

## **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**

*In a virtual format, many common non-verbal empathic gestures, such as gently placing one's hand on a patient's shoulder or offering a box of tissues, are not possible. Therefore, verbal responses to emotion become even more important when conducting video visits*

*'Webside manner during the COVID-19 pandemic: Maintaining human connection during virtual visits' (p.5), in *Journal of Palliative Medicine*.*

## **U.S.A.**

### **Palliative care on the pandemic's front lines**

*U.S. NEWS & WORLD REPORT* | Online – 10 June 2020 – An unforeseen virus with no credible answers has overwhelmed many facets of healthcare, including palliative and primary teams that manage patients' end-of-life care (EoLC). Teamwork was the only viable response, and we suddenly saw the need to partner with physicians from various other specialties – like orthopedics and endocrinology – some of whom treated dying patients for the first time. These providers quickly learned that EoLC is a unique scenario that tests an individual's mental acuity and ability to make sensible decisions under time constraints. It requires identifying signs and symptoms of distress, knowing the pharmacologic properties of specific medications utilized for symptom management, being able to assess and reassess symptom relief – a difficult task when a large percentage of patients cannot communicate – and having the compassion to interact with a dying patient and their family. De-

veloping protocols, coaching and being available 24/7 were key elements for my team members who were supporting providers new to EoLC. A key part of these protocols and our overall approach is communication. Like a surgeon has his forceps or a pulmonologist has a ventilator, palliative care specialists are equipped with their own tools – none more important than communication. <https://bit.ly/3dLXckK>

### **COVID-19: End-of-Life Care**

**'The role of palliative care in caring for the families of patients with COVID-19'** (p.4), in *American Journal of Hospice & Palliative Medicine*.

**'Integration of palliative care into COVID-19 pandemic planning'** (p.4), in *BMJ Supportive & Palliative Care*.

## Palliative care nursing curriculum could impact staff shortages

*HOSPICE NEWS* | Online – 9 June 2020 – A program designed to incorporate hospice and palliative care (PC) principles into undergraduate and graduate nursing education could help make a difference in ongoing staffing shortages in those fields. The roots of this curriculum were planted five years ago when a group of hospice and palliative experts convened in Oregon to find strategies for improving and expanding education in their disciplines. A study published this month<sup>1</sup> ... indicated that the program is effective at advancing nursing students' and graduates' skills in PC, with many graduate participants (52%) indicating that the program had a significant impact on their clinical practice. <https://bit.ly/3hgtFSf>

1. 'Preparing new graduate RNs to provide primary palliative care,' *Journal of Continuing Education in Nursing*. 2020;51(6):280-286. **Abstract:** <https://bit.ly/3fmX4c3>

## Populations underserved by hospice hardest hit by COVID-19

*HOSPICE NEWS* | Online – 8 June 2020 – Demographic populations that historically have been underserved by hospice are also among the most severely impacted by the COVID-19 pandemic. Members of the African American, Hispanic and Native American communities have been disproportionately represented in the numbers of COVID-19 infections and associated mortality. U.S. counties with a predominantly African American population, for example, tend to see three times the number of infections and six-times the number of COVID deaths than predominantly white counties, according to data published in April.<sup>1</sup> While no cause-and-effect relationship exists between lower hospice utilization and the rate of COVID-19 cases, both factors are indicative of a number widespread disparities in the healthcare system as well as society at large... Factors contributing to the rates of COVID-19 deaths among underserved communities include higher rates of chronic illness that render patients more vulnerable to the virus, general mistrust of the healthcare system due to negative past experiences, as well as housing instability and inadequate access to jobs that provide health insurance... <https://bit.ly/37grd9Z>

1. 'COVID-19 and African Americans,' *Journal of the American Medical Association*, 2020;323(19):1891-1892. **Full text:** <https://bit.ly/30m4eZG>

## International

### Coronavirus: Unlawful do not resuscitate orders imposed on people with learning disabilities

U.K. (England) | *The Independent* – 12 June 2020 – Unlawful “do not resuscitate” orders are being placed on patients with a learning disability during the coronavirus pandemic without families being consulted. National charities have successfully challenged more than a dozen unlawful do not resuscitate orders (DNRs) that were put in place because of the patient’s disability rather than due to any serious underlying health risk. Turning Point said it had learned of 19 inappropriate DNRs from families while Learning Disability England said almost one-fifth of its members had reported DNRs placed in people’s medical records without consultation during March and April. Although a DNR is a medical decision and not something that re-

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### COVID-19: End-of-Life Care

**'Palliative care: Essential support for patients with heart failure in the COVID-19 pandemic'** (p.4), in *European Journal of Cardiovascular Nursing*.

