

**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.

1 November 2021 Edition | Issue #741



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Despite the mature, established evidence base for palliative care integration early in the course of illness (including for those still receiving curative treatment), palliative care tends to remain associated in the minds of both healthcare providers and the public as exclusively end-of-life care.

'Reframing palliative care to improve the quality of life of people diagnosed with a serious illness' (p.7), in *Medical Journal of Australia*.

## Canada

### Dying in Canada is costing a fortune – and worse, it's not how we want to go

*THE GLOBE & MAIL* | Online – 26 October 2021 – In Canada, 61% of deaths occur in hospital. By comparison, that number sits at 30% in The Netherlands, and 20% in the U.S. This is a gross systemic failure, and a tremendous waste of money. It's also the polar opposite of what people say they want – which, ideally, is to die in a homelike setting, surrounded by family and friends. Only about 15% of Canadians die at home,<sup>1</sup> despite polls that consistently show that is the preference of about 85% of the population. And when Canadians do get access to palliative care, it's rarely in an appreciable way. Too often, we are dying in pain, scared and alone – overtreated and under-cared for. "Canadians spend more on end-of-life (EoL) care than other high-income countries, including the U.S., yet we achieve poor results compared to most," according to Kieran Quinn, Sarina Isenberg and James Downar, the perhaps overly polite authors of a new report published by the C.D. Howe Institute that focuses on the economics of Canada's EoL problem.<sup>2</sup> "There are structural factors and inefficiencies within our healthcare system that facilitate unhelpful and unwanted medical interventions at the EoL." When you are speaking to politicians, they say, you need to speak their language: in terms of money. But this is about much more than money. It's about respect and dignity, especially of our elders. <https://tgam.ca/3b9y5ZF>



1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. [Noted in Media Watch 24 September 2018 (#582, p.1)] **Download at:** <http://bit.ly/2MqmCYO>
2. 'Expensive Endings: Reining In the High Cost of End-of-Life Care in Canada,' C.D. Howe Institute, October 2021. **Download at:** <https://bit.ly/3pAhfvi>

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Would the C.D. Howe Institute report be of interest to a colleague?

Noted in Media Watch 19 April 2021 (#713, p.5):

- **BMC HEALTH RESEARCH** | Online – 13 April 2021 – **‘The association between varying levels of palliative care involvement on costs during terminal hospitalizations in Canada from 2012 to 2015.’** Inpatient palliative care (PC) is associated with lower inpatient costs; however, this has yet to be studied using a more nuanced, multi-tiered measure of inpatient PC and a national population-representative dataset. This is the first national population-representative analysis on the impact of inpatient PC on costs using a tiered PC variable. Future research should explore whether this relationship holds for other hospitalizations towards the end of life, as well as whether PC in other settings impacts inpatient costs. **Full text:** <https://bit.ly/3uHjXhU>

### **First of its kind website aims to provide resources about palliative care for kids**

MANITOBA | CTV News (Winnipeg) – 24 October 2021 – Called ‘caringtogether.life,’ the website is the first of its kind for child palliative care (PC), based off the model of the adult version for Canadian Virtual Hospice, which provides information and support on PC and advanced illness for adults. “I want these families to know that there are supports available, that there is education available, that the ‘what if’ questions that many of them are asking, typically late at night when there is nobody there to turn to, they can go online and get those answers and find out who are the people locally that they can connect to to have further conversations on this,” Dr. Adam Rapaport, a pediatric PC specialist with Sick Kids Hospital, told CTV News. The website aims to serve as a hub to connect people with services and other families who may be going through many of the same challenges. It also has pages walking families through the impact on members of the family outside of the child who is suffering, as well as resources on how to plan for end-of-life care and the grieving process. <https://bit.ly/3mbs5G4>

**N.B.** Caringtogether.life: <https://bit.ly/3EjrqZr>; Canadian Virtual Hospice: <https://bit.ly/3nwEqUO>

## **U.S.A.**

### **California providers: Hospice license moratorium could boost non-profits**

CALIFORNIA | *Hospice News* – 28 October 2021 – California Governor Gavin Newsom earlier this month signed two hospice reform laws designed to strengthen hospice oversight. While some stakeholders applauded these steps as a way of thinning the crowded California market, they could lead to frustration for providers seeking to grow their presence in the state. The bills ... came after a *Los Angeles Times* investigation into alleged misconduct among California hospice providers. The new laws put a moratorium on new licenses and mandate an extensive audit of California’s licensing and oversight processes, including an anti-kickback stipulation that prohibits hospices from paying health care providers for

referrals. The new laws are critical steps towards leveling the playing field for hospice providers in the state and preserving the quality of end-of-life care, according to Michael Milward, CEO of the California Hospice Network, a strategic partnership of community-based non-profit hospice providers. <https://bit.ly/3vYAzTW>

#### **Specialist Publications**

**‘American Academy of Nursing Expert Panel consensus statement on nursing’s roles in ensuring universal palliative care access’** (p.8), in *Nursing Outlook*.

