

**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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***It's surprising how difficult it is without family members, for sure. You recognize their value to provide context for medical care, to provide support for healing. I'll never take that for granted again.***

*'Clinician perspectives on caring for dying patients during the pandemic: A mixed-methods study' (p.8), in Annals of Internal Medicine.*

## Canada

### **Comorbidities, seeking palliative care might affect whether patients die by medically assisted death in Nova Scotia**

NOVA SCOTIA | *The Chronicle Herald* (Halifax) – 9 December 2020 – About 40% of patients who requested a medically assisted death in Nova Scotia during the first 30 months that it was legally available died without completing the process. The factors associated with dying a natural death versus a medically assisted death are largely unexplored. A resident physician in palliative care (PC) aimed to close that gap through a study funded by the Nova Scotia Health Authority Research Fund. “Many patients who request medical assistance in dying (MAiD) don't actually end up getting (that) for a variety of reasons,” said Dr. Caitlin Lees, the lead author of the study in an interview.<sup>1</sup> “We found that patients who were seen by PC, patients that had comorbidities, and patients that lived with somebody else had decreased odds of having a medically assisted death.” The study analyzed the experience of all patients in Nova Scotia who requested MAiD between 17 June 2016 and 31 December 2018. All patients included in the study were 18 or older when they requested MAiD and were deceased

at the time of analysis. A total of 402 patients made requests during the specified period with 383 of those being deceased and consequently included in the study. <https://bit.ly/3m3Fix6>

1. ‘A retrospective review of medically assisted deaths in Nova Scotia: What do we know and where should we go?’ *Journal of Palliative Medicine*, published on line 20 November 2020. **Abstract:** <https://bit.ly/3oJ6a7D>

### Specialist Publications

**‘Assisted dying and palliative care in three jurisdictions: Flanders, Oregon, and Quebec’** (p.9), in *Annals of Palliative Medicine*.

**‘The impact of the COVID-19 pandemic on medical assistance in dying (MAiD) in Canada and the relationship of public health laws to private understandings of the legal order’** (p.9), in *Journal of Law and the Biosciences*.

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Noted in Media Watch 26 October 2020 (#689, p.1):

- **POLICY OPTIONS** | Online – 19 October 2020 – ‘**An unacceptable number of people who requested medical assistance in dying received little or no quality palliative care in the months before death.**’ When a person with a failing organ, stroke or other chronic life-limiting disease has persistent suffering that goes untreated, they can become depressed and hopeless. It’s a common pathway to severe distress that can lead people to request medical assistance in dying (MAiD). This is a medical error. The error is not in receiving MAiD, as the person may meet all the requirements: unbearable suffering, a grievous and permanent condition, an advanced state of decline, ability to give informed and voluntary consent. The error occurred in the months before... <https://bit.ly/2lMetzJ>

### **Bill 3 is a good start but more must be done for palliative care**

ONTARIO | *Healthy Debate* – 9 December – Improving death care is a topic no one wants to talk about, but patients who will not survive their illnesses also need medical care and supportive services. The need for quality palliative care (PC) is overwhelming: In 2014-2015, just under half of all patients began receiving PC in their last month of life. Nearly two-thirds died in hospital. Less than half received palliative home care services in their last month of life. About one-third received a home visit from a doctor in their last month of life. **COVID-19** has had an unprecedented impact on PC. As more families opt to avoid hospitals for fear of COVID-19 exposure, there is even more need for support for hospice or home-based PC. Bill 3, a Private Member’s bill ... [was] ... approved 2 December, calls for a provincial framework to support improved access to hospice PC provided through hospitals, home care, long-term care homes and hospices. This is a good start but we need to do more. Firstly, we need more direct government support for hospices. Only about 40% of hospice funding comes from government with hospices left to fundraise for the rest. Even before the pandemic and despite their best fundraising efforts, hospices could not begin to meet their needs. Now, COVID-19 has forced the cancellation of fundraising events and put hospice services in jeopardy. Expanding palliative hospice care not only allows people to die with dignity but also eases the burden on the healthcare system. When a hospice bed costs about 40% less than a hospital bed – \$470 a day versus \$1,100 – hospice care makes even more sense. <https://bit.ly/3402num>

Noted in Media Watch 7 December 2020 (#695, p.1):

- ONTARIO | Canadian Society of Palliative Care Physicians – 1 December 2020 – ‘**Compassionate care act becomes law in Ontario.**’ Bill 3, an ‘Act providing for the development of a provincial framework on palliative care,’ passed third reading in the Ontario legislature... The purpose of the Act is to develop a framework to ensure that every Ontarian has access to quality palliative care (PC). The Act requires the Minister of Health to develop a provincial framework designed to support improved access to PC. The Minister must table a report setting out the provincial framework in the Legislative Assembly within one year after the Bill comes into force. Within three years after the report is tabled, the Minister must prepare and table a report on the state PC in Ontario. **Download/view Bill 3 at:** <https://bit.ly/3mMDhGU>

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

### **End-of-life care has boomed in California. So has fraud targeting older Americans**

CALIFORNIA | *The Los Angeles Times* – 9 November 2020 – Martin Huff is among a legion of mostly older Americans targeted for audacious, widespread fraud in an industry meant to provide comforting care in their final days, a Los Angeles Times investigation found. Like Huff, many are unwitting recruits by unscrupulous providers who bill Medicare for hospice services and equipment for “terminally ill” patients who aren’t dying. Intense competition for new patients – who generate \$154 to \$1,432 a day each in Medicare payments – has spawned a cottage industry of illegal practices, including kickbacks to crooked doctors and recruiters who zero in on prospective patients at retirement homes and other venues, the *Times* found. The exponential boom in providers has transformed end-of-life care that was once the realm of charities and religious groups into a multibillion-dollar business dominated by profit-driven operators. Nowhere has that

