

**Media Watch...** is intended as an advocacy, research and teaching tool. The 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 1997, the then [U.S.] Institute of Medicine described a “good death” as one “free from avoidable distress and suffering for patients, families, and caregivers; in general accord with the patients’ and families’ wishes; and, reasonably consistent with clinical, cultural, and ethical standards.” After 24 years...

‘Drivers of racial/ethnic differences in perceived end-of-life care quality: More questions than answers’ (p.4), in *Journal of the American Geriatric Society*.

## News Media

### **End-of-life care will become a legal right**

U.K. (England) | *The Times* (London) – 25 February 2022 – Dying people will be given an explicit legal right to healthcare for the first time in National Health Service history, requiring every part of England to provide specialist palliative care (PC). End-of-life (EoL) charities said that the news was a milestone and could end a postcode lottery under which tens of thousands of people die every year without adequate support or pain relief. New analysis from the charity Marie Curie shows that about 215,000 people a year miss out on EoL care and that without intervention this could rise to 300,000 within 20 years.<sup>1</sup> The government will back an amendment to the Health & Care Bill in the House of Lords. Baroness Finlay of Llandaff, a professor of PC medicine and supporter of the amendment, said: “This change is incredibly important.” <https://bit.ly/3ltccna>

1. The analysis is detailed in a Marie Curie press release: <https://bit.ly/3lfZq3L>

### **Doctors who care for the dying face additional challenges amid the pandemic**

CANADA (Ontario) | *The Toronto Star* – 24 February 2022 – As a patient takes their last breath in a silent hospital room, Dr. Warren Lewin thinks to himself, “I really hope we did our best.” Palliative care (PC) doctors like Lewin have spent the pandemic desperately trying to manage patients’ symptoms, control their pain and ensure their end-of-life wishes are met from a medical standpoint. But even as the worst of COVID-19’s highly infectious Omicron wave appears to be over, critically ill COVID patients continue to fill hospital beds. And two years after the pandemic first emerged in Canada, PC doctors are exhausted, but holding steadfast. The *Star* spoke to three PC doctors about their experiences caring for the sickest of patients as the pandemic enters its third year. <https://bit.ly/33Ljh35>



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## These classes are near-death experiences, and that's a good thing

U.S. | *Time Magazine* – 23 February 2022 – Nationwide, students are clamoring to study death from all angles – philosophically, biologically, sociologically, and historically – at ages when most people see themselves as invincible. But it's not morbid curiosity or grim fatalism at work. Grief is surging among college students, and many are shouldering multiple losses during the pandemic...<sup>1</sup> While the most common reported loss was of a sense of normality, more than 10% of college students surveyed said a loved one had died of COVID-19. More than 26% said someone close to them had perished for other reasons. In the face of endless death, classes and other experiences that bring death into focus have become an outlet for young people to process their grief, manage their fears of dying... <https://bit.ly/3hbsQvk>

1. 'College student experiences of grief and loss amid the COVID-19 global pandemic,' *Omega – Journal of Death & Dying*, published online 23 June 2021. Full text: <https://bit.ly/3IkTw8O>

## Government & Non-Government Organizations et al

"You're the first person who's sat on that sofa in 12 months"

### *Experiences of loneliness among people at the end of life and their carers in Northern Ireland*

U.K. (Northern Ireland) | Marie Curie/Queens University (Belfast) – 28 February 2022 – The first study looking at loneliness and terminal illness in Northern Ireland has revealed a stark picture of the scale and impact that loneliness has on dying people and their carers. Nine in ten of Marie Curie frontline staff have supported dying patients who were lonely, while only slightly less have supported end-of-life carers who were lonely. The COVID-19 pandemic has also exacerbated the issue with nearly all frontline staff reporting an increase in the number of people they were supporting who were living with a terminal illness and experiencing loneliness. People with life-limiting illnesses are nearly twice as likely to report deep feelings of loneliness than those without such conditions. Download at: <https://bit.ly/3teEICj>

