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

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Compiled & Annotated by Barry R. Ashpole

Further investigation of the public's views of palliative care (PC) is vital to help inform and target a future public education programme that provide key messages within a public health approach, which may change attitudes to PC thus ultimately improving access and end of life outcomes.

'Examining public knowledge, attitudes and perceptions towards palliative care: A mixed method sequential study' (p.5), in *BMC Palliative Care*.

Canada

A prescription to reform Canada's broken eldercare system

FORBES | Online – 18 March 2021 – Canada's healthcare system is often held up as an example to other countries. And Canada's COVID-19 response has been more thoughtful and science-based than countries such as the U.S. or U.K. But one it's biggest failures was brutally exposed during the ongoing pandemic: an unacceptably high rate of COVID-19 deaths among elders living in long-term care facilities. Of the 22,500 COVID-19 deaths in Canada thus far, nearly 75% occurred among elders living in institutional settings. Overall, 88% of COVID-19 deaths have been in people over the age of 70. Many elders died alone, without family or friends, and often without palliative care. And nobody has been held accountable for this disastrous outcome. How did Canada fail to protect it's elders? How did a country with a large elderly and ageing population fail to learn from other countries (notably European countries that were hit early in the pandemic) and take early measures to protect the seniors from COVID-19? Why does the Canadian healthcare system ignore the needs of elders, and push the institutional care model, over home-based care that is widely preferred by seniors? http://bit.ly/38UIp77

Extract from *Forbes* article

The vast majority of deaths in Canada occur in hospital, another example of how the health system is hospital-centric. Between 16% and 35% of Canadians who would be eligible for palliative care (PC) actually have access, and that varies tremendously by community. There are some wonderful hospices, but they are largely funded with charitable donations, so they tend to be in higher-income communities. Paradoxically, one of the hardest places to PC is in a long-term care (LTC) home; while residents live, on average, only 18 months in LTC facilities, only 6% of them access PC. That speaks to the fact that provision of different health services is very siloed.

Cont.

Noted in Media Watch 10 February 2020 (#652, p.1):

- *THE CATHOLIC REGISTER* | Online – 5 February 2020 – **'Palliative care in Canada: Harsh facts, sad realities.'** A guaranteed right to doctor-assisted death in Canada has still not been matched with a right to palliative care (PC) as the vast majority of Canadians continue to die among strangers in institutions, either without PC or with too little PC delivered too late in their disease trajectory. Of Canadians who died at home in 2016-2017, even though two-thirds received home care during their last year, less than one-in-six received PC, according to the Canadian Institutes of Health Information.[1] Just 22% of long-term care residents with less than six months to live received PC. Only 15% of Canadians die at home. In contrast, 40% of medical aid in dying procedures provide death at home. http://bit.ly/3bgP1Mk

  1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, Ottawa, Ontario, September 2018. [Noted in Media Watch 24 September 2018 (#582, p.1)] **Download/view at:** http://bit.ly/2MqmCYO

Noted in Media Watch 3 February 2020 (#651, p.13):

- *PLOS ONE* | Online – 31 January 2020 – **'Does early palliative identification improve the use of palliative care services?'** In this propensity-score matched cohort study of patients who were likely to die within one year, the authors found that actively identifying patients who may benefit from a palliative care (PC) approach increased the utilization of PC services and community-based care such as home care, physician home visits, and outpatient opioid use. Earlier access to PC is in line with quality standards for quality care in the province of Ontario. Nevertheless, the most recent data from the Canadian Institute for Health Information shows that in Ontario and Alberta, fewer than 15% receive PC at home. The results of this study are also congruent with other end-of-life studies. **Full text:** http://bit.ly/31gyd3N

Noted in Media Watch 4 January 2020 (#698, p.1):

- *HEALTHY DEBATE* | Online – 28 December 2020 – **'If not now, when? Applying a palliative approach in long-term care.'** Earlier this month, the federal government committed to a $1-billion investment into long-term care (LTC) homes across Canada over two years as part of its economic update. While the investment is welcome, and greatly needed, there is an omission in the list of deliverables, one we believe would greatly enhance the quality of LTC services across Canada – committing to, or deepening the commitment to, a palliative approach to care in long-term homes. The pandemic's impact on LTC has been unprecedented and has exposed the growing trend over the last several years towards increased numbers of residents dying in LTC. http://bit.ly/2Mj8ggl

  N.B. A requirement to provide PC has been in the Ontario Long Term Care Homes Act for many years but the LTC licensees, both for-profit and non-profit, have ignored this legislated requirement. **Source:** Judith Wahl, retired Executive Director of the Advocacy Centre for the Elderly. Posted comment on *Healthy Debate* article.

U.S.A.

Hospices employ gap analyses to build palliative care programs

HOSPICE NEWS | Online – 18 March 2021 – An assessment of community needs is essential for hospices working to establish or grow their palliative care (PC) programs. Providers need to understand the population that they serve in terms of demographics, culture and the availability of PC and other healthcare services in that region. While no standard definition exists for "palliative care," the U.S. Centers for Medicare & Medicaid Services defines the term as "patient and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. PC throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice." Palliative services remain widely underutilized throughout the globe. The U.S. ranks among the lowest nations in duration of PC for people with life-limiting and terminal illnesses…[1] though a growing number of hospices are diversifying their business lines to include this service. http://bit.ly/311ku16

1. 'Duration of palliative care before death in international routine practice: A systematic review and meta-analysis,' *BMC Medicine*, published online 26 November 2020. [Noted in Media Watch 30 November 2020 (#694, p.6). **Full text:** https://bit.ly/3mfMdo8

Hospices engage volunteers, certification programs to boost recruitment and retention

