

**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.

6 December 2021 Edition | Issue #746



Compilation of Media Watch 2008-2021 ©

Compiled & Annotated by Barry R. Ashpole

**Transitioning smoothly between healthcare settings is challenging for patients and clinicians, requiring proactive communication about advance care planning and goals-of-care, collaboration between distinct health care entities, and robust logistical planning to ensure safe, comfortable transitions between acute care, long-term, and home settings.**

'Home-based palliative care: Known benefits and future directions' (p.2), in *Current Geriatrics Reports*.

## International

### **Dying patients go without care as community nurses “on their knees”**

U.K. (England) | *The Independent* (London) – 29 November 2021 – Dying patients are going without care in their own homes because of a collapse in community nursing services, new data shared with *The Independent* reveals.<sup>1</sup> Across England a third of district nurses say they are now being forced to delay visits to end-of-life care patients because of surging demand and a lack of staff. This is up from just 2% in 2015. In an investigation into the service, more than half of district nurses said they no longer have the capacity to do patient assessments and psychological care. Professor Alison Leary, director of the International Community Nursing Observatory, said her study showed the country was “sleepwalking into a disaster.” She said the situation was now so bad that nurses were being driven out of their jobs by what she called the “moral distress” they were suffering at not being able to provide the care they knew they should. People are at the end of their tether. District nurses are reporting having to defer work much more often than they did two years ago. What they are telling us is that the workload is too high. This is care that people don't have time to do.” The findings come as community nursing is

being leaned on by other parts of the National Health Service to keep patients out of hospital. <https://bit.ly/3d3iH1H>

### Specialist Publications

'Feeling called to care: A qualitative interview study on normativity in family caregivers' experiences in Dutch home settings in a palliative care context' (p.3), in *BMC Palliative Care*.

'Hospital care for the dying patient with cancer: Does an advance care planning invitation influence bereaved relatives' experiences? A two country survey' (p.9), in *BMJ Supportive & Palliative Care*.

'National and international non-therapeutic recommendations for adult palliative and end-of-life care in times of pandemics: A scoping review' (p.7), in *Palliative & Supportive Care*.

'Values and preferences for future end-of-life care among the indigenous Sámi' (p.8), in *Scandinavian Journal of Caring Sciences*.

Cont.

1. 'District Nursing Today: The View of District Nurse Team Leaders in the U.K.,' International Community Nursing Observatory, November 2021. **Download at:** <https://bit.ly/3o8rBl4>

Noted in Media Watch 15 November 2021 (#743, p.2):

- U.K. (England & Wales) | *The Telegraph* (London) – 10 November 2021 – '**Number of people dying at home is highest in 20 years.**' The number of people dying at home is now the highest since the turn of the century as patients continue to struggle to access healthcare, official statistics suggest. Between January and June this year, 21,471 excess deaths occurred in private homes in England and Wales – almost 2,000 more compared to the same time last year. 85,910 people died at home during the first six months of the year, the highest figure in Office for National Statistics data, which goes back to 2001, when 51,517 people died at home. Excess deaths are the number of deaths above the average when compared to the same period in the pre-pandemic years of 2015-2019. <https://bit.ly/2YFbIIS>

## **Specialist Publications**

### **Family physicians supporting patients with palliative care needs within the patient medical home in the community: An appreciative inquiry study**

*BMJ OPEN* | Online – 2 December 2021 – This study explores and describes behaviours and health system components that are required to improve the coordinated and collaborative care for community-based patients with palliative care (PC) needs and their family and unpaid caregivers. The authors interviewed family physicians (FPs) who practice in a large Canadian city and surrounding rural area. They identified "possibility statements" that described a future "destiny" state. These "possibility statements" were presented to bereaved caregivers and patient focus groups, as well as two palliative home care teams, to determine their reactions and perspectives to then create a panoramic view of the "destiny" state. The authors subsequently developed a conceptual framework that describes how to achieve this "destiny" state with the patient and family journey as the central focus. It is anchored by two 'Loran' triads that describe the effective collaboration required between the four different

groups of clinicians (FPs, specialists, PC consultants, home care), who support the patient and family. This conceptual framework is a significant development in the primary PC literature as its key contribution identifies the explicit ways that the healthcare team, healthcare system and societal attitudes can be optimised to improve the care of patients with PC needs. While the roles and responsibilities of different healthcare providers have been explored in the provision of PC, this is the first comprehensive framework that pulls all of these perspectives and roles together. **Full text:** <https://bit.ly/3lw1OS7>

