

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.

19 April 2021 Edition | Issue #713



Compilation of Media Watch 2008-2021 ©

Compiled & Annotated by Barry R. Ashpole

Cultivate disproportionate attentiveness to the suffering of Black people, Indigenous people, and other people of color; when you see their disproportionate suffering, provide them with disproportionate care and support.

'In this together: Navigating ethical challenges posed by family clustering during the COVID-19 pandemic' (p.12), in *The Hastings Report*.

Canada

Group asks for more funding for grief counselling: “Canadians have been robbed of goodbyes”

NOVA SCOTIA | *Halifax Examiner* – 16 April 2021 – As the pandemic continues to take its toll, a national organization is calling on the federal government to include \$30 million in its upcoming budget as an emergency measure to support local grief services across Canada. “Basically we’re saying that a whole year has passed, there hasn’t been action, and the amount that we’re talking about is \$30 million dollars,” Paul Adams, co-founder of the Canadian Grief Alliance, said in an interview from Ottawa. “When you put that in the context of the Air Canada bailout with a \$5 billion dollar loan and half a billion in equity...it’s a rounding error on a rounding error in terms of the federal budget, but it would make a huge difference in people’s lives.” In a media release, members of the Canadian Grief Alliance demanded more funding to help Canadians as they cope with a “parallel pandemic of grief” caused by deaths (not just COVID-19 related) and other losses over the last year. “What we know is that when grief is unsupported, when it’s complicated, it can often lead to mental health issues such as depression, anxiety, and suicidal ideation,” Adams said. “And of course, that means absenteeism at work, difficulty in studies, and these kinds of things.” The organization was created last year at the begin-

ning of the pandemic as members realized the impact COVID-19 deaths would have on Canadians. But they also acknowledged early on that public health protocols would change the way we mourn and grieve all deaths, regardless of their cause. <https://bit.ly/3akaC7M>

Specialist Publications

‘The association between varying levels of palliative care involvement on costs during terminal hospitalizations in Canada from 2012 to 2015’ (p.5), in *BMC Health Research*.

‘Hospice care providers’ experiences of grappling with medical assistance in dying in a hospice setting: A qualitative descriptive study’ (p.7), in *BMC Palliative Care*.

‘A good death: Non-negotiable personal conditions for clinicians, healthcare administrators and support staff’ (p.5), in *BMJ Supportive & Palliative Care*.

‘Disparities in access to palliative care facilities for patients with and without cancer: A retrospective review’ (p.6), in *Palliative Medicine*.

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>

U.S.A.

The grief crisis is coming

THE NEW YORK TIMES | Online – 12 April 2021 – The end of the COVID-19 crisis in the U.S. is in sight, thanks to effective vaccines being deployed on a massive scale. But the still growing death toll will leave behind millions of bereaved people, wracked by the suffering that the loss of a loved one can bring. This is a public health crisis with consequences that may last generations, and for which we do not currently have the policy tools or resources to address. We first need to get a sense of the scope of our national grief. Researchers are just beginning to count the bereaved, and while current estimates suggest five million Americans have lost a loved one to COVID-19, the final tally is likely to be much larger. Ashton Verdery, an associate professor of sociology and demography at Pennsylvania State University, recently led a study that introduced the COVID-19 Bereavement Multiplier.¹ By his team’s calculus, for every person who dies of COVID-19, nine loved ones are left behind. To arrive at that number, the researchers included the losses of spouses, siblings, parents, children and

grandparents. If other relationships like nieces, nephews, aunts, uncles, stepparents and friends are taken into account, “you may get 10 times or more” people in grief, Mr. Verdery said. A recent study found that at least 37,000 children in the U.S. have lost a parent to COVID-19 so far.² <https://nyti.ms/32ltvDf>

Specialist Publications

‘Ten Urgent Priorities Based on lessons learned from more than a half million known COVID-19 cases in U.S. prisons’ (p.12), in *American Journal of Public Health*.

