that there are substantial PC needs among lung transplant candidates, particularly physical symptoms and end-of-life (EoL) concerns. These findings support integrating PC and EoL discussions in the management of lung transplant candidates. **Abstract:** <https://bit.ly/342cLB2>

N.B. Selected articles on PC and organ transplantation noted in Media Watch 28 October 2019 (#637, p.12).

The effectiveness and cost-effectiveness of hospital-based specialist palliative care for adults with advanced illness and their caregivers

COCHRANE SYSTEMATIC REVIEW | Online – 30 September 2020 – Very low- to low-quality evidence suggests that when compared to usual care, hospital-based specialist palliative care (HSPC) may offer small benefits for several person-centred outcomes including patient health-related quality of life (QoL), symptom burden and patient satisfaction with care, while also increasing the chances of patients dying in their preferred place (measured by home death). While the authors found no evidence that HSPC causes serious harms, the evidence was insufficient to draw strong conclusions. Although these are only small effect sizes, they may be clinically relevant at an advanced stage of disease with limited prognosis, and are person-centred outcomes important to many patients and families. More well conducted studies are needed to study populations with non-malignant diseases and mixed diagnoses, ward-based models of HSPC, 24 hours access (out-of-hours care) as part of HSPC, pain, achieving patient preferred place of care, patient satisfaction with care, caregiver outcomes (satisfaction with care, burden, depression, anxiety, grief, QoL), and cost-effectiveness of HSPC. In addition, research is needed to provide validated person-centred outcomes to be used across studies and populations. **Full text:** <https://bit.ly/2GnHi4g>

Enhancing mentoring in palliative care: An evidence based mentoring framework

JOURNAL OF MEDICAL EDUCATION & CURRICULAR DEVELOPMENT | Online – 23 September 2020 – Novice mentoring in palliative care (PC) enhances mentees' clinical skills, instills appropriate attitudes and practices in caring for dying patients, and advances the reputation of the host organization. Mentoring is increasingly used in the training of PC residents and specialist trainees. However, inertia to the resumption of novice mentoring programs following the loosening of COVID-19 restrictions has caught many off guard. At the heart of concerns amongst administrators, program designers and curriculum advisor as well as some mentors and mentees are growing concerns over reports of ethical issues in mentoring. Attributed to poor understanding and consequently ineffective structuring of mentoring programs recent reports list misappropriation of mentees' work, breaching professional boundaries, and bullying as just some of the issues faced by mentees in poorly structured and supported programs. Addressing gaps in understanding and structuring novice mentoring is hampered by a lack of data. **Full text:** <https://bit.ly/2GbxyKj>

Noted in Media Watch 29 April 2019 (#612, p.11):

- *PLOS ONE* | Online – 24 April 2019 – 'Mentoring stages: A study of undergraduate mentoring in palliative medicine in Singapore.' Mentoring nurtures a mentee's personal and professional development. Yet conflation of mentoring approaches and a failure to contend with mentoring's nature makes it difficult to study mentoring processes and relationships. The authors explore mentee experiences in a palliative medicine initiative. The initiative uses a consistent mentoring approach amongst a homogeneous mentee population and offers a unique opportunity to circumnavigate conflation of practices and the limitations posed by mentoring's nature. The data from this study will advance understanding of mentoring processes. **Full text:** <http://bit.ly/2ZxQA2L>

Estimating the number of patients receiving specialized palliative care globally in 2017

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 September 2020 – Significant disparities in palliative care (PC) access exist both by region and income group. The European and Pan-American regions had most while the Eastern Mediterranean, Southeast Asian, and African regions had least. Much more needs to be done to develop and deliver PC in low and middle-income countries (LMICs) where 80% of the need for PC exists. With about 70% of operating PC services in high income countries and only 30% in LMICs, a major effort to develop PC in these settings is urgently needed. If every country had a PC registry, we would have more accurate numbers but that is only available in high income countries like the U.S., the U.K. and Australia. The number of patients receiving PC was estimated in 2011 to be around three million while six years later the 2017 estimate has climbed to about seven million. This is more than double the numbers served in 2011. Likewise, the number of PC services increased from approximately 16,000 to 25,000, a 64% increase. This represents a significant advance in access to PC globally, however access to PC remains very limited. The disparity between the need for PC and its availability is striking. Too often PC is seen as a specialty that only well-resourced countries can afford. This is a wrong way to think as PC is an essential component of every healthcare system and is included in the continuum of universal health care under goal three of the 2016 UN Sustainable Development Goals for the world. **Full text:** <https://bit.ly/314f2CX>

