

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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Understanding contemporary community attitudes and feelings towards death is valuable because it may inform the development of future health services, improve patient and family care at the end-of-life, and it may also inform policy on ways to encourage conversations leading to greater death preparedness and planning.

'Words describing feelings about death: A comparison of sentiment for self and others and changes over time' (p.8), in *Plos One*.

International

Palliative Care and COVID-19 Series Briefing Notes

WORLDWIDE HOSPICE PALLIATIVE CARE ALLIANCE | Online – 6 January 2021 – This compilation collects the twenty-seven original and lightly edited briefing notes prepared for the Global Palliative Care and COVID-19 Series developed between April and September 2020 in response to the emergency of the pandemic and its unprecedented effects on patients and palliative care (PC) providers around the world. They are addressed to civil society organizations, United Nations (UN) member states, secretariat staff at the UN Organizations, policymakers, administrators, service recipients, and healthcare providers. Each briefing note provides a snapshot of globally relevant information and guidance on an issue relating to PC in the context of the COVID-19 pandemic. The series was developed jointly by a working group composed by the Executive Directors and Officers of the International Association for Hospice & Palliative Care, the International Children's Palliative Care Network, Palliative

Care in Humanitarian Aid Situations & Emergencies and the Worldwide Hospice Palliative Care Alliance. **Download/view at:** <http://bit.ly/35i5DIL>

Specialist Publications

'Ethical implications of **COVID-19: Palliative care, public health, and long-term care facilities**' (p.6), in *Journal of Hospice & Palliative Nursing*.

'End-of-life care in the time of **COVID-19: Communication matters more than ever**' (p.9), in *Journal of Pain & Symptom Management*.

'Dying at home of **COVID-19: Meeting the need for home-based care**' (p.8), in *Preventive Medicine*.

'Can you hear me now? Improving palliative care access through telehealth' (p.9), *Research in Nursing & Health*.

COVID-19 “lottery”: Doctors draw up triage protocol in the event treatment has to be rationed

U.K. | *The Telegraph* (London) – 5 January 2021 – COVID-19 patients could ultimately be selected for treatment by “lottery” or their potential to contribute to society if the health service becomes overwhelmed, according to a draft emergency triage protocol drawn up by specialists at a major National Health Service (NHS) trust. The document, first published in the *Journal of Medical Ethics* in November,¹ is now being urgently circulated among NHS specialists in the absence of national guidance from either the Department of Health & Social Care or NHS England. The authors stress that the tipping point has not yet been reached but on Monday the Chief Medical Officers for the four nations [i.e., England, Northern Ireland, Scotland & Wales] raised the national alert level to “Level Five” meaning there is “a material risk of the NHS in several areas being overwhelmed over the next 21 days.” The protocol – drafted by medical, legal and palliative care specialists at

the Royal United Hospital Bath NHS Trust – is the most sophisticated attempt yet to devise an ethical system for rationing care in the event that there are insufficient resources to treat everyone. <http://bit.ly/3nlsa78>

Extract from *Journal of Medical Ethics* discussion paper

Where critical care is not offered, other appropriate care must be provided, whether this be ward-based medical care or palliative care.

N.B. This is the only mention of palliative care (PC) in the discussion paper proper. The listed references, however, includes ‘Care at the End-of-life: A guide to best practice, discussion and decision-making in and around critical care,’ Faculty of Intensive Care Medicine, London, England, 2019 This document provides more detailed discussion of PC. **Download at:** <http://bit.ly/38jEGA8>

1. ‘Development of a structured process for fair allocation of critical care resources in the setting of insufficient capacity: A discussion paper,’ *Journal of Medical Ethics*, published online 20 November 2020. **Full text:** <https://bit.ly/2JUGpT2>

Noted in Media Watch 15 June 2020 (#670, p.4):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 9 June 2020 – ‘**Integration of palliative care into COVID-19 pandemic planning.**’ 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. The authors describe some of the important palliative care considerations that need to be incorporated into COVID-19 pandemic planning. **Full text:** <https://bit.ly/2YsllRp>