‘Palliative medicine integration in the U.S.: Cancer centre executives’ attitudes’ (p.8), in *BMJ Supportive & Palliative Care*.

‘Completion of advance directives among African Americans and Whites adults’ (p.14), in *Patient Education & Counseling*.

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>
2. ‘Estimates and projections of COVID-19 and parental death in the U.S.,’ *JAMA Pediatrics*, published online 5 April 2021. [Noted in Media Watch 12 April 2021 (#712, p.2)] **Full text:** <https://bit.ly/3fRVoku>

Noted in Media Watch 8 February 2021 (#703, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 5 February 2021 – **‘Witnesses and victims both: Healthcare workers and grief in the time of COVID-19.’** With the scope and unpredictability of the ongoing COVID-19 public health crisis, we must acknowledge a growing, global mental health crisis, including among healthcare workers (HCWs). While no one can predict definitively what it takes for HCWs to mourn, grieve, process, and heal in the time of COVID-19, it is imperative to try to prevent when possible and mend when necessary the psychological injury being caused by the pandemic. Clearly, much research is needed into how to prevent and treat complicated grief in patients as well as in HCWs in the time of COVID-19. **Full text:** <https://bit.ly/3rtXd3q>

International

Classifying place of death in Australian mortality statistics: A pilot study applying a framework for the classification of place of death to the Australian mortality dataset

AUSTRALIA | Australian Bureau of Statistics – 14 April 2021 – Place of death, the location or setting in which an individual dies, is an important indicator for end-of-life care (EoLC). With the number of Australians aged 85 years and over expected to double to more than one million people by 2042, the importance of information on place of death from an economic and health service provision perspective will continue to grow. EoLC is a focus for all levels of government, with the 2018 National Palliative Care Strategy focused on ensuring the highest possible level of palliative care (PC) is available to all people,¹ and the Palliative Care Outcomes Collaboration focused on improving PC patient and carer outcomes.² Despite the value of place of death data, there are currently no nationally consistent systems in place to accurately monitor statistics relating to place of death in Australia... The Australian Productivity Commission highlighted this as a data gap and recommended the establishment of a “national minimum data set for EoLC (including collecting and publishing linked information on place of death,

primary and secondary diagnoses and details of service provision at time of death).”³ Given the increasing importance of information on place of death, the Australian Bureau of Statistics commenced a pilot project to examine ways of corraling source data into meaningful and usable information. This article provides information on how this project was conceptualised and how data was coded and analysed. Initial results are presented with an aim to assess the quality of the outputs and the feasibility of including place of death as an integrated part of the national mortality dataset into the future. <https://bit.ly/32gc7zG>

Specialist Publications

‘What constitutes a palliative care need in people with serious illnesses across Africa? A mixed-methods systematic review of the concept and evidence’ (p.13), in *Palliative Medicine*.

1. ‘The National Palliative Care Strategy 2018,’ Department of Health, Government of Australia, February 2018. **Download at:** <https://bit.ly/2ZHAK7t>
2. Palliative Care Outcomes Collaboration, University of Wollongong: <https://bit.ly/3e7BB7X>
3. ‘Reforms to Human Services,’ Productivity Commission, Australian Government, March 2018. [Draft of the report noted in Media Watch 5 June 2017 (#515, p.4)]. <http://bit.ly/3q9Q1s8>

“Quietly dying on the streets”: Medical charity helps the homeless in St. Petersburg

