

**Media Watch...** is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

**The delay of palliative care measures and the uncertainty of when end-of-life care begins can miss the opportunity to plan for end of life, allowing patients to “slip through the net” and die without adequate support or medical provision.**

‘Delivering end-of-life care for patients with cancer at home: Interviews exploring the views and experiences of general practitioners’ (p.7), in *Health & Social Care in the Community*.

## Canada

### **New online resources for LGBTQ community to help with end-of-life care**

CBC NEWS | Online – 10 May 2021 – After battling cancer for eight years, Aimee Taylor, who lives with her wife and daughter in Vancouver, says heteronormativity and discrimination still permeate the health-care system for LGBTQ people, especially in palliative care (PC). “I’ve had social workers ask if I have a supportive husband at home ... and even one that wasn’t sure how to fill out forms because I was married to a woman,” Taylor told the CBC. Canadian Virtual Hospice says it is filling the gap with a collection of online resources, called ‘Proud, Prepared, and Protected,’ to help the community navigate its PC needs. The materials include a step-by-step guide for planning care with family members and healthcare providers, a form to record personal healthcare information and preferences and an extensive Bill of Rights for community members

with late-stage illnesses who are facing the end of their lives. Executive Director Shelley Cory says more than 100 community members ... and more than 40 organizations contributed hundreds of hours to address this need. “The healthcare system commonly underserves people who identify as Two-Spirit and LGBTQ+, and there were no resources tailored to their PC needs,” she said. <https://bit.ly/3tD7yKP>

### Specialist Publications

‘The role of volunteers in enhancing resident quality of life in long-term care: Analyzing policies that may enable or limit this role’ (p.7), in *Canadian Journal on Aging*.

**N.B.** Canadian Virtual Hospice website: <https://bit.ly/3o87LEA>. Search back issues of Media Watch for additional articles on end-of-life care for the LGBTQ community at: <http://bit.ly/2ThijkC>.



Would the CBC News report be of interest to a colleague?

## U.S.A.

### Long-haul COVID-19 renews push to expand palliative care

*THE WASHINGTON POST* | Online – 10 May 2021 – The pandemic, which has left an estimated tens of thousands of Americans with long-term debilitating symptoms, has prompted a renewed push to provide full palliative care (PC) services to seriously ill patients in their homes. Palliative and hospice organizations are in talks with the Biden administration to create such a benefit as a demonstration project in Medicare, the health plan for older Americans. If successful, they hope it would become a permanent benefit in Medicare and then be offered under Medicaid, the federal-state program that covers lower-income Americans, and commercial insurance plans, as well. Advocates point to numerous studies showing that PC results in a higher quality of life for patients, better management of their pain and symptoms and lower healthcare costs as a result of fewer hospitalizations. But most insurance plans, including Medicare and Medicaid, cover only comprehensive home- or community-

based PC services for people in hospice care, which generally means they have a prognosis of six months or less to live and are forgoing treatment intended to prolong their lives. Those pushing for changes say many who are not in hospice but who are afflicted with illnesses such as cancer, heart disease and Alzheimer's would benefit from a full array of PC services delivered to them at home. <https://wapo.st/3eE41rD>

#### Specialist Publications

**'Quality of end-of-life care for Vietnam-era Veterans: Implications for practice and policy'** (p.8), in *Healthcare*.

**'Complexities of Corona Virus Disease-19: The role of palliative care at a Veterans Affairs hospital'** (p.8), in *Journal of Palliative Medicine*.

## International

### Dying well: Whānau seek tikanga Māori at end of life

NEW ZEALAND | Newsroom (Wellington) – 11 May 2021 – It takes a village to raise a person, but it takes a village to bury them, too. So says Dr. Tess Moeke-Maxwell, one of the researchers behind Te Ipu Aronui, a website and campaign to share ways Māori can use their ancestral tikanga to cope with caring for loved ones at the end of their lives. As a founding member of Te Ārai Palliative Care & End of Life Research Group, she helped interview more than 60 whānau, Māori healthcare professionals and practitioners of rongoā and tohunga. The research found Whānau felt that the healthcare system was often dominated by Pākehā viewpoints which let the most disadvantaged members of society fall through the cracks – a problem expected to grow with a rapidly ageing population. Moeke-Maxwell says families often experience a sense of isolation when dealing with death. "It can be a very lonely time for kaumātua and their whānau," she said. "Access to information, knowledge, resources and broader whānau support helps to strengthen whānau who care for kaumātua. So

we needed to find a way to gather up information and share it with whānau." The campaign's centrepiece is a website telling the stories of end-of-life care bolstered by Māori cultural values and customary practices. <https://bit.ly/3uFH2Sp>

#### Specialist Publications

**'Barriers to the provision of optimal care to dying patients in hospital: An international cross-sectional comparison study of nurses' perceptions'** (p.7), in *Collegian*.

**"Saying goodbye" during the COVID-19 pandemic: A document analysis of online newspapers with implications for end-of-life care'** (p.11), in *Palliative Medicine*.

