

**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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Lying at the heart of inequitable access to palliative is a failure to recognise that diverse communities might have many strengths in the ways they support their dying. Palliative care services often do not recognise these strengths and might make common assumptions about needs that do not match the wishes or social context of diverse communities.

'Access to palliative care: The primacy of public health partnerships and community participation' (p.10), in *The Lancet*.

## Canada

### **New pilot program looks to expand hospice supports in rural communities**

ONTARIO | *Guelph Today* – 5 October 2021 – Hospice Wellington is hoping to expand services for palliative care (PC) patients and their families in rural Wellington County through a new three-year pilot program. The project will see an “advocate resource counsellor” travelling throughout Wellington County connecting people with services and building partnerships with local organizations. Research has identified the need for in-home supports, help facilitating conversations with family about illness and dying, and more bereavement and PC supports to counteract isolation among rural older adults among other objectives. <https://bit.ly/3DgpKiy>

Noted in Media Watch 12 July 2021 (#725, p.5):

- *BC MEDICAL JOURNAL*, 2021;63(6):255. **'Rural-urban inequities in palliative care.'** There are significant inequities in the delivery of palliative healthcare between rural and urban populations in British Columbia (BC). On average, BC's rural populations are older, poorer, and have a higher chronic disease burden than urban populations. It might be thought, therefore, that the Ministry of Health and health authorities would recognize this inequity and assign palliative care resources accordingly. In fact the opposite is true, and like many other inequities, the COVID-19 pandemic has worsened this divide. Both the 2018 Health Canada Framework on Palliative Care and the BC Centre for Palliative Care address the need for equity in the delivery of PC services.<sup>1,2</sup> **Full text:** <https://bit.ly/3qX89re>

1. 'Framework on Palliative Care in Canada,' Health Canada, 2018. [Noted in Media Watch 10 December 2018 (#593, p.1)] **Download/view at:** <http://bit.ly/2AVEghF>

2. 'Palliative Care is a Public Health Issue,' BC Center for Palliative Care, August 2015. (See Chapter 3: 'Palliative care is an increasingly important public health issue.') **Download at:** <https://bit.ly/3wk8vsZ>

### Specialist Publications

'Public knowledge and attitudes concerning palliative care' (p.11), in *BMJ Supportive & Palliative Care*.

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Noted in Media Watch 15 April 2019 (#610, p.7):

- **JOURNAL OF HEALTH SERVICES RESEARCH & POLICY** | Online – 10 April 2019 – ‘**Awareness as a dimension of healthcare access: Exploring the case of rural palliative care provision in Canada.**’ This analysis identifies awareness-associated barriers to delivering rural palliative care (PC) services, along with suggestions for improving service delivery from the perspective of local healthcare providers. Identified barriers to awareness and suggestions on how to enhance this awareness, and ultimately PC delivery, corresponded with three key themes: 1) Limited PC knowledge/education; 2) Communication; and, 3) Coordination. A thorough understanding of these as well as the connections between them, may help enhance how rural PC is delivered in the future. **Abstract:** <http://bit.ly/2Z7ubcj>

## U.S.A.

### **Sebastopol woman works to dignify death for San Quentin prison’s ailing inmates**

CALIFORNIA | *The Press Democrat* (Santa Rosa) – 7 October 2021 – Incarcerated populations are getting older due to war on drugs-era policies and punitive sentencing laws in the past several decades. Nearly a quarter of the state’s 125,472 people in custody were over age 50 in June 2019, the most recent year for which data from the California Department of Corrections and Rehabilitation is available. And the average age within prisons has steadily increased every year. People who are incarcerated on life sentences in San Quentin have few options for where and how they’ll take their last breaths: they may die in the prison infirmary, alone. If lucky, they may fill one of 17 dedicated palliative beds at California Medical Facility, a prison hospital in Vacaville, one of the only prisons out of the state’s 32 that has hospice services. They may be brought to a hospital in the outside community, where they are chained to a bed and guarded until they die. Or they die in their prison cell, with their cellmate sent to grieve afterward in isolation while the circumstances are investigated for any foul play – standard protocol in the case of an inmate death. In most scenarios, people behind bars die without loved ones and without palliative care. Although reform advocates have pushed for compassionate release for people in prison near the end of their lives ... that isn’t always what those people prefer. Approval for compassionate release takes too long for people on their deathbed. And often, their only home is their cellblock – their only family after decades of incarceration their fellow inmates. <https://bit.ly/3iJEcbj>

#### **Specialist Publications**

‘**Predicting potential palliative care beneficiaries for health plans: A generalized machine learning pipeline**’ (p.9), in *Journal of Biomedical Informatics*.

‘**A culturally-responsive approach to advance care planning education in African American communities**’ (p.8), in *Journal of Social Work in End-of-Life & Palliative Care*.

‘**Hospice and palliative care clinicians’ perceptions of post-traumatic stress disorder at end-of-life in military veterans**’ (p.12), in *Progress in Palliative Care*.

