

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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A strategy focused only on educating healthcare providers, including non-physicians, may still be insufficient to achieve population-wide access to palliative care. Instead, we also need to harness the power of patients who are facing serious illness and their families.

'Activating patients and families to improve palliative care: The waiting room revolution' (p.8), in *Healthcare Quarterly*.

Canada

Ontario “a few bad days away” from making life and death decisions about critically ill patients, says triage protocol author

ONTARIO | *The Ottawa Citizen* – 19 April 2021 – With intensive care units running out of space and COVID-19 cases at record levels, Ontario is just “a few bad days away” from doctors having to make decisions about who gets life-saving critical care and who does not, says one of the authors of an emergency triage protocol now circulating in Ontario hospitals. The 42-page protocol ... is designed to be used as a “last resort” if demand for critical care exceeds available resources. But the worsening situation in Ontario means it is crucial to have the plan in place, even if it isn't needed, says Dr. James Downar, head of the division of palliative care at the University of Ottawa, a member of the Bioethics Table and an author of the triage document. Even as hospitals hold town halls to help doctors prepare to triage critical-care patients, the plan has been largely hidden from the public. There have been growing calls from disability advocates and others for more transparency. The protocol, which has not yet been triggered by the Ontario government, states plainly that critical-care triage represents a departure from normal times: If it needs to be triggered, preventable deaths will occur and some people will

have care withheld or withdrawn without consent. Under the plan, every patient who becomes critically ill will be assessed using a standardized mortality risk tool, which could help doctors determine which patients would be most likely to survive that illness. The tool allows people with different illnesses to be compared equally, say its authors. Under the triage tool, ideally, all patients who could benefit from critical care would receive it, but patients with the best chance of survival would be offered it first in order to save the most lives. <https://bit.ly/3v1Dolz>

Specialist Publications

'Impact of physician-based palliative care delivery models on health care utilization outcomes: A population-based retrospective cohort study' (p.10), in *Palliative Medicine*.

'Community paramedicine to support palliative care' (p.11), in *Progress in Palliative Care*.

Cont.

Noted in Media Watch 15 March 2021 (#708, p.7):

- **INTENSIVE CARE MEDICINE** | Online – 7 March 2021 – ‘**Ten things to consider when implementing rationing guidelines during a pandemic.**’ COVID-19 has reaffirmed the need to establish an ethical basis for rationing decisions during pandemics. In some jurisdictions, medical resources, intensive care unit beds or healthcare workers became scarce and rationing of life-sustaining treatment was needed. Principles and processes for triage have been proposed and guidelines developed. Critiques arose pertaining to legal issues, equity concerns, and the practicality of these recommendations, given many unprecedented features of this pandemic. This commentary provides additional guidance to support and enhance development and implementation of such guidelines... **Full text:** <https://bit.ly/3ca0iPW>

N.B. Search back issues of Media Watch for additional articles on “rationing” and “triage” guidelines during the COVID-19 pandemic at: <http://bit.ly/2ThijkC>

U.S.A.

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

STATELINE (The Pew Charitable Trusts) – 20 April 2021 – The COVID-19 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 health care costs as a result of fewer hospitalizations. But most insurance plans, including Medicare and Medicaid, only cover 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://bit.ly/32BLwNo>

Extract: A problem of definitions

Hospice and PC overlap, but they are not the same, even as many lay people often use the terms interchangeably. PC can be administered apart from hospice, for patients not deemed terminal but still living with chronic, serious and life-limiting conditions. If hospice-eligible, a patient can tap a range of services, both medical and otherwise, which can be provided in a hospital, at home or elsewhere in a community, such as a residential hospice, assisted living facility or nursing home. The services can encompass help with pain relief and symptom management, in-person medical care, personal care, patient and caregiver education and advance life planning, respite care and social services, as well as psychological, spiritual and grief counseling for the patient and family members. PC often delivers a similar set of services, but it is not time limited.

Specialist Publications

‘**A national profile of kinlessness at the end of life among older adults: Findings from the Health & Retirement Study**’ (p.9), in *Journal of the American Geriatrics Society*.



Media Watch: Access Online

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

National report highlights benefit of collaborative care models for people with dementia

NATIONAL ACADEMIES OF SCIENCES, ENGINEERING & MEDICINE | Online – 19 April 2021 – There are between 3.7 million and 5.8 million people living with dementia in the U.S., and that number is likely to grow as the population ages. A new report details the state of dementia care and research in America and provides guidance on future research to make sure both patients and their families are having their needs met by the care they receive.¹ The report looks at the various needs of people with dementia. It notes several limitations of current care interventions. However, an independent systematic review found two types of interventions that are supported by low-strength evidence of benefit... **Download press release at:** <https://bit.ly/3xiOXqG>

Extract from National Academies of Sciences, Engineering & Medicine report

Early discussions between providers and a person living with dementia and his or her family regarding the goals and desires of the person living with dementia are important to ensure respect for that person. Planning should continue throughout the disease's progression, with increasing dependence on the primary caregiver to communicate the goals and values of the person living with dementia when the person can no longer participate in this process. Given the unpredictable nature of dementia, initiation of palliative care is based on need and preferences, not prognosis.