**'Continuums of change in a competence-building initiative addressing end-of-life communication in Swedish elder care'** (p.12), in *Quality Health Research*.

Cont.

N.B. Te Ipu Aronui website: <https://bit.ly/3f3Qk48>. Māori dictionary: <https://bit.ly/3exYNxn>. Search back issues of Media Watch for additional articles on meeting the end-of-life care needs for Māori peoples at: <http://bit.ly/2ThijkC>.

## Thousands of Brits dying every year without their wishes being met: Research for the Dying Matters

U.K. | Dying Matters – 10 May 2021 – Brits do not have sufficient plans in place for the end of their lives because they are unaware of what to do and unsure of how to talk about it, according to research published by Dying Matters. The findings raise concerns that, despite the pandemic thrusting death into the public consciousness like never before, taboo and lack of knowledge mean thousands of people are dying each year without their needs and wishes being met – especially those who die at home. The new research reveals: 1) Just 13% of adults say they've let a close friend or family member know where they want to be when they die (rising to only 15% among over 55s); 2) Fewer than one in ten (8%) have put in place medical and/or emotional support for the end of their lives (dropping to 6% among over-55s); 3) Just three in ten (31%) adults know how to make arrangements to ensure they die in the place they would wish to; and, 4) Only one in five (20%) adults believe they will be able to control where they are at the end of life (EoL). Data shows that on average more than 1,000 additional deaths took place each week in the U.K. in private homes through the first year of the pandemic, over and above five-year averages, leaving approximately one million people bereaved. But little is known about the quality of those deaths, and Dying Matters' research indicates a worrying lack of knowledge and confidence among the public about dying at home. While, for many, dying at home is seen as the best option, only a third (33%) believe they'd be able to receive EoL care at home, and less than a quarter (23%) were confident that they would not be in pain. <https://bit.ly/3bc0e2s>

## Thousands dying at home in “traumatic final days” without proper palliative care

U.K. (England) | *The Telegraph* (London) – 10 May 2021 – Nearly 15,000 people are likely to have died painful and undignified deaths at home when hospitals were closed to them last year, experts have revealed. A major new report warns of a palliative care crisis brought on by the pandemic, which has seen a huge shift in the number of people dying outside of hospital without the necessary support.<sup>1</sup> Cancer patients and those with severe heart disease are among those who have been left to manage their final days without expert care, according to the Institute for Public Policy Research. The organisation warns that the shortcomings are likely to become the “new normal” due to the National Health Service backlog built up since the start of the crisis. It found that there was a 36% rise in deaths in private homes in England in 2020 and a 23% rise in care homes. Health chiefs have for years been trying to increase the proportion of patients who die at home, recognising that it is often a more humane

experience, provided the right community care is in place. However, the report reveals that the shift has taken place without the corresponding support, leaving many patients and their loved-ones feeling “abandoned.” <https://bit.ly/3bfHNK6>

### Extract from Institute for Public Policy Research report

There is a clear need to support end-of-life care (EoLC) providers through the pandemic and ensure swift recovery after it. However, the evidence also indicates that recovery is unlikely to be enough to ensure good EoLC in the years to come. As challenging as the pandemic has been, there are three mid- to long-term challenges that put significant onus on policymakers to look beyond just what happened in 2020-2021. A failure to do so may expose EoLC to the pressures of 2020, every year from 2030 onwards.

1. 'The state of end-of-life care: Building back better after CPVID-19,' Institute for Public Policy Research, April 2021. Download at: <https://bit.ly/2QY7GaJ>



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## Love and justice at the end of life: Studying palliative care in India

INDIA | Social Science Space (Sage) – 7 May 2021 – The article 'The conflicting conventions of care: Transformative service as justice and agape,' currently in press in the *Journal of Service Research*, examines the transformative service provided by a community palliative care (PC) initiative in Kerala, India. In the community-based approach, teams of doctors, nurses, and community volunteers provide free home-based PC, including medical, social, financial, bereavement, and rehabilitation support. This model is thus distinct from the conventional hospice and hospital-based PC services that are anchored around professional care delivery. The authors examine the conflicts and unintended consequences that arise from the diverse social conventions constituting such a transformative service. This study offers several implications for policy development and practice. The spread of COVID-19 ... and the dramatic rise in serious health-related suffering, particularly in low- and middle-income countries, have cast in high relief the need for community healthcare models. The pandemic is a sharp reminder that collective consciousness and actions are crucial for human survival. There is thus an urgent need to explore service delivery models beyond the prevailing hospital or hospice-based approaches and the neoliberal market-based models that are limited in coverage and affordability. Kerala's community model is one exemplary model that offers an alternative by remodeling health services through empowered communities. <https://bit.ly/3nYRgLh>

**N.B.** *Journal of Service Research* website: <https://bit.ly/3uFiBoc>. Search back issues of Media Watch for additional articles on the community PC model developed in "Kerala" at: <http://bit.ly/2ThijkC>.