**N.B.** End-of-life care in prisons has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report is available by way of a ‘Backgrounder,’ last updated 1 August 2021. **Downloaded at the Palliative Care Network website:** <http://bit.ly/2RdegnL>

### **COVID deaths leave thousands of U.S. kids grieving parents or primary caregivers**

NATIONAL PUBLIC RADIO | Online – 7 October 2021 – Of all the sad statistics, the U.S. has had to deal with this last year and half, here is a particularly difficult one: A new study estimates more than 140,000 children in the U.S. have lost a parent or a grandparent caregiver to COVID-19.<sup>1</sup> The majority of these children are racial and ethnic minorities. “This means that for every four COVID-19 deaths, one child was left behind without a mother, father and/or a grandparent who provided for that child’s home needs and nurture – needs such as love, security and daily care,” says Susan Hillis, an epidemiologist at the Centers

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for Disease Control & Prevention, lead author of new study. The study ... estimates the number of losses from April 2020 through the end of June 2021 at 140,000. Of course that number has risen in the last three months: Hillis estimates that today that number is around 175,000. And, just as COVID-19 has killed more people in communities of color, children in these communities are the most impacted by loss of parents and primary caregivers. The study also tracked the loss of caregiving grandparents. <https://n.pr/3uN5aDD>

1. 'COVID-19-associated orphanhood and caregiver death in the U.S.,' *Pediatrics*, 7 October 2021. **First page view:** <https://bit.ly/3BI8Fnf>

Noted in Media Watch 26 July 2021 (#727, p.2):

- **FORBES** | Online – 20 July 2021 – '**New study estimates there are 1.5 million bereaved children due to pandemic.** An estimated 1.5 million children worldwide have experienced the death of a parent, custodial grandparent, or other relative who cared for them as a result of the COVID-19 pandemic, according to a new study.<sup>1</sup> This study offers the first global estimates of the number of bereaved children due to the pandemic. The figures are based on COVID-19 mortality data from March 2020 through April 2021. Findings suggest more than a million children experienced the death of one or both parents during the first 14 months of the pandemic, and another half a million experienced the death of a grandparent caregiver living in their own home. <https://bit.ly/2V5vpan>

1. 'Global minimum estimates of children affected by COVID-19-associated orphanhood and deaths of caregivers...', *The Lancet*, published online 20 July 2021. **Full text:** <https://bit.ly/36Qd5Vk>

**N.B.** See literature review at 'The Crossroads of Grief: Understanding Grief & Diversity,' published by the Children & Youth Grief Network, Ontario, Canada, in particular, 'Children's Understanding of Death & Dying' (p.5) and 'Death of a Parent' (p.30) at: <http://bit.ly/2OB4Y6C>

### **Hospice reforms to become law after *Times* investigation reveals widespread fraud, abuse**

CALIFORNIA | *The Los Angeles Times* – 4 October 2021 – Decades of unchecked growth in the California hospice industry will come to a halt 1 January 2022 when a moratorium on new licenses takes effect along with reforms aimed at curbing widespread fraud in end-of-life care (EoLC). The licensing moratorium and a crackdown on kickbacks and patient-recruiting schemes are at the heart of legislative reforms outlined in two bills largely spurred by a *Los Angeles Times* investigation of the state's booming hospice business last year.<sup>1,2,3</sup> An extensive examination by the state auditor also is underway to identify deficiencies and recommend improvements to hospice licensing and oversight. The *Times* investigation ... found that explosive growth in hospice providers has transformed EoLC that was once the realm of charities and religious groups into a multibillion-dollar business dominated by profit-driven operators. <https://lat.ms/3oy2usk>

1. 'End-of-life care has boomed in California. So has fraud targeting older Americans,' *The Los Angeles Times*, 9 November 2020. <https://lat.ms/3m0qsOH>
2. 'Dying Californians suffer harm and neglect from an industry meant to comfort them,' *The Los Angeles Times*, 9 November 2020. <https://lat.ms/2KaWfbF>
3. 'What you need to know if you or a loved one requires end-of-life care,' *The Los Angeles Times*, 9 November, 2020. <https://lat.ms/37NvCSr>

**N.B.** *The Los Angeles Times* articles were noted in Media Watch 14 December 2020 (#696, pp.2-3).

Noted in Media Watch 4 October 2021 (#737, p.8)

- *JAMA HEALTH FORUM*, 2021;2(9):e213745. '**Hospice acquisitions by profit-driven private equity firms.**' Profit is a key, driving focus of many businesses. Although private equity investment in healthcare could lead to improvement by injecting needed capital, a pressing concern is that many private equity firms often operate on the model of buying and quickly selling for a substantial profit within 3 years. A recent commentary on private equity used the metaphor of an experiment that observed what happened to an ecosystem when a new predator was introduced: contrary to the hypothesis that this event would lead to an improved ecosystem, the opposite occurred. We are now witnessing a natural experiment in the hospice market. **Full text:** <https://bit.ly/3utOHUA>