**N.B.** California Hospice Network website: <https://bit.ly/3EwhxHB>

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@ <http://bit.ly/2ThijkC>

Noted in Media Watch 11 October 2021 (#738, p.3):

- CALIFORNIA | *The Los Angeles Times* – 4 October 2021 – ‘**Hospice reforms to become law after Times investigation reveals widespread fraud, abuse.**’ 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. <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/3m0gsOH>
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).

### **National Hospice & Palliative Care Organization’s new facts and figures report shows changes in hospice patient diagnoses**

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 28 October 2021 – The Organization’s report is produced annually to provide an overview of hospice care delivery in the U.S., with specific information on hospice patient characteristics, location and level of care, Medicare hospice spending, hospice provider characteristics, and more. In 2019 there was continued growth in the number of Medicare hospice patients with non-cancer diagnoses, including a principal diagnosis of Alzheimer’s, dementia, or Parkinson’s, which represented more than four times the number of patients who had cancer. For several decades, hospices primarily served people with cancer diagnoses. As recently as 2007, cancer continued to be the leading principal diagnosis of those receiving care. However, that has shifted dramatically over the last decade. Hospice professionals continue to be concerned about the number of people accessing hospice care late in the course of an illness. The report indicates that 10% of Medicare decedents received hospice care for two days or less in 2019. Twenty-five percent of beneficiaries received care for five days or less, and 50% received care for 18 days or less. <https://bit.ly/3jNMwHc>

### **Pulmonary Fibrosis Foundation position statement recommends addressing palliative care early in patient journey**

PULMONARY FIBROSIS FOUNDATION | Online – 25 October 2021 – The Foundation recommends healthcare providers address the incorporation of palliative care (PC) early in the medical journey of patients living with pulmonary fibrosis (PF). Developed by an expert Task Force, the statement guides providers to effectively address the subject of PC with patients and, ultimately, increase quality of life and survival of those living with PF. A version of the position statement written for patients is also available. The position statement recommends healthcare providers raise the subject of PC early in the disease course of patients, so they are informed that there may be treatments to help ease symptom burden that are outside the expertise of their pulmonologist. While there may be challenges, the statement outlines best practices for overcoming common barriers to the introduction of PC at a time many patients are coming to terms with an uncertain future due to an unfamiliar disease. <https://bit.ly/3BhrJSo>

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Noted in Media Watch 13 January 2020 (#648, p.13):

- **PULMONARY THERAPY** | Online – 4 January 2020 – ‘**The role of palliative care in reducing symptoms and improving quality of life for patients with idiopathic pulmonary fibrosis: A review.**’ Despite the increasing prevalence of idiopathic pulmonary fibrosis and its growing recognition among providers, there remains a significant lag time between initial diagnosis and multidisciplinary evaluation. While beneficial in other patient populations, the benefits of palliative care have not been replicated in this patient population. It may be misconstrued as hospice and end-of-life care, resulting in delayed evaluation often far too late in a patient’s disease course to have meaningful symptomatic benefit. **Full text:** <http://bit.ly/2N0IOuS>

Noted in Media Watch 6 August 2018 (#575, p.13):

- **PALLIATIVE MEDICINE** | Online – 30 July 2018 – ‘**Early integrated palliative approach for idiopathic pulmonary fibrosis: A narrative study of bereaved caregivers’ experiences.**’ Idiopathic pulmonary fibrosis has an uncertain and rapid trajectory after diagnosis. Palliative care is rarely utilized, although both patients and caregivers experience a distressingly high symptom burden. Most patients die in hospital. Five major themes were identified: 1) Having a terminal disease; 2) Planning goals and wishes for care; 3) Living life and creating memories; 4) Feeling strain and responsibility; and, 5) Nearing the end. Caregivers interviewed had little understanding of prognosis prior to advance care planning conversations. **Abstract (w. references):** <http://bit.ly/2T1az90>

## International

### **Nurse shortages leave people dying in pain, charity warns**

U.K. | *The Independent* (London) – 26 October 2021 – People are dying at home without the correct nursing support or pain relief because of staff shortages, according to the end-of-life charity Marie Curie. One in three nurses, responding to a survey by the charity and *Nursing Standard*, say a lack of staff is the main challenge providing quality care to dying people.<sup>1</sup> More than half of the nurses said they feel the standard of care has deteriorated during the coronavirus pandemic. Some 548 nursing staff across acute and community settings in the U.K. completed the survey in September. They raise concerns about the increased number of people dying at home and insufficient numbers of community nurses to support these people and their families. There have been more than 74,000 excess deaths in private homes in England and Wales since the start of

the pandemic, according to the Office for National Statistics.<sup>2</sup> <https://bit.ly/3BpTNTW>

#### Specialist Publications

‘**Role and support needs of nurses in delivering palliative and end-of-life care**’ (p.8), in *Nursing Standard*.