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growth been more explosive, and its harmful side effects more evident, than in Los Angeles County. The county's hospices have multiplied sixfold in the last decade and now account for more than half of the state's roughly 1,200 Medicare-certified providers, according to a *Times* analysis of federal healthcare data. Scores of providers have sprung up along a corridor stretching west from the San Gabriel Valley, where California Hospice Care was located, through the San Fernando Valley, which now has the highest concentration of hospices in the nation. <https://lat.ms/3m0gsOH>

#### Related:

- CALIFORNIA | *The Los Angeles Times* – 9 November 2020 – ‘**Dying Californians suffer harm and neglect from an industry meant to comfort them,**’ At a time when the U.S. population is aging and the hospice industry is booming, a *Times* investigation found hundreds of instances in which California were harmed, neglected or put at serious risk, their mistreatment sometimes exacerbated by serious gaps in government oversight. Quality-of-care failures ran the gamut from mismanaged medications to neglected wounds that became infested with maggots. But even when regulators identified such failures, hospices were rarely penalized, according to a review of lawsuits, Medicare data and state licensing and inspection records spanning a decade.. <https://lat.ms/2KaWfbF>
- CALIFORNIA | *The Los Angeles Times* – 9 November 2020 – ‘**What you need to know if you or a loved one requires end-of-life care.**’ Conceived as an end-of-life option for terminally ill patients, hospices provide palliative care, medications, nursing services and counseling for those diagnosed with six months or less to live. The number of U.S. hospices has roughly doubled in the last 20 years, as more for-profit providers vie for a share of \$19.2 billion a year in Medicare spending that covers hospice care. More than 1.5 million Medicare beneficiaries now receive care from some 5,000 hospices... While hospice has been a godsend for millions of dying Americans and their families, a *Times* investigation found that intense competition for new patients has spurred billing fraud and other illegal practices... <https://lat.ms/37NvCSr>

#### How to grieve during a pandemic

*THE WASHINGTON POST* | Online – 7 December 2020 – Our culture resists talking about death. So it's fallen to the bereaved to demand attention for COVID-19's human toll – and begin to heal our collective trauma. The mental health consequences of so much sudden death in so short a time could be dire. Based on age patterns in the pandemic's spread and kinship networks in the U.S., a team of sociologists ... [has] ... estimated that nine people will experience the loss of a close relative – defined as a grandparent, parent, sibling, spouse or child – for each COVID-19 death.<sup>1</sup> This “COVID-19 bereavement multiplier” suggests that as many as 2.5 million Americans are mourning the deaths of the 281,000 people the coronavirus has killed. Grief therapists expect a nationwide spike in the level of “complicated grief” – the kind that destabilizes a person's life in significant ways – and foresee a rise in substance

abuse and suicidal thoughts. And yet there have been few formal acknowledgments of the lives lost and of the anguish of those left behind – unlike, say, after the 11 September 2001 terrorist attacks, which killed approximately 3,000 people. No consoling presidential addresses. No flags at half-staff. Instead, mourners told me they felt half the country treated their losses as no big deal, while the other half reduced them to a partisan talking point. <https://wapo.st/2VRNbeH>

#### **Specialist Publications**

‘**Grief: The epidemic within an epidemic**’ (p.7), in *American Journal of Hospice & Palliative Medicine*.

‘**Dying poor in the U.S. – disparities in end-of-life care**’ (p.9), in *JAMA Health Forum*.

1. ‘Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the U.S.,’ *Proceedings of the National Academy of Sciences of the United States of America*, published online 10 July 2020. [Noted in Media Watch 13 July 2020 (#674, p.11)] Full text: <https://bit.ly/322myb8>



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## International

### **Advance care planning may influence place of death, avoid dying in hospital**

U.K. (England) | Brinkwire – 10 December 2020 – Having discussions about end-of-life care preferences and recording and sharing these decisions with relevant healthcare professionals may influence your where you die, according to analysis of 21,231 U.K. urgent care register records. Martina Orlovic of The Royal Marsden National Health Service Foundation Trust and Imperial College London, and colleagues present these findings in the open-access journal *PLOS ONE*.<sup>1</sup> The authors of the present study used the U.K.'s largest electronic palliative care register, Coordinate My Care, to analyze the anonymised recorded care preferences and place of death outcomes for 21,231 adults on this register who died between March 2011 and July 2019. The researchers found that of the 16,593 individuals where both preferred place of death and actual place of death was recorded, 56% (9,328) preferred to die at home, while just 1% (210 individuals) wished to die in hospital. 73% of patients (12,171) died in their place of choice. Across the whole cohort, which included individuals without a recorded place of death preference, 22% of individuals (4,626) died in hospital, with 78% dying in non-hospital settings, including at home (7,709, 36%) or in a care home (5,645, 27%). <https://bit.ly/2W6Tr1X>

1. 'Impact of advance care planning on dying in hospital: Evidence from urgent care records,' *Plos One*, published online 9 December 2020. **Full text:** <https://bit.ly/3402k21>

### **Palliative Care, COVID-19 and Universal Health Coverage**

WORLDWIDE HOSPICE & PALLIATIVE CARE ALLIANCE | Online – 10 December 2020 – Based on a survey conducted in June 2020, this report provides recommendations to governments to integrate palliative care (PC) into COVID-19 responses, train healthcare workers in PC and build back better through the integration of PC into health systems, including through universal health coverage reforms. It is a moral imperative to ensure that adults and children are not experiencing avoidable serious health related suffering during the COVID-19 pandemic which could be alleviated through access to integrated and cost-effective PC. The Alliance's report focusses on

five areas: 1) Access to PC; 2) Government integration of PC; 3) Financial sustainability of PC organisations; 4) Universal health coverage and PC; and, 5) Partnerships for PC **Download/view at:** <https://bit.ly/3qVuLrN>

#### Specialist Publications

**'Inclusion of palliative care in health care policy for older people: A directed documentary analysis in 13 of the most rapidly ageing countries worldwide'** (p.12), in *Palliative Medicine*.