**'The crucial role of nurses and social workers in initiating end-of-life communication to reduce overtreatment in the midst of the COVID-19 pandemic'** (p.5), in *Gerontology*.

**'Clinical uncertainty and Covid-19: Embrace the questions and find solutions'** (p.5), in *Palliative Medicine*.

**'Prolonged grief related to COVID-19 deaths: Do we have to fear a steep rise in traumatic and disenfranchised griefs?'** (p.5), in *Psychological Trauma: Theory, Research, Practice & Policy*.

Quires patient consent, not consulting with the patient or their family is an unlawful breach of human rights. It has come to the fore during the coronavirus pandemic after multiple reports of blanket DNRs being applied to elderly and vulnerable patients by GPs in care homes. Both the Care Quality Commission and National Health Service England have issued warnings to doctors that blanket DNRs are wrong and decisions must be made on the individual patient. <https://bit.ly/2MOAvAG>

### Why palliative care is also pertinent in the pandemic

AFRICA | *Forbes Africa* – 11 June 2020 – The real heroes are also palliative care providers who go out of their way for patients with chronic illnesses, like this Rwandan team of professionals that conducts home visits offering critical care to those afflicted even more during the Covid-19 pandemic. It's a Tuesday morning in mid-May, and the team from the Rwanda Palliative Care & Hospice Organisation (RPCHO) is preparing to visit the homes of terminally-ill patients in need of palliative or specialized medical care. The team, led by the organization's Executive Secretary, Eric Kabisa, comprises a doctor, a nurse, a social worker and a psychologist. For this team, their work tending to needy patients is more than just a job – it's a deep calling. This small team cares for over 70 patients with life-threatening illnesses; visiting them in their homes, providing medical consultation and nursing care as well as addressing some of their basic needs. They also offer counseling services to patients and care-givers. The Covid-19 pandemic has no doubt disrupted the momentum of their work, though RPCHO was part of the es-

sential services that had the green light to operate during the government-imposed lockdown in the country... <https://bit.ly/3dTbifF>

#### **Specialist Publications**

**'Provision of palliative care in National Cancer Grid treatment centres in India: A cross-sectional gap analysis survey'** (p.5), in *BMJ Supportive & Palliative Care*.

**'A multi-country assessment in Eurasia: Alignment of physician perspectives on palliative care integration in pediatric oncology with World Health Organization guidelines'** (p.6), in *Cancer*.

**'Approaches to integrating palliative care into African health systems: A qualitative systematic review'** (p.7), in *Health Policy & Planning*.

**'Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years'** (p.11), in *Palliative Medicine*.

### Advocacy for appropriate use of opioids for palliative care patients

AUSTRALIA | *Palliative Care Australia* – 11 June 2020 – Governments across the world are making policy and regulation changes to address the high number of deaths and hospitalisations due to prescription opioids. This has sometimes had inadvertent consequences for palliative care (PC) patients. As PC advocates and health professionals know, appropriate use of opioids is essential for PC patients to manage the pain and breathlessness associated with their life-limiting illness, not just for people with cancer. While recognising that safety regulations are required, put simply, the issues of addiction and misuse are not critical factors for PC patients. <https://bit.ly/2B6XOTt>

**N.B.** Selected articles on the impact on pain management of opioid prescribing restrictions noted in 1 June 2020 issue of *Media Watch* (#668, pp.14-15).

#### **Barry R. Ashpole**

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



## Specialist Publications

### **An adapted conceptual model integrating palliative care in serious illness and multiple chronic conditions**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 June 2020 – Seriously ill adults with multiple chronic conditions (MCC) who receive palliative care (PC) may benefit from improved symptom burden, healthcare utilization and cost, caregiver stress, and quality of life (QoL). To guide research involving serious illness and MCC, PC can be integrated into a conceptual model to develop future research studies to improve care strategies and outcomes in this population. Fifty-eight articles were synthesized to inform the development of an adapted conceptual model including serious illness, MCC, and PC. Concepts were organized into four main conceptual groups, including factors affecting needs (socio-demographic and social determinants of health), factors affecting services received (health system; research, evidence base, dissemination, and health policy; community resources), service-related variables (patient visits, service mix, quality of care, patient information, experience), and outcomes (symptom burden, QoL, function, advance care planning, goal-concordant care, utilization, cost, death, site of death, satisfaction). The adapted conceptual model integrates PC with serious illness and multiple chronic conditions. The model is intended to guide the development of research studies involving seriously ill adults with MCC and aid researchers in addressing relevant evidence gaps. **Abstract (w. list of references):** <https://bit.ly/2A4JQBK>