Noted in Media Watch 6 April 2020 (#660, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 March 2020 – ‘**Goals-of-care in a pandemic: Our experience and recommendations.**’ The authors propose that the palliative care (PC) team response will occur in two waves: first communication and second symptom management. Their experience with discussing goals-of-care with the family of a COVID-19 positive patient highlights some expected and unexpected challenges. They describe these challenges along with recommendations for approaching these conversation ... [and] ... also propose a framework for proactively mobilizing the PC workforce to aggressively address goals-of-care in all patients, with the aim of reducing the need for rationing of resources. **Full text:** <https://bit.ly/2Jsy18d>

Noted in Media Watch 30 March 2020 (#659, p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 March 2020 – ‘**What should palliative care’s response be to the COVID-19 epidemic?**’ Widespread transmission of COVID-19 in the U.S. could translate into large numbers of people needing medical care at the same time. This will push many health systems to the point of rationing limited resources such as ICU beds and life sustaining machinery, as has occurred in Italy. Patients and their families at the peak of the pandemic will face symptoms, emotional distress, and decision-making in the face of uncertainty and limited options. No one is more prepared to handle these needs than providers on palliative care (PC) consult teams. However, PC consult teams are themselves a limited resource. **Full text:** <https://bit.ly/2xtZkxh>

Specialist Publications

Supportive and palliative care in hemato-oncology: How best to achieve seamless integration and sub-specialty development?

ANNALS OF HEMATOLOGY | Online – January 2021 – While recent medical advances have led to cure, remission, or long-term disease control for patients with hematologic malignancy, many still portend poor prognoses, and frequently are associated with significant symptom and quality of life burden for patients and families. Patients with hematological cancer are referred to palliative care (PC) services less often than those with solid tumors, despite higher inpatient mortality and shorter interval between first consultation and death. The complexity of individual prognostication, ongoing therapeutic goals of cure, the technical nature and complications of treatment, the intensity of medical care even when approaching end of life, and the speed of change to a terminal event all pose difficulties and hinder referral. A modified PC model is an unmet need in hemato-oncology, where PC is introduced early from the diagnosis of hematological malignancy, provided alongside care of curative or life-prolonging intent, and subsequently leads to death and bereavement care or cure and survivorship care depending on disease course. From current evidence, the historical prioritization of cancer care at the center of palliative medicine did not

guarantee that those diagnosed with a hematological malignancy were assured of referral, timely or otherwise. Hopefully, this article can be a catalyst for debate that will foster a new direction in integration of clinical service and research, and subspecialty development at the interface of hemato-oncology and PC. **Abstract (w. list of references):** <https://bit.ly/3n9xMBz>

Research Matters

'Missing not at random in end-of-life care studies: Multiple imputation and sensitivity analysis on data from the ACTION study' (p.9), in *BMC Medical Research Methodology*.

'The role of research in improving responsiveness of palliative care to migrants and other underserved populations in The Netherlands: A qualitative interview study' (p.10), in *BMC Palliative Care*.

'A case analysis of partnered research on palliative care for refugees in Jordan and Rwanda' (p.10), in *Conflict & Health*.

Related:

- *SUPPORTIVE CARE IN CANCER* | Online – 7 January 2021 – **'Needs assessment of current palliative care education in U.S. hematology/oncology fellowship programs.'** Palliative care (PC) education for fellows in hematology/oncology (H/O) is widely accepted, but no studies to date have assessed PC education practices and values among program leadership. Significant disparities exist between those modalities rated most effective for PC education and those currently in use. Clinical orientation of program leadership can affect both personal comfort with PC skills and estimations of PC curriculum effectiveness and fellows' competency. Programs would benefit from greater standardization and prioritization of active PC education modalities and content. **Abstract (w. list of references):** <https://bit.ly/39c8tJZ>

Noted in Media Watch 20 April 2020 (#662, p.9):