## International

### WHO takes steps to address glaring shortage of quality palliative care services

WORLD HEALTH ORGANIZATION | Online – 5 October 2021 – Worldwide, it is estimated only 1 in 10 people who need palliative care (PC) are receiving it and global demand for care for people with life-threatening illnesses will continue to grow as populations age and the burden of non-communicable diseases rises. By 2060, the need for PC is expected to nearly double. The world therefore needs urgent and concerted action to scale up access to quality PC services. To address this need, WHO is releasing two new resources to support countries in assessing the development of PC and improving the quality of PC services. The two resources<sup>1,2</sup> ... include a WHO technical report providing a globally applicable and robust set of PC indicators for countries. These indicators can be used to assess and monitor the provision of PC services in countries worldwide. The report aims to create a global consensus on indicators to measure PC development and its use will provide reliable data to support decision-making by informing health priorities and resource allocation. The second resource is a technical brief on quality health services and PC, looking at practical approaches and resources to support policy, strategy, and practice. The brief will guide action at the national, district and point of care to improve the quality of PC services. <https://bit.ly/2YjbB5g>

1. 'Assessing the development of palliative care worldwide: A set of actionable indicators,' World Health Organization, September 2021. <https://bit.ly/3iwf4V1>
2. 'Quality health services and palliative care: Practical approaches and resources to support policy, strategy and practice,' World Health Organization, October 2021 <https://bit.ly/3FnBpOm>

#### Specialist Publications

'Primary palliative care integrated model in paediatric ICU: An international cross-sectional study' (p.7), in *BMJ Supportive & Palliative Care*.

'International consensus-based policy recommendations to advance universal palliative care access from the American Academy of Nursing Expert Panels' (p.11), in *Nursing Outlook*.

'PARPACT – Paramedic Palliative Care Test' (p.12), in *Der Schmerz*.



#### European Association for Palliative Care Blog

'Abstract Watch' highlights selected articles, noted in past issues of Media Watch, on a range of issues specific to palliative and end-of-life care. Past postings, for example, focus on the hospice and palliative care workforce, palliative and end-of-life care for patients living with intellectual and developmental disabilities, paediatric palliative care and transition to adult care, and advance care planning and advance directives. **Access at:** <https://bit.ly/3wvL5RW>



#### 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

### Neuropalliative care

#### End-of-life neuropsychological impairments and psychological care of persons with advanced Parkinsonism

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 October 2021 – The authors summarize the limited research on the motor and cognitive predictors of mortality in advanced Parkinson's disease (PD). They provide 2 case vignettes of patients with end of life (EoL) advanced PD who demonstrated a substantial decline in working memory and speech festination. The authors contrast these patients' neuropsychological features to a third patient with advanced PD who shows no signs of impending death. Monitoring neuropsychological signs of executive dysfunction, explaining the neuropsychological dysfunctions to the patient and spouse while recognizing the past and retained cognitive competencies of the person is an important component of EoL psychological care. In the context of this type of consultation, the patient may experience an opportunity to communicate their emotional concerns prior to death which further reduces the anxiety associated with death. **Abstract (w. references):** <https://bit.ly/3FizsD1>

#### Next steps in palliative care education for neurology residents

*NEUROLOGY* | Online – 5 October 2021 – Many neurologic diseases are life-limiting and markedly impair patients' quality of life. Growing recommendations in the field recommend that neurologists have primary skills in palliative medicine that will allow them to manage symptoms and discuss end-of-life (EoL) decisions with patients and families. Previous work has shown that formal palliative care training in neurology residencies is very limited. The authors describe a national survey of neurology residents where they assess both the quantity and quality of the teaching they receive in EoL care as compared to a common and an uncommon neurologic condition. Based on the gaps identified, as well as previous studies and recommendations in neuropalliative care, the authors provide nine recommendations to help neurology residency programs improve their teaching of primary neuropalliative care skills. **Abstract:** <https://bit.ly/3aewmBA>

#### Related:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 3 October 2021 – **'Bereavement and support experiences of informal caregivers of persons with amyotrophic lateral sclerosis: A qualitative study.'** Informal caregivers provide the major part of care for persons with amyotrophic lateral sclerosis (ALS). Apart from providing care, they are themselves in need of support to fulfill the task of daily caregiving and to reduce their burden of caregiving. This need for support does not end with the death of the person cared for. The authors explore the themes of bereavement and support experience of informal caregivers of persons with ALS: 1) Reacting to bereavement; 2) Finding support; and, 3) Adjusting to life without the person with ALS. **Abstract:** <https://bit.ly/3l6DC8Q>
- *SEMINARS IN NEUROLOGY* | Online – 7 October 2021 – **'Neuropalliative care in the inpatient setting.'** The palliative care (PC) needs of inpatients with neurologic illness are varied, depending on diagnosis, acuity of illness, available treatment options, prognosis and goals-of-care (GoC). PC should be integrated with lifesaving treatments using a framework of determining GoC, thoughtfully prognosticating, and engaging in shared decision-making. Because prognostic uncertainty characterizes much of neurology, inpatient neurologists must develop communication strategies that account for uncertainty while supporting shared decision-making and allowing patients and families to preserve hope. The authors illustrate the approach to PC in inpatient neurology. **Abstract:** <https://bit.ly/3Fqfwhz>