### **Integration of palliative care into COVID-19 pandemic planning**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 9 June 2020 – The COVID-19 pandemic is expected to surpass the healthcare system's capacity to provide intensive care to all patients who deteriorate as a result of the disease. This poses a unique challenge to healthcare teams of rationing care during a pandemic when resources are scarce. Healthcare providers will need to acquire new skills in care decision making and effective symptom control for patients who do not receive life-saving measures. In this review, the authors describe some of the important palliative care (PC) considerations that need to be incorporated into COVID-19 pandemic planning. The main aspects to be considered include decision algorithms for rationing care, training on effective symptoms management, alternative delivery methods of PC services such as telemedicine and finally death and bereavement support for surviving family members who are likely to be isolated from their loved one at the moment of death. **Full text:** <https://bit.ly/2YsII Rp>

#### **Related:**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 June 2020 – **'The role of palliative care in caring for the families of patients with COVID-19.'** The authors' New York City-based palliative care team has found that caring for patients' loved ones has proven to be an even more important aspect of the care they have provided during the COVID-19 epidemic. In this article, the authors describe the multi-component interdisciplinary interventions they have implemented to enhance the ability to create a therapeutic alliance with family members and facilitate the provision of goal concordant care to patients with COVID-19 during this extremely difficult time. **Abstract (w. list of references):** <https://bit.ly/2XlreQL>
- *EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING* | Online 9 June 2020 – **'Palliative care: Essential support for patients with heart failure in the COVID-19 pandemic.'** This short paper highlights just some of the evolving care components required in the clinical environment arising from the ongoing COVID-19 pandemic to fulfil the ethical imperative of providing palliative support for heart failure patients, often subject to significant existential distress. Clinical protocols have had to flex to address this challenging global emergency, and perhaps some of the lessons learned, including renewed attention to the integration of a palliative approach, will ultimately drive positive outcomes in societal attitudes as well as medical and nursing practice and research. **Full text:** <https://bit.ly/3cRDLWh>

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- *GERONTOLOGY* | Online – 9 June 2020 – ‘**The crucial role of nurses and social workers in initiating end-of-life communication to reduce overtreatment in the midst of the COVID-19 pandemic.**’ The COVID-19 epidemic has placed an extraordinary burden on health systems worldwide and reignited awareness of the need for hastier decision-making near the end of life (EoL). This unprecedented high level of demand for intensive care services, which cannot be satisfied, may be an opportunity to explore an expanded scope of practice for key members of the broader healthcare team, i.e., nurses and social workers. They are ... intimately familiar with the social/clinical circumstances to take on the role of initiators/facilitators of EoL discussions with patients and families. **Full text:** <https://bit.ly/2zIKFpl>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 June 2020 – ‘**Webside manner during the COVID-19 pandemic: Maintaining human connection during virtual visits.**’ As the death rate numbers in the U.S. related to COVID-19 are in the tens of thousands, clinicians are increasingly tasked with having serious illness conversations. However, in the setting of infection control policies, visitor restrictions, social distancing, and a lack of personal protective equipment, many of these important conversations are occurring by virtual visits. From a multisite study exploring the effectiveness of virtual palliative care, the authors have identified key elements of webside manner that are helpful when conducting serious illness conversations by virtual visit. **Full text:** <https://bit.ly/2zo5EHU>
- *PALLIATIVE MEDICINE* | Online – 10 June 2020 – ‘**Clinical uncertainty and Covid-19: Embrace the questions and find solutions.**’ The one thing we know with certainty about the Covid-19 pandemic, which has arrived in all our lives with devastating force, is how troubling uncertainty associated with this disease can be. A non-exhaustive list of the uncertainties associated with Covid-19 includes uncertainty at the level of the disease and its management, including its prognosis; how health and social care systems and professionals who work within them should respond; how best to communicate with the public and impart information about the illness; and, of central importance, how patients and their families live alongside the “known unknowns” and “unknown unknowns.” **Full text:** <https://bit.ly/2BTEpGe>
- *PSYCHOLOGICAL TRAUMA: THEORY, RESEARCH, PRACTICE & POLICY* | Online – 11 June 2020 – ‘**Prolonged grief related to COVID-19 deaths: Do we have to fear a steep rise in traumatic and disenfranchised griefs?**’ The circumstances of COVID-19-related deaths embed multiple traumatic characteristics, alongside several external factors that can disenfranchise individual grief. The authors of this article propose avenues for meaning-making practices to facilitate individual and collective mourning process, and invites clinicians to pay attention to the traumatic characteristics of COVID-19-related deaths adopting a holistic approach of prolonged grief disorder clinical manifestations, as well as in evaluation and treatment of cases. **Full text:** <https://bit.ly/2Yrtkns>

### Provision of palliative care in National Cancer Grid treatment centres in India: A cross-sectional gap analysis survey