## Specialist Publications

### **The geriatrician's role in end-of-life care**

*AGE & AGEING* | Online – 10 December 2020 – Healthcare aims to help older people to live well, but ultimately must also support them to die well. Most people die in old age, but predicting death in both short- and long-term is impossible for many, although not all, older people. Frail older people live with hope and pride in coping, and often anticipate recovery when ill. Key objectives of healthcare for older people are to maintain independence, minimise suffering and preserve dignity, which requires active medical, mental health and rehabilitation management, even when extending life is not the main goal. Thorough medical diagnosis and appropriate treatment and rehabilitation minimise disability, physical and mental distress and problems resulting from acute illness and crises. In these terms, "health gain" can be achieved from medical intervention, even when life expectancy is short. Assumptions derived from cancer care about lack of reversibility with medical interventions are sometimes unwarranted. This has to be balanced against investi-

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gation- and treatment-burden, including that associated with hospital admission and the adverse effects of drugs and therapy interventions, and the need to respect the identity and autonomy of individuals. The resolution of these tensions requires anticipation of care options, multi-professional assessment, judicious and targeted treatment, good communication with patients and stakeholders and rigorous shared decision-making. In this commentary, we compare geriatric and palliative medicine, and describe how the geriatric medical approach can deliver appropriate healthcare towards the end of life. This is well supported by the broad knowledge, skill-set, flexibility and professional values displayed by geriatricians working in multi-professional teams. **Abstract:** <https://bit.ly/378Yjdl>

Noted in Media Watch 10 October 2020 (#687, p.8):

- *CLINICS IN GERIATRIC MEDICINE*, 2020;36(4):559-567. **‘How do geriatric principles inform healthy aging?’** Healthy aging long has been held as a core belief and priority of geriatrics, yet clinical, scholarly, and advocacy efforts have not kept pace with attention to multimorbidity and end-of-life care. With an aging US population and trends toward higher rates of lifestyle diseases, there is imperative for geriatricians to engage in efforts to promote healthy aging. Lifestyle medicine offers an evidence-based approach to healthy aging at any point in the life span. This emerging branch of medical practice has synergistic principles and frameworks with the field of geriatrics, which should further empower geriatricians to engage in promoting healthy aging. **Abstract (w. list of references):** <https://bit.ly/3lclVqA>

**N.B.** Selected articles on the “potential overlap” of geriatric medicine and palliative and end-of-life care noted in Media Watch 6 January 2020 (#647, pp.6-7).

### Using the RE-AIM framework to evaluate existing services and inform the development of a new model of dementia palliative care

*ALZHEIMER'S & DEMENTIA* | Online – 7 December 2020 – The Model for Dementia Palliative Care Project is developing a new service delivery model for dementia palliative care (PC) for the Irish healthcare system. In-depth examination of a purposive sample of existing services across Ireland and the U.K. was carried out, using robust evaluation methods. ‘Reach’ data included service users’ demographics and geographical coverage of the service used to estimate the size of a service needed for a certain location. ‘Effectiveness’ data pertained to service users’ satisfaction, for example a good service was associated with flexibility and good communication. ‘Adoption’ and ‘Implementation’ data assessed how well staff “bought into” dementia PC practices, as well as barriers to certain components being implemented such as under-funded homecare services blocking the goal of living and dying at home. ‘Context’ data helped to identify the local driving forces underpinning each service, e.g., an effective volunteer programme, or the local context of a hospice being located on hospital grounds encouraging transfers of non-cancer patients, through awareness of the service. By using this summative evaluation technique to identify components/activities at each service, it aided the research team to make decisions on the core components to include in the proposed model of PC. The novel model of dementia PC will have to be flexible, will have a strong multidisciplinary team aspect, support for people with dementia and their families in the community, and education and training for both staff and loved ones of people with dementia. **Abstract:** <https://bit.ly/2W2azWZ>



**N.B.** The RE-AIM framework is a tool for implementation scientists, health promotion professionals and practitioners. RE-AIM is an acronym for the framework’s five evaluation components: Reach, Effectiveness, Adoption, Implementation, and Maintenance. Additional articles on PC for people living with dementia noted in Media Watch 19 October 2020 (#688, p.7).

## **The premise and development of Check-in for Exchange of Clinical and Key Information (CHECK-IN) to enhance palliative care discussions for patients with limited English proficiency**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 December 2020 – Communication regarding serious illness is challenging in most circumstances. Patients with limited English proficiency (LEP) have unique language and cultural needs that often require collaboration with a trained medical interpreter, especially when the clinical encounter involves serious illness decision-making or elucidation of patient goals, preferences, and values. Although there is mounting evidence to support interpreter/clinician huddles before a serious illness communication encounter, no current initiatives exist to operationalize this evidence. The authors are currently in the process of developing, evaluating, and implementing a formal interpreter/clinician huddle process to promote high quality care for patients with LEP. Their huddle guide – CHECK-IN – is designed to facilitate collaboration between an interpreter and clinician during a serious illness encounter by prompting exchange of relevant sociocultural and clinical information between clinicians and interpreters. **Abstract (w. list of references):** <https://bit.ly/3qB6h6V>

Noted in Media Watch 17 February 2020 (#653, p.8):