1. 'Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward,' National Academies of Sciences, Engineering & Medicine, April 2021. **Download at:** <https://bit.ly/3x7ckTY>

N.B. Search back issues of Media Watch for articles on palliative and end-of-life care for people living with "Alzheimer's" and "dementia" at: <http://bit.ly/2ThijkC>

For-profit nursing homes and hospices are a bad deal for older Americans

STAT (BOSTON GLOBE MEDIA) | Online – 19 April 2021 – Many nursing homes and hospice care organizations are now for-profit institutions. There is ample evidence they are putting profits ahead of people ... taking a deadly toll during the COVID-19 pandemic. Private equity has successfully infiltrated hospice care. Hospice is a service provided mostly in people's homes by nurses and social workers for individuals expected to live for six months or less. Borne out of a movement to provide humane care to people and their caregivers at the end of life, two-thirds of hospice agencies in the U.S. are now for-profit companies. Research ... shows that even as the cost of hospice care is increasing, the quality of care is plummeting.¹ This has to do with patients receiving care in for-profit hospices, which provide poorer staffing, fewer community benefits, and enroll patients who stay in hospice for longer and therefore accrue more revenue, while requiring less intensive care, such as that needed for people with dementia. There is increasing convergence between for-profit nursing homes and hospice, as more than 20% of nursing homes and hospices now have common ownership, often as part of a chain. <https://bit.ly/3gkRU3J>

1. 'Trends and characteristics of Medicare hospice beneficiaries in the U.S.,' *Journal of General Internal Medicine*, published online 19 October 2021. **Access article at:** <https://bit.ly/2ROak2P>

American Gastroenterological Association recommends palliative care for patients with cirrhosis

AMERICAN GASTROENTEROLOGICAL ASSOCIATION | Online – 13 April 2021 – The Association has released a new 'Clinical Practice Update' providing 10 best practice advice statements on palliative care (PC) for patients with cirrhosis.¹ To meet the needs of the increasingly prevalent cirrhosis population, it is important that all clinicians who care for these patients are able to work together to deliver PC as a standard of care. <https://bit.ly/3tAugLK>

1. 'American Gastroenterological Association clinical practice update on palliative care management in cirrhosis: Expert review,' *Clinical Gastroenterology & Hepatology*, 2020;19(4):646-656. **Full text:** <https://bit.ly/2OZQCzW>

Cont.

Noted in Media Watch 24 September 2018 (#582, p.11):

- *JOURNAL OF HEPATOLOGY* | Online – 19 September 2018 – ‘**Supportive and palliative care in people with cirrhosis: International systematic review of the perspective of patients, family members and health professionals.**’ The authors identify two key areas where supportive and palliative care (PC) for patients with cirrhosis could be improved: 1) Identifying appropriate patients for early supportive and PC; and, 2) Reconfiguring service delivery, improving care coordination between the different specialities responsible for patient care. More specific initiatives include the need to design clearer pathways for interdisciplinary care for those not eligible for transplant and joint work by specialist hepatology and PC in drawing up guidelines and care frameworks for people with cirrhosis. **Full text:** <https://bit.ly/3edHKiN>

International

Dying apart, buried together

AUSTRALIA | *Pursuit* (University of Melbourne) – 21 April 2021 – Last April, as New York City’s COVID-19 death toll soared, a photographer captured images of dozens of pine coffins being lowered into trenches. The picture underscored the grim reality of a virus that was killing hundreds a day. But the pictures – soon followed by others of mass graves in Iran and Brazil – also spoke to an even deeper fear – the loss of individuality in death. The pandemic has exposed some of our deepest fears – dying alone and being buried together. But where does this fear of communal burial come from and can it change? <https://bit.ly/3v8CCU6>

Specialist Publications

‘**Withholding and withdrawing treatment in pediatric intensive care. Update of the Groupe Francophone de Réanimation et d’Urgences Pédiatriques recommendations**’ (p.7), in *Archives de Pédiatrie*.

‘**Mapping palliative care provision in European prisons: A European Association for Palliative Care task force survey**’ (p.7), in *BMJ Supportive & Palliative Care*.

‘**A national survey of hospice pharmacists and a comparison with international models**’ (p.9), in *International Journal of Pharmacy Practice*.