#### **Research Matters**

**'A race-conscious approach toward research on racial inequities in palliative care'** (p.9), in *Journal of Pain & Symptom Management*.

### **Home-based palliative care: Known benefits and future directions**

*CURRENT GERIATRICS REPORTS* | Online – 25 November 2021 – Home-based palliative care (HBPaIC) is clearly beneficial from a cost-savings perspective, and mounting evidence suggests benefits from a patient-centered perspective. Across geography and illness type, homebound patients, their caregivers, and their health systems benefit from palliative care (PC) services. Models for HBPaIC delivery are heterogeneous, but refined quality standards and further study may lead to a more coherent narrative about its benefits. None of the studies the authors reviewed primarily focused on the role of HBPaIC in improving access to – or quality of – PC for under-represented populations. None focused on the dynamic between HBPaIC and existing home-based primary care programs. Additionally, while the majority of studies reviewed included older adults, no studies described partnerships between geriatric medicine and PC specialists. **Full text:** <https://bit.ly/3D5fvx1>

**N.B.** Selected articles on the interface between geriatric and palliative medicine noted in Media Watch 15 November 2021 (#743, p.11).

Cont.

**Related:**

- *BMC PALLIATIVE CARE* | Online – 27 November 2021 – ‘**Feeling called to care: A qualitative interview study on normativity in family caregivers’ experiences in Dutch home settings in a palliative care context.**’ Due to their often unique relationship with and valuable knowledge about the patient, family caregivers (FCGs) are essential in providing emotional support, communicating with professionals and services, relieving pain and other symptoms, or doing practical tasks. However, especially if the patient desires to stay and die at home, as most people prefer initially, the roles and responsibilities of their families and friends are intensified and caregiving may be burdening. This study explores why FCGs ... persevere, despite the challenges... **Full text:** <https://bit.ly/3d1WuBf>

**The 2021 Medicare Advantage hospice carve-in**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 29 November 2021 – In 2021, the U.S. Centers for Medicare & Medicaid Services began testing the value-based insurance design model in 9 Medicare Advantage organizations providing plans in 206 counties nationwide. Under this model, which will become more widespread in the future (anticipated to increase to 15 Medicare Advantage organizations providing plans in 461 counties in 2022), hospice services are paid for and overseen by Medicare Advantage, unlike the existing structure that carves out hospice services from Medicare Advantage. In the carve-out approach, when Medicare Advantage enrollees elect hospice, their hospice benefits are provided under traditional Medicare coverage and are not overseen by the Medicare Advantage plan. Proponents of the Medicare Advantage carve-in suggest it has the potential to reduce fragmentation, produce new opportunities for coordination, and create new programs for patients at the end of life (EoL) by consolidating accountability under Medicare Advantage. However, older adults, and particularly those with serious illness, whose EoL experiences would be shaped by Medicare Advantage under the carve-in, may potentially be at risk to receive lower-quality care because of the incentives to control the costs of care in Medicare Advantage plans. This Viewpoint summarizes some of these concerns and outlines the possible implications of the Medicare Advantage hospice carve-in for EoL care if existing trends continue. **Full text:** <https://bit.ly/3rqVPI9>

**Related:**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 December 2021 – ‘**Effectiveness of pediatric concurrent hospice care to improve continuity of care.**’ In the U.S., the 2010 Patient Protection & Affordable Care Act mandated landmark hospice care legislation for children at end of life (EoL). Little is known about the impact of pediatric concurrent hospice care. Using national Medicaid data, the authors conducted a quasi-experimental designed study to estimate the effect of concurrent vs standard hospice care to improve EoL care continuity for children. Care continuity (i.e., hospice length of stay, hospice disenrollment, emergency room transition, and inpatient transition) was measured via claims data. These findings have policy implications. **Abstract (w. references):** <https://bit.ly/3Gf0qUq>