RUSSIA | Radio Free Europe – 14 April 2021 – The winter months are especially harsh for the homeless in Russia’s northern city of St. Petersburg, especially for those suffering serious medical problems. “Recovering from many illnesses in the winter and on the streets is impossible. After release from the hospital, they end up back on the streets in conditions that aren’t conducive to recovery,” said Sergei Iyevkov, the founder and direct of Charity Hospital, which has more than 100 volunteers -- including dozens of doctors -- delivering healthcare to the homeless. An estimated 50,000 people in St. Petersburg, Russia’s second-largest city, are believed to lack a permanent home. Beyond the daily struggle to find food and shelter, those in need of medical attention face further hurdles. Many lack health insurance or even basic identification documents. Without those, only emergency wards and the city’s sole specialized hospital for infectious diseases will treat them. Discrimination and hostility on the part of some healthcare workers also dissuades many of the homeless from seeking hospital treatment, experts say. And even if they are treated for an illness, many of them never fully recover. Charity Hospital and other non-government organizations (NGO) -- including the Bus of Mercy, which is run by the Russian Orthodox Church -- are providing the much-needed help the homeless aren’t getting elsewhere. Much of the medical care Charity Hospital is dispensing is done inside vans, including the Bus of Mercy and the Night Bus, run by another NGO, Nochlezhka. <https://bit.ly/3uWFdQZ>

Next Welsh government must make sure seriously ill children can access hospice respite breaks and 24/7 end-of-life care at home

U.K. (Wales) | Together for Short Lives – 14 April 2021 – The U.K. charity for children’s palliative care (PC), is urging the next Welsh Government to address the postcode lottery faced by families of seriously ill children in accessing end-of-life care (EoLC) at home. There is a shortfall of 240 community children’s nurses across Wales. This significant gap means that many seriously ill children are unable to access palliative and EoLC at home. Children’s hospices Tŷ Hafan and Tŷ Gobaith receive less than 10% of their annual funding from the Welsh Government – the poorest levels of government funding across the U.K. Together for Short Lives is calling on the next Welsh Government to sustainably fund children’s PC in the community and in children’s hospices. The charity is also calling on the parties contesting the Senedd elections to sustainably fund Wales’ children’s hospices if they form the next Welsh Government in May. Together for Short Lives’ new briefing ... shows that a significant gap in Wales’ community children’s nursing (CCN) workforce.¹ 240 CCNs are needed across the country. CCNs play a crucial role in providing PC to seriously ill children, who need access to them 24 hours a day, seven days a week if they and their families choose to access EoLC at home. Currently there only 43 CCNs out of the 283 CCNs needed in total across Wales, which means too many children and families are missing out on the care and support they need – when and where they need it. It also means that too many seriously ill children need unplanned, prolonged emergency hospital admissions, when their needs could potentially have been met at home. <https://bit.ly/3tnlmtQ>

1. ‘Ensuring every seriously ill child in Wales can access the palliative care they need: policy priorities for the next Welsh Government,’ Together for Short Lives, April 2021. **Download at:** <https://bit.ly/3dgP91n>

N.B. Additional articles on funding children’s hospices in Wales noted in Media Watch 29 March 2021 (#710, p.3).

[Specialist Publications](#)

Examining the role of specialist palliative care in geriatric care to inform collaborations: A survey on the knowledge, practice and attitudes of geriatricians in providing palliative care

AGE & AGEING | Online – 9 April 2021 – Given specialist palliative care (PC) has been shown to improve overall care and reduce healthcare costs, how best to provide this care to older people is internationally significant. This was a voluntary anonymous online survey, distributed to all full members of the Australian & New Zealand Society of Geriatric Medicine. 168 completed responses were received; 58.3% were female and 36.6% had over 20 years of clinical experience. Most geriatricians (85%) reported caring for patients in their last 12 months of life represented a substantial aspect or most of their practice. Geriatricians overwhelmingly believed they should coordinate care (84%) and derived satisfaction from providing PC (95%). The majority (69%) believed all patients with advanced illness should receive concurrent specialist PC. Regarding knowledge, participants scored an average of 13.5 correct answers out of 18 in a Modified Palliative Care Knowledge Test. Geriatricians find reward in

providing generalist PC to their patients; however, potential exists for improved collaborations with specialist PC services. An evidence base for geriatric patients who benefit most from specialist PC services is needed to improve resourcing, collaborative practice and ultimately PC delivery. **Full text:** <https://bit.ly/3g0MLO9>

[Research Matters](#)

‘Mapping an agenda for psychedelic-assisted therapy research in patients with serious illness’ (p.15), in *Journal of Palliative Medicine*.