HOSPICE NEWS | Online – 16 March 2021 – With workforce shortages expected to continue plaguing the hospice industry, providers have stepped up staffing support and are focused on developing career growth opportunities. Some providers are engaging volunteers as well as certification programs in their recruitment and retention strategies. The hospice and palliative care (PC) workforce has been shrinking in recent years, with staff burnout, retirement and limited opportunities in specialty training leading the charge on contributing factors. Shortages are expected to worsen during the next 25 years, with research indicating that supply of a hospice and PC specialized workforce will be exceeded by demand of a growing aging patient population. Widespread shortages heightened during the pandemic, with many hospices struggling to fill their ranks and sustain operations while taking heavy blows from COVID-19. Staff burnout has forced many hospices to reevaluate their policies around paid leave and paid time off (PTO) as employees respond to childcare needs with school closures and remote learning. Some have also fallen ill to the virus themselves or are quarantining after possible exposures. http://bit.ly/3qWrKWE

Noted in Media Watch 15 March 2021 (#708, p.2):

- *HOSPICE NEWS* | Online – 11 March 2021 – **'Reform hospice education to combat workforce burnout.'** The U.S. has 13.35 hospice and palliative care (PC) specialists for every 100,000 adults 65 and older, according to an April 2018 study.[1] The research estimated that by 2040 the patient population will need 10,640 to 24,000 specialists; supply is expected to range between 8,100 and 19,000. Research published in 2019 found that the hospice and PC workforce will likely deplete even further during the next two decades due to retirement and burnout.[2] …widespread burnout among hospice and PC clinicians is an issue that will rise as medical education programs nationwide fall short in terms of fellowship opportunities, training and experience in end-of-life and serious illness care. http://bit.ly/38yMrBF

    1. 'The growing demand for hospice and palliative medicine physicians: Will the supply keep up?' *Journal of Pain & Symptom Management*, published online 2 February 2018. [Noted in Media Watch 5 February 2018 (#549, p.12] **Full text:** http://bit.ly/2CRjxwO

    2. 'Policy changes key to promoting sustainability and growth of the specialty palliative care workforce,' *Health Affairs*, 2019;38(6):910-918. [Noted in Media Watch 10 June 2019 (#617, p.1)] **Full text:** http://bit.ly/2QMAU7N

International

Hundreds of patients including care home residents subjected to unlawful "do not resuscitate" orders, Care Quality Commission confirms

U.K. | *The Independent* (London) – 18 March 2021 – Hundreds of elderly patients have been subjected to unlawful do not resuscitate decisions that included blanket orders on care home residents, a watchdog has found. In a review of the use of the controversial notices during the [COVID-19] pandemic, the Care Quality Commission (CQC) said it had uncovered evidence of patents not being involved in discussions and in some cases even being denied treatment.[1] Care home providers told the watchdog there were a total of 508 do not attempt cardiopulmonary resuscitation (DNACPR) decisions that had been put in place after 17 March last year without any discussion with the patient or their family. The CQC said a third, 180, of these orders were still in place in December. It said this raised "serious concerns that individuals' human rights – to be involved in DNACPR decisions about themselves or their families – were potentially being breached in more than 500 cases." There were also fears over widespread "blanket" do not resuscitate decisions being made on entire care homes and groups of disabled patients. http://bit.ly/3ltbOu2

Specialist Publications

'Public knowledge, preferences and experiences about medical substitute decision-making: A national cross-sectional survey' (p.7), in *BMJ Supportive & Palliative Care*.

Cont.

1. 'Protect, respect, connect – decisions about living and dying well during COVID-19,' Care Quality Commission, March 2021. http://bit.ly/3eMn6Iy

N.B. See '"Don't judge the book by its cover": Clinicians and charities speak out about the positive role DNACPR conversations can play in providing good care,' *BMJ Supportive & Palliative Care*, published online 8 March 2021. Full text: http://bit.ly/30SMcNx

We cannot ignore family wellbeing any longer

U.K. | Together for Short Lives – 17 March 2021 – Together for Short Lives received a call to our helpline from a mother in a desperate state. She was shielding at home, as a single parent with three children. Her daughter had a life-limiting condition and very complex needs, which required round the clock attention and support. She was sleep deprived and awaiting assessment for Universal Credit. She only had a few pence left in her purse. She was emotionally and physically shattered – perpetually anxious about her sick child's fragile health and the well-being of her other children in equal measure. While shocking and heart breaking, this is not an uncommon story for parents of seriously ill children. Sure, there are some pandemic impacts here. Shielding and homeschooling undoubtedly exacerbate isolation from friends and family and many of the excellent local services they might rely on in more normal circumstances have had to change and adapt themselves. But the truth is, in Britain in 2021, one of the most developed countries in the world, this is the day-to-day reality for many parents. They often tell us that caring for a seriously ill child brings many life-enriching joys and experiences that, however bittersweet, they would not change for anything. But they also tell us that caring round the clock is exhausting and lonely and takes a huge toll on the whole family. It has serious longer term impacts too. Research from … Martin House Research Centre at the University of York … made stark and worrying reading.[1] The study clearly demonstrates that the mothers of children with life-limiting illness are much more likely to develop serious physical and mental health problems. http://bit.ly/3qSY8tj

Extract from the *Archives of Disease in Childhood* article

While these findings highlight higher incidence rates of physical and mental health conditions, it cannot identify how these mothers could be better supported. Some research supports the use of peer support services to maintain the health and well-being in parents of children with disabilities, but to date, none have accounted for the additional pressure of being told that your child may die.