**N.B.** Search back issues of Media Watch for additional articles on "Parkinson's," "ALS," and also "neuropalliative" carer at: <http://bit.ly/2ThijkC>



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## Transitioning end-of-life care from hospital to the community: Case report

*BRITISH JOURNAL OF NURSING* | Online – 2 October 2021 – Palliative/end-of-life (EoL) care is an integral part of the district nursing service. There is increasing demand for palliative care (PC) to be delivered in the community setting. Therefore, there is a need for excellent collaboration between staff in primary and secondary care settings to achieve optimum care for patients. This article critically analyses the care delivered for a palliative patient in the hospital setting and his subsequent transition to the community setting. The importance of effective communication, holistic assessment in PC, advance care planning, organisational structures and the socio-cultural aspects of caring for patients at the EoL are discussed. Additionally, the article highlights the impact of standard assessment and communication and the consequent effect on patients and families. **Abstract:** <https://bit.ly/3mfcwfc>

Noted in Media Watch 1 March 2021 (#706, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 22 February 2021 – “**Going home [is] just a feel-good idea with no structure**”: A qualitative exploration of patient and family caregiver needs when transitioning from hospital to home in palliative care.’ Theory can inform the creation of an intervention aimed at improving the hospital-to-home transition. Adults receiving inpatient palliative care (PC) who were being discharged to home-based PC, and their family caregivers, were recruited from two health centres in Toronto, Canada. Through examining the expectations and subsequent experiences of the transition, and exploring the gaps between them, the authors identified various transitions needs, health and well-being needs and practical needs. **Abstract (w. references):** <https://bit.ly/37CN7Wm>

**N.B.** Selected articles on care “transitions” noted in Media Watch 26 October 2020 (#689, pp.2-3), 28 September 2020 (#685, p.6), and 31 August 2020 (#681, pp.1-2).

## Hastening death in Canadian ICUs: End-of-life care in the era of medical assistance in dying

*CRITICAL CARE MEDICINE* | Online – 4 October 2021 – The purpose of this study was to determine how Canadian intensivists perceive medical assistance in dying (MAiD) and whether they believe their approach to withdrawal of life-sustaining therapies has changed following introduction of MAiD. Participants were recruited from 11 pediatric ICU programs and 14 adult ICU programs across Canada. The authors obtained 150 complete questionnaires (33% response rate), of which 50% were adult practitioners and 50% pediatric. Of respondents, 86% were familiar with MAiD legislation, 71% in favor, 14% conflicted, and 11% opposed. Only 5% thought it had influenced their approach to withdrawal of life-sustaining therapies. Half of participants had no standardized protocol for withdrawal of life-sustaining therapies in their unit, and 41% had observed medications given in disproportionately high doses during withdrawal of life-sustaining therapies, with 13% having personally administered such doses. Most had experienced explicit requests from families to hasten death, and almost half believed it was ethically permissible to intentionally hasten death following withdrawal of life-sustaining therapies. Most Canadian intensivists surveyed do not think that MAiD has changed their approach to end of life in the ICU. **Abstract:** <https://bit.ly/3ovLFyg>

### Related:

- *HEALTH POLICY* | Online – 1 October 2021 – “**Because it was new**”: Unexpected experiences of physician providers during Canada’s early years of legal medical assistance in dying.’ Implementing newly legalized euthanasia or assisted dying presents challenges. The procedure is high-stakes and irreversible and the context is controversial and associated with high emotions and strong opinions. The authors reports unexpected experiences of medical doctors who provided medical assistance in dying in the first years after legalization... The phrase “because it was new” occurred multiple times as doctors attributed unanticipated experiences to lack of individual and collective experience or knowledge. Positively viewed surprises included increased awareness of palliative care.. **Abstract:** <https://bit.ly/3Fo81b2>

## Pediatric palliative care

### **Community hospice nurses' perspectives on needs, preferences, and challenges related to caring for children with serious illness**

*JAMA NETWORK OPEN* | Online – 4 October 2021 – In this qualitative study, nurses providing hospice and palliative care (PC) to patients and families across Tennessee, Mississippi, and Arkansas expressed their lack of comfort and training in pediatric care provision, their strong desire for pediatric-specific education, and their belief that there is an urgent need for development of resources and training to improve pediatric palliative and hospice care practice in the community. Additionally, nurses stated clear preferences with respect to source, delivery, and topical content; recognized practical threats to educational resources and programs; and proposed solutions for circumventing or overcoming these barriers. The authors found few meaningful differences thematically between nurses stratified by self-reported levels of comfort with provision of care to children and their families. The most striking finding echoed across the 41 interviews was the immediacy with which hospice nurses expressed a need for pediatric-specific training and support. Nearly all nurses felt both privileged and burdened by the responsibility of caring for dying children, conveying urgency in their need for interventions to ensure provision of optimal care. These findings are a call to action for the PC community to collaborate in rapid implementation of educational programs and networks to systematically support hospice nurses in the field. **Full text:** <https://bit.ly/3oynZJz>