- *BRITISH MEDICAL JOURNAL* | Online – 11 February 2020 – ‘**Can patients use family members as non-professional interpreters in consultations?**’ Sofia Sarfraz, senior clinical fellow in paediatrics and medical education, says: “For patients who don’t share your language the gold standard is to use a professional interpreter. We’ve all, however, used patients’ family members or other health professionals (HPs) as interpreters in consultations. It’s hard to see how medicine could function in our multicultural society without them, especially in emergencies. But non-professional interpreters should be used with caution and you should consider the risks. Medical interpreters have training and experience, which family members and other HPs may lack. **Full text:** <http://bit.ly/2SzE401>

Noted in Media Watch 10 April 2017 (#507, p.13):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 3 April 2017 – ‘**Understanding patient needs without understanding the patient: The need for complementary use of professional interpreters in end-of-life care.**’ In linguistically and culturally diverse societies, language discordant consultations become daily practice, leading to difficulties in eliciting patient preferences toward end-of-life care. The case discussed generated a triple-layered ethical dilemma: 1) How to safeguard patient autonomy against paternalistic interventions by family members; 2) How to respect the relational context in which patient autonomy can be realized; and, 3) How to respect the ethno-cultural values of the patient and his family. **Abstract (w. list of references):** <http://bit.ly/2JqsyjL>

## **Disparities in palliative and hospice care and completion of advance care planning and directives among non-Hispanic blacks: A scoping reviews of recent literature**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 December 2020 – It is well-established that disparities in diversity, equity and inclusivity are widespread in American society and in the U.S. healthcare system. Receiving palliative care for people with serious illness, and hospice services for people approaching the end of life (EoL) is no exception. It is urgent that we understand and eliminate both disparities in serious illness care and disparities in EoL care. The story about race and palliative and hospice care in U.S. is very much the same story of racism in healthcare. In a comprehensive speculative essay, one researcher paints a troubling picture of racism and Black-White relationships in EoL care in the U.S. He argues that “the racial system operates in ways that bruise some people and that make it difficult for those who are advantaged by the system to understand the system and their place in it; and so, ideally one way for EoL care facilities to deal with potential difficulties in black-white relationships is to provide contexts for dealing with bruises and obliviousness.” Discrimination and racism exist and are severely impacting the EoL of minority patients. It is more righteous to address these issues directly than to pretend they are not present or are too unimportant to address. The healthcare system, in both private and public settings, that is engaged with financing, managing, and providing palliative and hospice care must directly address the issue of racism, discrimination, and disparities, particularly among marginalized underserved non-Hispanic Blacks. **Full text:** <https://bit.ly/37Juxv0>

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## Related:

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 7 December 2020 – ‘**Promoting advance care planning in African American faith communities: Literature review and assessment of church-based programs.**’ Analysis of advance care planning (ACP) education initiatives in African American faith institutions reveal nine key themes related to program success and sustainability. Successful implementation and ongoing effectiveness of ACP programs in primarily African American congregations is contingent on building capacity, fostering sustainability by involving faith leadership, using existing resources and ministries, exhibiting cultural competency, preserving a spiritual/Biblical context, addressing health disparities, building trust and selectively employing technology. **Full text:** <https://bit.ly/39Qw84D>

## Grief: The epidemic within an epidemic

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 December 2020 – While there are many facets to this pandemic, the authors raise the issue of grief and its public health implications as our death toll rises and rises. And if, by definition, this virus and subsequent limitations on social contacts and diminished grief rituals, complicates our grief and exacerbates the negative outcomes, then we need to acknowledge the epidemic within the epidemic. Waiting for a vaccine has shown that the graphs of mortality just keep climbing. The authors urge policymakers to acknowledge the pervasive grief and its many consequences. Beyond recognition, policymakers can take tangible steps now to stem the flow of grief following so much loss. For now, policy must address the needs of those who are unable to access support and rituals due to current restrictions. One way to do this would be through primary preventive interventions, which would make bereavement counseling available to anyone who wants it. Interventions of this sort

have been proven to be effective at reducing the negative health outcomes of bereavement when the bereaved person is able to decide for themselves if they want to pursue counseling. This will require funding and online infrastructure, as well as coordinated efforts to disseminate the availability and benefits of such a program. **Full text:** <https://bit.ly/3ozQu6f>

### Extract

Perhaps we can follow the lead other countries, such as the U.K. or Israel, who recognize that grief and bereavement are embedded in social and political contexts. Perhaps just knowing that we acknowledge the grief, and that we are being intentional, will offer some basic support as the Grief absence Policy for Students program did for college students. Until a stronger solution like a vaccine arrives, then it is policy, both now and later that can help immunize and soften the grief that is a hidden epidemic within an epidemic.

Noted in Media Watch 7 December 2020 (#695, p.4):

- AUSTRALIA | Palliative Care Australia – 4 December 2020 – ‘**Palliative Care and COVID-19: Grief, Bereavement and Mental Health.**’ The association’s new outcomes paper provides recommendations for policymakers, health and aged care leaders and professionals, and consumers and carers to meet the mental health, grief and bereavement needs of Australians during the current pandemic and any future pandemics or disasters. As part of its planning and leadership for the palliative care (PC) sector during the COVID-19 pandemic, the association held two strategic forums in 2020 with experts in PC, grief, bereavement and mental health to identify the emerging issues, available resources and gaps in current service provision. **Download/view report at:** <https://bit.ly/2L8nX9H>

Noted in Media Watch 30 November 2020 (#694, p.1):

- CANADA | CBC News – 23 November 2020 – ‘**National grief strategy needed to help Canadians cope with loss due to COVID-19, group says.**’ An organization called the Canadian Grief Alliance has been pushing the federal government for a national strategy to help people cope with the increased loss society is facing – fearing it will have long-term mental health repercussions. Health Canada says the federal government is investing \$240.5 million to support provinces and territories to develop, expand and launch virtual care tools, including supports for mental health. But the alliance says grief services specifically are falling through the cracks. The pandemic’s impact on Canada and the number of people who are grieving is “astounding.” <https://bit.ly/3lWxrxz>

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Noted in Media Watch 24 August 2020 (#680, p.6).