1. 'Health of mothers of children with a life-limiting condition: A comparative cohort study,' *Archives of Disease in Childhood*, published online 16 March 2021. **Full text:** http://bit.ly/3eOaYqp

Church of England study exposes depth of mourning in U.K. pandemic

U.K. (England) | *Church Times* (London) – 17 March 2021 – Most people who experienced a bereavement after the pandemic hit the U.K. in March 2020 were unable to attend the funeral, say goodbye properly, or fulfil the deceased's funeral wishes, a new Church of England study suggests.[1] The study of 2,008 people aged 18 to 75 was conducted by 9 Dot Research in January… The Church was not revealed as the sponsor, however, until specific church-related questions were introduced further on in the questionnaire. The 35 respondents who said that they worked for a religious organisation were omitted from the analysis to "avoid bias." About two-thirds (62%) of respondents said that, since the first lockdown a year ago, they had experienced a bereavement of someone whose funeral they would have attended in normal times. More than one quarter (27%) had experienced more than one bereavement. Three-quarters (72%) of bereaved people had not been able to attend the funeral. For 42% of respondents, their bereavement had been of someone close to them; ten per cent had lost more than one person whom they were close with. Most people (86%) agreed that they had not been able to say goodbye properly or fulfil funeral wishes (82%); the same percentage said that grieving people needed more support. http://bit.ly/3eOGZ1H

1. 'Funerals & Bereavement Research,' 9 Dot Research, March 2021. **Download/view at (scroll down to 'Notes to Editors'):** https://bit.ly/3s5kTfe

Specialist Publications

Challenges and facilitators in delivering optimal care at the end of life for older patients: A scoping review on the clinicians' perspective

AGING CLINICAL & EXPERIMENTAL RESEARCH | Online – 13 March 2021 – The concepts and elements determining quality of care at the end of life (EoL) may vary across professional groups, but there is consensus that high-quality care at the EoL is beneficial for the patient, families, health systems and society at large. This scoping review aimed to elucidate gaps in the delivery of this specific type of care in older people from the clinicians' perspective, and to identify potential solutions to both improve this care and promote work satisfaction by the involved clinicians. Twelve studies published since 2010 with data from 18 countries identified four major gaps: 1) Core clinical competencies; 2) Shared decision-making; 3) Healthcare system, environmental context, and resources; and, 4) Organisational leadership, culture and legislation. Multiple suggestions for staff communications training, multidisciplinary mentoring, and advance care planning alignment with patient wishes were identified. However, a clear picture arose of consistently unmet needs that have been previously highlighted in research for more than a decade. This indicates poor uptake of previous recommendations and highlights the difficulties in changing the service culture to ensure provision of optimal services at the EoL. Future investigations on the reasons for poor uptake and identification of effective approaches to execute the agreed recommendations are warranted. **Abstract (w. references):** https://bit.ly/2Q7estR

Research Matters

'Palliative and end-of-life care for sexual and gender minority cancer survivors: A review of current research and recommendations' (p.14), in *Current Oncology Reports*.

'An evaluation of the experiences of young people in patient and public Involvement for palliative care research' (p.14), in *Palliative Medicine*.

Publishing Matters

'Preferred reporting items for journal and conference abstracts of systematic reviews and meta-analyses of diagnostic test accuracy studies (PRISMA-DTA for Abstracts): Checklist, explanation, and elaboration' (p.14), in *British Medical Journal*.

'The reporting of race and ethnicity in medical and science journals' (p.15), in *Journal of the American Medical Association*.

Examining public knowledge, attitudes and perceptions towards palliative care: A mixed method sequential study

BMC PALLIATIVE CARE | Online – 17 March 2021 – Whilst the findings indicate the public may claim to be aware of the term palliative care (PC), there is an inadequate understanding of the concept, with only a fifth of the sample obtaining full scores. The current study identified 14.2% of participants had no knowledge of PC. This is consistent with previous international, and national literature. For example, a study undertaken in Northern Ireland that reported 19% of the 600 members of the public who completed a cross-sectional survey had no understanding of PC and a further 56% had very low knowledge. This also correlates with an American study … [that] … found limited understanding or PC…, with a significant proportion of the 301 participants responding "I don't know" for every item. The timing of these studies would also suggest that understanding is not improving, despite policy initiatives, media and wider public engagement strategies. Personal experience shaped many participants' views on PC and potentially their misconceptions, which is also a common thread in the literature. For example, over half of the participants … [in one] … study held a misperception about PC and were not aware of the major components. The most common misconception about PC in this study was that it is exclusively for people in the last 6 months of life. This is supported by previous literature internationally, which repeatedly reports a public perception of PC provided at the very end of life. Internationally, it is also reflected in health systems insurance policy, were PC is provided 6 months prior Other common misconceptions included a tendency to associate PC for those diagnosed with cancer, a focus on pain relief whilst other aspects such as spiritual care were not mentioned. **Full text:** http://bit.ly/38TI7hM

End-of-life care in natural disasters including epidemics and pandemics: A systematic review

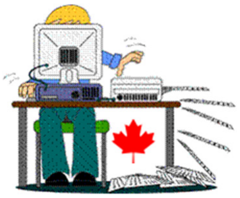
BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 March 2021 – Natural disasters are becoming more frequent and severe, and place additional strains on end-of-life (EoL) care services and users. Although EoL and palliative care (PC) are considered essential components of disaster planning and response, there are gaps in understandings about their real-life application, and how natural disasters impact end-of-life care. Thirty-six empirical studies met the authors' inclusion criteria and quality assessment. Findings were synthesised into three key themes: 1) Impacts on service provision; 2) Impacts on service providers; and, 3) Impacts on service users. This review demonstrates that natural disasters impact profoundly on EoL care, representing a stark departure from a PC approach. Clinical practitioners, policymakers and researchers must continue to collaborate for viable solutions to achieve universal access to compassionate and respectful EoL care, during natural disasters. Using models, policies and practices already developed in PC, involving those most impacted in disaster planning and anticipating barriers, such as resource shortages, enables development of EoL care policies and practices that can be rapidly implemented during natural disasters. **Abstract:** http://bit.ly/3vHgUYr

Related:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 15 March 2021 – **'International collaboration in the time of COVID-19: The World Hospice & Palliative Care Social Work Network.'** In the context of widespread loss, isolation, and grief due to COVID-19, palliative social workers came together in the fall of 2020 to form an international group named the World Hospice & Palliative Care Social Work Network. This emerging global network is committed to amplifying the innovative work, nuanced skills, research, and education and training provided by palliative social workers across different settings around the world. This article highlights some of the novel interventions developed by social workers in response to the pandemic... **Abstract:** https://bit.ly/3rWPyLy