**N.B.** See 'Urgent appeal from hospice nurses for pediatric palliative care training and community,' *JAMA Network Open*; commentary on 'Community hospice's nurses perspective....,' published online 4 October 2021. **Full text:** <https://bit.ly/3oAqB9Y>

#### **Related:**

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 5 October 2021 – '**Primary palliative care integrated model in paediatric ICU: An international cross-sectional study.**' The authors found universal though heterogeneous and overall insufficient fulfilment of Initiative for Paediatric Palliative Care recommendations, indicating that healthcare providers complete numerous palliative care (PC) tasks in pediatric intensive care units worldwide, although inconsistently and imperfectly. In general, high income countries' units exhibited better adherence to the delivery of primary PC than units in lower income groups. Although the integrated model of care was applied in diverse settings, all units surveyed had opportunities for considerable improvement. **Full text:** <https://bit.ly/3uKMJ2g>
- *PEDIATRIC BLOOD & CANCER* | Online – 4 October 2021 – '**Palliative care is not associated with decreased intensity of care: Results of a chart review from a large children's hospital.**' Palliative care (PC) is an important component of pediatric oncology care, especially for children who will not be cured of their disease. However, barriers remain to integration of this service. One barrier is the perception that it indicates "giving up." This study examined if PC involvement was associated with a decreased intensity of care at the end of life for children with malignancy at a large academic center with a well-established PC program. Palliative involvement was not associated with a decrease in the intensity of care in the last three months of life. **Abstract:** <https://bit.ly/3FiCyqM>

**N.B.** Data for this study was gathered from 34 pediatric ICUs from 18 countries in the Americas, Europe, Asia and Africa. Initiative for Paediatric Palliative Care website: <https://bit.ly/3iDvBGP>

### **What's wrong with advance care planning?**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 8 October 2021 – Advance care planning (ACP) has emerged during the last 30 years as a potential response to the problem of low-value end-of-life (EoL) care. The assumption that ACP will result in goal-concordant EoL care led to widespread public initiatives promoting its use, physician reimbursement for ACP discussions, and use as a quality measure by the U.S. Centers for Medicare & Medicaid Services, commercial payers, and others. However, the scientific data do not support this assumption. ACP does not improve EoL care, nor does its documentation serve as a reliable and valid quality indicator of an EoL discussion. The history of ACP is the story of

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science working. There was logic to the belief that ACP would lead to better care for seriously ill patients. During the last 25 years, studies have evaluated ACP with various methods and across large groups of patients. Despite the intrinsic logic of ACP, the evidence suggests it does not have the desired effect. Many clinicians may be disappointed that promoting conversations with patients well in advance of needed medical decisions has not improved subsequent care as hoped. New research focused on training clinicians and preparing patients and families to engage in high-quality discussions when actual (not hypothetical) medical decisions must be made is needed to achieve the outcomes that ACP has not. The clinical and research communities should learn from the evidence that does not support prior hypotheses and proceed with different approaches to improve care for seriously ill patients. **Full text:** <https://bit.ly/3FyPlje>

**Related:**

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 5 October 2021 – ‘**Complex advance care planning interventions for chronic serious illness. How do they work? A scoping review.**’ This scoping review identified components of complex advance care planning (ACP) interventions for chronic serious illness, as well as seven mechanisms by which nine outcome categories were proposed to be affected by these interventions. In reporting primary effectiveness in randomized control trials studies, the mechanisms by which the intervention is anticipated to impact the chosen outcomes are, however, frequently unstated or unclearly stated; reporting emphasises “what” is being done, but less frequently refers to “why” this is being done. **Full text:** <https://bit.ly/3msDyQq>
- *JOURNAL OF THE AMERICAN COLLEGE OF EMERGENCY PHYSICIANS OPEN* | Online – 1 October 2021 – ‘**Addressing end-of-life care in the chronically ill: Conversations in the emergency department.**’ This article addresses the use of common advance directives and roadblocks to their use from the perspectives of families, patients, and physicians. Cases to examine new approaches to optimizing end-of-life conversations in patients who are chronically ill, such as the Improving Palliative Care in Emergency Medicine Project, a decision-making framework that opens discussion for patients to gain understanding and determine preferences, and the Brief Negotiated Interview, a 7-minute, scripted, motivational interview ... are used. **Full text:** <https://bit.ly/2Yrxgrl>
- *JOURNAL OF EMERGENCY NURSING* | Online – 30 September 2021 – ‘**Remote advance care planning in the emergency department during COVID-19 disaster: Program development and initial evaluation.**’ The Remote Goals-of-Care program was created to continue vital goals-of-care (GoC) discussions for patients and families while restrictions on family visitation and provider time and resources were mounting. As the majority of patients were not able to participate in the GoC conversations due to the acuity of their illness, fast and open communication with families was vitally important. This program relied heavily on the relationship between the Division of Geriatrics and Palliative Medicine and the Emergency Medicine Service Line that was created prior to the pandemic. **Full text:** <https://bit.ly/3iysu3b>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 3 October 2021 – ‘**A culturally-responsive approach to advance care planning education in African American communities.**’ The author describes the development of ‘The Let’s Talk about Advance Care Planning’ toolkit and discusses the results of the pilot study workshop. The procedures of the pilot study included a critical evaluation of an innovative curriculum and workshop process for engaging African Americans around advocacy for the healthcare experience they prefer. Factors such as cultural, generational, and spiritual beliefs and values influenced decision-making. Distrust was one of the most prominent factors raised by participants. **Abstract:** <https://bit.ly/3oup05q>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 7 October 2021 – ‘**The conscious state of the dying patient: An integrative review.**’ In the last days of life, the physical and conscious state of the dying patient declines, resulting in an inability to express their care needs. Dignity in dying and freedom from pain and suffering are both an imperative and a human right; and unvoiced care needs can result in unnecessary suffering and distress. This review revealed that little is known about how healthcare professionals assess holistic care needs at this vulnerable time. Although much has been written about palliative and end-of-life care, the assessment of care needs when patients are no longer able to voice their own needs has largely been ignored... **Abstract (w. references):** <https://bit.ly/3BmHBDZ>