## Specialist Publications

### Reasons for physician-related variability in end-of-life decision-making in intensive care

*ANAESTHESIOLOGICA SCANDINAVICA* | Online – 8 May 2021 – The aim of this study was to investigate factors contributing to physician-related variability in end-of-life (EoL) decision-making, i.e., different assessment of patient preferences, as well as intensivists' personality and values. Personality was expressed mainly through pace and determination in the decision-making process. Personal prejudices appeared in decisions, but few physicians interviewed had personally witnessed this. Avoidance of criticism and conflicts as well as individual strategies for emotional coping were other factors that influenced physician-related variability. Many interviewees feared criticism for making their assessments, and the challenging nature of EoL decision-making lead to avoidance as well as emotional stress. Variability in EoL decision-making is an important topic that needs further investigation. It is imperative that such variability be acknowledged and

addressed in a more formal and transparent manner. The ethical issues faced by intensivists have recently been compounded by the devastating impact of the COVID-19 pandemic, demonstrating in profound terms the importance of the topic. **Abstract:** <https://bit.ly/2REXkME>

#### Research Matters

'Dealing with death as an outcome in supportive care clinical trials' (p.12), in *JAMA Internal Medicine*.

#### Publishing Matters

'How the Centre for Journalology hopes to fix science' (p.12), in *Chemical & Engineering News*.

Noted in Media Watch 4 January 2021 (#698, p.12):

- *JOURNAL OF CRITICAL CARE* | Online – 24 December 2020 – '**Moral distress in end-of-life decisions: A qualitative study of intensive care physicians.**' This study explored physicians' moral distress in end-of-life decisions in intensive care... Drawing upon patient case studies of decisions about non-escalation and/or withdrawal of life support, the authors undertook in-depth interviews with senior and junior physicians. Senior physicians' triggers included constraint of clinical autonomy. Junior residents reported most instances of moral distress, triggered by perceived futility, lack of continuity, protracted decisions, and failure to ensure "good death." Moral distress was far reaching, affecting personal life, working relationships and career choice. **Abstract:** <http://bit.ly/3mTB8IP>

## Facilitators and barriers to the delivery of palliative care to children with life-limiting and life-threatening conditions: A qualitative study of the experiences and perceptions of healthcare professionals

*ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 12 May 2021 – Seventy-one healthcare professionals (doctors, nurses and allied healthcare professionals) working in children's palliative care (PC) services in four regions of England participated in focus groups. Three overarching themes were identified which influenced whether and when children were referred to and started to receive PC: 1) The unspoken background of clinical uncertainty which often delayed PC; 2) The cultural "collusion of immortality," where conversations about the possibility of dying can be avoided or deferred; and, 3) The role of paediatric PC teams in "illuminating the blind spot" of PC as well as providing hands-on care. PC is a holistic approach to care that focuses on quality of life for people living with life-limiting and life-threatening conditions that can be delivered alongside active treatment. There is a need to prioritise and integrate this into healthcare services for children more effectively if improvements in care are to be realised. While more specialist paediatric PC services are needed, the unspoken background of clinical uncertainty needs to be addressed together with the collusion of immortality within healthcare culture and organisations. **Abstract:** <https://bit.ly/3eLzE2n>

### Related:

- *ITALIAN JOURNAL OF PEDIATRICS* | Online – 12 May 2021 – '**Children with medical complexity and paediatric palliative care: A retrospective cross-sectional survey of prevalence and needs.**' This survey provides the basis for an extended application of pediatric palliative care (PC)... It has resulted in the setting up of a permanent pediatric PC network that is constantly updating its patient list. The knowledge of patient characteristics and caregiver needs has been highly valuable in designing and improving the network, because pediatric PC can extend throughout the illness trajectory, and it is therefore important to adopt an integrated model with community-based pediatric PC and family centred care and to properly disseminate pediatric PC throughout the health system. **Full text:** <https://bit.ly/3y8xHER>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 May 2021 – '**Pediatric death by neurologic criteria: The ever-changing landscape and the expanding role of palliative care professionals.**' Pediatric palliative care (PC) providers are especially suited to support families and medical teams facing a potential diagnosis of brain death, or death by neurologic criteria (DNC), when a child suffers a devastating brain injury. To support pediatric PC providers' effectiveness in this role, this article elucidates the clinical determination of DNC and the evolution of the ethical and legal controversies surrounding DNC. Describe are conceptual definitions and legal challenges then explore some potential reasons why families may dispute a determination of DNC. **Abstract (w. references):** <https://bit.ly/3hlUS8G>
- *PATIENT EDUCATION & COUNSELING* | Online – 7 May 2021 – '**Conflicting goals and obligations: Tensions affecting communication in pediatric oncology.**' The authors identify 5 themes of tensions, defined as challenges experienced when clinicians and psychosocial professionals are trying to achieve multiple conflicting goals or obligations while communicating: 1) Supporting parental hopes while providing honest opinions and information; 2) Disclosing all possible outcomes while avoiding the creation of new worries or uncertainties; 3) Building relationships while maintaining personal boundaries; 4) Disclosing sensitive information while adhering to professional role and perceived authority; 5) Validating parental beliefs or decisions while fulfilling obligation for honesty. **Abstract:** <https://bit.ly/3eEw4Hv>