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 9 June 2020 – The majority of the National Cancer Grid (NCG) centres have the facilities to provide palliative care (PC), but suffer from poor implementation of existing policies, funding and human resources. Eighty-nine NCG centres responded to a web-based survey: 72.5% of centres had doctors with generalist PC training, whereas 34.1% of centres had full-time PC physicians; 53.8% had nurses with 6 weeks of PC training; 68.1% of the centres have an outpatient PC and 66.3% have the facility to provide inpatient PC; 38.5% of centres offer home-based PC services; 44% of the centres make a hospice referral and 68.1% of the centres offer concurrent cancer therapy alongside PC. Among the centres, 84.3% have a licence to procure, store and dispense opioids, but only 77.5% have an uninterrupted supply of oral morphine for patients; 61.5% centres have no dedicated funds for PC, 23.1% centres have no support from hospital administration, staff shortage – 69.2% have no social workers, 60.4% have no counsellors and 76.9% have no volunteers. Although end-of-life care is recognised, there is a lack of institutional policy. Very few centres take part in quality control measures.

**Abstract:** <https://bit.ly/3dRgu8q>

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Noted in Media Watch 2 March 2020 (#655, p.13):

- *NATIONAL MEDICAL JOURNAL OF INDIA* | Online – 18 February 2020 – ‘**Making end-of-life and palliative care viable in India: A blueprint for action.**’ India is distinctly not a country to die in! The country’s failure begins with an underfunded public health system. However ... it has become obvious that public funding is far less effective than voluntary action and philanthropy. Governments’ involvement, however, is necessary to enable, mandate and support these efforts by legislative or executive action or both. There is scope for private healthcare as well ... where these services ... are usually funded by medical insurance. How well a healthcare system manages death seems to depend on some rather simple, low-cost and low-technology factors. **Full text:** <http://bit.ly/2SS47kw>

**N.B.** Additional articles on end-of-life and PC in India noted in 13 January and 3 February 2020 issues of Media Watch (#648, p.10, and #651, pp.7-8, respectively).

### **A multi-country assessment in Eurasia: Alignment of physician perspectives on palliative care integration in pediatric oncology with World Health Organization guidelines**

*CANCER* | Online – 12 June 2020 – The World Health Organization (WHO) advocates for early integration of palliative care (PC) for all children with life-threatening illness. Provider awareness and misperceptions, however, can impede this imperative. In the Eurasian region, little is known about physician knowledge and perspectives on PC. The Assessing Doctors’ Attitudes on Palliative Treatment survey was developed as an evidence-based and culturally relevant assessment of physician perceptions on PC integration into childhood cancer care in Eurasia. Iteratively tested by American and Eurasian PC experts, the survey was culturally adapted, translated, and piloted in English, Russian, and Mongolian. The survey was distributed to physicians caring for children with cancer. This study received 424 responses from 11 countries in Eurasia. The mean alignment between provider perspectives and WHO recommendations was 70% (range, 7%-100%). Significant independent predictors of higher alignment included country, prior PC education, and greater experience with patient death. Respondents primarily described PC as end-of-life care and symptom management. Two-thirds of respondents (67%) reported not feeling confident about delivering at least one component of PC. This is the first study assessing physician perspectives and knowledge of PC in Eurasia and reveals wide variability in alignment with WHO guidelines and limited confidence in providing PC. **Abstract:** <https://bit.ly/3hoq4lo>



**N.B.** Wikipedia source of map.

### **Randomized trial of a hospice video educational tool for patients with advanced cancer and their caregivers**

*CANCER* | Online – 8 June 2020 – The authors conducted a single-site randomized trial of a video educational tool versus a verbal description of hospice in 150 hospitalized patients with advanced cancer and their caregivers. Patients without a caregiver were eligible. Intervention participants (75 patients and 18 caregivers) viewed a 6-minute video depicting hospice. Control participants (75 patients and 26 caregivers) received a verbal description identical to the video narrative. A hospice video did not significantly impact patients’ preferences for hospice care. Patients with advanced cancer and their caregivers who were assigned to view the video were more informed regarding hospice and reported more favorable perceptions of hospice. Patients were more likely to use hospice and to have a longer hospice length of stay. **Abstract:** <https://bit.ly/2XFWFeE>



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

## **Nurses' experiences of providing "sensitive nursing care" for terminally-ill individuals with cancer: A qualitative study**

*EUROPEAN JOURNAL OF ONCOLOGY NURSING* | Online – 1 June 2020 – Participants in this study were 16 hospice specialists and four non-specialist nurses with experience in caring for terminal cancer patients in hospice specialized institutions in South Korea. Eight theme clusters were drawn from the data and these clusters had two dimensions consisting of sensitive attitudes and sensitive nursing behaviors. The sensitive attitudes included reflecting on past experiences, developing an accepting attitude toward death, using intuition to address critical situations, and having an open mind regarding collaborating with colleagues. The sensitive nursing behaviors contained listening to patients' needs, responding to patients in a manner suitable to their conditions, quickly responding to patients' problem, and providing a moment saying farewell. Teamwork and role models can help hospice specialists and non-specialist nurses caring for terminally-ill individuals with cancer to improve the sensitive nursing care. The sensitive attitudes and behaviors can be used as basic data for training programs designed to enhance nurses' sensitivity. **Abstract (w. list of references):** <https://bit.ly/2BKUU7s>