‘**How does English national end-of-life care policy impact on the experience of older people at the end of life? Findings from a realist evaluation**’ (p.11), in *Primary Health Care, Research & Development*.

‘**A new model for a palliative approach to care in Australia**’ (p.8), in *Rural & Remote Health*.

1. ‘Dying at home: not enough community staff to support a good death, nurses say,’ *Nursing Standard*, Royal College of Nursing, 27 October 2021. <https://bit.ly/3EjIU8R>
2. ‘Care home resident deaths registered in England and Wales...,’ Office for National Statistics, 28 September 2021. [Noted in Media Watch 4 October 2021 (#737, p.3)] <https://bit.ly/39ODSDe>



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## **National framework for the delivery of bereavement care**

U.K. (Wales) | Welsh Government – 28 October 2021 – The framework has been developed in line with the five ways of working, in the Wellbeing of Future Generations Act and the priorities set out in the Programme for Government to provide effective, high quality and sustainable healthcare and in particular to improve service access and integration. It describes a longer-term vision along with short to medium term actions that require a collaborative approach across health, social care and the third sector. Public involvement has been key to shaping the framework, and is fundamental to the delivery of bereavement care. The framework also has a strong focus on preventive activity through the recognition of anticipatory grief and support for families, friends and carers. **Download at:** <https://bit.ly/3Br86rk>

## **Specialist Publications**

### **Children’s palliative care education and training: Developing an education standard framework and audit**

*BMC MEDICAL EDUCATION* | Online – 25 October 2021 – The need to align the range of guidance and competencies concerning children’s palliative care (PC) and develop an education framework have been recommended by a U.K. All-Party Parliament Group and others. A Children’s Palliative Care Education & Training Action Group ... was formed across U.K. and Ireland in 2019 to take this work forward. The Action Group reviewed sources of evidence and guidance including PC competency documents and ... quality and qualification frameworks. Expected levels of developing knowledge and skills were then agreed and identified competencies mapped to each level. The mapping process led to the development of learning outcomes, local indicative programme content and assessment exemplars. Four sections depicting developing levels of knowledge and skills were identified: 1) Public health; 2) Universal; 3) Core; and, 4) Specialist. Each level has four learning outcomes: a) Communicating effectively; b) Working with others in and across various settings; c) Identifying and managing symptoms; and d) Sustaining self-care

and supporting the well-being of others. An audit tool template was developed to facilitate quality assurance of programme delivery. The framework and audit tool repository is on the International Children’s Palliative Care Network website...<sup>1</sup> While there are education programmes in children’s PC, this is the first international attempt to coordinate education, to address lay carer education, and to include public health. **Full text:** <https://bit.ly/2XKxCK8>

#### **Research Matters**

**‘Use of theoretical frameworks in the development and testing of palliative care interventions’** (p.12), in *Journal of Pain & Symptom Management*.

#### **Publishing Matters**

**‘Predatory publishers’ latest scam: Bootlegged and rebranded papers’** (p.12), in *Nature*.

1. ‘Children’s Palliative Care Education Standard Framework & Self Audit Tool,’ International Children’s Palliative Care Network. <https://bit.ly/3BhCWCC>

### **Education on palliative care for Parkinson patients: Development of the “Best Care for People with Late-stage Parkinson’s disease” curriculum toolkit**

*BMC MEDICAL EDUCATION* | Online – 25 October 2021 – Palliative care (PC) education among all stakeholders involved in the care of patients with late-stage Parkinson’s disease (PD) is not adequate. In fact, there are many unmet educational and training needs as confirmed with a targeted, narrative literature review. To address these needs, the authors developed the “Best Care for People with Late-Stage Parkin-

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son's Disease" curriculum toolkit. The toolkit is based on recommendations and guidelines for training clinicians and other healthcare professionals involved in PC, educational material developed in recent research efforts for patients and caregivers with PD and consensus meetings of leading experts in the field. The final version of the proposed toolkit was drafted after an evaluation by external experts with an online survey, the feedback of which was statistically analysed with the chi-square test of independence to assess experts' views on the relevance and importance of the topics. A sentiment analysis was also done to complement statistics and assess the experts positive and negative sentiments for the curriculum topics based on their free text feedback. In this article, the methods for the development of the toolkit, its stepwise evolution, as well as the toolkit implementation as a Massive Open Online Course, are presented. **Full text:** <https://bit.ly/2ZsoQ4c>