- *BMC PALLIATIVE CARE* | Online – 13 April 2020 – **'Palliative care utilization in oncology and hemato-oncology: A systematic review of cognitive barriers and facilitators from the perspective of healthcare professionals, adult patients, and their families.'** This study systematically reviewed current literature on using palliative care (PC) in oncology and hemato-oncology. The focus was on cognitive barriers and facilitators influencing the use of PC services from the perspectives of health professionals, adult patients with cancer, and their families. Literature on this topic is very heterogeneous in objectives and focus, mainly addressing PC use, PC provision, and PC service referral. Findings show that barriers and facilitators can be summarized in four areas... **Full text:** <https://bit.ly/2xk9Jw0>



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Stakeholder perspectives and requirements to guide the development of digital technology for palliative cancer services: A multi-country, cross-sectional, qualitative study in Nigeria, Uganda and Zimbabwe

BMC PALLIATIVE CARE | Online – 4 January 2021 – This study identified widespread use of digital technologies across the provision of palliative care (PC) services by patients, caregivers and health professionals in Nigeria, Uganda and Zimbabwe. It is the first study to explore preferences for the development of digital technology approaches across all key stakeholders in the sub-Saharan Africa (SSA) region. Both acceptability and reservations about digital health approaches were identified. Preferences and needs for the use of technology were mostly device agnostic, reflecting instead the dynamic of interaction that can be supported through digital technologies such as the frequency of contact and drivers of digital technology use. For policymakers, digital technology approaches feed into a wider vision for the development of data and its availability and use to inform the planning and development of services for patients with cancer. This study is the first to report consultation across stakeholder groups, including patients, caregivers, and policymakers in three countries in the SSA region. Involvement of key stakeholders and potential users of technologies is crucial for health technology development and increasing understanding of the context in which they are to be implemented. Previous research has highlighted the need to capture the needs of end-user perspectives to inform the development and evaluation of digital health approaches for PC in SSA, and willingness of health professionals to develop digital health approaches for PC in Nigeria. This study addresses these gaps in knowledge, deriving a set of 15 requirements that align data and information needs of stakeholders with digital health intervention components for palliative cancer care in SSA. **Full text:** <http://bit.ly/3ogEIOL>



Specialised outpatient paediatric palliative care team-parent collaboration: Narrative interviews with parents

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 5 January 2021 – In Germany, children with life-limiting conditions and complex symptoms are eligible for specialised outpatient palliative care (SOPC). In the federal state of Hesse, SOPC for children is delivered by teams with paediatric expertise. While burdened by the life-limiting condition of their child, parents must also fulfill their roles as main care providers and decision-makers. Collaboration between parents and SOPC teams is important, as the intermittent care and uncertainty it entails often lasts for several months or years. The authors explored parents' experiences and their demands of collaboration with SOPC teams. Parents stressed the importance of paediatric expertise, honesty, psychosocial support, an individualised approach, experience of self-efficacy and the need to be recognised as experts for their children. The narrative interviews showed that collaboration between parents and SOPC teams was characterised by parents' need for specialised professional assistance and their simultaneous empowerment by SOPC teams. Parents' perceptions of what good collaboration with SOPC teams entails are manifold. To meet these complex needs, SOPC requires time and specialised expertise. **Abstract:** <http://bit.ly/2XiKfIs>

Related:

- *BMJ OPEN* | Online – 6 January 2021 – '**Experiences of general practice of children with complex and palliative care needs and their families: A qualitative study.**' Findings suggest general practice (GP) should be playing a more important role in the provision of holistic, family-centred healthcare to children with life-limiting and life-threatening conditions and their family members. Children and families described multiple benefits associated with consciously fostering their relationship with GP clinicians in order to access important aspects of care... Clinicians in GP could develop their skills and expertise in this area to provide assessment and management of acute illness, and long-term holistic support, in close partnership with family members and paediatric specialists. **Full text:** <http://bit.ly/2MBsQbX>