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 15 March 2021 – **'Collateral damage of the COVID-19 pandemic: Isolation, rapid decision-making and multifaceted distress as observed by an inpatient palliative care service.'** Whether being treated for COVID-19 related complications or otherwise, patients, families, and healthcare providers are all enduring various impacts of the COVID-19 pandemic. The inpatient Palliative Care Service at the University of California, Los Angeles, has observed prevailing themes of isolation, rapid decision-making, and multifaceted distress during the COVID-19 pandemic. The authors of this article discuss lessons learned and provides resources to mitigate these additional complexities to care being provided. **Abstract:** https://bit.ly/2Np6AD3

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 15 March 2021 – **'The long shadow: Collateral impact and finding resilience amidst a global pandemic.'** This article illuminates the nuanced ways in which the COVID-19 pandemic has impacted the pediatric palliative care social work role and clinical care in caring for children with life-limiting illnesses and their families throughout the country. The authors discuss memorable moments, logistical impacts, telehealth usage, decision-making experiences, end of life care, bereavement practices, specialized interventions, and self-care. The article concludes with lessons learned and practical recommendations for the future. **Abstract:** https://bit.ly/38Ns7wr



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

Public knowledge, preferences and experiences about medical substitute decision-making: A national cross-sectional survey

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 15 March 2021 – This study describes the Australian adult public's knowledge and experiences regarding substitute decision-making for medical decisions and their preferences for obtaining more information about the substitute decision-maker (SDM) role. Less than four in ten participants reported that they had heard of, or discussed, advance care planning (ACP) and only 11% reported having documented their ACP preferences. Similarly, few participants had acted in the SDM role and the median score of two correct responses out of five in all participants indicates low to moderate knowledge about the SDM role. It is striking that only 33% of participants reported knowing that SDM laws existed in Australia. Of those who had acted in the SDM role, challenges about knowing the best decision to make and making decisions about end of life were the most frequently reported. In addition, while most ranked a health professional as their preferred source of obtaining information about how to support SDMs in their role, few participants indicated they had obtained any support in the SDM role. The Australian community's ability to appoint an SDM, and for the SDM to act appropriately, depends on awareness of the requirements of these roles. It is likely that SDMs would be more likely to advocate on behalf of the person regarding treatment preferences or use legal recourse … if they are aware of existing legislation that will support them in this process. However, this study found low awareness of ACP, limited engagement with ACP behaviours … and low to moderate SDM knowledge in the sample overall, suggesting these may be problematic. **Full text:** http://bit.ly/3lpVpX9

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 15 March 2021 – '**Bereaved families' experiences of end-of-life decision-making for general medicine patients.**' Patients and families [i.e., study participants] depended on physicians to explain clinical complexity and treatment beneficence; however, trust in medical judgement was mediated by participant's own interpretations of clinical progress. Families sought to be respected as advocates and experienced distress if physicians disregarded their perspectives and insight concerning patient preferences. Families often felt burdened by or excluded from medical decision-making and experienced distress and confusion regarding their rights to request or refuse treatment. **Abstract:** http://bit.ly/38Gdond

Faith-sensitive end-of-life care for children, young people and their families

BRITISH JOURNAL OF NURSING | Online – 18 March 2021 – This article is part of an at-a-glance series on palliation and end-of-life care (EoLC) in paediatrics and focuses on the provision of faith-sensitive EoLC. Particular religions are discussed, with some key points for care of patients from some of the most prevalent religions within the U.K. This article is intended to give points for discussion and consideration, but health professionals are encouraged to speak to every patient and family on an individual level to ensure an understanding of their personal beliefs. Although there is a range of literature discussing faith during EoLC, there is little that outlines the practical specifics and for this reason some of the supporting literature in this article is dated and, where possible, this has been supported with contemporary sources. **Abstract:** https://bit.ly/3tBe1q1

Hospital at home: Home-based end-of-life care

COCHRANE DATABASE OF SYSTEMATIC REVIEWS | Online – 16 March 2021 – The authors systematically reviewed the literature to see if the provision of end-of-life (EoL) home-based care reduced the likelihood of dying in hospital and what effect this has on patients' and caregivers' satisfaction and health service costs, compared with being admitted to a hospital or hospice. This is the fifth update of the original review. People who receive EoL care at home are more likely to die at home. There were few data on the impact of home-based EoL services on family members and lay caregivers. Several countries have invested in health services to provide care at home to people with a terminal illness who wish to die at home. The preferences of the general public and people with a terminal illness seem to support this, as most people indicate that they would prefer to receive EoL care at home. The authors included four trials in their review. They found that people receiving EoL care at home were more likely to die at home. Admission to hospital while receiving home-based EoL care varied between trials. **Abstract:** https://bit.ly/3qWiamX

Making community palliative and end-of-life care sustainable; investigating the adaptability of rural Australian service provision

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 17 March 2021 – With the increased attention and demand on community-based palliative and end-of-life (EoL) care services comes the question of how to ensure their sustainability. Sustainability has three key attributes: acceptability, affordability and adaptability. Having established the acceptability and affordability of the community-based service, this article focusses on adaptability as the remaining issue affecting long-term sustainability. The aim of this study was to identify components of the palliative and EoL service which require adaptability to ensure long-term sustainability for the service. The setting was a rural town in Victoria, Australia. Nine family members were interviewed, and 16 health professionals were interviewed or took part in a focus group. Four themes were identified: 1) The uniqueness of the patient; 2) Workforce issues; 3) Collaboration between services; and, 4) Symptom and pain management. All themes indicated that the palliative and EoL service faces challenges which may threaten the sustainability of the service and require adaptability. Families regard palliative and EoL care as special and valued, and appreciate the endeavour, care and support taken to assist their loved one to die with dignity regardless of the location and setting. With sufficient attention paid to the adaptability of the service, community palliative and EoL care service can become more sustainable, thus offering choice and dignity for people approaching the EoL. **Abstract:** https://bit.ly/3vFgNwg