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

### **The right to pain relief: Its origins in end-of-life care and extension to chronic pain care**

*CLINICAL JOURNAL OF PAIN* | Online – 26 October 2021 – The claim of a right to pain relief was made in recent decades by pain professionals, courts, and patient advocacy groups and likely contributed to increased opioid prescribing, overdose deaths, and addictions, but the origins and nature of this right have not been investigated. The record describes the effort to improve end-of-life (EoL) and cancer pain care in the 1980s and 1990s, which simultaneously legitimated pain relief as an independent goal of medical care and opioids as a safe and effective means to achieve this relief. In 1997, the U.S. Supreme Court denied the right to assisted suicide but affirmed a right to palliative care to prevent dying in overwhelming pain. Other guidelines and regulations extended this right to pain relief from EoL care to chronic pain care, along with the titrate-to-effect principle, which specified that the correct opioid dose was the dose that relieved pain. The most important consequence of combining the right to pain relief with the titrate-to-effect principle was the idea that a high pain score must not be ignored. This extension of the right to pain relief neglected important differences between EoL care and chronic pain care including: time frame, clinical setting and context, target of titration, and nature of iatrogenic harms. To help end the current opioid epidemic and prevent a future epidemic, we need to demedicalize pain and reintegrate it with the rest of human suffering as an experience connected to other personal behaviors and meanings. **Abstract:** <https://bit.ly/2Zt6PCv>

### **Drastic changes in the practice of end-of-life care during the COVID-19 pandemic**

*JOURNAL OF CRITICAL CARE* | Online – 22 October 2021 – Globally, COVID-19 continues to strain physical and emotional healthcare resources. For the first time in modern critical care history in the U.S., the pandemic forced values of autonomy and beneficence to yield to justice, and end-of-life care (EoLC) had to transform accordingly. Resource limitations changed the urgency and stakes of critical conversations that traditionally occurred over days and usually in person. The scale of the disaster meant that clinicians using critical care resources had to become more comfortable with palliation in different environments and more carefully consider the appropriateness in care during an acute patient decline. COVID-19 has claimed 4.3 million lives globally and over 600,000 lives in the U.S. One way of honoring those who died will be learning the lessons taught by the crisis in EoLC and improving how we as a society and individual clinicians approach these issues in future patients. **Full text:** <https://bit.ly/3Bfwa07>

### **Top ten tips palliative care clinicians should know about strokes**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 October 2021 – Stroke is a common cause of long-term disability and death, which leaves many patients with significant and unique palliative care (PC) needs. Shared decision-making for patients with stroke poses distinct challenges due to the sudden nature of stroke, the uncertainty inherent in prognostication around recovery, and the common necessity of relying on surrogates for decision-making. Patients with stroke suffer from frequently underrecognized symptoms, which PC clinicians should feel comfortable identifying and treating. This article provides 10 tips for palliative clinicians to increase their knowledge and comfort in caring for this important population. **Abstract:** <https://bit.ly/3GoyCW1>

## Who thinks about death? A psychoanalytically informed interpretive study of communication about death among nursing home staff

*JOURNAL OF SOCIAL WORK PRACTICE* | Online – 20 October 2021 – The authors investigated the emotional struggles that healthcare providers are confronted with when working with dying patients in nursing homes, and how this struggle affects their ability to communicate about death with both colleagues and patients. Care providers from all cultural and faith backgrounds shared a common existential fear of death. To tackle such fear in an institution where death is a regular occurrence can lead to the development of a social defence system, which allows staff to keep strongly unpleasant emotions associated with death at bay. In this study, the authors saw evidence of such a defence system through the striking lack of organised guidance and reflection, which would foreground care providers' own experiences, feelings and thoughts related to death as matters of importance to care work in these institutions. In contrast to aversion of death or emotional numbing, conditions should be provided for healthcare professionals to open up to the impression of death – to allow their own experiences, thoughts and feelings related to death to emerge from embodied experience to a more fully articulated account. The crucial opportunity for healthcare providers to “digest” their emotional experiences connected to death must be organised in, and secured by, the workplace. In this way, healthcare providers will be better able to mature as professionals and be more equipped to use their capacity both to feel for their patients and reflect upon their patients' inevitable fear of death as it approaches. **Full text:** <https://bit.ly/3jylIDw>