### End-of-life care in prisons

PENAL REFORM INTERNATIONAL | Online – 21 February 2022 – There is no global data on the number of older persons in prison. Known rates are from 1.8% of the national prison population in Indonesia to as high as 20% in Japan, and in many countries the number has been growing at a faster rate than the general prison population. This poses specific challenges for health and age-related policy and practice in prisons, as older people in prison are more likely to have disabilities, multiple, chronic health conditions or age-related cognitive impairment... Palliative care in prisons can be challenging not least because of the restrictions of the environment. <https://bit.ly/3leePJ4>



**N.B.** Palliative and end-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the report can be downloaded from the Palliative Care Network website: <http://bit.ly/2RdegnL>



### 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

### **Palliative care: A survey of program benchmarking for productivity and compensation**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 February 2022 – Referrals to palliative care (PC) often come from healthcare clinicians who lack the time and skill required to address the needs of the patient and their caregivers. At its heart, PC is individualized to the values, beliefs, and goals of the patient. The process ... takes time and expertise and, correspondingly, PC is labor intensive. To date, there has been no concentrated focus on how to accurately capture the productivity or work of PC clinicians. As a result, there is not a universally accepted method of measuring the effort which includes impact, activity, composition, and productivity of a PC program. **Abstract (w. references):** <https://bit.ly/3pqj3WN>

### **Contemporary occupational priorities at the end of life mapped against model of human occupation constructs: A scoping review**

*AUSTRALIAN OCCUPATIONAL THERAPY JOURNAL* | Online – 23 February 2022 – This review provides important insights into the occupational priorities of people at end of life (EoL) and the importance of supporting agency and volition at this time. The model of human occupation and its client-centred focus offer a framework for a more robust examination of ways to enhance volitional capacity and enable occupational participation for people at EoL. The majority of findings sat within the construct of volition, particularly around sense of personal capacity, self-efficacy and values. People prioritise ongoing engagement in valued occupations even if participation is effortful. As disease progresses, opportunity to exert influence and control over this participation and engagement increases in importance. **Abstract:** <https://bit.ly/33MSzHv>

**N.B.** A selection of articles on the role of occupational therapy in palliative and EoL care noted in Media Watch 15 February 2021 (#704, p.11).

### **End-of-life care for people with severe mental illness: Mixed methods systematic review and thematic synthesis of published case studies (the MENLOC study)**

*BMJ OPEN* | Online – 22 February 2022 – Case studies demonstrate the complexities and the ethical dilemmas associated with the provision of care to people with severe mental illness at the end of life. They reveal stark challenges presented by delayed diagnosis, patients' fluctuating capacity to make decisions and a concern about the futility of treatment. Palliative care (PC) staff may lack mental health knowledge, and mental health staff often have little or no experience of PC. Despite this, professionals want to learn from each other across specialities to provide better care. Synthesised case study findings also show the dangers of ascribing delays in mobilising (or continuing with) PC services in response to patients' challenging presentations, or difficult behaviour. **Full text:** <https://bit.ly/3sd7iVn>

#### **Related:**

- 'Person-centered care considerations for end-of-life care to persons with severe and persistent mental illness,' *Journal of Gerontological Nursing*, 2022;48(3):11-16. **Abstract:** <https://bit.ly/3pg5A3N>

#### Research Matters

**'Pragmatic trials and improving long-term care: Recommendations from a National Institutes of Health Conference'** (p.10), in *Journal of the American Geriatric Society*.

**'Stakeholders' views on priorities essential for establishing a supportive environment for clinical trials in nursing homes'** (p.10), in *Journal of the American Geriatric Society*.

**'Designing psychosocial intervention pilot studies: A tutorial for palliative care investigators'** (p.10), in *Journal of Pain & Symptom Management*.