Noted in Media Watch 16 March 2020 (#657, p.13):

- *PUBLIC HEALTH RESEARCH & PRACTICE* | Online – 10 March 2020 – **'Improving palliative and end-of-life care for rural and remote Australians.'** Recent reports highlight an inconsistent provision of palliative and end-of-life care across Australia, particularly in regional, rural and remote areas. A palliative approach to care is crucial in rural and remote Australia where there is a reliance for such care on generalist providers amid the challenges of a limited workforce, poorer access, and vast geography. This article describes the development and implementation of the Far West New South Wales Palliative & End-of-Life Model of Care, a systematic solution that could drive improvement in the provision of a quality palliative approach to care and support... **Full text:** http://bit.ly/335nQR4

N.B. Additional articles on the provision and delivery of palliative and EoL care in rural and remote regions of Australia noted in Media Watch 9 December 2019 (#643, p.16).

Community nurses' experiences of the Swedish Dignity Care Intervention for older persons with palliative care needs: A qualitative feasibility study in municipal home healthcare

INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING | Online – 13 March 2021 – The results of this study showed that the Swedish Dignity Care Intervention (DCI-SWE) gave community nurses (CNs) structure while providing palliative care, and it helped … to respond to their existential and sensitive needs. Healthcare professionals may have knowledge about how to nurture older people's dignity, but they do not always put their knowledge into practice. This suggests a need for interventions that are helpful in structuring care. In this study, the CNs perceived the DCI-SWE as a help to remember important aspects and said that it gave suggestions on what can be done for older people to enhance their dignity. The DCI-SWE helped the CNs who participated in this study to talk about existential and sensitive needs. It has been stated that older people often express their concerns vaguely or implicitly, but that CNs can respond to them in their communication. More knowledge on how to perform communication in a person-centred way is needed. **Full text:** https://bit.ly/3rPZ9na

Noted in Media Watch 28 January 2019 (#599, p.7):

- *BMC PALLIATIVE CARE* | Online – 24 January 2019 – **'How to conserve dignity in palliative care: Suggestions from older patients, significant others, and healthcare professionals in Swedish municipal care.'** Dignity conserving care is not just what is done for the patient, but also how the patient is viewed. This can be operationalised through specific and concrete care actions, as well as all-embracing attitudes and behaviours that conserve the patient's dignity. In adapting the dignity care intervention to a Swedish context (DCI-SWE), the authors took into consideration the perspectives of older persons with palliative care (PC) needs, their significant others, nurses and physicians. The DCI-SWE has the potential to facilitate nurses' knowledge and ensure evidence-based quality in PC. **Full text:** https://bit.ly/3vqwEP6

A critical realist evaluation of advance care planning in care homes

JOURNAL OF ADVANCE NURSING | Online – 15 March 2021 – The findings of this qualitative study showed that although the importance of advance care planning (ACP) was well recognized, the emotional labour of frequently engaging in discussions about death and dying was a problem for some care home staff. In some cases, care home staff's unmet emotional needs led them to rushing and avoiding discussions about death and dying with residents and relatives. Despite these difficulties, the authors' findings indicated a sparsity of mechanisms to support care home staff's emotional needs. A lack of training and knowledge, particularly amongst non-registered care home staff and those with non-formal caring roles, appeared to inhibit their ability to engage in meaningful care planning conversations with those living with dementia due to preconceived assumptions and communication barriers. Findings presented in this study suggest that more needs to be done to support staff to sensitively engage in discussions about death and dying to improve the quality of ACP discussions. **Full text:** https://bit.ly/3tql1G8

Advance care planning practices in the nursing home setting: a secondary analysis

THE GERONTOLOGIST | Online – 24 February 2021 – How does advance care planning (ACP) influence the relationship between resident values and clinical expertise when determining a direction of care at the time of a resident deterioration? Analysis of data from a study involving 184 hours of participatory observation, 40 semi-structured interviews, and ACP policies and document review undertaken in two nursing homes in Melbourne, Australia, may contribute towards a reductionist approach to decision-making. There is an urgent need for the development of evidence-based policy and legislation to support residents, families, and healthcare workers to make appropriate decisions. **Abstract:** https://bit.ly/3bEKq7I

N.B. This article first noted in Media Watch 1 March 2021 (#706, p.7). Additional articles on ACP in the nursing home setting, including long-term care facilities, noted in Media Watch 22 February 2021 (#705, pp.7-8).

Related:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 15 March 2021 – '**Goals-of-care conversations at the end-of-life: Perceived impact of an interprofessional training session on professional practices.**' Three months after the training, participants revealed three main changes in professional practice: 1) Better use of the unified form as a communication tool to discuss end-of-life care with patients; 2) Improved interprofessional practices in complex goals-of-care conversations situations through better affirmation of their role along with recognition of other professionals' roles in this decision-making process; and, 3) Assumption improved recognition of advocacy, support and enabler roles with patients and families during goals-of-care conversations. **Abstract:** https://bit.ly/3lp6t6Q

- *SOCIOLOGICAL RESEARCH ONLINE* | Online – 14 March 2021 – '**Preparing end-of-life talks in palliative care: Exploratory remarks on a social process.**' In this article, the authors develop an exploratory analysis of some of the interactional strategies developed by palliative care (PC) professionals in order to prepare end-of-life (EoL) talks with patients and their families, namely in the frame of specifically social problem-solving work which they develop on a daily basis. In this sense, their object of analysis is not EoL talks in themselves, but the broader social processes that tend to precede them in PC, that is, all the work both of approaching the patient and his or her family and of coordination within the teams that PC professionals routinely do in order to propitiate EoL talk. **Full text:** http://bit.ly/3s5fHrE