The wish to die and hastening death in amyotrophic lateral sclerosis: A scoping review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 4 January 2021 – Existing research suggests the wish to hasten death (WTHD) in amyotrophic lateral sclerosis (ALS) occurs in the early illness trajectory and at crucial points over the course of the disease, when certain functions and abilities are lost. While some studies report a stable WTHD, others show the WTHD diminishes during the coping process. Suicide, assisted suicide and euthanasia are options many people with ALS at least consider and seek information about at some point. For a variety of reasons, counselling on these options is incomprehensive and insufficient. Therefore, suicide prevention and assistance in the coping process should be provided, in particular during the first year after diagnosis, but must also be available thereafter during decision-making about treatment options. The motives and determinants of people with ALS

for the WTHD are extremely diverse in terms of their content, their regional or cultural background and their occurrence during the disease trajectory. Hence, healthcare professionals should investigate the reasons, meaning and strength of the desire to die to detect unmet needs and examine which alternatives or offers of interventions and counselling are appropriate in each individual case. **Full text:** <https://bit.ly/3ofWXng>

Extract:

An early introduction of palliative care can also lead to a less traumatic disease experience and help with adjusting to loss and feelings of uncertainty. Furthermore healthcare professionals should be aware of the psychological distress people with ALS experience.

Noted in Media Watch 24 February 2020 (#654, p.10):

- *JOURNAL OF PALLIATIVE CARE* | Online – 17 February 2020 – ‘**Engaging specialist palliative care in the management of amyotrophic lateral sclerosis: A patient-, family-, and provider-based approach.**’ Stakeholders’ [i.e., study participants] general impressions of specialist palliative care (PC) were highly variable. Many expressed limited or inaccurate understandings of PC’s definition and purpose. Perceptions of PC as hospice were common. Stakeholders generally supported the integration of specialist PC into amyotrophic lateral sclerosis management, and many recognized the value of early integration of palliative services in both the community and the clinical setting. **Abstract (w. list of references):** <http://bit.ly/3bGB1E>

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

Inadequate completion of advance care directives by individuals with dementia: National audit of health and aged care facilities

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 4 January 2021 – The authors provide insight into current rates of advance care directives and advance care planning (ACP) documentation by persons with dementia in Australia, and may serve as a baseline against which future audits may be compared. Their findings suggest there is a significant population of people with dementia who have no ACP documentation in place, and another group with ACP documentation that has been completed for them by someone else. In the case of a person who never wished to document their own preferences and who has since lost decision-making capacity, this may reflect an appropriate outcome consistent with the individual’s values. However, such cases can also be seen as a missed opportunity for promoting ACP earlier in the course of illness to provide people with the choice to plan for their future care needs. This is of particular importance given evidence that there are discrepancies in values and preferences between caregivers of people with dementia, and people with dementia themselves. Further Australian research regarding congruence in care decisions between caregivers of people with dementia and people with dementia themselves is required. Recent studies trialing tailored dementia-specific approaches to ACP that address known barriers to discussion have shown promising early results. The implementation of clear ACP policies and guidelines at an organisational level is consistent with existing quality standards in Australia, and can provide a foundation for further initiatives to promote ACP across health and aged care organisations. **Full text:** <https://bit.ly/38eBUf7>

Advance Care Planning Australia

Ethical implications of COVID-19: Palliative care, public health, and long-term care facilities

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 6 January 2021 – Outbreaks of COVID-19 among nursing homes, assisted living facilities, and other long-term care facilities in the U.S. have had devastating effects on residents. Restrictions such as banning visitors, sequestering residents, and testing healthcare staff have been implemented to mitigate the spread of the virus. However, consequences include a decline in mental and physical health, decompensation, and a sense of hopelessness among residents. The authors present and explore a case study at an assisted living facility addressing the ethical issues in balancing the management of the community versus the resident's right to autonomy and self-determination. A team of palliative care (PC) experts was brought into assisted living facilities to manage patients, care for well residents, and provide input in advance care planning and symptom management. The principles of self-determination and autonomy, stewardship, and distributive justice were explored. The use of nursing skills in triage and assessment, principles in public health, and the 8 domains of PC provided a comprehensive framework for structuring emergency operations. Palliative interventions and the role of PC nurses played an integral part in addressing ethical challenges in the containment of the virus and the deleterious effects of social isolation among the elderly. **Abstract:** <http://bit.ly/3hSqdOu>