## Utilization of palliative care for patients with COVID-19 and acute kidney injury during a COVID-19 surge

*CLINICAL JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY* | Online – 24 February 2022 – This study demonstrates important findings with considerations that extend beyond the COVID-19 pandemic. Currently, the benefits of palliative care (PC) for patients with acute kidney injury (AKI) are a knowledge gap in nephrology. The high mortality of those with AKI and the greater use of life-sustaining interventions that often do not prevent death suggest that AKI can serve as a trigger for proactive and early involvement of PC. Further multicentered studies of the timing of PC in critically ill patients may lead to opportunities for system-based interventions that identify patients at high risk of mortality or suffering who may benefit from early PC consultation. **Full text:** <https://bit.ly/3slELgF>

### Related:

- 'COVID-19 and palliative care: Observations, extrapolations, and cautions,' *Clinical Journal of the American Society of Nephrology*, published online 24 February 2022. **Full text:** <https://bit.ly/3t9bzso>

## Telehealth in outpatient delivery of palliative care: A prospective survey evaluation by patients and clinicians

*INTERNAL MEDICINE JOURNAL* | Online – 21 February 2022 – In Australia ... new funding models were introduced to support telehealth consultations, resulting in their widescale adoption in palliative care service delivery. In this multi-site prospective, cross-sectional, observational study ... there were 127 matched patient-physician data of telehealth consultations, and a further 812 physician-only assessments. Telehealth was generally acceptable and satisfactory, with patients providing greater positive scores than clinicians. Telehealth incorporating both audio and video were more acceptable and satisfactory, particularly with the presence of a carer, and during routine reviews. Physicians were less satisfied using telehealth when there was increasing symptom complexity across all domains. **Abstract:** <https://bit.ly/3I6zBue>

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

## Drivers of racial/ethnic differences in perceived end-of-life care quality: More questions than answers

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 28 February 2022 – In 1997, the then Institute of Medicine described a “good death” as one “free from avoidable distress and suffering for patients, families, and caregivers; in general accord with the patients’ and families’ wishes; and, reasonably consistent with clinical, cultural, and ethical standards.”<sup>1</sup> After 24 years, health systems, community organizations, and care providers continue to search for the “what” and “how” of care delivery needed to achieve this goal. While gains have been made, providing the type of high-quality end-of-life (EoL) care that enables people of all identities to have a “good death” has proved elusive. It is unsurprising loved ones of Black and Hispanic decedents ... report worse ratings of care quality at the EoL. **Full text:** <https://bit.ly/3svGBeG>

### Research Matters

**‘Application of critical race theory in palliative care research: A scoping review’** (p.10), in *Journal of Pain & Symptom Management*.

1. ‘Approaching Death: Improving Care at the End of Life,’ Institute of Medicine (Committee on Care at the End of Life), Institute of Medicine. [National Academies Press, 1997] <https://bit.ly/3hrdDX1>

**N.B.** See reader response to ‘Top ten tips palliative care clinicians should know about delivering antiracist care to Black Americans,’ *Journal of Palliative Medicine*, published online 16 November 2021 [Noted in Media Watch 22 November 2021, (#744, p.12)] <https://bit.ly/3tmsWGi>

Cont.

#### Related:

- 'Race and birth country are associated with discharge location from hospital: A retrospective cohort study of demographic differences for patients receiving inpatient palliative care,' *eClinicalMedicine*, published online 18 February 2022. **Full Text:** <https://bit.ly/3BEtN95>
- 'Examining regional differences in nursing home palliative care for Black and Hispanic residents,' *Journal of Palliative Medicine*, published online 10 February 2022. **Abstract:** <https://bit.ly/3tveJ9n>

#### The surprise question in older hospitalized patients: To use or not to use?

*JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 17 February 2022 – One way of determining whether a patient is in the palliative phase is via the 'Surprise Question' (SQ), a widely recommended single-item tool ("Would I be surprised if this patient died in the next 12 months?"). However, there is a distinct lack of studies into the performance of the SQ in older hospitalized patients. Relatively few frail older patients have the opportunity to discuss end-of-life care with their physician, even though most would appreciate such a conversation. The aims of this study were to establish the predictive validity of the SQ in older hospitalized patients and assess whether the validity of the SQ is different between physicians and nurses, between patients... **Abstract (w. references):** <https://bit.ly/3H9V0kS>