[Publishing Matters](#)

‘Opinion: The rise of preprints is no cause for alarm’ (p.16), in *The Scientist*.

Cont.

Noted in Media Watch 15 February 2021 (#704, p.7):

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 13 February 2021 – ‘**Geriatrics and palliative medicine leadership is needed now more than ever: What are the training gaps?**’ Geriatrics and palliative medicine specialists are uniquely trained to provide expert coordinated care for older adults and seriously ill and complex patients. Health system leadership geared towards this patient population is critically important as Society ages. To assess the leadership training needs of geriatrics and palliative medicine fellowship graduates, the authors conducted a needs assessment to identify: 1) Early career leadership trajectories and challenges; and, 2) Knowledge and skills deemed essential for effective leadership. **Abstract:** <https://bit.ly/3qikTHv>

Noted in Media Watch 8 February 2021 (#703, p.9):

- *EUROPEAN GERIATRIC MEDICINE* | Online – 1 February 2021 – ‘**Palliative care competencies for geriatricians across Europe: A Delphi consensus study.**’ Early identification of patients in need of palliative care (PC) becomes crucial in particular for older patients with chronic conditions. The Delphi process described enabled the development of a European specific core competency catalogue to improve competencies of geriatricians to enable them to guide their patients through the last period of life. The current version of the PC competency catalogue represents an important step in the development of effective PC education within the training of geriatricians, which is essential given the condition’s increasing relevance to twenty-first century healthcare. **Full text:** <https://bit.ly/36wpzSo>

N.B. The final version of core PC competences recommended by the European Geriatric Medicine Society included 35 competencies: <https://bit.ly/3oLrw3u>

Palliative and end-of-life care in Canada

The association between varying levels of palliative care involvement on costs during terminal hospitalizations in Canada from 2012 to 2015

BMC HEALTH RESEARCH | Online – 13 April 2021 – Inpatient palliative care (PC) is associated with lower inpatient costs; however, this has yet to be studied using a more nuanced, multi-tiered measure of inpatient PC... Using a population-based cohort of Canadians who died in hospital, the authors’ objectives were to: describe patients’ receipt of PC and active interventions in their terminal hospitalization; and, examine the relationship between inpatient PC and hospitalization costs. There were 250,640 adults who died in hospital. Mean age was 76, 47% were female. The most common comorbidities were: metastatic cancer (21%), heart failure (21%), and chronic obstructive pulmonary disease (16%). Of the decedents, 95,450 (38%) had no PC involvement, 98,849 (38%) received low involvement, and 60,341 (24%) received medium to high involvement. Controlling for age, sex, province and predicted hospital mortality risk at admission, the cost per day of a terminal hospitalization was: \$1,359 ... (no involvement), \$1175 ... (low involvement), and \$744 ... (medium-high involvement). Increased involvement of PC was associated with lower costs. Future research should explore whether this relationship holds for non-terminal hospitalizations, and whether PC in other settings impacts inpatient costs. **Full text:** <https://bit.ly/3uHjXhU>

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 12 April 2021 – ‘**A good death: Non-negotiable personal conditions for clinicians, healthcare administrators and support staff.**’ All 3,495 clinical, administrative and support staff of a healthcare network were asked to rank 10 conditions according to how non-negotiable they would be for themselves during their final 3 months or few hours for their own deaths to be considered as good. They were asked about whether they had thought about their own death in the last 3 months, if they had a will, believed in God, and in the possibility of a good death... Most of conditions for a good death of interest to healthcare professionals could be provided without sophisticated medical infrastructure or specialised knowledge... **Abstract:** <https://bit.ly/3g5qMFM>

Cont. next page



Would the *BMC Health Research* article be of interest to a colleague?