## **Approaches to integrating palliative care into African health systems: A qualitative systematic review**

*HEALTH POLICY & PLANNING* | Online – 8 June 2020 – Africa is characterized by a high burden of disease and health system deficits, with an overwhelming and increasing demand for palliative care (PC). Yet only one African country is currently considered to have advanced integration of PC into medical services and generalized PC is said to be available in only a handful of others. The integration of PC into all levels of a health system has been called for to increase access to PC and to strengthen health systems. Contextually appropriate evidence to guide integration is vital yet limited. This qualitative systematic review analyses interventions to integrate PC into African health systems to provide insight into the "how" of PC integration. Forty articles were identified, describing 51 different interventions. This study found that a variety of integration models are being applied, with limited best practices being evaluated and repeated in other contexts. Interventions typically focused on integrating specialized PC services into individual or multiple health facilities, with only a few examples of PC integrated at a population level. Four identified issues could either promote integration (by being present) or block integration (by their absence). These include the provision of PC at all levels of the health system alongside curative care; the development and presence of sustainable partnerships; health systems and workers that can support integration; and, lastly, placing the client, their family and community at the centre of integration. These echo the broader literature on integration of health services generally. There is currently a strong suggestion that the integration of PC contributes to health system strengthening; however, this is not well evidenced in the literature and future interventions would benefit from placing health systems strengthening at the forefront, as well as situating their work within the context of integration of health services more generally. **Full text:** <https://bit.ly/3firkVt>

Noted in Media Watch 17 February 2020 (#653, p.4):

- *AFRICAN HUMAN RIGHTS LAW JOURNAL*, 2019;19(2):653-674. **'The right of palliative care for the most vulnerable in Africa is everyone's responsibility.** In sub-Saharan Africa over 80% of needy children are unable to access palliative care services. Since the introduction of the Convention on the Rights of the Child and the African Charter on the Rights & Welfare of Children, South Africa, Uganda and Kenya, have committed themselves to protect and promote the rights of children. Within the broader framework of international human rights, countries are obligated to realise a child's right to health and provide adequate healthcare. Yet, children living in these countries with life-threatening and life-limiting illnesses suffer from physical, psychological and emotional pain. **Full text:** <http://bit.ly/2UNxypb>

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Noted in Media Watch 21 May 2018 (#564, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 May 2018 – ‘**An analysis of palliative care development in Africa: A ranking based on region-specific macro-indicators.**’ Data were obtained from the African Palliative Care Atlas of Palliative Care...<sup>1</sup> 19 indicators were developed/defined through interviews with African palliative care (PC) experts and a two-round modified Delphi consensus process with international experts on global PC indicators. Indicators were grouped by the WHO public health strategy for PC dimensions. These were sent as a survey to key informants in 52/54 African countries. 89% (48/54) of African countries responded. The top three countries in overall PC development were Uganda, South Africa and Kenya. **Full text:** <https://bit.ly/2ASJhLi>
  1. ‘African Palliative Care Atlas of Palliative Care in Africa,’ African Palliative Care Association, 2017. **Download/view at:** <https://bit.ly/2Yh0XYR>

Noted in Media Watch 26 March 2018 (#556, p.13):

- *THE LANCET GLOBAL HEALTH*, 2018;6(Suppl.2):S21. ‘**The African Palliative Care Association Atlas of Palliative Care Development in Africa: A comparative analysis.**’ The authors developed/deployed a set of indicators to measure the current state of palliative care (PC) development in Africa according to World Health Organization’s Public Health Strategy for integrating PC, including policies, availability and access to medicines, education and service provision. Surveys were received from 48 countries. There is limited PC development in Africa, but there is also a significant improvement in the number of countries with hospice and PC services... Improvements in advocacy were identified, with more than half of countries reporting a national PC association. **Abstract:** <https://bit.ly/37dq2YX>