#### Selected articles on the SQ:

- 'The prognostic value of the 12-, 6-, 3- and 1-month 'Surprise Question' in cancer patients: A prospective cohort study in three hospitals,' *European Journal of Cancer Care*, published online 26 January 2022. [Noted in Media Watch 7 February 2022 (#752, p.12)] **Full text:** <https://bit.ly/3Hbzddu>
- 'An online international comparison of palliative care identification in primary care using the "surprise" question,' *Palliative Medicine*, published online 1 October 2021. [Noted in Media Watch 4 October 2021 (#737, p.7)] **Full text:** <https://bit.ly/3A31wq0>

#### Development of an electronic Poor Outcome Screening (ePOS) score to identify critically ill patients with potential palliative care needs

*JOURNAL OF CRITICAL CARE*, 2022;69(6):154007. The ePOS score can easily be implemented in electronic health records and used for automated screening and stratification of ICU patients, pinpointing those in whom a comprehensive assessment of palliative care (PC) needs should be performed. Using the score at 48/hour after ICU admission allows for early identification of patients at high risk for poor outcome while still permitting clinicians and families to observe the effect of a time-limited period of full ICU treatment. The ePOS score is not intended as a substitute for, but rather as a tool to foster comprehensive PC assessments in the ICU early in the course of disease. However, the score should be externally validated. Moreover, future research needs to study which outcomes will benefit most... **Full text:** <https://bit.ly/3I9ER0k>

#### Related:

- 'Validation of 'Care Of the Dying Evaluation' (CODE™) within an international study exploring bereaved relatives' perceptions about quality of care in the last days of life,' *Journal of Pain & Symptom Management*, published online 4 March 2022. **Abstract (w. references):** <https://bit.ly/3MmHdeF>
- 'Identifying patients in need of general or specialised palliative care with ID-PALL®,' *Revue Médicale Suisse*, 2022;18(769):288-291. **Abstract:** <https://bit.ly/3LRUko3>

N.B. French language article.



**Palliative Care Network**  
Palliative Care for Everyone, Everywhere

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

## COVID-19: Impact on pediatric palliative care

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 February 2022 – This report reveals the ways in which the COVID-19 pandemic and subsequent response has impacted the lives of children and young people (CYP) with life-limiting or life-threatening conditions and their families. The psychological impact of the uncertainty about the pandemic and the future, and loss of support networks on the mental wellbeing of CYP and their families is evident. CYP and their families must be informed of the potential impact of the pandemic for them specifically and should be actively engaged in decision-making if treatment plans change. Service providers should carefully review their responses to the pandemic to ensure they are able to continue to assess and support family psychosocial needs. **Full text:** <https://bit.ly/3BS9YuS>

### Research Matters

**‘Developing a more tailored approach to patient and public involvement with children and families in pediatric clinical research: Lessons learned’** (p.11), in *Therapeutic Innovation & Regulatory Science*.

#### Related:

- “‘It is a whole different life from the life I used to live’”: Assessing parents’ support needs in paediatric palliative care,’ *Children*, published online 1 March 2022. **Full text:** <https://bit.ly/3txeBXo>
- ‘Bereaved parent perspectives on end-of-life conversations in pediatric oncology,’ *Children*, 2022;9(2): 274. **Full text:** <https://bit.ly/3v9MzDT>
- ‘Defining core competencies and a call to action: Dissecting and embracing the crucial and multifaceted social work role in pediatric palliative care,’ *Journal of Pain & Symptom Management*, published online 26 February 2022. **Abstract (w. references):** <https://bit.ly/3pATOBb>
- ‘When the child is terminally ill: The function of interdisciplinary exchange time in pediatric palliative care,’ *Médecine Palliative*, published online 19 February 2022. **Abstract:** <https://bit.ly/3tbdhN>