- *PALLIATIVE MEDICINE* | Online – 15 April 2021 – ‘**Disparities in access to palliative care facilities for patients with and without cancer: A retrospective review.**’ This study is the first to examine characteristics of patients who are referred and accepted into palliative care beds. The authors found a significant inequity between patients with and without cancer, representing a potential system-level discrepancy that needs to be addressed. Other factors that appeared to affect equality of access were functional status, anticipated prognosis, and presence of care needs. However, patients with the poorest performance status and prognosis, who were over-represented in the non-cancer group, tended to be disadvantaged in terms of acceptance for admission. **Full text:** <https://bit.ly/3tnq9eA>

The impact of uncertainty on bereaved family’s experiences of care at the end of life: A thematic analysis of free text survey data

BMC PALLIATIVE CARE | Online – 13 April 2021 – This study highlights the ongoing impact on bereaved family when uncertainty is not made explicit in conversations regarding end of life (EoL) for people with heart disease. Timely and sensitive conversations regarding the uncertainty of when death may occur is an important factor in ensuring that bereaved family are not left with unresolved narratives, i.e., feelings of missed opportunities, uncertainty that they had made the right decisions, and lack of clarity around their relative’s death. These impacts may remain present indefinitely. The authors offer some reframes for thinking and talking about uncertainty in EoL, as this and other studies have shown that clinicians’ uncertainties may not always reflect or match up with families’ uncertainties. Being explicit about physicians’ inability to be certain about the timing of death may thus lead to a more positive and complete experience for bereaved family. **Full text:** <https://bit.ly/3aajptb>

“It’s given me confidence”: A pragmatic qualitative evaluation exploring the perceived benefits of online end-of-life education on clinical care

BMC PALLIATIVE CARE | Online – 13 April 2021 – A key finding in this study was the participants’ self-reported enhanced confidence to initiate or engage in discussions about end-of-life (EoL) care with patients, carers and colleagues following module completion. Improving confidence to engage in EoL care discussions is important as patient satisfaction with care has been found to improve when health professionals (HPs) engage in EoL discussions in a timely manner. Enhancing HPs’ ability to initiate these conversations is vital as patients don’t always speak up about approaching EoL, assuming the health professional will initiate this. Engaging in EoL care with patients has been identified as one of the most challenging but most important considerations for HPs when caring for people at the EoL. Although communication skills training is included in most health professional education, minimal time is spent on how to broach EoL conversations. The modules provided a framework by which HPs could proactively respond to patient and carer needs. Participant responses in this study are consistent with other research that identifies a need for communication skills training, how to best care for family carers and improvement in multidisciplinary team communication about patient and carer needs. Since its launch, more than 20,000 HPs have registered with End-of-Life Essentials with over 36,000 module completions, indicating an interest in this general level of education about EoL care. Self-directed learning is considered an adaptive response, empowering people to work in complex changeable workplaces. However, research also that suggests informal self-directed learning competence requires active cultivation. **Full text:** <https://bit.ly/3wW9vor>



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>

Hospice care providers' experiences of grappling with medical assistance in dying in a hospice setting: A qualitative descriptive study

BMC PALLIATIVE CARE | Online – 12 April 2021 – The introduction of medical assistance in dying (MAiD) in Canada represents a new and evolving choice for end-of-life care (EoLC) which has affected the dynamic of care within the hospice environment. The experience of navigating MAiD within a non-provider context challenged care providers to rethink and redefine their roles and left some uncertain about how best to support their patients and others. Care providers worked to navigate the uncharted territory of the MAiD trajectory within a non-provider hospice setting and sought to remedy the moral complexities, philosophical fit, and practical challenges of MAiD, while focusing on provision high quality patient-centered care. The initiation and provision of MAiD gave rise to a disrupted, distinct, and fragmented care pathway, one that excluded most of those at the frontline of hospice care. The different pathway for those who chose MAiD may lead some care providers to struggle with relational challenges and interpersonal unease. To deliver high quality palliative EoLC, framed through a patient and family approach and emphasizing whole person care in the hospice care environment, each member of the interdisciplinary care team needs to be able to access necessary education and supports. Therefore, a multi-faceted range of clinical, regulatory, and logistical supports at the practice, organizational, and health system levels are needed to specifically address care providers role since introduction of MAiD. Further research may also be warranted to address how these supports impact care providers within the hospice context. **Full text:** <https://bit.ly/3sgHEvP>