### [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>

## **“A good death but there was all this tension around”: Perspectives of residential managers on the experience of delivering end-of-life care for people living with dementia**

*BMC GERIATRICS* | Online – 12 May 2021 – Managers of residential aged care homes in this study described their role as overseeing and navigating a complex intersection between residents with advanced dementia, staff, general practitioners (GPs) and families. Managers perceived that families of residents varied considerably in their understanding of dementia and their preparedness to participate in end-of-life (EoL) discussions and decision-making. Managers described how some families wanted to “fight and fix” the dementia and these families were perceived to seek medical intervention and hospital care. Managers tried to promote acceptance of death and hospital avoidance by iterative conversations chipping away at any misconceptions or denial, but sometimes found themselves balancing family wishes for life-prolongation with their own desire to provide comfort directed care. Managers highlighted the critical role of GPs and front-line staff in communicating with families and providing EoL care for residents. However, the ability and willingness of GPs, nurses and care staff to provide this care was seen to be undependable. Ultimately the managers experienced the navigation of residents, families, care workers, nurses and GPs, who may all have different reactions to EoL dementia care, to be a relentless but rewarding vocation. The findings suggest that continuous front line aged care staff skill development, reiterative family discussions to enable family acceptance of the resident’s terminal condition, and partnership building between aged care staff and GPs, are all required to promote optimal end of life dementia care. **Full text:** <https://bit.ly/33W0G0Z>

**N.B.** Search back issues of Media Watch for additional articles on EoL care for people with “dementia” at: <http://bit.ly/2ThijkC>.

### **Implantable cardioverter defibrillator devices**

#### **When, how and who should discuss deactivation with patients: A systematic literature review**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 May 2021 – Implantable cardioverter defibrillators (ICDs) are used to treat life-threatening cardiac arrhythmias and prevent sudden cardiac arrest. As recipients age they may develop greater risk of dying as a result of progressive multimorbidity rather than sudden cardiac death. Defibrillation shocks may prolong an uncomfortable dying process. Deactivation of the defibrillator would prevent this, yet is not always discussed and planned. Of the 8,893 articles identified, 22 papers met the inclusion criteria. Deductive approach led to identification of five main themes: 1) Timing of ICD deactivation discussions; 2) Initiation of deactivation discussions; 3) Advance directives; 4) Barriers to discussions; and, 5) Facilitators of discussions. Despite available guidelines, conversations on device deactivation are not being undertaken consistently. Evidence suggests lack of professional awareness of guidelines and limited training in communication skills. To prevent distress and promote comfortable dying, there needs to be a proactive clinical and policy initiative in the education of both professionals and patients and their relatives about device deactivation. **Abstract:** <https://bit.ly/3vNCPfu>



**N.B.** Selected articles on implantable cardioverter defibrillator deactivation noted in Media Watch 30 September 2019 (#633, p.8).



Photo: Lori Waselchuk. Philadelphia, PA

#### **Prison Hospice: Backgrounder: Updated 05.01.2021**

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 weekly report can be downloaded at the Palliative Care Network website: <http://bit.ly/2RdegnL>

## **The role of volunteers in enhancing resident quality of life in long-term care: Analyzing policies that may enable or limit this role**

*CANADIAN JOURNAL ON AGING* | Online – 11 May 2021 – Long-term care (LTC) volunteers play important roles in enhancing the quality of life (QoL) of older LTC residents, often through providing unique forms of relational care. The authors analyzed how unique volunteer roles are represented and supported in provincial policies in Alberta, British Columbia, Ontario, and Nova Scotia. They found that policies define volunteer roles narrowly, which may limit residents' QoL. This happens through: 1) Omitting volunteers from most regulatory policy; 2) Likening volunteers to supplementary staff rather than to caregivers with unique roles; and, 3) Overemphasizing residents' safety, security, and order. The authors offer insights into promising provincial policy directions for LTC volunteers, yet they argue that

further regulating volunteers may be an inadequate or ill-suited approach to addressing the cultural, social, and structural changes required for volunteers to enhance LTC residents' QoL effectively. **Full text:** <https://bit.ly/3tE1fa2>

### **Extract from *Canadian Journal on Aging* article**

Volunteer roles in palliative care (PC) policy were given scant attention in the policy documents that were reviewed. Based on the authors' literature review, volunteer roles are particularly developed and crucial in PC approaches, yet these are not reflected in provincial regulations or government-endorsed documents.