### **Human touch via touchscreen: Rural nurses’ experiential perspectives on telehealth use in pediatric hospice care**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 June 2020 – Telehealth, through its utilization of technology to connect medical professionals with patients and family caregivers, has been recognized as one potential solution to address critical access issues in hospice care. As the COVID-19 pandemic has necessitated the rapid incorporation of screen modalities into palliative care (PC), that suddenness warrants pause to consider the baseline barriers or discomforts with telehealth, particularly as they relate to the provision of palliative or hospice care. Prior studies have revealed reasons for PC providers’ tangible concerns about telehealth: lack of training and lack of incentives, lack of equipment availability or lack of perceived ease of equipment use, concern about technology functionality and uncertainty about patient eligibility criteria for telehealth. User-friendly, reliable, accessible, secure technologies, and clear connectivity are well-established requirements for successful telehealth, as is provider training. The deeper concern with telemedicine use in palliative and hospice care is the concern with whether this communication modality is a facilitator or a barrier for the relationality so core to the profession. A fear about virtual interaction is whether the communication format depersonalizes the team or family experience, particularly when discussing the sensitive topics relevant to pediatric end-of-life care. Palliative and hospice teams have shared concerns about the way telehealth impacts professional roles: telehealth’s impact on professional autonomy, fear of decay in the quality of care provided, and concern for risk of not being present to assist the patient such as in adverse medication reactions. **Full text:** <https://bit.ly/3cKa0qk>

Noted in Media Watch 11 May 2020 (#665, p.5):

- *JOURNAL OF MEDICAL INTERNET RESEARCH*, 2020;22(5):e16218. ‘**Patients’ experiences of telehealth in palliative home care: Scoping review.**’ Telehealth increases and improves access to healthcare professionals at home and enhances the feelings of security and safety. Furthermore, the visual features of telehealth allow a close connectedness with healthcare professionals... There were contradicting results on whether the use of telehealth improved burdensome symptoms and quality of life. The results further suggest 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. **Full text:** <https://bit.ly/2SIGaeP>

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Noted in Media Watch 16 December 2019 (#644, p.7):

- *BMC PALLIATIVE CARE* | Online – 13 December 2019 – ‘**Telehealth in palliative care is being described but not evaluated: A systematic review.**’ This review demonstrates that a variety palliative care (PC) telehealth initiatives continue to be described in the published literature. Since a 2010 review there particularly appears to have been an increase in the number of home tele-monitoring interventions... Despite the description of telehealth development and implementation, there remains a lack of robust study design and evaluation of these interventions meaning that clear conclusions around the benefit of telehealth in PC cannot be drawn; there is insufficient high quality evidence to comment on any influence on access to emergency or unscheduled care. **Full text:** <http://bit.ly/2PJKJmT>

### **Translating pediatric hospital interpreters’ feedback from difficult conversations into improved communication**

*JOURNAL OF PALLIATIVE CARE* | Online – 2020 – The objective of this pilot study was to provide suggestions from medical interpreters to palliative care teams as to how to effectively incorporate medical interpreters into end-of-life conversations. The translation of cultural contexts, awareness of the mixed messages the family received from healthcare teams, and the emotional intensity of the interactions were depicted as the most challenging aspects of the medical interpreter’s role. Despite these challenges, 9 of the participating interpreters reported they would willingly be assigned for interpreting “bad news” conversations if given the opportunity. Medical interpreters recognized their relationship with the family and their helping role for the family as meaningful aspects of interpreting even in difficult conversations. Medical interpreters shared seven thematic suggestions for improved communication in language-discordant visits: content review, message clarity, advocacy role, cultural understanding, communication dynamics, professionalism, and emotional support. As experts in cultural dynamics and message transmission, the insights of medical interpreters can improve communication with families. **Abstract (w. list of references):** <https://bit.ly/2XZg1vz>

Noted in Media Watch 17 February 2020 (#653, p.8):

- *BRITISH MEDICAL JOURNAL* | Online – 11 February 2020 – ‘**Can patients use family members as non-professional interpreters in consultations?**’ Sofia Sarfraz, senior clinical fellow in paediatrics and medical education, says: “For patients who don’t share your language the gold standard is to use a professional interpreter. We’ve all, however, used patients’ family members or other health professionals as interpreters in consultations. It’s hard to see how medicine could function in our multicultural society without them, especially in emergencies. But non-professional interpreters should be used with caution and you should consider the risks. Medical interpreters have training and experience, which family members and other health professionals may lack. **Full text:** <http://bit.ly/2Sze401>

Noted in Media Watch 10 April 2017 (#507, p.13):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 3 April 2017 – ‘**Understanding patient needs without understanding the patient: The need for complementary use of professional interpreters in end-of-life care.**’ In linguistically and culturally diverse societies, language discordant consultations become daily practice, leading to difficulties in eliciting patient preferences toward end-of-life care. The case discussed generated a triple-layered ethical dilemma: 1) How to safeguard patient autonomy against paternalistic interventions by family members; 2) How to respect the relational context in which patient autonomy can be realized; and, 3) How to respect the ethno-cultural values of the patient and his family. **Abstract (w. list of references):** <http://bit.ly/2JqsyjL>