Noted in Media Watch 12 April 2021 (#712, p.1):

- CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS | Online – 31 March 2021 – ‘**Canadian Society of Palliative Care Physicians submission to College of Physicians & Surgeons of Ontario consultation on medical assistance in dying and professional obligations and human rights policies.**’ Palliative care (PC) must remain distinct from medical assistance in dying (MAiD) to ensure clarity and to avoid the risk of confusion and the potential for people to refuse PC services. This does not, however, preclude people who contemplate, request, or opt for MAiD from receiving PC. This is particularly vital for people in communities that have an underlying distrust of the healthcare system who decline PC because they may confuse it with MAiD. **Download Society’s brief at:** <https://bit.ly/3dERsdP>

Noted in Media Watch 18 January 2021 (#700, p.11):

- *CANADIAN JOURNAL OF NURSING RESEARCH* | Online – 12 January 2021 – ‘**Hospice care provider perspectives of medical assistance in dying in a Canadian hospice that does not provide medical assistance in dying.**’ Participants in this study included hospice administrators, nurses, staff and volunteers who provide care at an in-patient hospice facility in a geographically isolated medium sized city ... in a western Canadian province. Introduction of medical assistance in dying (MAiD) challenged and disrupted care practices, for example, situating MAiD within hospice and palliative care, caring for patients undergoing MAiD within a non-provider facility, and balancing interpersonal dynamics in an interdisciplinary team environment. **Abstract (w. list of references):** <http://bit.ly/3qr09x7>

Related:

- *CMAJ OPEN* | Online – 13 April 2021 – ‘**Assessment of capacity to give informed consent for medical assistance in dying: A qualitative study of clinicians’ experience.**’ Under the Canadian Criminal Code, medical assistance in dying (MAiD) requires that patients give informed consent and that their ability to consent is assessed by two clinicians. The participants in this study were comfortable doing MAiD assessments and used their clinical judgment and experience to assess capacity in ways similar to other clinical practices. The findings of this study suggest that experienced MAiD assessors do not routinely require formal capacity assessments or tools to assess capacity in patients requesting MAiD. **Full text:** <https://bit.ly/3e0okO9>



Share this issue of Media Watch with a colleague

Palliative medicine integration in the U.S.: Cancer centre executives' attitudes

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 12 April 2021 – The authors sought to compare cancer centre (CC) executives' attitudes towards palliative care (PC) between National Cancer Institute-designated CCs (NCI-CCs) and non-NCI-designated CCs (non-NCI-CCs) in 2018 and to examine the changes in attitudes and beliefs between 2009 and 2018. CC chief executives at all NCI-CCs and a random sample of non-NCI-CCs were surveyed from April to August 2018. Twelve questions examined the executives' attitudes towards PC integration, perceived barriers and self-assessments. The primary outcome was agreement on the statement “a stronger integration of PC services into oncology practice will benefit patients at my institution.” 52 of 77 (68%) NCI-CCs and 88 of 126 (70%) non-NCI-CCs responded to a survey. A vast majority of executives at NCI-CCs and non-NCI-CCs endorsed PC integration (89.7% vs 90.0%). NCI-CCs were more likely to endorse increasing funding for PC (52.5% vs 23.1%) and hiring physician specialists (70.0% vs 37.5%) than non-NCI-CCs. The top three perceived barriers among NCI-CCs and non-NCI-CCs were limited institutional budgets (57.9% vs 59.0%), poor reimbursements (55.3% vs 43.6%), and lack of adequately trained PC physicians and nurses (52.6% vs 43.6%). Both NCI-CCs and non-NCI-CCs favourably rated their PC services (89.7% vs 71.8%) with no major changes since 2009. CC executives endorse integration of PC, with greater willingness to invest in PC among NCI-CCs. Resource limitation continues to be a major barrier. **Abstract:** <https://bit.ly/3mGMrFP>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 April 2021 – ‘**Increasing readiness for early integrated palliative oncology care: Development and initial evaluation of the EMPOWER 2 intervention.**’ Using feedback from four stakeholder meetings, the authors developed a multimedia intervention tailored to three levels of health-literacy. The intervention provides knowledge and reassurance about the purpose and nature of palliative care (PC), addressing cognitive and emotional barriers to utilization. This formative research outlines the development of a psychoeducational intervention about PC. This study will guide clinical teams in improving patients' readiness for PC and inform the forthcoming EMPOWER 3 randomized clinical trial. **Abstract (w. references):** <https://bit.ly/3mUUPLj>