## Reframing palliative care to improve the quality of life of people diagnosed with a serious illness

*MEDICAL JOURNAL OF AUSTRALIA* | Online – 22 October 2021 – Palliative care (PC) is an essential component of the goal of universal quality health coverage. A name change is not required, but attention should instead focus on how PC is framed. A national public PC education campaign in Australia is required. The authors set out one framework to help inform this in their own health service, in an attempt to locally influence the manner in which they talk about and conceptualise PC. While other models framing PC have been put forward, the authors suggest their framework explicitly highlights the ways PC may be integrated to complement treatment intention, respond to varying prognoses, and facilitate a response to patient and family needs throughout the care process. Nevertheless, their approach has its limitations and will require subsequent work to refine and adapt it in a way that gathers further evidence and ensures it is acceptable to a broader range of health services. Importantly, application of the framework will require a response to the individual needs and preferences of patients and family carers. While the implementation of an effective framework can open the door to PC, poor service experience can also close it. To change the landscape, the quality of PC service delivery must match the promise of outcomes from consistent and evidence-based care. **Full text:** <https://bit.ly/3Ec8ZFW>

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### Key messages:

*PALLIATIVE CARE IS CENTRED AROUND YOU.* The healthcare system can be complex and confusing; PC fits into your needs, your beliefs, your wishes, and your aims for your life. Then, you get to choose your way forward, informed by people who genuinely care.

*PALLIATIVE CARE ENABLES YOU TO BE PREPARED.* Regardless of your disease stage or prognosis, PC helps you explore your expectations for the future and promotes prospects of peace and dignity.

*EVERYONE DESERVES PALLIATIVE CARE.* PC is “enhanced care” that focuses on you and your family. It is sometimes misunderstood but will one day be available to everyone automatically as the gold standard of best practice care.

*PALLIATIVE CARE IS CREATIVE.* Being based on your needs and those of your family, PC is flexible and responsive. In this way, PC can assist a sense of achievement and hopefulness by helping you realise and achieve your goals.



**Palliative Care Network**

Palliative Care for Everyone, Everywhere

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

Noted in Media Watch 2 July 2018 (#570, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2018;56(3):363-370. ‘**Reframing global palliative care advocacy for the sustainable development goal era: A qualitative study of the views of international palliative care experts.**’ Palliative care (PC) represents a value proposition that is not currently being maximized by advocacy. Participants strongly supported the rollout of national PC policies around the world to ensure PC attracts national funding streams and to attract global funding for PC. The absence of a global indicator for PC development is considered a severe impediment to the inclusion of PC within global efforts toward universal healthcare. Advocacy partnerships, using human rights approaches with economic frames are effective methods of influencing policymakers. **Full text:** <http://bit.ly/2TF43Vs>

#### Related:

- *RURAL & REMOTE HEALTH* | Online – 23 October 2021 – ‘**A new model for a palliative approach to care in Australia.**’ There is an inconsistent provision of palliative and end-of-life (EoL) care across Australia, particularly in regional, rural and remote areas. Systematic solutions can help to address identified gaps and improve access to and quality of care and support for patients, their families and carers... The Far West New South Wales Palliative & End of Life Model of Care is a systematic solution for a rural and remote palliative approach to care. The model enables a consistent and contextually adaptable, patient-focused palliative approach to care so that everyone receives the care they need from appropriately skilled and informed clinicians, in a timely manner... **Full text:** <https://bit.ly/314JisD>

#### **American Academy of Nursing Expert Panel consensus statement on nursing's roles in ensuring universal palliative care access**

*NURSING OUTLOOK* | Online – 25 October 2021 –Part I of this consensus paper provides the rationale and background to support the policy, education, research, and clinical practice recommendations put forward in Part II. On behalf of the Academy, the 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. The consensus paper's 43 authors represent eight countries (Australia, Canada, England, Kenya, Lebanon, Liberia, South Africa, the U.S.) and extensive international health experience, thus providing a global context for the subject matter. The authors recommend greater investments in palliative nursing education and nurse-led research, nurse engagement in policymaking, enhanced intersectoral partnerships with nursing, and an increased profile and visibility of palliative nurses worldwide. By enacting these recommendations, nurses working in all settings can assume leading roles in delivering high-quality palliative care globally, particularly for minoritized, marginalized, and other at-risk populations. **Abstract (w. references):** <https://bit.ly/3GvVBPO>



#### **Role and support needs of nurses in delivering palliative and end-of-life care**

*NURSING STANDARD* | Online – 25 October 2021 – The COVID-19 pandemic has led to a significant increase in the demand for palliative and end-of-life care (EoLC), particularly in the community. Furthermore, palliative and EoLC services face growing pressures due to the increasing number of older people and increasing prevalence of chronic illness. Palliative and EoLC cannot be provided solely by specialists but needs to be integrated into mainstream healthcare. All nurses have a role in supporting patients with life-limiting conditions, and their families, by providing what is termed “generalist palliative care.” However, some nurses may feel unprepared, unsupported or lacking the confidence and skills for that role. The authors of this article explore the definitions of palliative and EoLC, as well as the changes and challenges in service provision brought about by the COVID-19 pandemic. It also considers how nurses who have not specialised in this area of practice can be supported to care effectively for patients with life-limiting conditions, and their families, notably through workforce development initiatives such as training programmes and clinical supervision. This could not only increase the skills of the nursing workforce but also improve patient care. **Abstract:** <https://bit.ly/3vHcBMV>