Would the articles on advance care planning be of interest to a colleague?



## Predicting potential palliative care beneficiaries for health plans: A generalized machine learning pipeline

*JOURNAL OF BIOMEDICAL INFORMATICS* | Online – 2 October 2021 – Recognizing that palliative care (PC) improves the care quality and reduces the healthcare costs for individuals in their end of life, health plan providers strive to better enroll the appropriate target population for PC. Current research has not adequately addressed challenges related to proactively select potential PC beneficiaries from a population health perspective. This study presents a Generalized Machine Learning Pipeline (GMLP) to predict palliative needs in patients using administrative claims data. The GMLP has five steps: 1) Data cohort creation; 2) Feature engineering; 3) Predictive modeling; 4) Scoring beneficiaries; and, 5) Model maintenance. The GMLP is a novel approach that can be applied agnostically to the data and specific ML algorithms. To the best of the authors' knowledge, it is the first attempt to continuously score PC beneficiaries using administrative data. The GMLP and its use case example presented in the paper can serve as a methodological guide for different health plans and healthcare policymakers to apply ML in solving real-world clinical challenges, such as PC management and other similar risk-stratified care management workflows. **Abstract:** <https://bit.ly/3mmbuOp>

Noted in Media Watch 20 September 2021 (#735, p.10):

- *ONCOLOGY PRACTICE* | Online – 10 September 2021 – ‘**Impact of augmented intelligence on utilization of palliative care services in a real-world oncology setting.**’ Although several studies have evaluated machine learning (ML) tools to predict mortality in patients with cancer, to the authors' knowledge, thus far, only one has been shown to influence clinical practice, by increasing the number of serious illness conversations. However, the intervention in this trial combined the ML insights ... with behavioral nudges, using text message reminders, and performance reports and data on peer comparisons for serious illness conversations. The combined intervention makes it difficult to tease out the specific contribution of the ML insights to driving behavioral change. **Full text:** <https://bit.ly/3lesy8M>

Noted in Media Watch 24 May 2021 (#718, p.3):

- *MEDSCAPE* | Online – 17 May 2021 – ‘**Palliative care update: Delivery gaps, machine learning, and time-limited trials.**’ Three recent studies report important advances in our understanding of palliative care (PC) delivery. The first study was an analysis of differences in PC delivery patterns across different diagnoses...<sup>1</sup> In the second study, the authors used a machine learning algorithm to predict mortality risk in patients with serious illness and provide behavioral prompts to clinicians to initiate serious illness conversations in those patients with the highest risk...<sup>2</sup> The third study was conducted in an intensive care unit setting and explored the use of time-limited trials...<sup>3</sup> These three studies highlight gaps in PC delivery, build evidence for strategies that can lead to earlier care planning... <https://wb.md/33QrwXZ>

1. ‘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>
2. ‘Effect of integrating machine learning mortality estimates with behavioral nudges to increase serious illness conversions among patients with cancer: A stepped-wedge cluster randomized trial,’ *Journal of Clinical Oncology*, published online 20 May 2020. **Abstract:** <https://bit.ly/2T01tf1>
3. ‘Evaluation of time-limited trials among critically ill patients with advanced medical illnesses and reduction of non-beneficial ICU treatments,’ *JAMA Internal Medicine*, published online 12 April 2021. **Abstract:** <https://bit.ly/3oepexX>



### 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 beginning on p.13.

## **Use of traditional therapies in palliative care for Australian First Nations peoples: An integrative review**

*JOURNAL OF CLINICAL NURSING* | Online – 6 October 2021 – First Nations peoples face many barriers related to accessing and utilising specialised health services such as palliative care (PC). Whilst culturally appropriate care has been shown to improve these outcomes, there is little evidence regarding how this may be achieved. The review included six qualitative studies and one quantitative study. From these studies, five themes were identified in the literature: 1) Supporting a holistic approach; 2) Developing culturally appropriate care; 3) Conflict within a Western medical model; 4) Regulatory issues; and, 5) Geographical barriers. There is a dearth of current literature available discussing the utilization of traditional therapies in PC. More research is required in the provision of traditional therapies in PC. The incorporation of traditional medicines within a PC setting could help nurses provide holistic and culturally appropriate care, especially in rural and remote areas where they make up the majority of the healthcare force. **Abstract (w. references):** <https://bit.ly/3oCB1Ww>