The intersection of oncology, nephrology, and palliative care

JOURNAL OF ONCO-NEPHROLOGY | Online – 16 March 2021 – Onco-nephrology patients share a common feature: decreased survival. This is where palliative care (PC) finds a role in managing for these patients. However, during the course of illness and its treatment, providers often overlook the importance of assessing prognosis, predicting disease trajectory, and addressing goals-of-care discussions with patients and their family. Knowing which factors portend a poor outcome in this population helps bind together the subspecialties of oncology, nephrology and PC and frame interventions within patients' treatment goals. As the life expectancies of patients suffering from cancer and kidney disease is short, knowledge of these foreboding factors helps initiate end-of-life planning which has shown to be beneficial for our patients' quality of life. **Abstract (w. references):** http://bit.ly/3r4ObsK

Leveraging telehealth for delivery of palliative care to remote communities: A rapid review

JOURNAL OF PALLIATIVE CARE | Online – 18 March 2021 – To explore strategies for increasing access to palliative care (PC) among individuals living in remote/rural communities, a rapid review was conducted on studies that explored the use of telehealth applications with this population. The 18 studies found, published between 2004 and 2019, were conducted in seven countries and on five continents. Aims included evaluating feasibility, efficacy, and user satisfaction. Insights draw from a combined pool of 3,313 patients and 250 providers. Most studies involved oncology patients and employed videoconferencing or a web platform/online software with videoconferencing. Three themes emerged: 1) Delivery of care; 2) Symptom management and quality of life (QoL); and, 3) Patient/caregiver/provider satisfaction levels. Telehealth proved effective for patient and medication monitoring, provider and specialist appointments, and PC consultations. Operational benefits included clinician time saved, shorter appointment wait times, and reduced no show rates; implementation challenges also emerged. Statistical improvements in QoL and symptom management were reported. Nearly two-thirds of the studies reported positive experiences among patients, caregivers, and providers; about half included an interprofessional team. The studies primarily focused on the structure/process and physical aspects of quality PC, there was a paucity of insights on the spiritual, cultural, end of life, and ethical/legal aspects of care. **Abstract (w. references):** http://bit.ly/30WzXzz

> **N.B.** Search back issues of Media Watch for additional articles on telehealth/telemedicine in the provision and deliver of PC at: http://bit.ly/2ThijkC

Palliative nursing competencies required for different levels of palliative care provision: A qualitative analysis of healthcare professional's perspective

JOURNAL OF PALLIATIVE MEDICINE | Online – 15 March 2021 – Nurses must possess adequate competencies to provide high-quality palliative care (PC). Earlier statements have described certain competencies that are relevant for PC, yet only limited empirical research has focused on the perspective of healthcare professionals to clarify which competencies are required for different levels of PC provision. A sample of professionals, working in different levels of PC across various settings in Finland, was used to gain information about the aim of the study. Competencies relevant to basic PC were categorized under 17 main categories, which included a total of 75 sub-categories. "Competence in managing the most common symptoms" was the main category that contained the largest number of reduced expressions. An analysis of specialist PC data yielded 10 main categories, including 49 sub-categories, with "Competence in maintaining expertise and taking care of own well-being at work" containing the most reduced expressions. The study provides new knowledge; more specifically, competencies related to encounters and maintaining hope were described as PC nursing competences. The results can be used to ensure that palliative nursing education focuses on the competences that are necessary in practice. **Abstract:** https://bit.ly/3eLgZE7

Evidence-based management of depression in palliative care: A systematic review

JOURNAL OF PALLIATIVE MEDICINE | Online – 15 March 2021 – Depression can be quite common in the palliative care population. The estimated prevalence ranges from 24% to 70%. Depression in this population leads to a decreased quality of life and may lead to a desire for an earlier death. We conducted a systematic review to establish a better understanding of the available treatment interventions, both pharmacological and nonpharmacological specific to the palliative population. Thirty-nine eligible articles were found; 29 articles examined non-pharmacological options, while 10 focused on pharmacological options. The articles discussing non-pharmacological methods discussed 22 interventions. Of the 22 interventions, 10 showed therapeutic benefit. Of the studies focusing on pharmacological interventions, seven showed therapeutic benefit. This is the first systematic review that examined both non-pharmacological and pharmacological methods to treat depression in the palliative setting. **Abstract:** https://bit.ly/2OvvPnQ

A compassionate communities approach in a grief and bereavement support program: Bridging the gap in palliative care

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 15 March 2021 – Grief and bereavement support is a fundamental component of palliative care (PC), yet there is a gap in practice as not all PC services offer it. The compassionate communities (CC) approach aims to build community capacity to address grief as grief support is considered everyone's responsibility. This study describes the characteristics, development, growth and attendees of a grief support program that uses a CC approach to bridge the gap of grief support in PC. **Abstract:** https://bit.ly/3trQec4

Defining and timing of palliative opportunities in children with central nervous system tumors

NEURO-ONCOLOGY PRACTICE | Online – 12 March 2021 – Children with brain and central nervous system (CNS) tumors experience substantial challenges to their quality of life during their disease course. These challenges are opportunities for increased subspecialty palliative care (PC) involvement. Palliative opportunities have been defined in the pediatric oncology population, but the frequency, timing, and factors associated with palliative opportunities in pediatric patients with CNS tumors are unknown. Nine palliative opportunities were defined prior to data collection (progression; relapse; admission for severe symptoms; intensive care admission; bone marrow transplant; phase 1 trial; hospice; do-not-resuscitate (DNR) order). Demographic, disease, treatment, palliative opportunity, and end-of-life (EoL) data were collected. Opportunities were evaluated over quartiles from diagnosis to death. Children with CNS tumors suffered repeated events warranting PC yet received PC support only one-third of the time. Mapping palliative opportunities over the cancer course promotes earlier timing of PC consultation which can decrease suffering and resuscitation attempts at the EoL. **Full text (click on pdf icon):** https://bit.ly/3vnq6AZ

Noted in Media Watch 8 October 2018 (#584, p.14):