General anaesthesia should be more widely available for patients at the end of their lives says study

U.K. (England) | *About Manchester* – 21 April 2021 – General anaesthesia should be more widely available for patients at the end of their lives, according to Oxford experts in ethics and anaesthesia...¹ General anaesthesia is widely used for surgery and diagnostic interventions, to ensure the patient is completely unconscious. But it is not used generally for dying patients, to whom painkilling medications (analgesia) are more commonly given. But, according to the paper, this may not be enough, leading to the use of continuous deep sedation, also known as palliative or terminal sedation. Professor Julian Savulescu, Oxford’s Uehiro Chair of Practical Ethics and co-author, maintains: “For some patients these common interventions are not enough. Other patients may express a clear desire to be completely unconscious as they die.” He adds: “Some dying patients just want to sleep. Patients have a right to be unconscious if they are dying. We have the medical means to provide this and we should.” The authors make clear their proposal is not about assisted dying, currently illegal in the U.K. Instead, their focus is on options to ensure patients are comfortable at the end of their lives. <https://bit.ly/3vdejEz>

1. ‘General anaesthesia in end-of-life care: Extending the indications for anaesthesia beyond surgery,’ *Anaesthesia*, published online 20 April 2021. **Full text:** <https://bit.ly/3n7z0i7>

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



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Specialist Publications

Discordance between dementia caregivers' goal-of-care and preference for life-extending treatments

AGE & AGEING | Online – 22 April 2021 – The authors explore factors that influence caregiver preferences for potentially life-extending treatments for older adults with severe dementia, and reasons for discordance between overall end-of-life care (EoLC) goal and treatment preferences. Twenty-six caregivers of community-dwelling older adults with severe dementia in Singapore participated in this study. To most (77%) overall EoLC goal was “no life extension.” Yet, 80% preferred IV antibiotics for a life-threatening infection, 60% preferred tube feeding and 45% preferred CPR. Caregivers preferred these treatments because they perceived letting go by withholding treatments as unethical, felt they had no choice as they deferred to the healthcare provider, wanted to alleviate suffering rather than extend life, and desired trying minimally invasive treatments that had the potential to be withdrawn. Themes explaining discordance were feared regret about making the “wrong” decision, considered treatments to address immediate needs even when long-term goal did not match providing that treatment, and anticipated disagreement with other family members on overall goal-of-care. To reduce discordance between caregivers' overall EoLC goal and preferences for life-extending treatments, clinicians can use a shared

decision-making approach involving discussions of both their overall EoLC goal and treatment preferences. **Abstract:** <https://bit.ly/3tGQQLs>

Research Matters

'Characteristics of provider-focused research on complementary and integrative medicine in palliative care: A scoping review' (p.11), in *American Journal of Hospice & Palliative Medicine*.

'The power of specialty palliative care: Moving towards a systems perspective' (p.11), in *The Lancet Haematology*.

'Public health research in palliative care: Towards solutions for global challenges' (p.12), in *Palliative Care & Social Practice*.

Publishing Matters

'Misinformation in and about science' (p.12), in *Proceedings of the National Academy of Sciences of the United States of America*.

Models will only get us so far: Planning for place of care and death

AGE & AGEING | Online – 20 April 2021 – If aligning place of care and death with the dying person's preference is considered an outcome, the process of advance care planning (ACP) can be a useful mechanism for determining and preparing for such preferences. However, place is not the only “outcome” that matters to many people – they may be more concerned about how they are cared for, or who they can see, or how much control they feel they have. ACP can consider a much wider remit than just location of care, and it may be the processes of discussion that most beneficial for some. Importantly, decisions – in how they are made, enacted, and experiences – are inherently relational, involving and impacting the dying person and also those who care about them and for them, including health and social care professionals. There is therefore further scope to consider what good outcomes look like for this wider network and how to support them all through the changing contexts of care during the end of life and the COVID-19 pandemic. Models can be useful to support conversations, but they will only get us so far. **Full text (click on pdf icon):** <https://bit.ly/3ej57HU>

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Palliative Care Network

Palliative Care for Everyone, Everywhere

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

Related:

- *THE PATIENT – PATIENT-CENTERED OUTCOMES RESEARCH* | Online – 20 April 2021 – ‘**Valuing end-of-life care for older people with advanced cancer: Is dying at home important?**’ Most healthcare systems are facing the challenge of providing health services to support the increasing numbers of older people with chronic life-limiting conditions at the end of life (EoL). Many policies focus primarily on increasing the proportion of deaths at home. The responses to an online survey showed that investment in services to support people at the EoL would be better targeted toward programmes that improve patient and carer wellbeing irrespective of the location of care and death. **Abstract (w. references):** <https://bit.ly/3tHkM8>

Help me understand: Providing palliative care to individuals with serious mental illness