- SPAIN | *JOURNAL OF RELIGION & HEALTH* – 20 August 2020 – ‘**The dead with no wake, grieving with no closure: Illness and death in the days of Coronavirus in Spain.**’ The pandemic caused by the spread of [COVID-19](#) is giving rise to an exceptional social situation because of the great speed of propagation of the illness and the high level of mortality it has occasioned in a very short time. Moreover, the lockdown measures decreed in Spain prohibit the holding of wakes to avoid contagion, and limit funerals to three people plus the officiant. Thus, coronavirus is robbing people of the opportunity of a final farewell, stripping the dead of their dignity and worsening the grief of the living. This article investigates the situation and the social and cultural impact it has provoked. **Full text:** <https://bit.ly/3j03j77>

**N.B.** Selected articles on grief and bereavement during the [COVID-19](#) pandemic noted in Media Watch 10 August 2020 (#678, pp.3-4).

### **Enhancing care for long-term care residents approaching end-of-life: A mixed-methods study assessing a palliative care transfer form**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 December 2020 – Many barriers exist in providing quality end-of-life (EoL) care in long-term care (LTC), including transitions of care between acute care and LTC. Transfer forms can be beneficial in ensuring resident’s EoL care needs are coordinated between different settings. The NYGH-LTC Transfer Form is a newly developed tool created to enhance care for residents transferred from acute care back to their LTC home for EoL. The authors assessed the perceived ease of use, usefulness, and care-enhancing potential of the NYGH-LTC Transfer Form by interprofessional LTC staff at 2 LTC homes in Toronto, Canada. There were 34 participants. 79.4% of participants agreed the form was easy to use and 82.4% agreed it would improve care. The form was seen as most useful for those with less experience or less confidence in palliative care. Communication was identified as a major barrier to successful transitions of care and increased bidirectional verbal communication is needed in addition to the form. **Abstract (w. list of references):** <https://bit.ly/3ouFSWn>

### [COVID-19](#)

### **Clinician perspectives on caring for dying patients during the pandemic: A mixed-methods study**

*ANNALS OF INTERNAL MEDICINE* | Online – 8 December 2020 – Many barriers to end-of-life care (EoLC) arose because of infection control practices that mandated visiting restrictions and personal protective equipment, with attendant practical and psychological consequences. Stringent infection control policies ushered in changes to EoLC for hospitalized patients, their relatives, and clinicians – many counter to whole-person palliation and patient- and family-centered care – causing both direct and indirect suffering. In this study, the authors found that clinicians were inspired to express humanity, seek each patient’s story, ensure dignity-conserving care, adopt new roles, and catalyze connections. Interventions to support dying patients and their families reaffirm clinicians’ commitment to preserve compassionate EoLC during the pandemic – at times when it is needed the most. **Full text:** <https://bit.ly/3oqXh2i>

### **Related:**

- *FUTURE HEALTHCARE JOURNAL* | Online – Accessed 8 December 2020 – ‘**Care of the dying person before and during the COVID-19 pandemic: A quality improvement project.**’ This report details how a plan, do, study, act approach was taken to implementing improved, standardised multidisciplinary documentation of individualised care and review for people who are in the last hours or days of life... The documentation and training produced is subject to ongoing review via the specialist palliative care team’s continuously updated hospital deaths dashboard, which evaluates the care of patients who have died in the trust. Sharing the experiences and outcomes of this process will help other trusts to develop their own pathways and improve the care of dying people... **Full text:** <https://bit.ly/3oijmHR>

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- *JAMA HEALTH FORUM* | Online – 10 December 2020 – ‘**Dying poor in the U.S. – disparities in end-of-life care.**’ The COVID-19 pandemic has focused attention on stark disparities in the U.S., with higher rates of infections and deaths among lower-income populations and communities of color. Illness and death rates are not the only sources of health inequity in this country. There are also substantial differences in the care that patients with serious illnesses receive near the end of life (EoL) that are based on race or socioeconomic status. Although pandemic-related efforts to improve equity rightfully focus on preventing death, in this and numerous other contexts, policymakers and clinicians should also work to eliminate disparities in EoL care. **Full text:** <https://bit.ly/348ZO9x>
- *JCO ONCOLOGY PRACTICE* | Online – 11 December 2020 – ‘**Rapid conversion of a palliative care outpatient clinic to telehealth.**’ The coronavirus pandemic has transformed the practice of medicine, forcing a rapid transition to telehealth. Palliative care (PC) relies upon expert-level communication and interdisciplinary care. The authors describe the transition of the Dana-Farber Cancer Institute PC clinic into a predominantly telemedicine model. They document how they significantly increased goals-of-care conversations while maintaining patient volume and interdisciplinary care. The authors present how the components of a palliative visit translate into a virtual model and discuss how the pandemic changed the delivery of PC in ways that will endure beyond the coronavirus pandemic. **Abstract:** <https://bit.ly/37b3CZI>