**Managing medicines at the end of life: A position paper for health policy and practice**

*JOURNAL OF HEALTH ORGANIZATION & MANAGEMENT*, 2021;35(9):368-377. The impact of population ageing is significant, multifaceted and characterised by frailty and multi-morbidity. The COVID-19 pandemic has accelerated care pathways and policies promoting self-management and home-based care. One under-researched area is how patients and family caregivers (FCGs) manage the complexity of end-of-life (EoL) therapeutic medicine regimens. In this position paper the authors bring attention to the significant strain that patients and FCGs experience when navigating and negotiating this aspect of palliative and EoL care. Policymakers and healthcare professionals often lack awareness of the significant burden and emotional work associated with managing and administering often potent high-risk medicines (i.e., opioids) in the domiciliary setting. The recent “revolution” in professional roles associated with the COVID-19 pandemic, including remote consultations and expanding community-based care, means there are opportunities for commissioners to consider offering greater support. The prospect of enhancing the community pharmacist’s medicine optimisation role to further support the wider multi-disciplinary team is considered.

Cont.

The position paper takes a person-focused perspective and adopts a holistic view of medicine management. The authors argue for urgent review, reform and investment to enable and support terminally ill patients and FCGs to more effectively manage medicines in the domiciliary setting. There are clear implications for pharmacists and these are discussed in the context of public awareness, inter-professional collaboration, organisational drivers, funding and regulation and remote care delivery. **Full text (click on pdf icon):** <https://bit.ly/316wAtT>

### **Effects of an interprofessional spiritual care education project**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 25 November 2021 – Spiritual care (SC) is a critical aspect of end-of-life care that is often undervalued and under-addressed by hospice healthcare teams. The purpose of this quality improvement project was to determine if the implementation of an evidence-based SC protocol changed practices regarding the initial assessment of spiritual needs, frequency of reassessment of needs, the inclusion of spiritual interventions, and staff perspectives on SC. The pre-implementation and postimplementation data evaluation displayed increased compliance with spiritual needs assessment within five days of admission, increased reassessment intervals, an increase in the percentage of interactions that included spiritual interventions, and improved staff perspectives on SC. **Abstract:** <https://bit.ly/3d7Ahlp>

### **The grief and bereavement experiences of informal caregivers: A scoping review of the North American literature**

*JOURNAL OF PALLIATIVE CARE* | Online – 3 December 2021 – As more individuals face the reality of informal caregiving, there is a pressing need to understand their grief and bereavement experiences. The factors identified by the authors of this article provide valuable insight when developing support. In addition, the COVID-19 pandemic has highlighted further issues, causing grief to become “suspended” when family and friends are prevented from mourning together. The competing emotions and psychosocial outcomes experienced by caregivers reflect the nuanced nature of their care. Understanding the nuances of informal caregivers’ experiences with grief and bereavement will inform and advance practice, policy, and research. Practitioners should be further educated on how to properly acknowledge the complexity of grief and bereavement for informal caregivers, specifically paying attention to mediators of grief and culture. **Full text:** <https://bit.ly/3ljCeJL>