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 20 April 2021 – Individuals with serious mental illness (SMI) have shortened life expectancy with increased risk of developing comorbid medical illnesses. They might have difficulty accessing care and can be lost to follow-up due to complex socioeconomic factors, placing them at greater risk of dying from chronic or undiagnosed conditions. This, in combination with stigma associated with SMI, can result in lower quality end-of-life care (EoLC). Interdisciplinary palliative care (PC) teams are in a unique position to lend assistance to those with SMI given their expertise in serious illness communication, values-based care, and psychosocial support. However, PC teams might be unfamiliar with the hallmark features of the various SMI diagnoses. Consequently, recognizing and managing exacerbations of SMI while delivering concurrent palliative or EoLC can feel challenging. The goal of this narrative review is to describe the benefits of providing PC to individuals with SMI with concrete suggestions for communication and use of recovery-oriented language in the treatment of individuals with SMI. Recommendations for working with individuals who have SMI and other life-limiting illness are provided, including strategies to effectively manage SMI exacerbations. **Abstract (w. references):** <https://bit.ly/2QkASlz>

Noted in Media Watch 22 March 2021 (#709, p.13):

- *PROGRESS IN PALLIATIVE CARE* | Online – 19 March 2021 – ‘**Lean in, don’t step back: The views and experiences of patients and carers with severe mental illness and incurable physical conditions on palliative and end-of-life care.**’ People with severe mental illness (SMI) have a life expectancy of up to twenty years less than the general population and many live with incurable physical health conditions. Yet, they continue to experience barriers when trying to access palliative and end-of-life care. Little research has been carried out which includes the views and experiences of people with SMI, and this study presents first findings which include people with both SMI and an incurable condition and their carers. **Abstract:** <https://bit.ly/30XohwA>

Noted in Media Watch 24 August 2020 (#680, p.8):

- *JOURNAL OF PALLIATIVE CARE* | Online – 18 August 2020 – ‘**Working at the intersection of palliative end-of-life and mental healthcare: Provider perspectives.**’ The most prominent issues pertained to assessment of patients and differential diagnosis of chronic and persistent mental illness, and preparedness of caregivers to deliver mental health interventions, given the isolation of palliative care from other agencies. Among the assets mentioned, informal relationships with frontline caregivers were seen as the main support structure, rather than the formal policies and procedures of the practice settings. Strategies to improve mental healthcare in palliative and end-of-life care centered on holistic roles and interventions benefiting the entire palliative population... **Abstract (w. references):** <https://bit.ly/31fr7hr>

Noted in Media Watch 20 January 2020 (#649, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 January 2020 – ‘**Mental healthcare and palliative care: Barriers.**’ Psychological symptoms are common among palliative care (PC) patients with advanced illness, and their effect on quality of life can be as significant as physical illness. The demand to address these issues in PC is evident, yet barriers exist to adequately meet patients’ psychological needs. This article provides an overview of mental health issues encountered in PC, highlights the ways psychologists and psychiatrists care for these issues, describes current approaches to mental health services in PC, and reviews barriers and facilitators to psychology and psychiatry services in PC, along with recommendations to overcome barriers. **Abstract:** <http://bit.ly/35YIN1e>

Withholding and withdrawing treatment in pediatric intensive care. Update of the Groupe Francophone de Réanimation et d'Urgences Pédiatriques recommendations

ARCHIVES DE PÉDIATRIE | Online – 16 April 2021 – In 2005, the French-speaking task force on pediatric critical and emergency care issued recommendations on withholding and withdrawing treatments in pediatric critical care. Since then, the French Public Health Code, modified by the laws passed in 2005 and 2016 and by their enactment decrees, has established a legal framework for practice. Now, 15 years later, an update of these recommendations was needed to factor in the experience acquired by healthcare teams, new questions raised by practice surveys, the recommendations issued in the interval, the changes in legislation, and a few legal precedents. The objective of this article is to help pediatric critical care teams find the closest possible compromise between the ethical principles guiding the care offered to the child and the family and compliance with current regulations and laws. **Abstract:** <https://bit.ly/32xDTYk>

N.B. English-language article.