### Assisted dying and palliative care in three jurisdictions: Flanders, Oregon, and Quebec

*ANNALS OF PALLIATIVE MEDICINE* | Online – 4 December 2020 – The authors find that no clear or uniform relationship between palliative care (PC) and assisted dying can be identified in any of the three locations. Indeed, their analysis indicates that when a field of practice such as PC is potentially seen as threatened by another field, such as assisted dying, several patterns emerge that go beyond simple characterization of the relationship between the two. The relationship between assisted dying and PC is influenced by legal regulations that are subject to change, variable and sometimes inconsistent institutional policies and support systems, the type of assisted dying offered (medically or self-administered), and structures of healthcare funding. Cooperation or integration between the two practices may also be perceived by some as dependent upon whether PC professionals’ views of assisted dying are compatible with their views about “care.” An overarching concern which unites the three jurisdictions is a lack of public knowledge, recognition and understanding of appropriate PC, as well as obtaining access to it. The context and practicalities of how assisted dying is being implemented alongside access to PC need to be attended to in order to inform any future laws. The

authors seek a better understanding of whether and in what ways assisted dying presents a threat to PC. There is a clear need for more attention to how PC and assisted dying can co-exist, where both are available. **Full text (click on pdf icon):** <https://bit.ly/3ndmxss>

#### The treatment of patients with unbearable suffering – the slippery slope is real

*JAMA INTERNAL MEDICINE* | Online – 7 December 2020 – Physician-assisted death (PAD) is now legal in 9 U.S. states and the District of Columbia and is under consideration in 17 more. Legalization generally follows ballot, as opposed to legislative, initiatives in the setting of extensive marketing efforts by advocacy groups focused on convincing the public that they face a future of unbearable suffering if PAD is not available. Whereas fear of unbearable suffering at the end of life is a commonly expressed concern, most Americans should be able to expect reliable and expert relief of suffering as a result of medical advances in geriatrics and palliative care. The fact that the public is so easily persuaded at the ballot box that suffering is inevitable and that they cannot trust the health care system to be responsive to their suffering should give us pause. **Abstract:** <https://bit.ly/37asnVS>

#### Related:

- *JOURNAL OF LAW AND THE BIOSCIENCES* | Online – 11 December – ‘**The impact of the COVID-19 pandemic on medical assistance in dying (MAiD) in Canada and the relationship of public health laws to private understandings of the legal order.**’ The authors examined how physicians and nurse practitioners reconcile respect for the new, changing rules brought upon by the COVID-19 pandemic, along with their existing legal obligations and ethical commitments as healthcare professionals and MAiD providers. Respondents reported situations where they did not follow or did not insist on others following the applicable public health rules. The authors identify a variety of techniques that they deployed either to minimize, rationalize, justify or excuse deviations from the relevant public health rules. **Abstract:** <https://bit.ly/347CHvZ>

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- *PROGRESS IN PALLIATIVE CARE* | Online – 10 December 2020 – ‘**Reflecting on suffering at the end-of-life.**’ In the context of dying, the amelioration of suffering in all its presentations is an inevitable aspect of holistic care. Thus palliative care (PC) staff will continue to be faced with supporting those for whom suffering is unbearable and has no meaning. “Leaning into” these conversations, respecting the individual’s wishes and honouring their autonomous choices are key principles of PC practice. Further consideration of these reflections on contemporary understandings of suffering is needed, as well as the influence of these understandings on both the choices individuals make at the end of life, as well as the responses of PC clinicians. **Abstract:** <https://bit.ly/3qPyRBF>

### **Barriers in implementing the dying patient law: The Israeli experience – qualitative study**

*BMC MEDICAL ETHICS* | Online – 11 December 2020 – In Israel and the western world, the relationship between clinician-care teams and patients is strong. Medical teams in the community are in daily contact with elderly and sick populations. However, the proportionate increase in the elderly population of developed economies such as Israel in relation to the number of medical teams will, in the not-too distant future, strain care team access to this demographic. This will thus affect implementation of laws dealing with end-of-life (EoL). It is recommended that the role of the family doctor in EoL treatment should be strengthened. The structure and response of the units for home treatment should be taken into account, to enable greater accessibility to homes for the aged, medical assistance housing, and hospice homes that can provide appropriate response to EoL patient needs. At the same time, awareness must be raised among the general population, medical staff as well as other therapists in the health system. This is needed to channel the resources, knowledge, support, and tools to these medical teams for improving treatment and responding to patients who need information and support for mastering EoL laws, with the aim of promoting the legitimate rights of all citizens who are at the end of their lives. **Full text:** <https://bit.ly/3maEM0z>

### **End-of-life care for older first-generation migrants: A scoping review**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 9 December 2020 – The unprecedented scale of contemporary migration across countries over the last decade means that ageing and dying occur in a more globalised, multicultural context. It is therefore essential to explore the end-of-life (EoL) experiences of older people from migrant backgrounds. Fifteen studies met the inclusion criteria for this review, which addressed six key themes: 1) The reluctance among older migrants and their families to talk about death and dying; 2) Difficult communication in patient-clinician relationships; 3) The contrast between collectivistic and individualistic norms and its associated EoL preferences; 4) Limited health literacy in older adults from migrant backgrounds; 5) Experiences with systemic barriers like time pressure, inflexibility of service provision and lack of cultural sensitivity; and, 6) The need for care providers to appreciate migrants’ “double home experience” and what this means for EoL decision-making regarding place of care and place of death. To respond effectively to an increasingly culturally diverse population, healthcare staff, researchers and policy-makers need to invest in the provision of culturally sensitive EoL care. Areas for improvement include: 1) Increased awareness of cultural needs and the role of family members; 2) Cultural training for healthcare staff; 3) Access to interpreters and translated information; and, 4) Involvement of older migrants in EoL discussions, research and policymaking. **Abstract:** <https://bit.ly/3qJbMQU>

Noted in Media Watch 26 October 2020 (#689, p.11):