## **Barriers to the provision of optimal care to dying patients in hospital: An international cross-sectional comparison study of nurses' perceptions**

*COLLEGIAN* | Online – 8 May 2021 – Nurses play an important role in caring for patients who are dying in hospital, so it is important to understand their perceptions of the factors that may influence the quality of that care. Much of the existing literature is focused on end-of-life care (EoLC) provision in western settings. Little is known about how nurses' perceptions of EoLC provision may differ across Asian and Western locations. Understanding the similarities and differences between the perceptions of nurses in Asian and Western locations about the barriers to the provision of high-quality EoLC may help guide education and policy initiatives to improve EoLC in each location. Significant variation between the perceptions of nurses in each location was found in two-thirds of the survey items. The greatest difference was seen in the item doctors continue life-sustaining medical interventions for too long, which was considered a significant barrier by 60.1% of Australian nurses, 32.9% of South Korean nurses and 13.8% of Hong Kong nurses. The greatest cross-location agreement related to differences in religious beliefs and languages. These items were considered a significant barrier by fewer than one-quarter of nurses. Nurses in Hong Kong, South Korea and Australia perceived a range of challenges to the provision of optimal EoLC. The significant differences observed in two-thirds of response items support the hypothesis that strategies to improve the quality of EoLC in one location may not be effective in another. For interventions to be effective they must be tailored to the unique nature of care-provision in each location. **Abstract:** <https://bit.ly/3henGA4>

## **Delivering end-of-life care for patients with cancer at home: Interviews exploring the views and experiences of general practitioners**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 10 May 2021 – It has been suggested general practitioners (GPs) lack confidence in end-of-life care (EoLC). Nineteen GPs from London were purposively sampled from eight general practices and a primary care university department.... Five main themes were constructed: 1) The subjective nature of defining palliative and EoLC; 2) Importance of communication and managing expectations; 3) Complexity in prescribing; 4) Challenging nature of delivering EoLC; and, 5) The unclear role of primary care in palliative care (PC). GPs viewed EoLC as challenging; specific difficulties surrounded communication and prescribing. These challenges coupled with a poorly defined role created a spread in perceived confidence. Experience and exposure were seen as enabling confidence. Specialist PC service expansion had important implications on deskilling of essential competencies and reducing confidence levels in general GPs. This feeds into a complex cycle of causation, leading to further delegation of care. **Full text:** <https://bit.ly/3o41JVz>

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Noted in Media Watch 21 December 2020 (#697, p.5):

- *HEALTHCARE* | Online – 11 December 2020 – ‘**Bolstering general practitioner palliative care: A critical review of support provided by Australian guidelines for life-limiting chronic conditions.**’ General practitioners (GPs) are increasingly expected to provide palliative care (PC) as ageing populations put pressure on specialist services. Some GPs, however, cite barriers to providing this care including prognostication challenges and lack of confidence. PC content within clinical practice guidelines might serve as an opportunistic source of informational support to GPs. This review analysed PC content within Australian guidelines for life-limiting conditions to determine the extent to which it might satisfy GPs’ stated information needs and support them to provide quality end-of-life care. **Full text:** <http://bit.ly/21R9tu5>

Noted in Media Watch 30 November 2020 (#694, p.10):

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 19 November 2020 – ‘**More proactive GPs, well timed, and less acute care: A clustered, partially controlled before-after study.**’ This study investigated three groups of possible effects of the implementation of an integrated, multidisciplinary palliative care pathway: GPs’ experiences, experiences and satisfaction of relatives of patients, and healthcare utilization (primary care, hospital care, and medication). GPs reported not only that palliative patients die more often at home (their preferred place of death), but also that they now act more proactively toward palliative patients. More proactive attitude of GPs is seen in other studies, where the proactive assessment and palliative treatment were set as priorities. **Full text:** <https://bit.ly/398MsOg>

Noted in Media Watch 9 November 2020 (#691, p.5):

- *BMC FAMILY PRACTICE* | Online – 31 October 2020 – ‘**Home-based palliative care management: What are the useful resources for general practitioners? A qualitative study among GPs in France.**’ The problems related to the home-based practice of palliative care (PC) by GPs are well known, yet few studies highlight the resources actually used by GPs. This study outlines such resources, including structures (regional assistance networks, hospitalization at home), the use of resource personnel (medical, paramedical and family), and schedule organization. A GP’s status implies a tacit moral contract that involves managing home-based PC when needed. This moral responsibility is more a resource than a burden for GPs who rely on their care values in order to face difficulties. **Full text:** <https://bit.ly/2HW6T5f>

## Quality of end-of-life care for Vietnam-era Veterans: Implications for practice and policy

*HEALTHCARE*, 2021;9(2). In federal response to the aging population of Vietnam-era Veterans, Congress directed the Department of Veterans Affairs (VA) to create a pilot program to identify and develop best practices for improving hospice care for this population. A first step in VA’s response was to identify whether the end-of-life (EoL) care needs and outcomes of Vietnam-era Veterans differed from previous generations. Compared to prior generations, higher percentages of Vietnam-era Veterans had mental health/substance use diagnoses and disability. Similar percentages of family members in both groups reported that overall EoL care was excellent; however, post-traumatic stress disorder management ratings by families of Vietnam-era Veterans were significantly lower. Although current VA EoL practices are largely meeting the needs of Vietnam-era Veterans, greater focus on mental health comorbidity, including post-traumatic stress disorder, Agent Orange-related conditions, and ensuring access to quality EoL care in the community is warranted. Policymakers and

healthcare professionals should anticipate more physical and mental health comorbidities among Veterans at EoL as Vietnam-era Veterans continue to age. **Full text:** <https://bit.ly/3fi7MC8>