Mapping palliative care provision in European prisons: A European Association for Palliative Care task force survey

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 22 April 2021 – Prison populations around the world are ageing and numbers are rising, leading to greater demand for palliative care (PC) for prisoners approaching the end of life (EoL). The survey consisted of 40 questions in six sections and was completed for eight countries: Australia, Belgium, Czech Republic, England and Wales, France, Portugal, Scotland and Slovakia. Three main findings are reported here: healthcare and PC provision in prisons, deaths in custody, and compassionate release. Despite increasing numbers of older prisoners, relatively few prisons provide inpatient care, and only one country has any prisons that provide dedicated PC services. Early release on compassionate grounds is extremely rare in most countries. For the principle of equivalence to be adhered to, facilities for sick and dying prisoners need to be improved, or many more people need to be released on compassionate grounds at the EoL. This mapping study has identified key issues in relation to PC in prison and provides the basis for further international research. **Abstract:** <https://bit.ly/2QPihnz>

N.B. 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>

Death, taxes and uncertainty: Economic motivations in end-of-life decision-making

CLINICAL ETHICS | Online – 22 April 2021 – Economic motivations are key drivers of human behavior. Unfortunately, they are largely overlooked in literature related to medical decision-making, particularly with regard to end-of-life care. It is widely understood that the directions of a proxy acting in bad faith can be overridden. But what of cases in which the proxy or surrogate appears to be acting in good faith to effectuate the patient's values, yet doing so directly serves the decision-maker's financial interests? Such situations are not uncommon. Many patients care as deeply about economic wellbeing of their families as they do for their own lives and health. This brief work examines three scenarios that raise ethical issues regarding the role of pecuniary motives in making critical medical decisions. Each scenario presents a potential financial conflict of interest between an incapacitated patient and a third-party decision-maker and offers a framework for integrating ethical and legal concerns into clinical care. It is the authors' hope that this work prepares physicians for unexpected ethical conflicts of interest and enables them to further the interests of his or her patients. **Abstract (w. references):** <https://bit.ly/3dKdg9d>

Perinatal palliative care: Cultural, spiritual, and religious considerations for parents – what clinicians need to know

FRONTIERS IN PEDIATRICS | Online – 30 March 2021 – For perinatal palliative care (PC) to be truly holistic, it is imperative that clinicians are conversant in the cultural, spiritual and religious needs of parents. These needs for parents should be sensitively attended to are widely touted in the perinatal PC literature and extant protocols, however there is little guidance available to the clinician as to how to meet these needs. The objective of this review article is to report what is known about the cultural, spiritual and religious practices of parents and how this might impact neonates who are born with a life-limiting fetal diagnosis. Islam, Buddhism, Hinduism, Judaism, and Christianity are considered in terms of what may be helpful for clinicians to consider regarding rituals and doctrine related to perinatal PC. Inclusion criteria for this review includes all empirical and research studies published in English that focus on the cultural and religious needs of parents who opted to continue a pregnancy in which the fetus had a life-limiting condition or had received perinatal PC. Gray literature from religious leaders about the great religions are also considered. Results from these sources contributing to the knowledge base of cultural, spiritual and religious dimensions of perinatal PC are considered. **Full text:** <https://bit.ly/3gl7Cfu>



Noted in Media Watch 89 February 2021 (#703, p.8):

- *BMJ OPEN PAEDIATRICS* | Online – 1 February 2021 – ‘**Neonatal and perinatal palliative care pathway: A tertiary neonatal unit approach.**’ A lack of well-structured guidelines or care pathway result in inadequate, inconsistent and fragmented palliative care (PC) for babies and their families. The impact on the families could be emotionally and psychologically distressing. Not all neonatal units have specialist PC clinicians or teams, and such units will benefit from a well-planned perinatal PC pathway. In this article, the authors discuss a tertiary neonatal unit perinatal care pathway which provides guidance from the point of diagnosis and establishment of eligibility of a baby for PC through to care after death and bereavement support for families. **Full text:** <http://bit.ly/2LhdM2S>

N.B. Search back issues of Media Watch for additional articles on “neonatal” and “perinatal” PC at: <http://bit.ly/2ThijkC>

Activating patients and families to improve palliative care: The waiting room revolution

HEALTHCARE QUARTERLY, 2021;24(1):6-9. We need to support and educate palliative care (PC) specialists and generalist providers, especially family physicians, on how to integrate an early PC approach into care for those with a serious illness. There are very few care providers compared to the number of patients and caregivers in society. To increase access to PC at a population level, we need a waiting room revolution, one where patients and families shift from being passive to being active in shaping their experience with serious illness. A co-design approach with patients and families can help overcome barriers to accessing PC and improve the overall experience. **Full text:** <https://bit.ly/3sov7GR>

Worth Repeating

Great Lives: Dame Cicely Saunders

Actress and writer Maureen Lipman chooses the end-of-life care campaigner Dame Cicely Saunders as her subject in this episode of the BBC’s Great Lives series, originally broadcast in September 2016. Dame Cicely was known as “the woman who changed the face of death.” At almost 6’ tall, she could be intimidating, tiresome and relentless as she devoted her life to ensuring that terminally ill people could die with dignity and without pain. Also participating in the program is “expert witness” Professor David Clark from the University of Glasgow. <https://bbc.in/32EhNUj>



Would the *Healthcare Quarterly* article be of interest to a colleague?