### **Resident perspectives on palliative care at an urban teaching hospital**

*JOURNAL OF PALLIATIVE CARE* | Online – 29 November 2021 – There has been an increasing need to address end-of-life (EoL) care and palliative care (PC) in an era when measures to extend life for terminal illnesses are often initiated without consideration of quality of life. Addressing the barriers for resident physicians to initiate EoL conversations with patients is an important step towards eliminating the disconnect between patient wishes and provider goals. The authors solicited the experiences of pediatric, general surgery, and internal medicine residents through an anonymous survey to assess exposure to PC during training, comfort with providing PC, and barriers to implementing effective PC. 45% of residents reported exposure to PC prior to medical training. Ninety-three percent of these residents reported being formally introduced to PC during medical training through formal lecture, although the majority reported also being exposed through either small group discussions or informal teaching sessions. Time constraints and lack of knowledge on how to initiate and continue conversations surrounding EoL care were the greatest barriers to effectively caring for patients with terminal illnesses. Residents concurred that either attending physicians or hospital-designated PC providers should initiate PC discussions, with care managed by an interdisciplinary PC team; this consensus demonstrates a potential assumption that another provider will initiate EoL discussions. **Abstract (w. references):** <https://bit.ly/3nYCUMp>



Share this issue of Media Watch with a colleague.

## Top ten tips palliative care clinicians should know about caring for Muslims

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 December 2021 – Islam is the fastest-growing religion across the world and in the U.S. Adherents of Islam are known as Muslims. Globally, Muslims comprise the second largest religious group with 1.8 billion people, or 24% of the world's population, and range in racial and ethnic diversity. As this population continues to grow, palliative care (PC) clinicians will invariably care for a Muslim patient therefore making it important to have a basic understanding of values, traditions, and beliefs held by them. This article outlines 10 basic principles held by many Muslim patients and their families that can allow for PC to be delivered in a culturally inclusive way. **Abstract:** <https://bit.ly/3DhFyRS>

Noted in Media Watch 31 May 2021 (#719, p.4):

- *AL-RISALAH: JOURNAL OF ISLAMIC REVEALED KNOWLEDGE & HUMAN SCIENCES*, 2021;5(2): 167-185. 'Palliative care and hospice care from the perspective of the *maqasid al-shari'ah*.' It is crucial that Muslim healthcare professionals understand the Islamic perspective of life, health, illness, and death issues to provide a holistic care to their patients, especially those who are terminally or critically ill. Terminally ill patients would inevitably require specialized treatment such as palliative care (PC) or hospice care, depending on their conditions to improve their remaining quality of life. The authors examined the approach used by healthcare providers in providing PC and hospice care from the perspective of *maqasid shar'ah*... **Full text (click on pdf icon):** <https://bit.ly/3fM52Nl>

**N.B.** Search back issues of Media Watch for additional articles on the "Muslim" perspective on end of life and end-of-life care at: <http://bit.ly/2ThijkC>

## A scoping review of palliative care for adults with Huntington's disease: Current practice and future directions

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 November 2021 – Huntington's disease (HD) is a neurodegenerative disorder characterized by mid-life onset, cognitive decline, and behavioral disturbance. The authors conducted a review of the end-of-life (EoL) experience of HD patients and their families. They screened 1566 studies, assessed 244 studies, and included 27 studies. Decedent data showed greater likelihood of pneumonia, choking, nutritional deficiencies, and skin ulcers. HD patients in hospice experienced pain, anxiety, nausea, and dyspnea. Psychiatric symptoms included dysphoria, agitation, irritability, apathy, and anxiety. Psychosis is associated with worse cognition, function, and behavioral disturbance. Electroconvulsive therapy and venlafaxine improved depression. Suicidal ideation improved with talking, self-management, medication, and discussing EOL wishes. Tetrabenazine improved chorea. HD patients require home care within two years of diagnosis. Only one study reported use of palliative care (PC) services (4%). HD patients are admitted to the hospital late in disease course and are often discharged to long-term care facilities. Two studies created tools to navigate EoL decisions. Most HD patients had EoL wishes; only familiarity with HD predicted having EoL wishes. Few had advance directives or discussed EoL wishes with their families.