**N.B.** Search back issues of Media Watch for additional articles on palliative and end-of-life care for “indigenous” and “aboriginal” communities in Australia at: <http://bit.ly/2ThijkC>

## **Spirituality and meaning-making in bereavement: The role of social validation**

*JOURNAL OF LOSS & TRAUMA* | Online – 4 October 2021 – The objective of this study was to investigate the relation of daily spiritual experiences to multifaceted meaning-making in bereavement, and the role of social validation of sense making in mediating this effect. Three tools were used and validated in the Italian context: 1) Grief & Meaning Reconstruction; 2) Social Meaning in Life Events Scale; and, 3) Daily Spiritual Experiences Scale. There were direct effects of spirituality on continuing bonds, personal growth, and valuing life. There are positive direct effects of social invalidation on personal growth, sense of emptiness, valuing life, and negative direct effects on a sense of peace. This study confirms that spirituality and sociality are a significant part of the work of mourning and the construction of the sense of loss. It also highlights the importance of recognizing the different forms they assume. **Abstract:** <https://bit.ly/3FIOPUM>

## **Access to palliative care: The primacy of public health partnerships and community participation**

*THE LANCET* | Online – 8 October 2021 – Palliative care (PC) is widely recognised as a public-health concern, with both structural and social determinants of health affecting health inequalities for disadvantaged populations across high-income and low-income countries. For low-income countries, PC development has become a key focus to promote equitable access, with the International Palliative Care Initiative producing a roadmap to guide development and expansion of PC provision in resource-constrained countries.<sup>1</sup> However, disadvantaged groups are also found in resource-rich countries – Indigenous peoples, LGBTQI+ communities, and those incarcerated or homeless, in particular. A review of hospice-patient care in the U.K., Australia, New Zealand, and Canada found that older people, ethnic minorities, people with non-cancer illnesses, and people living in rural locations or areas of social deprivation had unequal access to PC. But these findings merely confirm what many have observed for quite some time; the reality that PC service provision reaches only a minority of those who need PC and inequities of access substantially affect those from diverse communities. Viewed through a population-health lens, present efforts to promote equity and access to PC are limited in that professional service provision models are increasingly unable to cope with demand to meet population needs. Compounding this have been ongoing recommendations to improve access that either problematise needs as community deficits to be filled by services or focus on the expansion and marketing of, or professional development within, service providers. Unfortunately, there has been little by way of new approaches to what is an old problem. Collectively, this represents both a lack of imagination on integration of services with community and a failure to prioritise equity of access. **Full text:** <https://bit.ly/2YBJO0h>

1. 'World Health Organization Public Health Model: A roadmap for palliative care development,' *Journal of Pain & Symptom Management*, published online 8 August 2017. [Noted in Media Watch 14 August 2017 (#525, p.14). **Full text:** <https://bit.ly/3iJFQJM>

Cont.

## Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 October 2021 – ‘**Public knowledge and attitudes concerning palliative care.**’ Other studies have reported on the public’s misunderstanding that palliative care (PC) is associated only with terminal care. This study demonstrated that this misunderstanding was greatest in those with the highest perceived knowledge of PC. Further, these participants were not only less likely than those with low perceived knowledge to believe that PC offered hope to patients, but also more likely to have learnt about PC from healthcare professionals. In previous surveys and qualitative studies, physicians tended to associate PC with terminal care, and patients and caregivers recalled conversations with healthcare providers who had equated PC with EoL care. **Full text:** <https://bit.ly/3oGAFhv>
- *NURSING OUTLOOK* | Online – 6 October 2021 – ‘**International consensus-based policy recommendations to advance universal palliative care access from the American Academy of Nursing Expert Panels.**’ The purpose of this consensus paper was to convene leaders and scholars from eight Expert Panels of the American Academy of Nursing and provide recommendations to advance nursing’s roles and responsibility to ensure universal access to palliative care (PC). On behalf of the Academy, these evidence-based recommendations will guide nurses, policymakers, government representatives, professional associations, and interdisciplinary and community partners to integrate palliative nursing services across health and social care settings. **Abstract:** <https://bit.ly/3Fol4Jp>
- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 6 October 2021 – ‘**New public health approaches to palliative care, a brave new horizon or an impractical ideal? An Integrative literature review with thematic synthesis.**’ Access to palliative care (PC) for marginalized communities is frequently problematized as a major challenge facing PC services. The traditional response of asking what services can do for the disadvantaged has been invigorated by a new wave of public health measures that embrace death and dying as social processes and ask, what can be done together with such communities as partners working in PC ... however, we are yet to see a consistent and sustained change in approach from providers. **Full text:** <https://bit.ly/2ZVNNoc>