A national survey of hospice pharmacists and a comparison with international models

INTERNATIONAL JOURNAL OF PHARMACY PRACTICE | Online – 17 April 2021 – Pharmacists can contribute to improved patient outcomes, improve medicine knowledge, reduce drug costs, and minimise errors. However, their role within hospice-based services is not well described. Most U.K. hospices have access to pharmacy support; however, much of this falls below recommended levels. Eighty-nine responses to an online survey were received from 82 hospices (response rate 50%). Pharmacists had a role in 75% of hospices providing between 6.6 min and 5.5 hours of pharmacist support per bed per week. The most frequent duty reported was provision of medicines information to the clinical team. Access to patient records varied considerably: 13% had full read and write access to GP records while 29% had no access. Job-specific training had not been received by 36% of the respondents and 47% reported training needs including basic training in palliative care (PC). U.K. hospice pharmacists carry out multiple clinical duties, despite having limited access to patient records. Many reported a lack of training, and there was an appetite for pharmacist-specific PC training in the sector. Sources of hospice medicines vary, and this could have cost implications for hospices and may provide opportunities for future savings. **Full text:** <https://bit.ly/2RFJObH>

Noted in Media Watch 19 October 2015 (#432, p.10):

- *EUROPEAN JOURNAL OF HOSPITAL PHARMACY* | Online – 13 October 2015 – ‘**The role of a pharmacist in a hospice: A nationwide survey among hospice directors, pharmacists and physicians.**’ Nineteen (61%) hospices in Poland collaborate with at least one pharmacist, who performs pharmaceutical services on the premises. Twelve (75%) pharmacists provide advice concerning medicines and 11 (69%) are involved in various roles related to procurement, dispensing and storage of drugs, as well as creating procedures for these activities. Most of them, however, are not members of the therapeutic team and they do not participate in ward rounds. Furthermore, the provision of clinical pharmaceutical services forms a minority of Polish hospital pharmacy practice. **Abstract:** <https://bit.ly/3v3msuS>

A national profile of kinlessness at the end of life among older adults: Findings from the Health & Retirement Study

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 21 April 2021 – The majority of end-of-life (EoL) caregiving is provided by unpaid family members. An increasing number of older adults are kinless (without close family/partnerships) and may have insufficient caregiver support to remain at home at the EoL. In a retrospective analysis of Health & Retirement Study decedents, 2002-2015, a total of 7.4% of decedents were kinless at the EoL. Kinless decedents were more likely to be female, non-white, enrolled in Medicaid, living alone, or living in a nursing home prior to death. Although community-dwelling kinless decedents received fewer hours of caregiving per week at the EoL and were more likely to die in nursing homes than those with kin, they did not have higher EoL symptom burden or treatment intensity (e.g., intensive care unit use). In multinomial logistic analysis, controlling for demographic and illness characteristics, kinless decedents living in the community before death had a twofold increased risk of dying in the nursing home and a trend toward increased risk of hospital death versus home setting. Expanded long-term care services and policies are needed to enable all older adults regardless of their family support systems to receive high-quality EoL care. **Abstract:** <https://bit.ly/3n6CYHX>

The role of a liaison team in ICU family communication during the COVID-19 pandemic

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 April 2021 – The formation of a family liaison team, tasked with the daily update of and communication with friends and relatives of ICU patients during the COVID-19 pandemic is feasible and well accepted by all stakeholders [i.e., study participants]. The overall feeling from patients’ family and friends was that of gratitude, as the team provided a link with the patient when visiting was restricted. Nonetheless, several cases of miscommunication, especially around end-of-life care, were reported both by relatives and ICU clinicians. Additionally, members of the family liaison team expressed feelings of distress, when the calls pertained the communication of “bad news.” The results of this study highlight the difficulties encountered during family communication in the COVID-19 era, which were exacerbated by the urgent introduction of a brand new, non-ICU team. **Full text:** <https://bit.ly/3avwGfR>

“Mums are sacred, and mums don’t die”: A mixed-methods study of adult child-parent dyadic relationships at the end of life

JOURNAL OF PSYCHOSOCIAL ONCOLOGY | Online – 19 April 2021 – The aim of this study was to report the specific challenges pertaining to the experiences and needs of terminally ill adult children and their parents and terminally ill parents and their adult children, regarding their relationship and relationship roles. The study sought to identify similar and differing relationship patterns between the two dyadic types. Sixty-five patients and 42 family caregivers participated. Interview data indicate that illness situation and dependencies were perceived in both dyads to represent a relationship role reversal contrary to the “natural order.” This was the first study to contribute to an understanding of the different needs of terminally ill adult children/parents and their parent/adult child caregivers, thus contributing to an understanding of the different needs of these parties... The results suggest that the dyads share similar themes, which should be integrated into general support interventions; however, some themes appear more relevant for one dyad, only. **Full text:** <https://bit.ly/3x4XxJn>