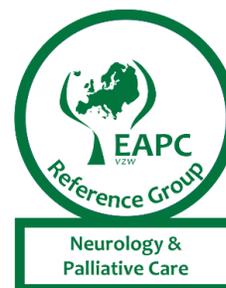
Clinicians drive EoL discussions. Research is needed to further assess the PC needs of HD patients and to provide care recommendations. **Abstract:** <https://bit.ly/3d7VnzZ>

### The Evolving Specialty of Neuropalliative Care

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Blog – 15 November 2021 – The focus of this posting is on the evolving specialty that is neuropalliative care with summaries of a representative sample

of journal articles on the subject published during the past year or so. Included are articles on Parkinson's disease, Amyotrophic Lateral Sclerosis, Multiple Sclerosis, Motor Neurone disease, **Huntington's disease**, Dementia, Epilepsy and Neuro-ICU (neurosciences intensive care unit). There is a short selection of articles on neuropalliative care in the context of the COVID-19 pandemic, from the family caregivers' perspective, and advance care planning (including advance directives and goals-of-care). <https://bit.ly/3cdwyIS>

**N.B.** This posting is part of a weekly series on neuropalliative care developed in partnership with the EAPC Neurology Reference Group: <https://bit.ly/3rqe50A>



## Stay home, work safe: Attitudes and beliefs of members of a department of palliative care, rehabilitation, and integrative medicine regarding remote work during the COVID-19 pandemic

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 November 2021 – Major epidemics such as COVID and SARS are likely to become more frequent as global travel increases. The well-being and safety of employees are important in maintaining a healthy workplace in the face of global crisis and in the new normal thereafter. Significant changes in the year since the pandemic was declared include multiple peaks of infection and vaccination efforts. It will also be important to evaluate the impact of working from home under more usual conditions. Working from home was received positively... However, some subgroups of individuals found working from home particularly distressing, and these may need additional support and solutions; clinicians may face different or more intensified stressors, and employees with significant home circumstances may need more flexibility in their work. Considerations may be needed for a hybrid model to optimize the best work environment or employ emerging technologies and work models to facilitate workplace well-being. Follow-up surveys are needed to track the progress of our work-from-home model, develop a more conclusive perception of the work-from-home transition, and find new solutions to maximize employee effectiveness. The knowledge gained this time will help ... prepare for work-from-home situations. It is also likely that hybrid models of work will become more common, and the authors' findings support the continuity of some work-from-home component as a permanent feature of palliative care programs. **Full text:** <https://bit.ly/3rpbZvn>



## How can social workers be meaningfully involved in palliative care? A scoping review on the prerequisites and how they can be realised in practice

*PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 30 November 2021 – Although the social aspects surrounding the end-of-life phase suggest a place for social work in it, the profession is often inadequately involved in daily practice. This contrasts strongly with the potential meaningful contributions of social workers in this field. To date, no comprehensive list of prerequisites for meaningful social work involvement in palliative care (PC) exists. This review aimed to gain more insight on the prerequisites for meaningful social work involvement in PC and how to realise them in practice. It could therefore provide pathways for future intervention development in enhancing the involvement of social workers and maximising their contributions in PC. A scoping review methodology was used. The 170 articles that met the eligibility criteria were analysed for relevant content using open and axial coding processes. The nine prerequisites listed in this review concern the level of individual social work capacities and the level of contextual factors structuring social work practices. A majority of articles have, however, focused on the level of individual social work capacities in a rather specialist view on PC. **Full text:** <https://bit.ly/3o9c4kE>

Noted in Media Watch 22 March 2021 (#709, p.6):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 15 March 2021 – ‘**International collaboration in the time of COVID-19: The World Hospice & Palliative Care Social Work Network.**’ In the context of widespread loss, isolation, and grief due to COVID-19, palliative social workers came together in the fall of 2020 to form an international group named the World Hospice & Palliative Care Social Work Network. This emerging global network is committed to amplifying the innovative work, nuanced skills, research, and education and training provided by palliative social workers across different settings around the world. This article highlights some of the novel interventions developed by social workers in response to the pandemic... **Abstract:** <https://bit.ly/3rWPyLy>

**N.B.** Selected articles on the role of social workers in palliative and end-of-life care noted in Media Watch 1 February 2021 (#702, pp.7-8).