**N.B.** French language article.

- ‘Care after death in children’s hospices: Recommendations for moving and handling, and for managing physiological deterioration,’ *Nursing Children & Young People*, published online 21 February 2022. **Full text:** <https://bit.ly/3h1HFjU>
- ‘Sustainability in pediatric palliative/hospice care,’ *Pediatric E-Journal*, published online 1 March 2022. **Download at:** <https://bit.ly/3C3aPc6>

## Support for informal caregivers in Canada: A scoping review from a hospice and palliative/end-of-life care lens

*JOURNAL OF PALLIATIVE CARE* | Online – 24 February 2022 – At a policy level, the needs of informal caregivers (ICs) providing end-of-life care (EoLC) are currently not sufficiently recognized in Canada. Firstly, services such as respite care, day programs, and home care, are often only short-term and do not adequately support long-term caregivers. There is a need to recognize and support a wide array of ICs socially and financially in order to better help them obtain more services and negotiate flexible work hours and space. In addition, changes need to be made to the Compassionate Care Benefit in order to better accommodate ICs providing EoLC. Specifically, policymakers need to think about expanding the criteria to make the benefits more accessible for ICs outside of the work force... **Full text:** <https://bit.ly/3BYzQFC>



Reader feedback on the focus and content of Media Watch is welcomed.

## Caught in a loop with advance care planning and advance directives: How to move forward?

*JOURNAL OF PALLIATIVE MEDICINE*, 2022;25(3):355-360. Completion of an advance care planning (ACP) process and/or an advance directive should result in patients receiving the care they desire at the end of life. However, three decades of research have shown that is just not the case. ACP has been a front runner in developing the science within palliative care (PC). Some positive outcomes such as lowering levels of surrogate grief may be associated with ACP. Yet, it does not appear that further ACP research will ensure that seriously ill patients will get goal-concordant care. An unfortunate consequence of PC research and advocacy so far is the misguided notion of many hospital systems trying to solve their PC problems by only implementing an ACP initiative. **Full text:** <https://bit.ly/3IAOQfh>

### Selected articles on ACP and advance directives:

- 'What's wrong with advance care planning?' *Journal of the American Medical Association*, 2021;326(16): 1575-1576. [Noted in Media Watch 11 October 2021 (#738, p.7)] **Full text:** <https://bit.ly/3FyPlje>
- 'Advance care planning vs. advance serious illness preparations and planning,' *Healthcare*, 2020;8(3): E218. [Noted in Media Watch 3 August 2020 (#677, p.9)] **Full text:** <https://bit.ly/30GUkAc>

## Communication strategies when patients utilize spiritual language to hope for a miracle

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 March 2022 – Even the most experienced clinicians may feel caught off guard when patients and families use religious- or spiritual-based coping to guide healthcare decisions. Even within the same faith or belief community, the implications of a given religious belief vary substantially. Hence, patients can imply vastly different meanings when they use spiritually-based language. For example, when a patient states that they do not wish to “give up hope for a miracle,” that patient may be requesting that the clinician “do everything” possible to help them live longer no matter the medical burden. For others, such words convey a wish to delay or discontinue standard treatment in favor of holistic or spiritual healing. **Full text:** <https://bit.ly/3C4kD5S>

### Selected articles on religious- or spiritual-based coping to guide healthcare decisions:

- 'Review of religious variables in advance care planning for end-of-life care: Consideration of faith as a new construct,' *American Journal of Geriatric Psychiatry*, published online 5 December 2021. [Noted in Media Watch 24 January 2022 (#751, p.3)] **Abstract:** <https://bit.ly/3GckZDR>
- 'The physician and end-of-life spiritual care: The PALliative approach,' *American Journal of Hospice & Palliative Medicine*, published online 19 January 2022. [Noted in Media Watch 24 January 2022 (#751, p.3)] **Abstract (w. references):** <https://bit.ly/3GLx1cv>