- *MEDICAL TEACHER* | Online – 17 October 2020 – ‘**Twelve tips to teach culturally sensitive palliative care.**’ With an increasingly ageing population there will be a rising demand for palliative care (PC), including from older migrants and ethnic minorities. While many physicians are unfamiliar with specific needs of older migrants and ethnic minorities regarding care and communication in PC, this may be challenging for them to deal with. Many medical teachers also feel unprepared to teach PC and culturally sensitive communication to students. Drawn from literature and the authors’ own experiences as teachers, these twelve tips provide practical guidance to both teachers and curriculum designers when designing and implementing education about culturally sensitive PC. **Full text:** <https://bit.ly/2lD0EU4>

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Noted in Media Watch 7 September 2020 (#682, p.7):

- *JOURNAL OF ADVANCE NURSING* | Online – 31 August 2020 – ‘**A systematic review exploring palliative care for families who are forced migrants.**’ This review offers valuable insights into the experience of children’s palliative care (CPC) for forced migrant families and contributes to existing knowledge in this area with the creation of a framework guiding healthcare professionals (HCP) towards culturally sensitive care provision. CPC guidelines advise individualized care for all families, but for forced migrant families, this is particularly important as experiences of persecution and displacement can reduce agency which needs to be fostered to rebuild self-worth and a sense of belonging. The “normality” of parenting can be cultivated through a model of family centred care. **Full text:** <https://bit.ly/31KK7V9>

### **Describing the end-of-life doula role and practices of care: Perspectives from four countries**

*PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 7 December 2020 – Contemporary concerns about the end of life (EoL) within the global North are driven by healthcare system restructuring; changing epidemiological, demographic, and social trends; ideologies of choice, autonomy, and person-centered holistic care; and, the desires of individuals, families, and communities to demedicalized dying. EoL doula evidence a new response to these complexities of modern dying. The authors’ findings contribute substantially new information to the small body of empirical research about the EoL doula role and their practices of care, and are the first research to employ an international comparative perspective. On the micro-level, their authors’ findings offer a current “snapshot” of their work as it continues to evolve, and situates the diversity of approaches not merely as a limitation to be eradicated but also as a self-reflexive and foundational component of practice. On the meso-level, findings provide the first detailed taxonomy of the EoL doula’s role and specific services on the basis of the perspective of subject experts in four countries [i.e., Australia, Canada, the U.K., and the U.S.], thereby strengthening the collaborative capacity and integration potential between diverse stakeholders and healthcare settings. On the macro-level, findings enable healthcare systems, professional associations, and policy makers to better understand the development of a new hybrid community-entrepreneurial social movement that both builds on, and differentiates from, conventional approaches to EoL care. **Full text:** <https://bit.ly/2Isp6bb>

Noted in Media Watch 10 August 2020 (#678, p.11):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 3 August 2020 – ‘**End-of-life doulas: A qualitative analysis of interviews with Australian and international death doulas on their role.**’ Seven themes emerged: what a death doula (DD) offers, what a DD does, challenges and barriers, occupational preferences, family support, contract of service/fee and regulation. There is a perception that healthcare professionals do not understand what it is that DDs do. The lack of a DD business model sees inconsistencies in what services each DD offers and what patients and families can expect. EoL is complex and confusing for patients and families and there is a need to further explore the DD role and how it can work when there are many inconsistencies in working practice. **Abstract:** <https://bit.ly/30speh6>

**N.B.** Additional articles on death doulas noted in this issue of Media Watch.



#### **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>

## **Caring, sharing, preparing and declaring: How do hospices support prisons to provide palliative and end of life care? A qualitative descriptive study using telephone interviews**

*PALLIATIVE MEDICINE* | Online – 10 December 2020 – Recent research has described in detail prison-based hospices in the U.S., the elements that contribute to their success, and the complex role played by inmate hospice volunteers. The typology presented here describes the ways that hospices in Scotland engage with prisons in Scotland. Yet the authors believe that this typology is of international relevance, particularly to the many countries who have not established hospices within the prison walls. The ongoing mapping exercise being conducted by the European Association for Palliative Care taskforce suggests that many countries are similar to Scotland in that they do not operate prison-based hospices. A series of literature reviews have identified that most research published on palliative care (PC) in prisons comes from the U.S., where hospice care is frequently delivered within the prison walls by a dedicated prison hospice. In this way, the evidence base does not fully represent the ways that different nations are contending with the global problem of people ageing and dying while in prison. This study is one of the first to describe an alternative model, one which relies on close collaboration between multiple agencies and individuals to balance the PC needs of the person at the end of life with the necessary functions of a criminal justice system. **Full text:** <https://bit.ly/3a1Ejv9>



School of Medicine,  
Dentistry & Nursing

**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/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>

## **Real-world ethics in palliative care: A systematic review of the ethical challenges reported by specialist palliative care practitioners in their clinical practice**

*PALLIATIVE MEDICINE* | Online – 10 December 2020 – This is, to the authors' knowledge, the first review to systematically detail specialist palliative care (PC) practitioner-reported ethical challenges and has important implications for PC and ethics training. The identified ethical challenges are far broader than those included in current major textbooks in the field. These challenges are located at diverse levels, from the bedside up to national policy. The authors found no data from low and middle-income settings where the majority of the world's population live and die. Finally, this review, through the breadth of data synthesised, demonstrates the utility of robust methodologies within empirical bioethics. That the review identified ethical challenges that are not included in the major textbooks reinforces the need for this approach alongside theoretical aspects of bioethics, if the aim is more ethically-informed clinical care. Further research is needed to explore patients and carers' perspectives, the nature of the individual challenges identified in this review, and how these may vary across settings and countries. **Full text:** <https://bit.ly/37Yi1aU>

## **Inclusion of palliative care in healthcare policy for older people: A directed documentary analysis in 13 of the most rapidly ageing countries worldwide**