### Complexities of Corona Virus Disease-19: The role of palliative care at a Veterans Affairs hospital

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 May 2021 –The authors of this article conducted a retrospective chart review on thirty-three patients to gather characteristics data and delineate palliative care (PC) team involvement in their clinical courses. The PC team participated in the care of 87.9% of patients who died from COVID-19. They were medically and psychosocially complex with 75.8% carrying at least four medical comorbidities, 87.8% presenting from an institutional facility, and 39.4% diagnosed with at least one psychiatric condition. **Full text:** <https://bit.ly/2Q56hi4>

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**N.B.** Selected articles on palliative and end-of-life care for veterans noted in Media Watch 18 November 2019 (#640, p.4).

### **Academic-community partnerships to promote end-of-life care competencies through interprofessional teamwork**

*JOURNAL OF INTERPROFESSIONAL EDUCATION & PRACTICE* | Online – 8 May 2021 – This curricular resource describes an interprofessional educational program and curricular structure for teaching a rare but critical skill: how to care for someone when there is no cure, and to do so in a home environment when death is expected and supported as a natural process. Through academic-community partnerships and a blended-experiential model, students learn from hospice patients, their family members, other community volunteer caregivers, and hospice staff while simultaneously engaging in curricular activities that include online training modules, reflective writing exercises, and weekly discussion sessions with peers, faculty, and providers, all key components identified for professional identity formation... The program was developed with the Learn, See, Practice, Prove, Do model, an evidence-based educational framework that helps students gain competence in their procedural skills and transition from the role of observer to that of a skilled care provider... Students were given pretest and posttest surveys, reflective journaling assignments, and a posttest questionnaire. Triangulation of data sources indicates that learning objectives and desired outcomes were consistently achieved. In addition, students reported high levels of satisfaction with the program, significant improvements in both empathy and self-efficacy to provide end-of-life care, and program impacts on both their personal perspectives and career goals/professional identities. **Abstract:** <https://bit.ly/3o9MpGY>

### **Approaching the end of their lives under blue lights and sirens: Scoping review**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 May 2021 – Emergency medical services (EMS) are frequently responding to calls involving patients in advanced stages of incurable diseases. Despite the competencies and potential of EMS in supporting patients and their families facing symptoms of advanced progressive illnesses, the role of EMS in providing palliative care (PC) remains unclear. The following research question was formulated: What is the role of ambulance EMS, EMS dispatch centres, paramedics and emergency medical physicians in the provision of PC to terminally ill patients? 31 articles were included in the qualitative synthesis and 3 main roles and one contextual factor were identified: 1) Providing complex care; 2) Adjusting patient's trajectory; 3) Being able to make decisions in a time and information limited environment; and, 4) Healthcare professionals are insufficiently supported in PC. There are limited data on the incidence of EMS calls to the patients at the end-of-life (EoL) and no data focusing on the EMS dispatch centres. Both paramedics and emergency physicians are aware of their role in the EoL care. EMS personnel are lacking special training and education in the PC. Cooperation between PC providers, the EMS providers and other out-of-hours services might improve the responsiveness of the healthcare system to needs and expectations of patients and their families, and possibly improve the overall healthcare system efficiency. **Abstract (w. references):** <https://bit.ly/3vTOdXt>

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

### **Cicely Saunders, “total pain” and emotional evidence at the end of life**

*MEDICAL HUMANITIES* | Online – 12 May 2021 – In this article, the author explores how Cicely Saunders championed the hospice movement and initiated what became palliative care (PC) by representing her emotional connections with others. She became friends (and, once or twice, fell in love) with dying patients and encouraged others to follow her example in listening to patients' descriptions of pain. Her approach was radical at a time when she believed doctors routinely “deserted” dying patients because it urged them to understand another's embodied pain as inextricably bound up with the emotional impact of a terminal diagnosis. Saunders' attention to how patients expressed their experience is summed up in her term “total

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pain,” which communicates how an individual’s pain is a whole overwhelming experience, not only physical but also emotional, social and spiritual. Previous research frames “total pain” in terms of narrative, emphasising Saunders’ focus on listening to her patients and her use of narratives as evidence in advocating for cultural and institutional change, both of which the author understands as engaging with a patient’s emotional reality. However, as Saunders’ ideals become mainstreamed as PC and amid calls for “narrative palliative care,” the author uses evidence from Saunders’ extensive written output alongside archival material to suggest that, just as PC is by its nature not a single specific intervention, “total pain” should not be understood as simply narrative. Building on existing work in this journal questioning the primacy of conventional understandings of narrative in the medical humanities, the author demonstrates how Saunders’ prominent use of fragments and soundbites alongside longer case narratives demonstrates the limits of narrative, particularly when someone is dying. **Abstract:** <https://bit.ly/2SPAZNb>