### 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.11.

## **Paramedics delivering palliative and end-of-life care in community-based settings: A systematic integrative review with thematic synthesis**

*PALLIATIVE MEDICINE* | Online – 1 December 2021 – Integrating palliative and end-of-life care (EoLC) into the provision of paramedic practice has gained considerable global attention in recent years. Overall, this review demonstrates the important role paramedics can play in facilitating home-based death and reducing avoidable hospital admissions. The known scope of palliative paramedicine was established, barriers and enablers of practice identified, and the perspectives of multiple stakeholders explored to reveal three key themes: 1) Broadening the traditional role; 2) Understanding patient wishes; and, 3) Supporting families. The authors' findings have novel implications for a multitude of stakeholders. Paramedics are a highly skilled workforce capable of filling a gap in palliative and EoLC provision to people in their homes, especially after-hours for palliative emergencies when other community palliative care (PC) services are unavailable. However, a multi-faceted approach to palliative paramedicine is needed to enable optimal care. This review will be helpful to policymakers when developing models of integration between PC services. If they have not done so already, ambulance services should broaden their clinical practice to include PC specific guidelines, accompanied by education and practical training addressing the complexities and legalities of EoLC. Finally, PC researchers have scope to investigate wider health professional perspectives on the paramedic's role in PC, as well as the efficacy and cost-effectiveness of targeted quality improvement programmes. **Full text:** <https://bit.ly/3rwwg3dk>

**N.B.** Search back issues of Media Watch for additional articles on the role of “paramedics” in EoLC at: <http://bit.ly/2ThijkC>

## **National and international non-therapeutic recommendations for adult palliative and end-of-life care in times of pandemics: A scoping review**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 2 December 2021 – The results of the scoping review indicate that besides the integration of advance care planning (ACP) in every clinical area and setting, the further development and expansion of digitalization in the healthcare sector is needed and must continue in order to be able to offer telecommunication and telemedicine. Using electronic devices in communication is helpful in non-pandemic times as well and will be increasingly requested. It also supports a lively exchange between professionals, patients and relatives, e.g., in goals-of-care discussions. Therefore, infrastructure must be provided, but staff must also be trained in specific “online communication skills.” In addition and especially in order to provide sufficient ACP, every healthcare professional should have basic knowledge of palliative care (PC), which must be trained across all relevant clinical disciplines. Finally, a national strategy for integrating PC in pandemic times should be developed in each country. This study adds an overview of relevant aspects and non-therapeutic recommendations in palliative and EoLC after one year into the SARS-CoV-2 pandemic. Only a very limited number of the included articles presented results from research studies. This is, of course, due to the limited time factor and the novelty of the global pandemic situation, but it also demonstrates that there are research gaps and enormous potentials to close them. Of particular interest are the long-term effects on the individuals involved, both patients and family members, as well as healthcare professionals. **Full text:** <https://bit.ly/3dcB3gT>

**N.B.** Search back issues of Media Watch for additional articles on “telehealth,” “telemedicine,” “telepalliative” and “virtual” care at: <http://bit.ly/2ThijkC>



### **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>

## Values and preferences for future end-of-life care among the indigenous Sámi

*SCANDANAVIAN JOURNAL OF CARING SCIENCES* | Online – 28 November 2021 – The authors investigate if and how the DöBra cards [a Swedish adaptation of the English-language GoWish cards] were able to support reflection and discussion of values and preferences for future end-of-life (EoL) care among a sample of Sámi individuals. Reactions varied on an individual basis among these participants who shared a Sámi background, but otherwise constituted a heterogeneous sample. Some commented on the taboos-laden nature of discussing EoL issues in other contexts, while many commented positively about EoL conversations in general, and benefits of using the DöBra cards in particular. The cards were said to be relevant, highlighting several issues previously not considered by those interviewed. Thirty-seven DöBra card statements were ranked among the top 10 priorities by at least one person, with the pre-formulated card item “to have those I am close to around me” chosen by most people, and along with the wild card for individually formulated preferences, most frequently ranked as highest priority. Participants used wild cards for preferences categorised as relating to attributes of contemporary Sámi culture most frequently; maintaining one’s (Sámi) identity and dying in places with personal or cultural meaning were other prominent preferences in this sample. The GoWish cards have been used in research studies with community-dwelling adults in several countries and as the DöBra cards with majority populations in Sweden, however, the authors have seen no other studies that have reported an extensive use of wild cards as in the present study. **Full text:** <https://bit.ly/3xC8fHQ>