*PALLIATIVE MEDICINE* | Online – 9 December 2020 – Palliative care (PC) is insufficiently integrated in the continuum of care for older people. It is unclear to what extent healthcare policy for older people includes elements of PC and thus supports its integration. The aim of this analysis was to develop a reference framework for identifying PC contents in policy documents, and to determine inclusion of PC in public policy documents on healthcare for older people in 13 rapidly ageing countries. Analysis of public policy documents (legislation, policies/strategies, guidelines, white papers) on healthcare for older people and using existing literature, the authors developed a reference framework and data extraction form assessing 10 criteria of PC inclusion. Of 139 identified documents, 50 met inclusion criteria. The most frequently addressed PC elements were coordination and continuity of care (12 countries), communication and care planning, care for family, and ethical and legal aspects (11 countries). Documents in 10 countries explicitly

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mentioned PC, nine addressed symptom management, eight mentioned end-of-life care (EoLC), and five referred to existing PC strategies (out of nine that had them). Healthcare policies for older people need revising to include reference to EoLC and dying and ensure linkage to existing national or regional PC strategies. The strong policy focus on care coordination and continuity in policies for older people is an opportunity window for PC advocacy. **Abstract (w. list of references):** <https://bit.ly/3IV2T36>

**N.B.** The countries that were the “focus” of this study: Austria, Belgium, Canada, Czech Republic, England, Japan, Mexico, The Netherlands, New Zealand, Singapore, Slovenia, South Korea, Spain.

### **A nationwide survey of bereaved family members’ perception of the place patients spent their final days: Is the inpatient hospice like or unlike a home? Why?**

*PALLIATIVE MEDICINE REPORTS* | Online – 3 December 2020 – This is the first large-scale study [in Japan] to clarify family perceptions of what it means for patients to spend the final days at home and in inpatient hospices. Of [779] family members surveyed, 37.6% felt that the inpatient hospice was like a home. For the family members who were with the patients during their end of life (EoL), the benefits of spending time at home were indicated by responses to: “He/she can do what he/she wants to do without worrying about the eye of other people,” and “reminisce about the past and connect with his/her loved ones,” while the benefit of spending time at the inpatient hospice was that it was “reassuring and safe as healthcare professionals are easily available.” Multiple studies have revealed that the key environmental factors shown to affect EoL care were those that improved: 1) Social interaction; 2) Positive distractions; 3) Privacy; 4) Personalization and creation of a home-like environment; and, 5) The ambient environment. This study confirms that the benefits of spending time at home/inpatient hospice, including these factors, should be considered when caring for patients and family members in each place to improve the physical, psychological, social, and spiritual needs at the EoL. **Full text:** <https://bit.ly/2JUTGuv>

### **Pathways for a “good death”: Understanding end-of-life practices through an ethnographic study in two Portuguese palliative care units**

*SOCIOLOGICAL RESEARCH* | Online – 28 November 2020 – Drawing upon ethnographic research developed in two Portuguese palliative care units, this article seeks to analyse end-of-life practices, namely how they are perceived and negotiated among the various actors involved. Over a period of 10 months in these units participant observation and in-depth interviews were conducted with 20 family members of patients with a life-threatening illness and 20 healthcare professionals. Against this backdrop, aspects related to the concept of a “good death,” the management of pain and suffering, and the loss of consciousness were explored. The main findings pointed to an appreciation, both by professionals and family members, of a holistic intervention that guarantees the patient’s physical, psychological, social, and spiritual well-being, where the relief of physical symptoms is of particular importance and palliative sedation emerges as a mechanism that allows the patient to achieve a “good death” (without suffering and in a peaceful way). **Abstract (w. list of references):** <https://bit.ly/2L8ILhb>

## **Publishing Matters**

### **Predatory journals enter biomedical databases through public funding**

*BRITISH MEDICAL JOURNAL* | Online – 8 December 2020 – In the past decade the scientific community has faced a serious threat to its integrity and credibility with the rise of predatory journals. These journals manipulate and exploit the open access publishing model but omit the quality checks and editorial services that are routinely provided by legitimate journals, such as peer review, plagiarism detection, and verification of ethical approval of experiments. Although the descriptor “predatory” has been criticised for grossly conflating poor quality with misconduct and for simplistically clas-



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sifying the scholarly publishing environment into bad and good (predatory or not), the term is now widely accepted to describe the phenomenon. In conjunction with the online spread of predatory journals, we have recently shown that a worryingly high number of predatory journal articles are indexed in PubMed, the free-to-access biomedical database maintained by the National Library of Medicine (NLM). PubMed contains over 30 million searchable abstracts and citations that are drawn from three NLM literature sources: Medline, a database of citations from selected journals; Bookshelf, a repository for books, reports, databases, and other documents; and PubMed Central (PMC), a digital repository for full text articles. PMC is particularly vulnerable to infiltration by predatory journal articles because individual authors upload their articles into the database in accordance with funder requirements, even though the journals might not meet the standard for indexing in PubMed. By doing so, individual articles are displayed in both PMC and PubMed, which is concerning because it potentially legitimises research that has not been appropriately reviewed, and represents a substantial waste of public money being used to pay for publication. **Introductory paragraphs:** <https://bit.ly/3m4UxpT>

**N.B.** Selected articles on predatory journals indexed on PubMed noted in Media Watch 29 July 2019 (#624, p.15).

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

### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/36XAaXg>

[Scroll down to 'Media Watch']

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

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

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

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

### Asia



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

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### 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  
Canadian Society of  
Palliative Care Physicians

SCMSP  
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 | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTPS://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>

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## South America

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

### 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.

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3. Links often remain active, however, for only a limited period of time.
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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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