## Consensus paper: Palliative renal care

*DER NEPHROLOGE* | Online – 24 September 2021 – Aspects of palliative medicine (PM) such as withholding and withdrawal of dialysis, initiating conservative therapy and cooperative end-of-life care have increasingly become part of standard renal care. The corresponding transfer of knowledge of PM principles has so far been lacking in training and further education. This consensus paper proposes structured curricular training for the kidney team based on principles of palliative care. **Full text:** <https://bit.ly/3B9xzGc>

**N.B.** German language article.

Noted in Media Watch 9 November 2020 (#691, p.3):

- *ADVANCES IN CHRONIC KIDNEY DISEASE*, 2020;27(4):350-355. ‘**Palliative care in nephrology: The work and the workforce.**’ Kidney palliative care (PC), a growing subspecialty of clinical practice, education, and research in nephrology, is an essential aspect of care for patients across the continuum of advanced kidney disease (AKD) who have high symptom burden, multidimensional communication needs and limited life-expectancy. Training in kidney PC can occur in a variety of ways, from didactic curricula and clinical experiences embedded in nephrology fellowship training to the pursuit of additional dedicated fellowship training in PC. This article discusses opportunities and challenges in building a skilled workforce that will address the palliative needs of patients living with AKD. **Full text:** <https://bit.ly/3kPTv0N>



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

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

## **Death anxiety associated with Coronavirus (COVID-19) disease: A systematic review and meta-analysis**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 7 October 2021 – Death anxiety is a feeling that exists since birth, continues throughout life, lies at the root of all fears, and develops after the awareness that people will no longer exist and that they can lose themselves and the world. It is associated with death-induced anxiety with many features of the COVID-19 pandemic, which can be seen as a threat to human existence. In this study, it is aimed to compile studies on death anxiety associated with coronavirus disease, list the general characteristics of these studies through descriptive summaries, and combine findings on the level of death anxiety associated with coronavirus disease through meta-analysis. The findings of this study suggest that COVID-19 pandemic process and is affected by socio-demographic factors such as fear of COVID-19, gender, and occupation. As a result of this study, it was determined that death anxiety was relatively high during the COVID-19 pandemic process. **Full text:** <https://bit.ly/3AqNrD8>

## **Hospice and palliative care clinicians' perceptions of posttraumatic stress disorder at end-of-life in military veterans**

*PROGRESS IN PALLIATIVE CARE* | Online – 4 October 2021 – At the end of life (EoL), individuals may re-engage with earlier life trauma as they reflect on life experiences and confront their mortality. As such, posttraumatic stress disorder (PTSD) symptoms at the EoL may worsen the quality of death experience. This is a concern for military veterans, who tend to have more trauma exposures and higher rates of PTSD, and particularly for veterans receiving care in rural areas where access to PTSD specialty services is limited. To better understand this issue, The authors conducted focus groups with clinicians serving veterans in rural communities across five U.S. states. The aims of this project were to evaluate: 1) Do hospice and palliative care providers/staff observe PTSD symptoms in veterans at the EoL? ...and, 2) if so, How are symptoms similar to and different from existing *Diagnostic & Statistical Manual of Mental Disorders-5* criteria for PTSD? Descriptions of PTSD symptoms aligned broadly with existing diagnostic nomenclature, but descriptions revealed specific presentations relevant to the EoL setting such as resistance to care, agitation, restlessness, and effects of delirium. In addition, some veterans expressed pride in service and openness to discussing military experiences. Further, clinicians noted that PTSD symptoms were relevant to family dynamics. Future research should further characterize these symptom differences through direct patient assessment and develop resources to improve quality of death experience for veterans with PTSD symptoms. **Abstract:** <https://bit.ly/2YlbB4Q>

**N.B.** Selected articles on palliative and EoL care for U.S. military veterans noted in Media Watch 18 November 2019 (#640, p.4) and 10 September 2018 (#580, p.4).

## **PARPACT – Paramedic Palliative Care Test**

*DER SCHMERZ* | Online – 30 September 2021 – Given the large number of palliative patients cared for by the emergency services, education and training in palliative care topics are playing an increasingly important role. To support decision-making in an emergency setting a palliative or emergency card has been introduced in many cities. To assess the success of educational interventions and the effect of the palliative or emergency card, a questionnaire was developed and validated to determine palliative knowledge and palliative self-efficacy expectations in the emergency services. In all, 291 of 750 paramedics participated in the voluntary survey. There was consensus that the important topics of pain, dyspnea, sedation, end-of-life care, euthanasia, and legal aspects were covered in the questionnaire. PARPACT is a validated measurement tool for testing educational interventions in paramedicine. **Full text:** <https://bit.ly/3a0fJJR>

**N.B.** German language article. Search back issues of Media Watch for additional articles on the role of “paramedics” in palliative and end-of-life care at: <http://bit.ly/2ThijkC>

## 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 – Updated 5 October 2021

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3FtoV7X>

[Scroll down to 'End-of-Life Medications']

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']

Cont.

## 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/3wvL5RW>

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

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

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