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## Related:

- *BRITISH JOURNAL OF CARDIOLOGY NURSING* | Online – 28 October 2021 – ‘**Nurse opportunities to overcome barriers to palliative care provision for patients with heart failure: An integrative review.**’ This study highlights a number of barriers that impede the adequate assessment and delivery of palliative care to patients with heart failure. It provides a timely reminder of the importance of effective teamwork and ensuring that the patient is the driving force behind any care decisions. It is fundamentally important that nurses continue to pursue opportunities to develop confidence, leadership and advocacy skills to ensure the multidisciplinary team maintain their patient-centred focus in future care. **Abstract (w. link to references):** <https://bit.ly/2ZB0Fk5>

## Implementation and outcomes of complementary therapies in hospice care: An integrative review

*PALLIATIVE CARE IN SOCIAL PRACTICE* | Online – 26 October 2021 – This integrative review of quantitative studies ... focused on implementation and outcomes of complementary therapy (CT) as a component of hospice care. The majority of studies had positive results; however, 40% had both significant and non-significant findings indicating that while there is evidence to support the use of some CTs for specific symptoms, it is not consistent, and improvements may not be sustained over time. In addition, a number of methodological issues should be considered related to study design and sample, implementation of the CT interventions, and data measurement and analysis. **Full text:** <https://bit.ly/3nvcnF1>

## Why does palliative care need to consider access and care for LGBTQ people?

*PALLIATIVE MEDICINE* | Online – 26 October 2021 – Equity in access to healthcare, suggests that individuals who need it most, are able to use healthcare services in a timely manner to achieve the best health outcomes. However, the evidence is clear that for LGTBQ people, this is not the case. The term “health equality” means that everyone has the same opportunities to access healthcare, whilst “health equity” means that people in minority groups with a greater level of need and additional barriers to accessing healthcare are provided with additional help to bring them up to the same level of health as others. Inequity in access to health services for LGBTQ people has been recognised as a concern globally. This is especially the case in many parts of the world where it remains unsafe to be LGBTQ, with homosexuality still criminalised in 70 countries and 42 countries having no legal recognition of transgender people. There is evidence that in these countries people perceived to be LGBTQ receive worse care, due to discrimination, which may involve treatment being withheld from them. Individuals are therefore forced to make the decision between attempting to conceal their sexual orientation and/or gender or to avoid accessing healthcare completely. Even in countries with anti-discrimination laws in place to protect LGBTQ individuals, discrimination unfortunately persists... There continues to be healthcare professionals who perceive an LGBTQ identity to be a mental illness which requires treatment, which may involve so-called conversion therapy. This leaves LGBTQ people with the decision of whether it is necessary to hide who they are to feel safe accessing healthcare. **Full text:** <https://bit.ly/3pE6ybd>

Noted in Media Watch 25 October 2021 (#740, p.10):

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 22 October 2021 – ‘**Development and evaluation of an LGBT+ education programme for palliative care interdisciplinary teams.**’ Despite national policy recommendations to enhance healthcare access for LGBT+ people, education on LGBT+ issues and needs is still lacking in health and social care curricula. Most of the available resources are focused on primary care, mental health, and sexual health, with little consideration to broader LGBT+ health issues and needs. The project described by the authors provides an example of how partnership working between different stakeholders can help respond to a real need within the health services to positively impact the care provided to marginalised populations. **Full text:** <https://bit.ly/3psiC3d>

**N.B.** Search back issues of Media Watch for additional articles on the palliative and end-of-life care needs of the “LGBT+,” “LGBTQ” or “LGBTQ2S” communities at: <http://bit.ly/2ThijkC>

## **Compassionate community structure and function: A standardised micro-model for end-of-life doulas and community members supporting those who wish to die at home**

*PALLIATIVE MEDICINE* | Online – 22 October 2021 – End-of-life (EoL) doulas are an emerging, non-medical support and advocacy role for the dying and their caregivers. As more and more people are dying at home, research shows EoL doulas are increasingly in demand as non-medical advocates and companions for the dying, and their friends and families. Compassionate communities are essential to those who wish to die at home by helping to avoid carer stress and burnout associated with physical and emotional labour when a person is at EoL. However, compassionate community models are top-down in nature as they focus on public policy, missing a domestic-scale, standardised design applicable when someone wishes to die at home. This gap affects care networks and communications and arguably hinders the work of EoL doulas. Findings from original qualitative research with EoL doulas in four countries demonstrated the importance of compassionate communities for death literacy and support for a person at EoL and their networks and that all practitioners were using ad hoc, variable approaches to compassionate community formation and maintenance. A micro-level standardised and replicable model for organising and maintaining compassionate communities for EoL doulas which completes the established compassionate community model was developed to fill this gap and provide a vital tool for EoL doulas and training programmes internationally. A model was developed that addresses a gap in international approaches to practice, offering a standardised way to discuss, teach, and implement compassionate communities for EoL doulas in a variety of countries and languages. This article discusses the research and model in detail. **Full text:** <https://bit.ly/3bd4FK3>