Views of disability rights organisations on assisted dying legislation in England, Wales & Scotland: An analysis of position statements

JOURNAL OF MEDICAL ETHICS | Online – 5 January 2021 – The purpose of this study was to collect and synthesize the views of an important stakeholder group – namely people with disabilities (PwD) – as expressed by disability rights organisations (DROs) in Great Britain. Parliamentary consultations were reviewed, together with an examination of the contemporary positions of a wide range of DROs. The authors' analysis revealed that the vast majority do not have a clear public stance; those that do exhibit a significant diversity of opinion. DROs opposing legislation on assisted dying have argued that it would be premature, misguided, inequitable and culturally undesirable. Some specify conditions that would have to be satisfied before they could support legalisation, such as radical improvements in health and social care services (especially those relating to end of life care) and the elimination of discrimination against PwD. DROs supporting assisted dying maintain that a change in the law would promote autonomy, end intense suffering, can be delivered safely and is supported by the DRO's membership. The discussion considers the reasons why several DROs adopt a neutral stance and the argument is made that, whatever their overarching stance on the issue, DROs need to be involved in the policy debate so that the crucial perspectives of PwD are heard and addressed. This is an important message for countries around the world that permit, or are considering legalising, assisted dying. **Abstract:** <http://bit.ly/3brdnWz>

End-of-life care for children with complex congenital heart disease: Parents' and medical care givers' perceptions

JOURNAL OF PAEDIATRICS & CHILD HEALTH | Online – 29 December 2020 – In complex congenital heart diseases (CHD), patients may remain affected by significant morbidity and mortality after surgery. The authors analysed the end-of-life (EoL) care in children with severe CHD who died in their institution [i.e., University Hospital, Padova, Italy] and investigated perspectives of parents and healthcare professionals (HCPs). The patient population studied included 30 children who died ... (median age: 45 days; range: 15 days to 3.4 years). 97% died in an intensive care unit setting and were intubated and sedated at EoL. 77% died without parents being present at bedside. Eighteen families and 10 healthcare professionals (HCPs) were interviewed. For 61% of the parents and 70% of the clinicians, the goal of therapy at the EoL was "to lessen your child's suffering as much as possible." 44% of parents and 50% of HCPs recognised that their child had no chance of survival "a few days before the child died." In the opinion of the authors, these data suggest an unconscious reluctance to change goals-of-care in EoL, shifting from intensive care to comfort and quality of life. **Abstract:** <https://bit.ly/3b3WO2z>

Noted in Media Watch 15 October 2018 (#585, p.15):

- *PEDIATRICS* | Online – 12 October 2018 – ‘**Unilateral withdrawal of life-sustaining therapy in a severely impaired child.**’ Doctors, patients and families often disagree about which treatments are efficacious or futile, appropriate or inappropriate, or obligatory or obligatorily withheld. Intractable disagreements about futility create significant moral distress. Many hospitals have policies used to specify a procedural framework for resolving such disagreements. Some states have a legal framework that permits unilateral withdrawal of life-sustaining treatment. But even with laws and policies, cases generate disagreement. The authors present a case in which professionals disagreed about the appropriateness of overriding a parental demand for continued life-sustaining treatment. **Full text:** <http://bit.ly/3ndJFpS>

Noted in Media Watch 2 May 2016 (#460, p.4):

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 21 April 2016 – ‘**The importance of early involvement of paediatric palliative care for patients with severe congenital heart disease.**’ The authors discuss the advantages of a fully integrated palliative care (PC) ethos in patients with congenital heart disease, offering the potential for improved symptom control, more informed decision-making and enhanced support for patients and their families throughout their disease trajectory. These core principles may be delivered alongside expert cardiac care via non-specialists within pre-existing networks or via specialists in paediatric PC when appropriate. An individualised set of values can be established around not just end of life but also quality of life decisions... **Abstract:** <http://bit.ly/2LnBES3>