Related:

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 29 September 2020 – ‘**Gaps in end-of-life care and lack of support for family carers in Poland and Central Eastern Europe.**’ End-of-life care (EoLC) is over medicalized in hospice-palliative care and hardly existing in long-term care. Dying is more a social than medical event, and as such, it should be cared for by compassionate communities, encouraging cooperation of professionals with family caregivers and society. Unfortunately, to date, there is no adequate cooperation in social dimension of EoLC in most of Central Eastern Europe. The social dimension of EoLC has to be recognized and empowered with the health promoting palliative care and introduction of compassionate communities in Central Eastern Europe. **Full text:** <https://bit.ly/30ncc3M>

Exploring the impact of the Coronavirus pandemic on pediatric palliative care clinician personal and professional well-being: A qualitative analysis of U.S. survey data

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 September 2020 – There is no doubt that the [COVID-19](#) pandemic has changed the way we practice clinical palliative care (PC) – be it with telehealth, physical distancing, or new approaches to communication. What is less described, is the direct personal and professional impact on PC clinicians. Indeed, while the aim of the PANDEMIC study was to describe how the field of pediatric PC was responding to the pandemic, survey respondents made clear that they, as individuals, were struggling, learning, and changing, too. Specifically, they reported both burdens and benefits affecting their personal and professional well-being. Their words focused on a sense of collective grief and uncertainty, a lack of professional productivity, and challenges with work-life balance. A minority focused on more positive experiences, such as new perspectives about personal values and opportunities for professional development. That the PC community articulated such universal stressors is not surprising. As a discipline, PC is particularly attuned to the holistic aspects of adversity. When it comes to serious illness, for example, we recognize that both personal and professional lives are impacted and need support. The findings of this study underscore the fact that challenging experiences influence all aspects of our lives. More, challenges in one sphere translate to challenges in others. The most self-evident example is the ubiquitous experience of working-from-home during COVID-19: balancing professional demands, personal worries, and the needs of family has been challenging for many. **Full text:** <https://bit.ly/2GjN7jl>



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.10.

Course of changes in emotional preparedness for death and its associations with caregiving outcomes for family caregivers of terminally ill cancer patients over their last year of life

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 25 September 2020 – Preparing family caregivers for a patient's death is an integral component of quality end-of-life (EoL) care, but temporal changes in emotional preparedness for death and its associations with caregivers' psychological well-being or quality of life (QoL) while providing EoL caregiving are under-researched. Without active, effective clinical interventions to promote caregivers' emotional preparedness for death, they cannot automatically become more prepared for the patient's death over time. Adequate emotional preparedness for the patient's death benefits caregivers by its associations with a lower likelihood of depressive symptoms and better QoL. Supportive programs for caregivers of terminally ill cancer patients should focus not only on enhancing caregiving skills, but also cultivating emotional preparedness for their relative's death to promote their psychological well-being and QoL. **Abstract (w. list of references):** <https://bit.ly/3mSyl3l>

Noted in Media Watch 6 July 2020 (#673, p.6):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 July 2020 – “**I could never prepare for something like the death of my own child**”: **Parental perspectives on preparedness at end of life for children with complex chronic conditions.** Parents of children who received care at Boston Children's Hospital and died between 2006-2015 completed 21 open-response items querying communication, decision-making and end-of-life (EoL) experiences as part of the Survey of Caring for Children with complex chronic conditions. Most ... described feeling unprepared for their child's EoL, despite palliative care and advance care planning, suggesting preparedness is a nuanced concept beyond “readiness.” **Abstract (w. list of references):** <https://bit.ly/2NU3r10>

Noted in Media Watch 4 May 2020 (#664, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 April 2020 –**Terminally ill cancer patients' emotional preparedness for death is distinct from their accurate prognostic awareness.** Emotional preparedness for death and prognostic awareness (PA), a distinct but related concept, each contributes to patients' practical, psychological, and interpersonal preparation for death. In this study, the distinction between death preparedness and accurate PA was supported by their poor agreement, lack of reciprocal associations, and two different sets of predictors. Healthcare professionals should not only cultivate cancer patients' accurate PA, but also facilitate emotional preparation for death to achieve a good death and improve end-of-life-care quality. **Abstract (w. link to references):** <https://bit.ly/2Ype9gc>