## Palliative sedation – The last resort in case of difficult symptom control: A narrative review and experiences from palliative care in Switzerland

*LIFE* | Online – 16 February 2022 – Palliative sedation (PS) might be one of the most challenging therapeutic options in the field of palliative care (PC), involving both ethical and practical issues. Since patients in Switzerland have the legal option of assisted suicide, PS is an alternative that has become increasingly important. The use of PS is reported in 17.5% of all patients admitted to PC in Switzerland... The aim of this narrative review is to discuss ethical and practical issues in PS, with specific focus on experiences from Switzerland. Indications, ethical considerations, drugs of choice and duration are discussed. Decision-making should be based on solid guidelines. When used correctly, PS is an important and useful tool in PC in order to provide good symptom relief. **Full text:** <https://bit.ly/3JlrHYr>

**N.B.** Search back issues of Media Watch for additional articles on palliative or terminal “sedation” at: <http://bit.ly/2ThijkC>

## **Poverty, choice and dying in the U.K.: A call to examine whether public health approaches to palliative care address the needs of low-income communities**

*MORTALITY* | Online – 4 March 2022 – In recognising that death is “everyone’s responsibility,” the compassionate city charter (as one example of a public health approach to palliative care) challenges the narrative of death and dying as an individual responsibility and places it in the community rather than solely with professionals. But the danger is that such approaches rarely acknowledge or call to account the impact of social policy ... and the power of the state to affect individual experience. Public health approaches are implemented differently in different places; it may be useful to examine whether some initiatives may rely on communities to be resource-rich ... or whether, by being led by statutory or medical institutions, they are failing to understand the priorities of those living on a low income. **Full text:** <https://bit.ly/3Kdpvs8>

## **Engagement of specialized palliative care services with the general public: A population-level survey in three European countries**

*PALLIATIVE MEDICINE* | Online – 1 March 2022 – There is growing recognition of a need for community capacity development around serious illness, dying and loss, complementary to strategies focussing on health services. The authors examined views towards and actual involvement in community engagement activities as reported by specialized palliative care services in Belgium, Sweden and the U.K. Based on a combination of engagement activities, 74% of U.K. services could be labelled as extending their focus beyond the clinical mandate compared to 16% in Belgium and 7% in Sweden. Services’ dependency on charitable donations was strongly associated with increased engagement with the general public. **Abstract (w. references):** <https://bit.ly/3tueBYI>

## **An examination and proposed definitions of family members’ grief prior to the death of individuals with a life-limiting illness: A systematic review**

*PALLIATIVE MEDICINE* | Online – 23 February 2022 – Research has extensively examined family members’ grief prior to the death of an individual with a life-limiting illness, but several inconsistencies in its conceptualization of related constructs, yet significant conceptualization issues exist. Grief occurring before the death of a person with a life-limiting illness, termed pre-death grief, is comprised of two distinct constructs: anticipatory grief and illness-related grief. Anticipatory grief is future-oriented and is characterized by separation distress and worry about a future without the person with the life-limiting illness being physically present. Illness-related grief is present-oriented and is characterized by grief over current and ongoing losses experienced during the illness trajectory. **Abstract (w. references):** <https://bit.ly/3hhDlqK>

## **Palliative care needs and models of care for people who use drugs and/or alcohol: A mixed methods systematic review**

*PALLIATIVE MEDICINE* | Online – 20 February 2022 – Providing palliative care (PC) for individuals who use alcohol and/or drugs poses a multi-faceted challenge. In addition to clinical and social needs, individuals may endure mental health problems, co-morbidities and homelessness, thus requiring a multi-disciplinary, flexible approach to care. The difficulties for individuals who use alcohol and/or drugs as well as their formal and informal carers in relation to end-of-life care were examined, revealing access, care and skills issues. Despite EoL needs of this population being different to others, challenges include creating inclusive policies, sensitising staff to distinctive individual needs and training exchanges for staff working in both drug and alcohol services and PC. **Abstract (w. references):** <https://bit.ly/3h0h86H>

**N.B.** Selected articles on terminal ill patients with drug and alcohol addictions noted in Media Watch 19 August 2019 (#627, pp.6-7).