Impact of physician-based palliative care delivery models on healthcare utilization outcomes: A population-based retrospective cohort study

PALLIATIVE MEDICINE | Online – 22 April 2021 – Increasing involvement of palliative care (PC) generalists may improve access to PC. It is unknown, however, if their involvement with and without PC specialists are associated with different outcomes. The authors describe physician-based models of PC and their association with healthcare utilization outcomes including: emergency department visits, acute hospitalizations and intensive care unit (ICU) admissions in last 30 days of life; and, place of death. Of the 231,047 decedents who received palliative services [all adults aged 18-105 who died in Ontario, Canada, between 1 April 2012 and 31 March 2017], 40.3% received generalist, 32.3% consultation and 27.4% specialist PC. Across models, the authors noted minimal to modest variation for decedents with at least one emergency department visit, acute hospitalization or ICU admission, as well as community death. Receipt of a physician home visit was a stronger predictor for increased likelihood of community death than PC model. The generalist PC model achieved similar healthcare utilization outcomes as consultation and specialist models. Including a physician home visit component in each model may promote community death. **Abstract (w. references):** <https://bit.ly/3xjQPjR>

Toward a socio-spiritual approach? A mixed-methods systematic review on the social and spiritual needs of patients in the palliative phase of their illness

PALLIATIVE MEDICINE | Online – 20 April 2021 – This review identified five synthesized findings that encompass patients’ social and spiritual needs: 1) Being autonomous; 2) Being connected; 3) Having meaning; 4) Having a positive outlook; and, 5) Dealing with death and dying. These findings were synthesized from both qualitative and quantitative studies. Patients do not distinguish between social and spiritual needs themselves. However, healthcare professionals should do so to allocate appropriate, patient-tailored care. The socio-spiritual approach to patients’ needs raises awareness about linguistic similarities in expression between social and spiritual needs that should be explored in-depth. Hence, this approach honors and preserves the multidimensionality of patients’ needs and enables comprehensive palliative care. Clinically applicable multi-dimensional Patient Reported Outcome Measures can support identifying and exploring patients’ social and spiritual needs. **Full text:** <https://bit.ly/3dwEOic>

Related:

- *PALLIATIVE MEDICINE* | Online – 20 April 2021 – **“Song of Life”: Results of a multicenter randomized trial on the effects of biographical music therapy in palliative care.** Awareness of the importance of psychological and spiritual needs in patients with terminal diseases has increased in recent years... Findings from this multicenter randomized trial suggest that Song of Life music therapy can serve as an effective psychosocial treatment in palliative care to facilitate psycho-spiritual integration and reduce distress in patients nearing the end of life. Future studies may continue to explore optimal study outcomes and should address the importance of patient characteristics ... in order to tailor biographical interventions to the individual’s situation and needs. **Full text:** <https://bit.ly/3dwW9aE>

Community paramedicine to support palliative care

PROGRESS IN PALLIATIVE CARE | Online – 23 April 2021 – This commentary describes community paramedicine (CP) and the potentiality of an expanded scope of practice to provide home-based palliative care (PC). CP is a novel approach to delivering care, allowing paramedics to provide community-based, non-urgent care as well as crisis and symptom management within the home. The need for home-based PC at earlier stages of the disease trajectory will be essential for the growing older adult population. Community-based models of care are essential in alleviating health systems burden by reducing emergency department visits and over-reliance on primary care. A rapid review was conducted to determine current scope of practice and geographical coverage of CP programming, as well as a broader literature search describing current roles. Pilot CP PC programs in Canada, in Alberta, Nova Scotia and Prince Edward Island, have demonstrated the benefits of community paramedics providing PC through reduced emergency department visits and improved patient satisfaction. **Abstract:** <https://bit.ly/3tOQbaZ>

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

Research Matters

Characteristics of provider-focused research on complementary and integrative medicine in palliative care: A scoping review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 23 April 2021 – The use of complementary and integrative medicine (CIM) continues to grow in palliative care (PC). While research supports the use of many CIM therapies for symptom relief, the scope of provider-focused research on CIM remains poorly characterized. The authors identified 34 studies that were conducted primarily in the U.S. and the U.K., focused mostly on nurse and physician providers, and employed questionnaires or qualitative methods. Studies investigated 58 CIM modalities, including massage, music therapy, and aromatherapy, to address common symptoms including pain, fatigue, and nausea/vomiting. Study outcomes included perceived benefits of CIM and types of CIM modalities that providers offer. Uncommonly studied phenomena included referral patterns, facilitators of provider recommendation of CIM, and rates of CIM use. Provider-focused research on CIM in PC can expand its scope by addressing perspectives of interdisciplinary providers, examining CIM modalities that patients report using, addressing symptoms commonly encountered in PC, and researching provider-use-focused outcomes. The authors identify possibilities for future studies in addition to opportunities for systematic investigations to enhance the safe and efficacious delivery of CIM in the PC setting. **Abstract (w. references):** <https://bit.ly/3xjzc2F>