### 50 Years of advance care planning: What do we call success?

*MONASH BIOETHICS REVIEW* | Online – 8 May 2021 – Advance care planning (ACP) is promoted as beneficial practice internationally. This article critically examines different ways of understanding and measuring success in ACP. It has been 50 years since Luis Kutner first published his original idea of the Living Will,<sup>1</sup> which was thought to be a contract between health carers and patients to provide for instructions about treatment choices in cases of mental incapacity. Its purpose was to extend a patient’s right to autonomy and protect health carers from charges of wrong-doing. Yet, it can be doubtful whether different types of ACP achieve these goals rather than aiming at secondary gains. The author’s discussion suggests that the current promotion of ACP is not always engaging critically with the original ACP intentions and may even pursue notions of success that may run contrary to respecting autonomy. The risk of this may especially be the case when high participation rates are taken as indicators of success for institutional ACP programs. The author further suggests that Kutner’s two original aims of protecting patient autonomy and preventing charges of wrong-doing are near impossible to achieve in conjunction, because their simultaneous pursuit fails to acknowledge that patients and carers have opposing needs for reassurance about possible judgment errors. The author concludes that the most realistic idea of success of modern ACP is an acknowledgement of the importance of ongoing dialogue about what constitutes appropriate care and a diversity of aims rather than any kind of advance, contractual insurance in the face of controversy. **Abstract (w. references):** <https://bit.ly/3eBShpD>

1. ‘Due process of euthanasia: The living will, a proposal,’ *Indiana Law Journal*, 1969;44(4):539-544. **Full text (click on pdf icon):** <https://bit.ly/3xZTfDC>

#### Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 May 2021 – ‘**Advance care planning, palliative care, and end-of-life care interventions for racial and ethnic underrepresented groups: A systematic review.**’ The effectiveness of advance care planning (ACP), end-of-life, and palliative care (PC) interventions in improving outcomes for underrepresented racial and ethnic populations remains uncertain. Randomized clinical trials and educational interventions indicate that interventions targeting underrepresented groups can have significant and positive effects on advance directives and/or ACP-related outcomes. More high-quality intervention studies that address racial and ethnic health disparities in PC are needed... **Abstract (w. references):** <https://bit.ly/3bjaFkS>



#### Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.13.

**IPCRC.NET** International Palliative  
Care Resource Center

Search Back Issues of Media Watch @  
<http://bit.ly/2ThijkC>

## “Saying goodbye” during the COVID-19 pandemic: A document analysis of online newspapers with implications for end-of-life care

*PALLIATIVE MEDICINE* | In print – Accessed 10 May 2021 – News media create a sense-making narrative, shaping, reflecting and enforcing cultural ideas and experiences. Reportage of COVID-related death and bereavement illuminates public perceptions of, and responses to, the COVID-19 pandemic. The authors explore British newspaper representations of “saying goodbye” before and after a COVID-related death and consider clinical implications. The seven most-read online newspapers were searched: *The Guardian*, *The Daily Mail*, *The Telegraph*, *The Mirror*, *The Sun*, *The Times* and *The Metro*. Fifty-five articles discussed bereavement after a human death from COVID-19, published during 18/03-24/03/2020 (the UK’s transition into lockdown) or 08/04-14/04/2020 (the UK peak of the pandemic’s first wave). The act of “saying goodbye” (before, during and after death) was central to media representations of COVID bereavement, represented as inherently important and profoundly disrupted. Bedside access was portrayed as restricted, variable and uncertain, with families

begging or bargaining for contact. Video-link goodbyes were described with ambivalence. Patients were portrayed as “dying alone” regardless of clinician presence. Funerals were portrayed as travesties and grieving alone as unnatural. Articles focused on what was forbidden and offered little practical guidance. Newspapers portrayed COVID-19 as disruptive to rituals of “saying goodbye” before, during and after death. Adaptations were presented as insufficient attempts to ameliorate tragic situations. More nuanced and supportive reporting is recommended. Clinicians and other professionals supporting the bereaved can play an important role in offering alternative narratives. **Abstract:** <https://bit.ly/3uBe5a5>

‘Communications with the Public,  
Politicians, and the News Media,’

*Oxford Textbook of Palliative Medicine*  
(5<sup>th</sup> Edition) **Synopsis:** <http://bit.ly/2rHlIEI>

Noted in Media Watch 8 March 2021 (#707, p.7):

- *PLOS ONE* | Online – 4 March 2021 – “‘It’s like being in a war with an invisible enemy’: A document analysis of bereavement due to COVID-19 in U.K. newspapers.” This study of online newspapers in the public domain has implications for how health-related and death-related news is communicated and how the media response to deaths could be improved in this and future mass bereavement events. There appears to be a delicate balance required in using fear-based narratives that can help generate action and solidarity without increasing fear in a way that may exacerbate the situation or negatively affect bereaved people. As noted in relation to other “sensationalist” topics and suicide, the media have a role to play in nuanced reporting. **Full text:** <http://bit.ly/3qg2nhV>