## **Navigating the transition from advanced illness to bereavement: How provider communication informs family-related roles and needs**

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 8 June 2020 – The authors report findings from a study exploring how communication and care in the later stages of an advanced illness influence family caregivers' well-being in bereavement. Findings from this study suggest that family caregivers assume the role of interpreter and advocate while engaged in both formal and informal communication with healthcare providers at the end of care-recipients' lives. Findings also suggest that families are more likely to feel emotionally prepared for loss and grief when healthcare providers are available to communicate in a concise, consistent, and compassionate manner. The results illuminate the important connection between communication during the transition from late-stage illness to end-of-life care and preparation for bereavement. The article concludes with a discussion of how findings from this study align with recent concerted efforts to establish standards and competencies for social work education and practice in palliative care. **Abstract:** <https://bit.ly/3dKX6Kh>

## **Insufficient advance care planning? Correlates of planning without personal conversations**

*JOURNALS OF GERONTOLOGY* (Series B) | Online – 7 June 2020 – Advance care planning (ACP) typically comprises formal preparations (i.e., living will and/or durable power of attorney for healthcare) and informal discussions with family members and healthcare providers. However, some people complete formal documents without discussing them with others. If they become incapacitated, their appointed decision makers may lack guidance on how to interpret or enact their formal wishes. We document the prevalence and correlates of this partial approach to ACP. Using multinomial logistic regression models and data from a U.S. sample of 4,836 older adults in the 2018 wave of the National Health & Aging Trends Study (NHATS), this brief report evaluated associations between social integration indicators and the odds of completing: 1) Both discussions and formal plans (two-pronged ACP); 2) Discussions only; 3) No ACP; and, 4) Formal ACP only (reference category). A minority (15%) of NHATS participants reported formal plans without having discussed them. Indicators of social isolation (e.g., smaller social networks, fewer social activities) increased the odds of engaging in formal planning only compared to two-pronged ACP. Socioeconomic disadvantage and probable dementia reduced the odds of having end-of-life conversations, whether as one's only preparation or in tandem with formal preparations. Socially isolated persons are especially likely to do formal planning only, which is considered less effective than two-pronged ACP. Healthcare professionals should recognize that older adults with few kin may require additional support and guidance when doing ACP. **Abstract:** <https://bit.ly/2Yjteye>

## **A strategy to improve end-of-life care offered by an ambulance service**

*NURSING TIMES* | Online – 8 June 2020 – In the U.K., North East Ambulance Service National Health Service Foundation Trust worked in partnership with Macmillan Cancer Support to develop a supportive palliative and end-of-life care (EoLC) service and tackle issues highlighted at a national level. They produced an information-sharing programme to ensure patients' wishes are met and prevent unnecessary hospital admissions. They also rolled out a training programme to clinical and non-clinical staff across the service and redesigned the trust's EoLC transport process. These changes resulted in an increasing number of patients' information being shared between relevant settings and fewer appropriate requests for EoLC transport being made. **Full text:** <https://bit.ly/3cM8Pa5>

**N.B.** Additional articles on the role of paramedics in EoLC noted in 1 June 2020 issue of Media Watch (#668, p.2).



### **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.13.

## **Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years**

*PALLIATIVE MEDICINE* | Online – 10 June 2020 – Service provision is a key domain to assess national-level palliative care (PC) development. Three editions of the European Association for Palliative Care (EAPC) Atlas of Palliative Care monitored the changes in service provision across Europe since 2005. The authors studied European trends of specialized service provision at home care teams, hospital support teams, and inpatient PC services between 2005 and 2019. Forty-two countries (82%) increased the number of specialized services between 2005 and 2019 with changes for home care teams (104% increase-rate), inpatient services (82%), and hospital support teams (48%). High-income countries showed significant increase in all types of services, while low-to-middle-income countries showed significant increase only for inpatient services. Central-Eastern European countries showed significant improvement in home care teams and inpatient services, while Western countries showed significant improvement in hospital support and home care teams. Home care was the most prominent service in Western Europe. Specialized service provision increased throughout Europe, yet ratios per 100,000 inhabitants fell below the EAPC recommendations. Western Europe ratios' achieved half of the suggested services, while Central-Eastern countries achieved only a fourth. High-income countries and Western European countries account for the major increase. Central-Eastern Europe and low-to-middle-income countries reported little increase on specialized service provision. **Full text:** <https://bit.ly/2UwwuFd>

**N.B.** 'European Association for Palliative Care Atlas of Palliative Care in Europe 2019.' [Noted in 27 May 2019 issue of Media Watch (#615, p.4)] **Download/view at:** <http://bit.ly/2whaYrF>

## **Building organizational compassion among teams delivering end-of-life care in the intensive care unit: The 3 Wishes Project**