Staffing in California public hospital palliative care clinics: A report from the California Health Care Foundation Palliative Care in Public Hospitals Learning Community

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 January 2021 – Although clinic-based palliative care (PC) services have spread in the U.S., little is known about how they function, and no studies have examined clinics that predominantly serve safety net populations. Twelve of 15 programs [in California] responded... All 10 programs use multiple disciplines to deliver care. Average full-time equivalent (FTE) used to staff an average of 2.75 half-day clinics per week includes 0.69 physician FTE, 0.51 nurse practitioner FTE, 1.37 nurse FTE, 0.79 social worker FTE, and 0.52 chaplain FTE. Clinic session schedules include an average of 1.88 new patient appointment slots ... and four follow-up appointment slots... The nine programs that reported on clinic volumes see 1,081 patients annually combined, with an annual average of 120 per program. Encounters per patient averaged 3.04... All reported offering seven core PC services: pain/symptom management, comprehensive assessment, care coordination, advance care planning, PC plan of care, emotional support, and social service referrals. An average of 77.4% of clinic financing came from the health systems. More research is needed to understand the most effective and efficient staffing models for meeting the PC needs of the safety net population. **Abstract:** <https://bit.ly/2L8zeHd>

The role of religion in physician outlook on death, dying, and end-of-life care

JOURNAL OF RELIGION & HEALTH | Online – 2 January 2021 – One of the many roles a physician provides to their patients is compassion and comfort, which includes tending to any psychological, spiritual, and religious needs the patient has. The goal of this pilot study was to explore whether religious or spiritual values of physicians at an urban academic hospital affect how physicians care for and communicate with their patients, especially when dealing with death, dying, and end-of-life (EoL) matters. After surveying 111 inpatient physicians at an academic hospital, the authors found that 92% of physicians are extremely or somewhat comfortable having EoL discussions. They also found that physician religiosity and spirituality are not necessarily required for discussing death and dying and that the religious and spiritual values of the physician do not correlate with their ability to have EoL conversations with the patient. The authors found no difference between years in practice and comfort discussing religion and spirituality, though they did find that, of the physicians who believe they are comfortable talking to patients about religion or belief systems, most of them had more than five EoL patients in the past 12 months. Lastly, referrals to palliative care or pastoral services were not impacted by the physician’s religious or spiritual beliefs. **Abstract (w. list of references):** <https://bit.ly/2JLqDd6>

Cont.

Noted in Media Watch 13 August 2018 (#576, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 August 2018 – ‘Physicians’ religious characteristics and their perceptions of the psychological impact of patient prayer and beliefs at the end of life: A national survey.’ Physicians who are more religious or spiritual may report more positive perceptions regarding the link between religious beliefs/practices and patients’ psychological well-being. 85% of survey participants believed that patients’ prayer has a positive psychological impact, 51% thought that patients’ belief in divine judgment has a positive psychological impact, and only 17% of physicians thought the same with patients’ expectation of a miraculous healing. Opinions varied based on physicians’ religious and spiritual characteristics. **Full text:** <http://bit.ly/3b5MfMi>

Words describing feelings about death: A comparison of sentiment for self and others and changes over time

PLOS ONE | Online – 6 January 2021 – Understanding public attitudes towards death is needed to inform health policies to foster community death awareness and preparedness. Linguistic sentiment analysis of how people describe their feelings about death can add to knowledge gained from traditional self-reports. This study provides the first description of emotive attitudes expressed towards death utilising textual sentiment analysis for the dimensions of valence, arousal and dominance. A linguistic lexicon of sentiment norms was applied to activities conducted in an online course for the general-public designed to generate discussion about death. The authors analysed the sentiment of words people chose to describe feelings about death, for themselves, for perceptions of the feelings of “others,” and for longitudinal changes over the time-period of exposure to a course about death. The results demonstrated that sadness pervades affective responses to death, and that inevitability, peace, and fear were also frequent reactions. However, words chosen to represent perceptions of others’ feelings towards death suggested that participants perceived others as feeling more negative about death than they do themselves. Analysis of valence, arousal and dominance dimensions of sentiment pre-to-post course participation demonstrated that participants chose significantly happier (more positive) valence words, less arousing (calmer) words, and more dominant (in-control) words to express their feelings about death by the course end. This suggests that the course may have been helpful in participants becoming more emotionally accepting in their feelings and attitude towards death. **Full text:** <http://bit.ly/38jJhCf>