Noted in Media Watch 22 April 2019 (#611, p.9):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 18 April 2019 – **Barriers and facilitators to preparedness for death: Experiences of family caregivers of elders with dementia.** Identified as barriers were: 1) Hindrances to information; 2) Barriers to hospice; 3) Ineffective attempts to comfort; and, 4) The nature of death with dementia. Identified as facilitators were: 1) Religious/spiritual beliefs; 2) Caregiver initiative; 3) Prior experience; 4) Bearing witness to decline; 5) Professionals alerting caregiver (of what to expect of impending death); and, 6) Culture and legacy of family caregiving. The results support the role of social work in addressing caregivers' awareness of impending death and helping prepare them for the death of an elder with dementia. **Abstract:** <http://bit.ly/2vd3vcw>



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>

Compassion in a crisis: The role of palliative care during the COVID-19 pandemic

MAYO CLINIC PROCEEDINGS | Online – 2 October 2020 – The current crisis underscores two principles of palliative care (PC) which should integrate across all of healthcare, even outside of an active crisis. First, discussing and documenting health care preferences – commonly referred to as advance care planning (ACP) – is essential for everyone, regardless of age or health status. A global pandemic reminds us all of the fragility of human life, and the universal need for knowing one is receiving “the right care” however that is defined by the person. Recent events have increased the feasibility of ACP, as insurers and regulators now allow clinician billing for telehealth-based delivery. Experiences to date have been positive, including high feasibility of remotely-performed conversations, and strong willingness of patients and families to engage with an array of clinical team members, not just physicians. Second, a core principle of PC is understanding the whole patient, including their life, their loved ones, and community. This involves understanding both medical and non-medical sources of strength and distress, such as social, cultural, spiritual, financial and emotional factors. The pandemic has illuminated the importance of these domains on access to high quality care. As the crisis waxes and wanes, disadvantaged populations lack financial and other reserves necessary to compensate for job and health insurance losses. Thus, the purposeful understanding of the person beyond the chief complaint and the problem list, coupled with questions about the role of the healthcare system in addressing social determinants of health, will be critical. **Download full text at:** <https://mayocl.in/33pKTYN>

Related:

- *SUPPORTIVE CARE IN CANCER* | Online – 1 October 2020 – ‘**Palliative care for cancer patients with severe COVID-19: the challenge of uncertainty.**’ Cases of coronavirus disease 2019 (COVID-19) are escalating rapidly across the globe, with the mortality risk being especially high among those with existing illness and multi-morbidity. Palliative care (PC) workers have an essential role in the response to COVID-19 by responding rapidly and flexibly; ensuring protocols for symptom management are available, considering redeploying staffs and volunteers to provide psychosocial and bereavement care and using technology to communicate with patients and carers. It is imperative that curative goals and success not be allowed to mask the concurrent needs for PC. **Full text:** <https://bit.ly/30uFy0h>

In your final moments; not alone

PALLIATIVE & SUPPORTIVE CARE | Online – 29 September 2020 – Prior to COVID-19, the *No One Dies Alone* program (at Michigan Medicine, the University of Michigan) was established for medical students to provide companionship for patients near the end of life (EoL) without family or friends at their bedside. As part of the medical team, I have had feelings of failure and sadness at EoL – like we did not do enough to prevent their decline – and a sense of helplessness from not being able to do more. As a volunteer for *No One Dies Alone*, it is a different perspective. I am not part of the medical team and I do not know the patient’s medical history. I am purely there to keep the patient company, with the focus on providing a calm, healing presence. No matter what form this takes, even as a singular as to be in the room until they pass away can provide comfort. As COVID-19 spread across the country and filled our hospital beds, it amplified barriers to families being bedside and highlighted the heartbreak of patients passing away without friends and family by their side. **First page preview:** <https://bit.ly/3n2qS28>



Palliative Care Network

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

[Scroll down to 'Media Watch: The ICU & ACP']

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
Care Network

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
Canadian Society of
Palliative Care Physicians

SCMSP
Société canadienne des
médecins de soins palliatifs

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): <https://bit.ly/3iZKjXr>

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

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>

IPCRC.NET International Palliative
Care Resource Center

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

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Cont.

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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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