Underutilisation of Electronic Palliative Care Coordination Systems in end-of life-care: A cross-sectional study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 9 April 2021 – To support greater personalisation of end-of-life care, Electronic Palliative Care Coordination Systems (EPaCCS) have been implemented across England. The authors describe patient factors associated with dying with an EPaCCS record and explore the association between having an EPaCCS record with cause and place of death. Data were extracted from primary care records in 20 of 86 general practices within one Clinical Commissioning Group in England. All deaths recorded between 22 February 2018 and 21 February 2019 were included to determine whether the deceased patient had an EPaCCS record at the time of death, a range of demographic factors, place of death and cause of death. Only 18% of the sample died with an EPaCCS record, and people who died of a non-cancer cause were less likely to have an EPaCCS record than those who died of cancer. Adjusting for patient demographic factors and cause of death, having an EPaCCS record was strongly associated with dying in the community. A small proportion of this sample died with an EPaCCS record, despite evidence of an association with dying in the community. **Abstract:** <https://bit.ly/3dVer4w>

Noted in Media Watch 8 February 2021 (#703, p.7):

- *BMJ EVIDENCE-BASED MEDICINE* | Online – 29 January 2021 – ‘**Using routine databases to evaluate Electronic Palliative Care Co-ordination Systems.**’ In response to the government's drive to expand Electronic Palliative Care Co-ordination Systems (EPaCCS) across England by 2020, further evidence for this intervention needs to be established quickly. With palliative and end-of-life care research being an underfunded area, the availability and lower costs of routine databases make it an attractive resource to integrate into studies evaluating EPaCCS without jeopardising research quality. This article describes how routine databases can be used to address the current paucity of high-quality evidence... **Abstract:** <http://bit.ly/2Yt03sZ>

N.B. Additional articles on EPaCCS noted in this issue of Media Watch.

Goal of a “good death” in end-of-life care for patients with hematologic malignancies: Are we close?

CURRENT HEMATOLOGIC MALIGNANCY REPORTS | Online – 16 April 2021 – Early studies assessing end-of-life (EoL) quality indicators to capture if a good death occurred demonstrated low rates of hospice use and high rates of intensive healthcare utilization near death among patients with hematologic malignancies, raising concerns about the quality of death. Several studies show that patients with blood cancers are often inadequately prepared for the dying process due to late goals-of-care (GoC) discussions and they experience low rates of palliative and hospice care. More recent analyses of population-based data demonstrate that some improvements over time, with significantly more patients receiving palliative care (PC), enrolling in hospice, and having the opportunity to die at home compared to a decade ago. These encouraging trends are paradoxically accompanied by concomitant increases in late hospice enrollment and intensive healthcare utilization near death. Although we are closer to the goal of a good death for patients with hematologic malignancies, there is ample room for growth. To close the gap between the current state of care and a good death, we need research that engages patients, caregivers, hematologic oncologists, and policymakers to develop innovative interventions that improve timeliness of GoC discussions, expand PC integration, and increase hospice use. **Abstract (w. references):** <https://bit.ly/3x1nLwr>

Cultures of practice: Specialty-specific differences in end-of-life conversations