Noted in Media Watch 27 September 2021 (#736, p.12):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 22 September 2021 – ‘**End-of-life doulas: Documenting their backgrounds and services.**’ This is an exploratory study to document the demographic characteristics, backgrounds, and services provided by trained and certified International End-of-Life Doula Association doulas. Like birth doulas, end-of-life (EoL) doulas represent a divergent, yet complementary form of care for dying persons. The purpose of EoL care is to facilitate comfort of the dying person and their closest family members. Surveys were completed by 618 EoL doulas regarding their demographic characteristics, employment backgrounds, services, and their experiences providing EoL care to dying persons and their closest family members. **Abstract (w. references):** <https://bit.ly/3AEu9eg>

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

## **Palliative care integration for patients with advanced chronic obstructive pulmonary disease: Identifying essential components using participatory action research**

*PALLIATIVE MEDICINE* | Online – 26 October 2021 – Despite increasing awareness about the role palliative care (PC) can play in care provision for patients with advanced chronic obstructive pulmonary disease COPD, integration in standard care remains underdeveloped. The unpredictability of the disease progression and misconceptions about PC being equivalent to end-of-life care often prevent a timely integrated approach in advanced COPD. Three elements of integrated PC in advanced COPD were identified: 1) Multidimensional assessment; 2) Healthcare professionals’ education; and, 3) Interdisciplinary team meetings, which are the pillars of a new integrated PC model for patients with advanced COPD. The new integrated PC model in advanced COPD includes essential elements with a focus on patients, healthcare professionals and care delivery. Further research on testing this model in clinical practice, service development, implementation processes and possible outcomes, including evaluation of the financial impact of integrated PC is necessary to foster this care approach across all possible settings. **Abstract (w. references):** <https://bit.ly/2Zqby7Z>

**N.B.** Search back issues of Media Watch for additional articles on the palliative and end-of-life care needs of people living with “COPD” at: <http://bit.ly/2ThijkC>

## How does English national end-of-life care policy impact on the experience of older people at the end of life? Findings from a realist evaluation

*PRIMARY HEALTH CARE, RESEARCH & DEVELOPMENT* | Online – 27 October 2021 – This research highlights the need to step back to reappraise how different parts of the health and social care system fit together and how we have arrived at the current set of priorities. Cuts in funding to social care over the last decade have exacerbated the inequities, with staff who care for the elderly at home being particularly poorly treated, underpaid and undervalued. Additionally, the potential to broaden responsibility for end of life (EoL), particularly promoting policies that enlist citizens to build local networks and mechanisms for supporting those at EoL, deserves closer investigation. Drawing on the notion of social capital a concept relating to the level of cohesiveness of the community and the strength of social ties, there has been a call to embrace a model of public health which places more emphasis on the social determinants of health and the influence of communities in the development of better health for all. A public health approach to palliative care seeks to build and operationalise social capital and encourage embedded civic action. Within this model, the focus is on empowering communities to support those dying, bringing to the fore expressions of a compassionate society and in so doing challenging the “professionalisation” of EoL care. The task confronted by politicians and commissioners, in dividing up the budget to support public services, is enormously difficult; with the need to consider a huge raft of moral, ethical, economic and social arguments. Yet unless the views of stakeholders at all positions in the social hierarchy ... resulting policy ... will fail to meet the needs and preferences of those it sets out to serve. **Full text:** <https://bit.ly/3EkxvVd>

### Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 October 2021 – ‘**Implementing a novel interprofessional caregiver support clinic: A palliative medicine and social work collaboration.**’ This quality improvement initiative involved the design and implementation of a novel and collaborative Caregiver Support Clinic (CSC), providing joint palliative medicine-social work encounters to caregivers of patients with advanced cancer. Caregivers felt the CSC provided a forum to discuss and review relevant, but previously neglected, care elements. The concerted collaborative efforts demonstrated by clinicians were found to be reassuring and comforting. Clinicians felt CSC visits prevented duplicative information gathering processes... **Abstract (w. references):** <https://bit.ly/3nvy2wN>