Noted in Media Watch 3 February 2020 (#651, p.10):

- *MORTALITY* | Online – 27 January 2020 – ‘**The past is present: Death systems among the indigenous Sámi in Northern Scandinavia today.**’ Psychologist Robert Kastenbaum’s model provides a framework for understanding aspects of the death system that are Sámi-specific, Sámi-relevant as well as what has changed over time. Whereas Kastenbaum differentiated among the components of the death system, the authors analysis indicated these were often so interrelated as to be nearly inseparable among the Sámi. Seasonal changes and relationships to nature instead of calendar time dominated death systems, linking people, places and times. The extended family’s role in enculturation across generations and end-of-life support was salient. **Full text:** <http://bit.ly/2O5aJn>

**N.B.** The Sámi people are an indigenous Finno-Ugric people inhabiting Sápmi, which today encompasses large northern parts of Norway and Sweden, northern parts of Finland, and the Kola Peninsula within the Murmansk Oblast of Russia.

## Barriers to equitable palliative care utilization among patients with cancer

*SURGICAL ONCOLOGY CLINICS OF NORTH AMERICA*, 2022;31(1):9-20. Palliative care (PC) has become a pillar of clinical oncology. As a community of surgeons who have dedicated careers to fighting cancer and alleviating suffering, we must acknowledge this. Patients with cancer not only deserve access to surgical, medical, and radiation oncologists when clinically appropriate but they should also be afforded PC interventions concomitantly with standard oncologic treatment. This is the current recommendation of the American Society of Clinical Oncology.<sup>1</sup> It is the product of significant progress in the development and growth of PC services over the past half century. Medicine is increasingly realizing the true mission of PC – to relieve suffering and optimize quality of life, not just deal with end-of-life decisions. PC is inequitably accessible, underutilized, and often introduced late in the care of patients receiving surgical intervention. Existing barriers to equitable PC utilization among patients with cancer are numerous and complex. Dismantling current barriers to equitable PC utilization among patients with cancer will require coordinated efforts at the level of both providers and professional organizations. **First page view:** <https://bit.ly/3Gh08E1>

1. ‘Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update,’ *Journal of Clinical Oncology*, 2017;35(1):96-112. [Noted in Media Watch 31 October 2016 (#486, p.7)] **Full text:** <http://bit.ly/2utXVSB>

Cont.

## Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 30 November 2021 – ‘**Hospital care for the dying patient with cancer: Does an advance care planning invitation influence bereaved relatives’ experiences? A two country survey.**’ In this post-bereavement survey, 56% of the participants had been invited to an advance care planning (ACP) conversation. The majority (68%) of those who were not invited would have wanted such a conversation. Having been invited to an ACP conversation was associated with more favourable perceptions of the support and care given to both the patients and the participants themselves in the patient’s final days. In cancer care, the growing demand for shared decision-making has led to an increasing focus on goals-of-care discussions. **Full text:** <https://bit.ly/3rrH1D2>
- *SUPPORTIVE CARE IN CANCER* | Online – 29 November 2021 – ‘**Pattern and characteristics of patients admitted to a hospice connected with an acute palliative care unit in a comprehensive cancer center.**’ Problems including fragmentation of services and late referrals prevent many patients from receiving the appropriate palliative care (PC) at the right time. Different options should be available for providing PC, at least in a comprehensive cancer center, including an acute supportive/palliative care unit where difficult symptoms are treated during the course of cancer disease, an outpatient clinic for a proper consultation for ambulatory patients, and hospice and home care for patients who have a shorter survival time. **Full text:** <https://bit.ly/3FWkZMG>