The power of specialty palliative care: Moving towards a systems perspective

THE LANCET HAEMATOLOGY, 2021;8(5):E376-E3821. Three palliative care (PC) clinical trials were presented at the 2020 American Society for Clinical Oncology Annual Meeting. The heterogeneity in populations, models of care, study design, and assessment of clinical outcomes across these three studies show the broad opportunities for research into interventions for PC. In this Viewpoint, the authors summarise the characteristics of these studies, discuss their novel features and lingering questions, and offer a suggestion for further expanding the focus of clinical trials for delivery of PC in the future. They argue that the propensity to characterise PC as if it was a clinical or biomedical intervention hampers the design and evaluation of complex clinical interventions that influence clinicians, systems for healthcare delivery, individual patients, and their families. **Summary:** <https://bit.ly/3azJZMa>



Media Watch: Behind the Scenes
<http://bit.ly/2MwRRAU>

Public health research in palliative care: Towards solutions for global challenges

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 19 April 2021 – An international audience of 122 delegates attended the ‘Public Health Research in Palliative Care: Towards Solutions for Global Challenges’ seminar hosted online by All-Ireland Institute of Hospice & Palliative Care in November 2020. This was the second International Research Seminar of the European Association for Palliative Care (EAPC) Research Network and EAPC Reference Group on Public Health & Palliative Care. This major international event included live presentations from leading researchers in the area of public health and palliative care (PC) including from Ireland, Scotland, Belgium, Australia, The Netherlands, and Sweden. Event organisation was overseen by a scientific committee which included leading researchers from public health and PC. The seminar was supported by the Irish Hospice Foundation. Published in this issue of *Palliative Care & Social Practice* are the abstracts of the seminar presentations covering a range of topics, including public health PC and the response to COVID-19, compassionate communities, caregiving and bereavement, health promotion and PC, population health models for PC, and issues of equity. **Full text:** <https://bit.ly/2QgZySc>



[Publishing Matters](#)

Misinformation in and about science

PROCEEDINGS OF THE NATIONAL ACADEMY OF SCIENCES OF THE UNITED STATES OF AMERICA | Online – 13 April 2021 – Misinformation has reached crisis proportions. It poses a risk to international peace, interferes with democratic decision-making, endangers the well-being of the planet, and threatens public health. Public support for policies to control the spread of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is being undercut by misinformation, leading to the World Health Organization’s “infodemic” declaration. Ultimately, misinformation undermines collective sense making and collective action. We cannot solve problems of public health, social inequity, or climate change without also addressing the growing problem of misinformation. Most of the research efforts and interventions examine broad, public consumption of misinformation – modeling the spreading dynamics of falsehoods, examining social network effects, and evaluating crowd-sourced mediation, with a special focus on crisis events and political elections. In this article, the authors turn the spotlight on science. They look at the ways that misinformation can travel within science due to misaligned incentives, out-of-date publishing norms, and sociotechnical systems that concentrate attention and credit on a small subset of the literature. **Full text:** <https://bit.ly/2QOcf73>

Extract: Predatory journals

Predatory publishers are not invested in the gate-keeping, curation, and manuscript improvement roles of traditional journal publishers. They are focused on collecting open access publication fees, the funds that authors pay to make their work available to the world without subscription charges. How serious is the problem? According to one study, predatory publishers produced nearly half a million articles in 2014, bringing in around \$74 million in publication fees. For comparison, the estimated market for reputable open access journals is around \$250 million annually, and the number of articles in the Web of Science in 2014 was about 2.5 million. When including the entire literature, predatory publishing likely comprises about 5 to 10%. So why do authors publish in these venues? Some authors may be duped by spam emails, but we suspect that in many cases, researchers are complicit. Scientists face strong pressures to publish frequently. With minimal or non-existent peer review, predatory publishers offer an easy route to rapid publication. Thus, a predatory publisher may not need to fool prospective authors about its legitimacy. The publisher instead may be offering authors an opportunity to fool any bureaucracy or committee that assesses productivity by merely counting publications.



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

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Links to Sources

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

Something Missed or Overlooked?

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

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/2RsCRKZ>

[Scroll down to 'Media Watch']

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

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

Cont.

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
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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



CSPCP SCMSP
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



EAPC
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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTP://BIT.LY/3EPKUAC>

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

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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