## Integrated palliative care: Triggers for referral to palliative care in ICU patients

*SUPPORTIVE CARE IN CANCER* | Online – 26 October 2021 – Palliative care (PC) within intensive care units (ICU) benefits decision-making, symptom control, and end-of-life care. It has been shown to reduce the length of ICU stay and the use of non-beneficial and unwanted life-sustaining therapies. However, it is often initiated late or not at all. There is increasing evidence to support screening ICU patients using PC referral criteria or “triggers”. The aim of the project was to assess the need for palliative care referral during ICU admission using “trigger” tools. All “trigger” tools reviewed identified a high proportion of patients who may have warranted a PC referral either before or during admission to ICU. The routine use of trigger tools could help streamline referral pathways and underpin the development of an effective consultative model of PC within the ICU setting to enhance decision-making about appropriate treatment and patient-centred care. **Abstract (w. references):** <https://bit.ly/2ZE6Wvt>

**N.B.** Selected articles on PC in ICUs noted in Media Watch 9 August 2021 (#729, p.11).



### Prison Hospice: Backgrounder Updated 1 November 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 from the Palliative Care Network website: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk, Philadelphia, PA

## Research Matters

### **Use of theoretical frameworks in the development and testing of palliative care interventions**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 October 2021 – Palliative care (PC) research has grown over the last 20 years. Yet, the causal components and pathways of PC interventions remain unclear. The authors conducted a secondary analysis of previously published systematic reviews of PC randomized clinical trials. Trials were evaluated for explicit mention of a theoretical framework, process or delivery model, or clinical practice guideline that supported the development of the intervention. The authors reviewed 85 PC trials conducted between 1984 and 2021. Thirty-eight percent of trials explicitly mentioned a theoretical framework, process or delivery model, or clinical practice guideline as a foundation for the intervention design. Only 9 trials included a theoretical framework, while the remaining 23 cited a process/delivery model or clinical practice guideline. Most PC trials do not cite a theoretical foundation for their intervention design. Future work should focus on developing and validating new theoretical frameworks and modifying existing theories and models to better explain the mechanisms of the variety of PC interventions. **Abstract (w. references):** <https://bit.ly/3pOX7pw>

## Publishing Matters

### **Predatory publishers' latest scam: Bootlegged and rebranded papers**

*NATURE* | Online – 26 October 2021 – In 2018, the U.S. Federal Trade Commission (FTC) won a US\$50-million ruling against the publishers OMICS for deceptive business practices. The FTC's investigation found that OMICS accepted and published nearly 69,000 articles in academic disciplines with little or no peer review. The judgement against the infamous publisher ... proved difficult to enforce. But the ensuing stigma still carries a penalty. In the two years after the FTC filed its complaint, the articles OMICS published under its imprint fell by 40%. Predatory publishers take publication fees without performing advertised services such as archiving, indexing or quality control. They often use outright deception, such as fake editorial boards or impact factors, to appear legitimate. Researchers might submit work to these outlets naively or cynically; even unread or sloppy articles are rewarded by some universities' tenure, hiring and promotion decisions. Often, these unvetted articles attract little attention. However, because they sometimes get harvested by non-selective academic search engines such as Google Scholar, they could be found – and read – as part of the scientific corpus. To get a better look at this many-headed monster, we constructed a database of publishers that have not been indexed in selective bibliographic databases such as Web of Science or Scopus. Currently, this database ... indexes more than 900,000 papers across 2,300 journals from 10 publishers, a small fraction of the fringe of academic publishing. At present it includes mainly journals that falsely advertise peer review and other scholarly services. However, our long-term goal is to index publications across the legitimacy spectrum, from malicious fakes to scrappy, under-resourced start-ups. Already, our preliminary work has uncovered deceptive practices we hadn't anticipated. OMICS branding has been removed from many titles, for example. And predatory journals are re-issuing – seemingly on their own initiative without any consent – actual, peer-reviewed articles that have been published elsewhere. **Full text:** <https://go.nature.com/3bgGksY>



Noted in Media Watch 7 January 2019 (#596, p.13):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 December 2018 – ‘**Predatory open-access publishing in palliative and supportive care.**’ Predatory publishing is commonly defined as an exploitative, fraudulent, open-access model that applies charges to authors without providing proper editorial services, characteristic of legitimate journals. This phenomenon is universally considered as one of the most serious threats to scientific community. To enhance awareness among scholars and clinicians, predatory publishing has been surveyed in several biomedical fields, such as neuroscience, orthopedics, rehabilitation, and anesthesiology. The aim of this study was to describe the characteristics of predatory publishers and journals in the field of palliative and supportive care. **Full text:** <https://bit.ly/3GjXtKq>

**N.B.** OMICS publications include the *Journal of Palliative Care & Medicine*: <http://bit.ly/2TVQkXv>

## Media Watch: Access on Online

### 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']

### 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/3q82uuS>

[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>



### 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>

### 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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