*PALLIATIVE MEDICINE* | Online – 10 June 2020 – The 3 Wishes Project is a semi-structured program that improves the quality of care for patients dying in the intensive care unit (ICU) by eliciting and implementing wishes. This intervention honors the legacy of patients and eases family grief, forging human connections between family members and clinicians. Interviews and focus groups were used to collect data from family members of dying patients, clinicians, and institutional leaders. Examining the 3 Wishes Project through the lens of organizational compassion reveals the potential of this program to cultivate the capacity for people to collectively notice, feel and respond to suffering. The authors' data document multi-directional demonstrations of compassion between clinicians and family members, forging the type of human connections that may foster resilience. **Abstract (w. list of references):** <https://bit.ly/37jzp9B>

## **Identification of patients with potential palliative care needs: A systematic review of screening tools in primary care**

*PALLIATIVE MEDICINE* | Online – 7 June 2020 – Despite increasing evidence of the benefits of early access to palliative care (PC), many patients do not receive PC in a timely manner. A systematic approach in primary care can facilitate earlier identification of patients with potential PC needs and prompt further assessment. From 4,127 unique articles screened, 25 reported the use or development of 10 screening tools. Most tools use prediction of death and/or deterioration as a proxy for the identification of people with potential PC needs. The tools are based on a wide range of general and disease-specific indicators. The accuracy of five tools was assessed in eight studies; these tools differed significantly in their ability to identify patients with potential PC needs with sensitivity ranging from 3% to 94% and specificity ranging from 26% to 99%. The ability of current screening tools to identify patients with advanced progressive diseases who are likely to have PC needs in primary care is limited. Further research is needed to identify standardised screening processes that are based not only on predicting mortality and deterioration but also on anticipating the PC needs and predicting the rate and course of functional decline. This would prompt a comprehensive assessment to identify and meet their needs on time. **Abstract (w. list of references):** <https://bit.ly/3cE1BEV>

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Noted in Media Watch 17 February 2020 (#653, p.7):

- *BMC PALLIATIVE CARE* | Online – 12 February 2020 – ‘**Identification of patients in need of general and specialised PALLiative care (ID-PALL®): Item generation, content and face validity of a new interprofessional screening instrument.**’ The results of this study represent the first step of the validation process of the newly developed ID-PALL® instrument. The methods used in the development have resulted in an instrument that is brief and tailored to the needs of all health professionals, nurses in particular, who are confronted with patients with a potential need for palliative care (PC). This instrument should allow the distinction between patients requiring general vs. specialised PC, regardless of their pathology. **Full text:** <http://bit.ly/2SHSprq>
- *BMC PALLIATIVE CARE* | Online – 10 February 2020 – ‘**Who needs and continues to need paediatric palliative care? An evaluation of utility and feasibility of the Paediatric Palliative Screening Scale (PaPaS).**’ The PaPaS promotes greater clarity and effective handover for everyone involved, particularly at care transitions. This can lead to important outcomes like alignment of expectations between stakeholders, and critically, optimal case management. Ultimately, the child and family living with life-shortening illness is flagged in a timely manner to receive PC based on needs rather than prognosis, in spite of challenges posed by disease diversity and uncertain trajectories, through a process of screening that is both robust and informational... **Full text:** <http://bit.ly/2UHdk0f>

### **The changing narratives of death, dying, and HIV in the U.K.**

*QUALITY HEALTH RESEARCH* | Online – 6 June 2020 – Death and infection were closely linked from the start of the HIV epidemic, until successful treatments became available. The initial impact of mostly young, gay men dying from HIV was powerful in shaping U.K. responses. Neoliberal discourses developed at the same time, particularly focusing on how citizens (rather than the state) should take responsibility to improve health. Subsequently “successful ageing” became an allied discourse, further marginalizing death discussions. The authors’ study reflected on a broad range of meanings around death within the historical U.K. epidemic, to examine how dying narratives shape contemporary HIV experiences. Fifty-one participants including people living with HIV, professionals, and activists were recruited for semi-structured interviews. Assuming a symbolic interactionist framework, analysis highlighted how HIV deaths were initially experienced as not only traumatic but also energizing, leading to creativity. With effective antiretrovirals, dying changed shape (e.g., loss of death literacy), and better integration of palliative care was recommended. **Abstract (w. list of references):** <https://bit.ly/2UoXRB7>

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

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

#### **Distribution**

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

#### **Links to Sources**

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.

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3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### [Something Missed or Overlooked?](#)

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

[Search Back Issues of Media Watch @ http://bit.ly/2ThijkC](http://bit.ly/2ThijkC)

## [Media Watch: Access on Online](#)

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3cT7i1O>

[Scroll down to 'Media Watch']

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

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

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

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

### **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**



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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