## Research Matters

### **A race-conscious approach toward research on racial inequities in palliative care**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 November 2021 – Racial inequities in palliative and end-of-life care have been well-documented for many years. This inequity is longstanding and resistant to many intervention efforts. One reason for this may be that research in racial inequity in palliative care (PC), and the interventions developed, do not account for the effects of race and the everyday racism that patients of color experience while navigating the healthcare system. Public Health Critical Race Praxis (PHCRP) offers researchers new routes of inquiry to broaden the scope of research priorities in PC and improving racial outcomes through a novel conceptual framework and methodology. PHCRP, based off critical race theory, contains ten principles within four foci to guide researchers toward a more race conscious approach for the generation of research questions, research processes, and development of interventions targeting racial inequities. **Abstract (w. references):** <https://bit.ly/3o38UPJ>



Noted in Media Watch 18 October 2021 (#739, p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 15 October 2021 – ‘**A framework for anti-racist publication in palliative care: Structures, processes, and outcomes.**’ Systemic or structural racism describes an embedded pattern of explicit and implicit racial biases that, through policy and action, systematically confer advantage to white people and disadvantage Black, indigenous, and other people of color. Hospice and palliative care (PC) journals participate in this broader system of racial discrimination. Building on PC’s explicit focus on patients’ goals and values, which may in and of itself comprise a form of social justice in healthcare, PC journals and their publishers have an opportunity to lead others in cultivating anti-racist practices... **Abstract (w. references):** <https://bit.ly/31NuJl0>

Cont. next page

Noted in Media Watch 20 September 2021 (#735, p.6):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 September 2021 – ‘**Lack of racial diversity within the palliative medicine workforce: Does it affect our patients?**’ A palliative medicine workforce that reflects the diverse population that it serves will understand their needs through lived experience and be better equipped to meet those needs. By addressing inequalities within our own workforce and understanding a range of perspectives, we can begin to tackle the health inequalities that exist in palliative care (PC) and in society. More research is needed and justified to understand the association between diversity among clinicians, and access to PC and diversity among patients. Diversity in the PC workforce should be a societal goal in itself... **Full text:** <https://bit.ly/2XnPGcw>

Noted in Media Watch 24 May 2021 (#718, p.14):

- *PAEDIATRICS & CHILD HEALTH* | Online – 22 May 2021 – ‘**A time to act: Anti-racist paediatric research.**’ Research offers the potential for new treatments, programs and services, and underlies decisions about funding that can have profound implications for people’s lives. When racism in research is not addressed, children and their families will be unjustly impacted by systemic discrimination, exclusion, and inequity. With a growing acknowledgement that racism is a social determinant of health, and as COVID-19 reveals staggering racial disparities, the authors believe now is the time for intentional anti-racism initiatives throughout the research ecosystem to prevent further harms in patient care and the lives and futures of children. **Abstract:** <https://bit.ly/2Siweey>

**N.B.** The focus of the 17 August 2021 issue of the *Journal of the American Medical Association* is racial and ethnic disparities and inequities in medicine and healthcare. [Noted in Media Watch 23 August 2021 (#731, p.13)] **Journal contents page:** <https://bit.ly/2WeRg01>

### [Media Watch: Editorial Practice](#)

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

### [Distribution](#)

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

### [Links to Sources](#)

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

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

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

## Media Watch: Access on Online

### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3CX3lr3>

[Scroll down to 'Media Watch: a Potpourri']

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

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

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

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

### Asia



Asia Pacific  
Hospice Palliative  
Care Network

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

[Scroll down to 'Media Watch']

### Australia

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

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

### Canada



BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION <https://bit.ly/3two4xX>

[Grief & Bereavement & Mental Health Summit 2021 'Resource Page.' Scroll down to 'International Palliative Care Resource Center']



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

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

ONTARIO | Acclaim Health: <https://bit.ly/3g82uuS>

[Scroll down to 'General Resources' and 'Media Watch']

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://bit.ly/3tby3b3>

### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <https://bit.ly/3wwL5RW>

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

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



**Palliative Care Network**

*Palliative Care for Everyone, Everywhere*

Closing the Gap Between  
Knowledge & Technology

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