## Developing neuropalliative care for sporadic Creutzfeldt-Jakob disease

*PRION* | Online – 3 March 2022 – This study provides an expanded understanding of challenges experienced by caregivers and persons with Creutzfeldt-Jakob disease (sCJD) and identifies opportunities for improvement. Challenges primarily related to clinical care and caregiving and were exacerbated by the unique nature of sCJD. This is the first in-depth description of palliative care needs of persons with sCJD. Earlier research studied caregivers' struggles to manage symptoms of patients with sCJD and found the most problematic to be mobility and coordination, mood and behaviour, personal care and continence, eating and swallowing, communication, and cognition and memory. Caregivers in this study voiced similar challenges ... and describes broader sources of distress and challenges. **Full text:** <https://bit.ly/3hFDLOi>

### Related:

- 'A scoping review of palliative care for adults with Huntington's disease: Current practice...', *Journal of Palliative Medicine*, published online 1 March 2022. **Full text:** <https://bit.ly/3vUaCav>

### 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/3cdwylS>

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



## The last year of life for patients dying from cancer vs. non-cancer causes: A retrospective cross sectional survey of bereaved relatives

*SUPPORTIVE CARE IN CANCER* | Online – 21 February 2022 – For the non-cancer patient group, a clear disadvantage was identified, including the gap in access to palliative care (PC) and the lack of communication around prognosis, including the information about the imminent death. The results underline the importance of early integration of PC for patient groups with non-malignant diseases, reconsidering the need for disease-modifying treatment strategies. Furthermore, since GPs have been identified as key healthcare providers for the non-cancer patients and access to PC is still limited for this patient population, it will be important for both GPs and outpatient disease-specific specialist physicians to avoid fragmentation of care by communicating relevant patient information. **Full text:** <https://bit.ly/3BNICHA>

### Selected articles on disparities in access to PC for non-cancer patients:

- 'Disparities in access to palliative care facilities for patients with and without cancer: A retrospective review,' *Palliative Medicine*, published online 15 April 2021. [Noted in Media Watch 19 April 2021 (#713, p.6)] **Full text:** <https://bit.ly/3tnq9eA>
- 'Comparison of palliative care delivery in the last year of life between adults with terminal non-cancer illness or cancer,' *JAMA Network Open*, published online 4 March 2021. [Noted in Media Watch 8 March 2021 (#707, p.9)]. **Full text:** <http://bit.ly/2NXvpGy>



### Media Watch: Access Online

Media Watch (or a link to the report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.12.

## Research Matters

National Institutes of Health

### **Pragmatic trials and improving long-term care: Recommendations**

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 23 February 2022 – Conducting clinical trials in nursing homes, assisted living, and other long-term settings is attendant with challenges, including but not limited to recruitment and retention of settings, participant attrition, staff time constraints, family resistance, research ethics concerns, burdensome implementation and measurement, cost, and mistrust. For these reasons and also because research protocols may dictate exclusionary eligibility criteria, participation rates may be low, data may be incomplete, and results may not be generalizable. Recognition of these challenges catalyzed a recent initiative to develop recommendations for a nursing home clinical trials network. **Full text:** <https://bit.ly/3BKrdOK>

**N.B.** The authors of this article make no mention of hospice or palliative care. There is a brief reference to end-of-life care (EoLC) in the context of patients living with dementia. **Abstract:** <https://bit.ly/35inKL6>.