- *BRAIN TUMORS IN CHILDREN* | Online – 30 September 2018 – **'Integrating palliative care into the ongoing care of children with central nervous system tumors.'** Children with brain tumors continue to experience high rates of morbidity and mortality and a substantial symptom burden, necessitating the integration of palliative care (PC) principles and practices throughout their illness trajectory. These patients experience a high number of hospital deaths, and there is often only a short interval between the initial PC consultation and death. Early introduction of PC is essential, and a broad-based approach that does not exclusively rely on consult-based PC services can help optimize the integration of PC into the continuum of care for pediatric neuro-oncology patients. **Full text:** https://bit.ly/2Q4RbbZ

Beyond last words: Patterns of linguistic and interactional behavior in a historical sample of dying hospital patients

OMEGA – JOURNAL OF DEATH & DYING | Online – 15 March 2021 – Patterns of linguistic and interactional behavior by people at the very end of their lives are not well described, partly because data is difficult to obtain. This paper analyzes descriptions of 486 deaths gathered from 1900 to 1904 in the first-ever clinical study of dying by noted Canadian physician, Sir William Osler. Only 16 patients were noted speaking, and only four canonical last words were reported. The most frequent observation by medical staff was that the deaths were quiet, though range of other behaviors were noted (e.g., moaning, delirium, seeming intention to speak). Osler's problematic study left behind data whose analysis is a small step toward empirically characterizing the linguistic and interactional details of a previously under-described phenomena as well as the importance of the social context in which they occur. **Full text:** http://bit.ly/3rTQwIu

Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

Specialist palliative care staff's varying experiences of talking with people with intellectual disability about their dying and death: A thematic analysis of in-depth interviews

PALLIATIVE MEDICINE | Online – 17 March 2021 – The cognitive and communication challenges experienced by people with intellectual disability present difficulties for health professionals, particularly in the face of illness and dying. Specialist palliative care (PC) staff [i.e., study participants] did not consistently talk with people with intellectual disability about their dying and death. Conversations were influenced by: 1) The perceived capacity of the person with intellectual disability; 2) Experience and expertise of PC staff; 3) The relationship between PC staff and dying person; and, 4) Values of PC staff and other caregivers (namely family members and paid carers). Specialist PC staff experience difficulties in talking with people with intellectual disability about their dying. Development of communication guidelines, resources and training for PC teams are urgently required to improve PC for this patient group. A more comprehensive research agenda on the needs of people with intellectual disability and their caregivers in PC is needed, with a particular focus on strategies to effectively communicate about dying and death. **Abstract (w. references):** http://bit.ly/30SHorN

> **N.B.** Search back issues of Media Watch for additional articles on EoL care for people living with intellectual or developmental disabilities at: http://bit.ly/2ThijkC

A systematic review of quality improvement initiatives for continuous sedation until death

PALLIATIVE MEDICINE | Online – 15 March 2021 – Twenty-one studies met the authors' criteria... Initiatives were focused on assessment tools of consciousness and discomfort (9), the use of guidelines and protocols (8), and expert consultation (3). All initiatives were reported as useful, acceptable, and feasible. Studies on the use of monitoring devices showed that a small proportion of patients were found to be awake, despite the patient being unresponsive according to the observer-based sedation scales. However, the wide range of values of these monitoring devices for comfortable and adequately sedated patients seems to hamper its overall implementation in daily clinical practice. Physicians reported changes in practice conform to guideline recommendations but the shift was modest at best. Expert consultation was regarded as supportive when sufficient expertise is lacking and helpful in avoiding possibly unnecessary sedations. The reviewed initiatives may contribute to improvement of continuous sedation until death, though their evidence base is rather limited. More insight is needed into their feasibility, preconditions for effective implementation and impact in actual practice. **Abstract (w. references):** http://bit.ly/3qS4EjZ

> **N.B.** Search back issues of Media Watch for additional articles on continuous sedation (i.e., palliative or terminal sedation) at: http://bit.ly/2ThijkC

The inaugural U.S. World Hospice & Palliative Care Day Celebration: A virtual coming together

PALLIATIVE & SUPPORTIVE CARE | Online – 15 March 2021 – The Worldwide Hospice Palliative Care Alliance initially launched World Hospice & Palliative Care Day (WHPCD) in 2005 as an annual unified day of action to celebrate and support hospice and palliative care (PC) around the world. A U.S.-based innovative virtual conference featured 23 interprofessional hospice and PC specialists and patient and family caregiver speakers across nine diverse sessions addressing priorities at the intersection of COVID-19, social injustice, and the global burden of serious health-related suffering. Two primary aims guided the event: community building and wisdom sharing. Nearly 270 registrants from at least 16 countries and one dozen states across the U.S. joined the free program focused on both personal and professional development. Unlike many other academic conferences and professional gatherings that were relegated to online forums due to pandemic-related restrictions, the U.S. WHPCD celebration was intentionally established to create a virtual coming together for collective reflection on the barriers and facilitators of PC delivery amid vast societal change. The goal to ensure a globally relevant and culturally inclusive agenda will continue to draw increased participation at an international level during future annual events. **Abstract (w. references):** http://bit.ly/2ORYFOT

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

PROGRESS IN PALLIATIVE CARE | Online – 19 March 2021 – 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 (PEoLC). 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. It aimed to seek their views, and those of their carers, on their experiences and expectations of accessing PEoLC and to understand how PEoLC for people with SMI could be improved. Four over-arching themes were developed. 1) Stigma and prejudice – see me, not my diagnosis; 2) Hesitancy and avoidance – treading on eggshells; 3) Collaborators in care – the ignored experts; and, 4) Connections – leaning in, not stepping back. This study presents the first accounts from the U.K. concerning experiences of PEoLC, barriers to access and how care can be improved, from the perspectives of patients with both a SMI and an incurable physical condition and their carers. The findings illuminate an under-researched area of clinical practice and contribute rich understandings to future service developments and innovations. **Abstract:** https://bit.ly/30XohwA

Infusing the palliative into paramedicine: Inter-professional collaboration to improve the end of life care response of U.K. ambulance services