Dying at home of COVID-19: Meeting the need for home-based care

PREVENTIVE MEDICINE | Online – 31 December 2020 – Despite the increased burden of COVID-19 on older adults, ethical and public health frameworks lack adequate guidance for elderly patients who manage severe, even fatal, illness at home. The U.S. Centers for Disease Control & Prevention and World Health Organization recognize the heightened risks of COVID-19 for older adults; however, both organizations presuppose that most cases of COVID-19 will be mild to moderate and recoverable at home. Yet, older adults are least likely to follow this trajectory. Older patients are more susceptible to experiencing severe illness at home from which they may not recover; and if they do seek medical care, they tend to suffer worse outcomes than younger patients in intensive care settings. Given their likelihood of severe illness, worse outcomes in intensive care settings, and potential difficulty accessing resources, frail, disabled, and otherwise vulnerable older patients may face COVID-19 at home without adequate resources, information, or support for home-based care. The authors of this editorial proposes three approaches to prevent needless suffering and ensure that this vulnerable population continues to receive needed care. **Full text (click on pdf icon):** <http://bit.ly/2KMSBFV>



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>

Can you hear me now? Improving palliative care access through telehealth

RESEARCH IN NURSING & HEALTH | Online – 4 January 2021 – Telehealth has been increasingly used to expand healthcare access over the last two decades. However, this had not been the case for palliative care (PC), because telehealth was considered nontraditional and impractical due to the sensitive nature of conversations and a “high touch” philosophy. Motivated by limited PC access to rural and underserved populations and positive PC telehealth studies, clinical PC telehealth models have been developing. However, nearly overnight, the **COVID-19** pandemic accelerated the use and uptake of telehealth across healthcare and especially in PC. As a result, clinicians, administrators, and others agree that telehealth is “here to stay,” and will likely maintain widespread use and refinement beyond rural areas. The purpose of this review is to describe exemplar PC telehealth programs in research and clinical practice, including pros and cons, lessons learned, and future directions for the ongoing development and expansion of PC via telehealth across diseases and the lifespan. **Abstract:** <https://bit.ly/3pMYhOX>

N.B. Search back issues of Media Watch for additional articles on telehealth/telemedicine in hospice and PC at: <http://bit.ly/2ThijkC>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 4 January 2021 – ‘**End-of-life care in the time of COVID-19: Communication matters more than ever.**’ Results of this study support the importance of communication, particularly remote communication, among family, patients and healthcare teams during periods of restricted visitation resulting from the COVID-19 pandemic. Family reports of effective remote communication with the patient and the healthcare team were associated with significantly better family experiences of end-of-life care (EoLC). Overall evaluation of EoLC, as well as communication-specific aspects of care – healthcare team listens and kept family informed – were more highly rated... **Full text:** <http://bit.ly/35fh25Q>

Research Matters

Missing not at random in end-of-life care studies: Multiple imputation and sensitivity analysis on data from the ACTION study