### Commentary

#### Re-framing self-care: Deepening the quality of our own care

*PROGRESS IN PALLIATIVE CARE* | Online – 8 May 2021 – In palliative care (PC), no matter the area of practice, we are very familiar with the concept of self-care. We understand its importance with regards to the area of practice that we all choose to work within, and it is actually very important for our health, our wellbeing, and how we move through our working days and what we experience within those days. I see PC as one of the “pointy ends” in healthcare. Yes, there is a life that is reaching its completion, but quite often everything in that life also comes to a head and we do see it all; the physical illness and the impact that this can have on a person, the psychological impact that this can have on the person and their loved ones and carers, what happens in the relationships a person has; the questioning of the very meaning of life and death and even the questioning of God, the universe or the belief system that someone aligns with and the legal implications of decisions to be made. Although not an exhaustive list, these are the types of things we navigate as health professionals (HPs) working within the sphere that is PC. These things are also not exclusive to PC; however, given the context of our work they become magnified. With this, there would be very few HPs working in PC that would argue the importance of self-care. In fact, most HPs, no matter their area of practice, would also agree. However, it remains something that a lot of us “struggle” with, for many reasons. **Full text:** <https://bit.ly/3f41wxx>

## Continuums of change in a competence-building initiative addressing end-of-life communication in Swedish elder care

*QUALITY HEALTH RESEARCH* | Online – 12 May 2021 – Competence-building is a multifaceted and relational concept that encompasses knowledge, skills, and empowerment among staff, and requires support from the organization. This study suggests that an approach to staff competence-building for end-of-life (EoL) conversations based on repeated reflection, discussions, and knowledge exchange, can support changes in: staff approaches to EoL communication; assumptions about what constitutes quality in EoL care; and, acknowledgment of staffs' own roles in EoL decision-making processes. Individual and joint reflection, using an appropriate and user-friendly tool, enabled staff to approach their own mortality and expand their frames of reference by shifting perspectives of EoL care, which were important mechanisms of change in this study. The authors' results add relevant nuance and detail about how reflection, involving introspection and extrospection, can prompt experiential learning and may contribute to the development of death literacy. The change continuums presented here indicate core aspects to include in EoL competence-building programs and death education, whereas the mechanisms provide insight into how death literacy might be fostered. These findings are important to consider in future educational initiatives to improve EoL communication between stakeholders in various care contexts. Nevertheless, the question of whether increased death literacy translates to changes in staff behavior in care practice remains critical for future research to explore. **Full text:** <https://bit.ly/3elkQBE>

## Research Matters

### Dealing with death as an outcome in supportive care clinical trials

*JAMA INTERNAL MEDICINE* | Online – 10 May 2021 – The past decade has witnessed a dramatic expansion in the number of randomized clinical trials (RCTs) testing palliative and other supportive care interventions, including methods to improve advance care planning, specialist and generalist palliative care delivery, and caregiver and clinician decision-making for patients with serious illnesses. However, like many welcome advances, this expansion in supportive care RCTs has engendered novel ethical and regulatory questions. Foremost among these questions is how to conceptualize and monitor mortality as an end point in trials of supportive care interventions. **Abstract:** <https://bit.ly/3bf7laf>

## Publishing Matters

### How the Centre for Journalology hopes to fix science

*CHEMICAL & ENGINEERING NEWS* | Online – 20 May 2021 – The Centre for Journalology ... is home to an array of experts with various backgrounds, including preclinical researchers, clinical epidemiologists, social psychologists, methodologists, behavioral scientists, and metrics literacy specialists.

The organization has three pillars: 1) Performing research on the subfields of metascience; 2) Developing a course to teach the subject; and, 3) Conducting outreach about the topic to stakeholders such as universities, researchers, journals, and policy makers. The Centre aims to improve science and make scientific publishing more robust and rigorous. In late 2019, for instance, the center unveiled a definition of predatory publishing.<sup>1</sup> To do that, researchers looked at the characteristics of predatory journals and compiled a review analyzing papers about predatory journals to identify common characteristics of such publications. The center then brought together 43 experts, who engaged in 12-hours of discussion followed by two rounds of revision and feedback to reach consensus: "Predatory journals and publishers are entities that prioritize self-interest at the expense of scholarship and are characterized by false or misleading information, deviation from best editorial and publication practices, a lack of transparency, and/or the use of aggressive and indiscriminate solicitation practices." **Full text:** <https://bit.ly/3o7hEiY>



**Centre for Journalology**

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1. 'Defining predatory journals and responding to the threat they pose: A modified Delphi consensus process,' *BMJ Open*, published online 9 February 2020. [Noted in Media Watch 17 February 2020 (#653, p.17)] **Full text:** <http://bit.ly/2SdQaNr>

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

### International



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

[Scroll down to 'Media Watch']

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

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

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

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

### Asia



Asia Pacific  
Hospice Palliative  
Care Network

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

[Scroll down to 'Media Watch']

### Australia

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

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

### Canada



Canadian Society of  
Palliative Care Physicians

Société canadienne des  
médecins de soins palliatifs

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): <HTTP://BIT.LY/3EPKUAC>

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

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

### South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>



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

### 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.

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Barry R. Ashpole, Ontario CANADA

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