PROGRESS IN PALLIATIVE CARE | Online – 14 March 2021 – Paramedics frequently encounter patients requiring palliative and end-of-life care (EoLC). This is anticipated to increase with an ageing U.K. population, a strengthening preference for care and death to occur in the home, alongside pressurized community services. Nationally education is lacking and despite localized efforts of improvement, widespread change within ambulance services to advance the quality of care for this patient group has been slow to emerge. The authors describe two U.K. ambulance service improvement programmes that have sought to address this need. South Western Ambulance Service NHS Foundation Trust and London Ambulance Service NHS Trust collaborated with a nationally renowned charity, Macmillan Cancer Support, to create innovative programmes of change. Both services targeted data exploration, valued inter-professional learning and effectively engaged local stakeholders. Experience demonstrates the need for collaboration with specialist palliative care (PC) and dependence on community services to access support and alternatives to hospital conveyance. The authors consider the future for EoLC leadership in U.K. ambulance services and the development of specialist paramedic roles. While the future of an alliance of paramedicine and PC is yet to be fully realized, our work exhibits the significant progress made by U.K. ambulance services. **Abstract:** https://bit.ly/3lgHvXn

Noted in Media Watch 8 March 2021 (#707, p.12):

- *PROGRESS IN PALLIATIVE CARE* | Online – 4 March 2021 – ‘**A national collaborative to spread and scale paramedics providing palliative care in Canada: Breaking down silos is essential to success.**’ A national collaborative has been launched in Canada to spread and scale up the Paramedics Providing Palliative Care model. This builds on the knowledge that paramedics in the 9-1-1 (emergency/unscheduled) and scheduled models of care are both historically and currently asked by the public to provide urgent symptom relief within the context of a palliative approach, and that approximately 40% of dying people visit the emergency department in the last two weeks of life despite 70% wishing to die at home. **Abstract:** https://bit.ly/3uVk8XB

N.B. Search back issues of Media Watch for additional articles on the role of paramedics in palliative and EoLC at: http://bit.ly/2ThijkC

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Research Matters

Palliative and end-of-life care for sexual and gender minority cancer survivors: A review of current research and recommendations

CURRENT ONCOLOGY REPORTS | Online – 14 March 2021 – Sexual and gender minority (SGM) cancer survivors – post-diagnosis to end-of-life (EoL) – can face inadequate services along the cancer care continuum, including palliative and EoL care. A growing literature base calls for more research on factors influencing palliative and EoL care access, outcomes, and distinct needs of SGM cancer survivors and caregivers. The authors analyzed peer-reviewed articles published 2015-present to identify trends. Ten articles were SGM-focused or inclusive, cancer-focused, and included substantive discussion of palliative and/or EoL care. Four were research studies (three case studies and one qualitative interview study) and six were literature reviews. Recurrent topics included disparities in cancer risk, access, and care; essential cultural and clinical competencies; and need for professional and organizational standards and policies addressing interpersonal and institutional discrimination and inclusion. Provision of equitable, competent palliative and EoL care depends on continued advancements in research, translated into person-centered approaches to care. The authors discuss implications of findings for improving palliative and EoL care for SGM cancer survivors. **Abstract (w. references):** https://bit.ly/3twoenJ

An evaluation of the experiences of young people in patient and public Involvement for palliative care research

PALLIATIVE MEDICINE | Online – 17 March 2021 – This evaluation provides new insights into the perspectives of young people involved in a palliative care (PC) research study. The findings of the evaluation support published guidance highlighting the importance of involving young people in research about their care. The insights provided should encourage researchers to involve young people, despite the potentially sensitive nature of PC research. Previous research suggests that young people do not want their involvement to be tokenistic, and researchers can be criticised if they fail to engage or update young people as the research progresses. These challenges can be overcome through the development of relationship between the researcher and the group over the time course of the study, with regular feedback and updates on the progress of the study and the impact of their involvement. **Full text:** http://bit.ly/2OEQhT2

Publishing Matters

Preferred reporting items for journal and conference abstracts of systematic reviews and meta-analyses of diagnostic test accuracy studies (PRISMA-DTA for Abstracts): Checklist, explanation, and elaboration

BRITISH MEDICAL JOURNAL | Online – 15 March 2021 – For many users of the biomedical literature, abstracts may be the only source of information about a study. Hence, abstracts should allow readers to evaluate the objectives, key design features, and main results of the study. Several evaluations have shown deficiencies in the reporting of journal and conference abstracts across study designs and research fields, including systematic reviews of diagnostic test accuracy studies. Incomplete reporting compromises the value of research to key stakeholders. The authors of this article have developed a 12-item checklist of preferred reporting items for journal and conference abstracts of systematic reviews and meta-analyses of diagnostic test accuracy studies (PRISMA-DTA for Abstracts). The authors of this article presents the checklist, examples of complete reporting, and explanations for each item of PRISMA-DTA for Abstracts. **Full text:** http://bit.ly/3czaVMq

Would the *British Medical Journal* article be of interest to a colleague?

The reporting of race and ethnicity in medical and science journals

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2021;325(11):1049-1052. For many years and increasingly in the last year, *JAMA* and the *JAMA Network* journals have published many important articles addressing disparities and racism in medical education, research, and healthcare and highlighting initiatives to help address deep-rooted inequities. In these articles, as in others, terminology, usage, and word choice are critically important, especially when describing people and when discussing race and ethnicity. Inclusive language supports diversity and conveys respect. Language that imparts bias toward or against persons or groups based on characteristics or demographics must be avoided. The indistinct construct of racial and ethnic categories has been increasingly acknowledged, and the important sensitivities and controversies related to use of these terms in medical and health research, education, and practice have been progressively recognized. Accordingly, for articles published in medical and science journals, language and terminology must be accurate, clear, and precise, and must reflect fairness, equity, and consistency in use and reporting of race and ethnicity. **Full text:** http://bit.ly/3rXWGHE

Media Watch: Access on Online

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

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

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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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