BMC MEDICAL RESEARCH METHODOLOGY | Online – 9 January 2021 – Missing data are common in end-of-life care (EoLC) studies, but there is still relatively little exploration of which is the best method to deal with them, and, in particular, if the missing at random (MAR) assumption is valid or missing not at random (MNAR) mechanisms should be assumed. The authors investigated this issue through a sensitivity analysis within the ACTION study, a multicenter cluster randomized controlled trial testing advance care planning in patients with advanced lung or colorectal cancer. Multiple imputation procedures under MAR and MNAR assumptions were implemented. Possible violation of the MAR assumption was addressed with reference to variables measuring quality of life and symptoms. The MNAR model assumed that patients with worse health were more likely to have missing questionnaires, making a distinction between single missing items, which were assumed to satisfy the MAR assumption, and missing values due to completely missing questionnaire for which a MNAR mechanism was hypothesized. The authors explored the sensitivity to possible departures from MAR on gender differences between key indicators and on simple correlations. Up to 39% of follow-up data were missing. Results under MAR reflected that missingness was related to poorer health status. Correlations between variables, although very small, changed according to the imputation method, as well as the differences in scores by gender, indicating a certain sensitivity of the results to the violation of the MAR assumption. The findings confirmed the importance of undertaking this kind of analysis in EoLC studies. **Full text:** <http://bit.ly/39j4ivV>



Palliative Care Network
Palliative Care for Everyone, Everywhere

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Knowledge & Technology
<http://bit.ly/2DANDFB>

The role of research in improving responsiveness of palliative care to migrants and other underserved populations in The Netherlands: A qualitative interview study

BMC PALLIATIVE CARE | Online – 6 January 2021 – Researchers play a key role in ensuring research demonstrates responsiveness to patients with a migration background and other underserved populations in order to obtain representative research findings and allow the development of an evidence base that can be used by service providers and policymakers to reduce disparities in palliative care (PC). Their efforts are affected by the interaction with research institutions, healthcare institutions and healthcare professionals. The authors' research suggests there are several ways to increase opportunities to improve responsiveness of PC through research. To address individual level factors they recommend training in responsiveness for researchers in the field of PC; to increase knowledge of patients with a migration background and other underserved populations in PC and familiarity with responsiveness measures. To address factors on the institutional level the authors also recommend training for healthcare professionals involved in PC research projects; to learn to address the topic of PC and increase enrolment of patients with a migration background and other underrepresented populations. Lastly, the authors encourage researchers as well as research institutions and funding agencies to allow flexibility in research practices and set a standard for responsive research practice. Providing the opportunity for practical support helps researchers to get responsiveness of PC on the agenda and take action to address it. When such opportunities to improve responsiveness of research are utilized, research can help identify and understand determinants of disparities, identify and evaluate interventions to eliminate them and contribute to quality improvement and innovation of equitable PC, in which patients and families receive care according to their needs. **Full text:** <http://bit.ly/3bbbUDv>

N.B. Search back issues of Media Watch for additional articles on PC for the immigrant population at: <http://bit.ly/2ThijkC>

A case analysis of partnered research on palliative care for refugees in Jordan and Rwanda

CONFLICT & HEALTH | Online – 6 January 2021 – In the best interest of those suffering or likely to die in conflict-induced humanitarian crisis settings, international collaborators should support local needs and engage in partnerships and collaborations, adapting research protocols as needed. Involvement of local research collaborators was essential for everything from research design and contextualizing findings, to practical processes such as hiring and training team members and for accessing the population the study was meant to serve. Common experiences across the study settings included the importance of building relations that are sensitive to multiple vulnerabilities and unequal power among research partners as much as with research participants, and the need to create spaces that facilitate the sharing of knowledge and experiences. The main outcomes of this case analysis include: the importance of understanding cultural norms in all research roles; considerations of how to promote the integrity and ethics of the research; and, the importance of training, reflection and discussion to support research team members and to promote participant voices in research with refugees. The importance of supporting team members during the research process was critical for ensuring quality data, grounded interpretation of participant information and translating the understanding of the results for culturally sensitive dissemination. The need for ongoing communication between international collaborators is vital for all future partnerships. Despite global social and political forces with longstanding roots that continue to hold barriers in place, active and engaged participation towards the goal of equitable partnering has been our attempt to overcome mechanisms of global inequities in order to bring partners together. **Full text:** <http://bit.ly/2LdUJGM>

N.B. Additional articles on palliative care for refugees noted in Media Watch 2 November 2020 (#690, p.7).

[Media Watch: Editorial Practice](#)

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International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/36XAaXg>

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Asia Pacific
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