#### **Related:**

- 'Stakeholders' views on priorities essential for establishing a supportive environment for clinical trials in nursing homes,' *Journal of the American Geriatric Society*, published online 21 February 2022. **Abstract:** <https://bit.ly/3l6FpEc>

### **Designing psychosocial intervention pilot studies: A tutorial for palliative care investigators**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 February 2022 – This is a tutorial on designing a persuasive pilot study of a psychosocial intervention (e.g., behavioral symptom management) in the palliative care (PC) setting. It is most relevant for early stages of intervention research that aims to progress toward a randomized controlled trial with a high degree of internal validity. Broadly, a pilot study aims to address multiple elements of feasibility and acceptability so that investigators are well positioned for the next study in their program of research. To assist investigators in writing compelling grant applications the authors designed this tutorial as an annotated checklist of goals that a pilot study within the PC domain should seek to accomplish.

**Abstract (w. references):** <https://bit.ly/3sqP2YO>

#### ***Journal of Palliative Medicine***

##### **Special series: Psychological elements of palliative care**

This series defines elements of the therapeutic relationship in palliative care (PC). PC is not psychotherapy. Yet, it can adapt terms and concepts from traditional talk therapy to help clinicians better understand what's going on when they interact with patients. These concepts include frame and formulation, transference and countertransference, clinical attunement, attachment, and the holding environment. **Access series at:** <https://bit.ly/3HVqGLv>

### **Application of critical race theory in palliative care research: A scoping review**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 26 February 2022 – Articles that specifically described racial differences were common in the topic areas of quality, hospice, palliative care (PC) services and spirituality/religion. Key reasons posited for racial differences were patient preference, physician bias, and cultural barriers. 65% of articles posited that a racial difference was something that needed to be rectified, while articles rarely provided narrative or other data on perspectives of people of color to explain assumptions about differences. Articles that examine racial differences often assume that differences need to be fixed, but posit reasons for differences without the narratives of those most affected by them. **Abstract (w. references):** <https://bit.ly/3t8GLb3>

## Developing a more tailored approach to patient and public involvement with children and families in pediatric clinical research: Lessons learned

*THERAPEUTIC INNOVATION & REGULATORY SCIENCE* | Online – 19 February 2022 – The pediatric research community needs to address how to meaningfully involve children and families if they are to succeed in designing clinical research that suits the needs of pediatric patients and their families. This paper describes how an international community working under the umbrella International Children’s Advisory Network and European Young Person’s Advisory Group Network has involved children and families in the design and delivery of pediatric clinical research.<sup>1,2</sup> It offers practical solutions through various case studies assessed against seven patient engagement quality criteria within the Patient Engagement Quality Guidance tool...<sup>3</sup> **Full text:** <https://bit.ly/3BCyHDb>

1. International Children’s Advisory Network website: <https://bit.ly/3H2Bl6>
2. European Young Person’s Advisory Group Network website: <https://bit.ly/3JJQhs3>
3. Patient Engagement Quality Guidance website: <https://bit.ly/3v3Dlno>

### Selected articles on pediatric palliative care research:

- ‘From lurking to engaging and finding meaning in pediatric palliative care research,’ *Cancer Care Research*, 2021;1(3):e010. [Noted in Media Watch 6 September 2021 (#733, p.12)] **Full text:** <https://bit.ly/3gWSZhv>
- ‘Research cooperative groups in pediatric palliative care research,’ *Palliative Medicine Reports*, published online 14 December 2020. [Noted in Media Watch 12 July 2021 (#725, p.13)] **Full text:** <https://bit.ly/2TF01zk>

### Media Watch: Editorial Practice

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### Something Missed or Overlooked?

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

### Media Watch: Access on Online

#### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3JfLL4a>

[Scroll down to 'Media Watch: Telehealth']

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**



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

[Grief & Bereavement & Mental Health Summit 2021 'Resource Page.' Scroll down to 'Links: 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/3wvL5RW>

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

Barry R. Ashpole, Ontario CANADA

e-mail: [BarryRAshpole@bell.net](mailto:BarryRAshpole@bell.net)