PALLIATIVE MEDICINE REPORTS, 2021;2(1):71-83. Goals-of-care (GoC) discussions at the end of life (EoL) give opportunity to affirm the autonomy and humanity of dying patients. Best practices exist for communication around GoC, but there is no research on differences in approach taken by different specialties engaging these conversations. Patients should not be subjected to treatments that violate their settled informed preferences. As a truism of patient care, all healthcare professionals – no matter the specialty – are expected to endorse this ethical commitment. To uphold this obligation, care teams, patients, and their healthcare decision-makers must communicate to achieve these preferences. When receiving care at the EoL, patients are not always treated in line with their preferences. Despite the widespread need for serious illness conversations to guide these decisions, most physicians report inadequate training in this area of practice and likely develop varied communication skills influenced by their culture of practice. Recognizing this trend, the medical literature is beginning to identify best practices for discussion of goals at critical junctures, and with better understanding of current communication approaches their standards could be more effectively taught across medical specialties. **Full text:** <https://bit.ly/3gige6b>

Noted in Media Watch 11 January 2021 (#699, p.3):

- *ANNALS OF HEMATOLOGY* | Online – 3 January 2021 – ‘**Supportive and palliative care in hemato-oncology: How best to achieve seamless integration and sub-specialty development?**’ A modified palliative care (PC) model is an unmet need in hemato-oncology, where PC is introduced early from the diagnosis of hematological malignancy, provided alongside care of curative or life-prolonging intent, and subsequently leads to death and bereavement care or cure and survivorship care depending on disease course. From current evidence, the historical prioritization of cancer care at the center of palliative medicine did not guarantee that those diagnosed with a hematological malignancy were assured of referral, timely or otherwise. **Abstract (w. references):** <https://bit.ly/3n9xMBz>
- *SUPPORTIVE CARE IN CANCER* | Online – 7 January 2021 – ‘**Needs assessment of current palliative care education in U.S. hematology/oncology fellowship programs.**’ Palliative care (PC) education for fellows in hematology/oncology (H/O) is widely accepted, but no studies to date have assessed PC education practices and values among program leadership. Significant disparities exist between those modalities rated most effective for PC education and those currently in use. Clinical orientation of program leadership can affect both personal comfort with PC skills and estimations of PC curriculum effectiveness and fellows’ competency. Programs would benefit from greater standardization and prioritization of active PC education modalities and content. **Abstract (w. references):** <https://bit.ly/39c8tJZ>

Cont.

Noted in Media Watch 20 April 2020 (#662, p.9):

- **BMC PALLIATIVE CARE** | Online – 13 April 2020 – ‘**Palliative care utilization in oncology and hemato-oncology: A systematic review of cognitive barriers and facilitators from the perspective of healthcare professionals, adult patients, and their families.**’ This study systematically reviewed current literature on using palliative care (PC) in oncology and hemato-oncology. The focus was on cognitive barriers and facilitators influencing the use of PC services from the perspectives of health professionals, adult patients with cancer, and their families. Literature on this topic is very heterogeneous in objectives and focus, mainly addressing PC use, PC provision, and PC service referral. Findings show that barriers and facilitators can be summarized in four areas... **Full text:** <https://bit.ly/2xk9Jw0>

Creating effective models for delivering palliative care in advanced liver disease

CURRENT HEPATOLOGY REPORTS | Online – 10 April 2021 – The current healthcare system is not fully equipped to provide comprehensive support for patients with advanced liver disease (ALD) and their caregivers resulting in concomitant suffering and reduced quality of life (QoL). Integration of palliative care (PC) within routine care has demonstrated benefits in improving symptoms and QoL and reducing healthcare utilization for other serious illnesses but has been underutilized or delayed for ALD care. The authors outline the domains and benefits of PC and discuss the misconceptions and barriers for PC integration, and healthcare delivery models supporting PC integration within ALD care. PC has eight key domains related to physical and mental health, goals for future care, and care of the caregivers. PC offers benefits to improve health outcomes and patient satisfaction and reduce healthcare utilization. To date there have been successful models of PC that are primarily hospital- or community-based; successful models have been PC specialist- or primary/generalist-led. PC within oncology has formed the basis for most evidence-based guidelines. PC integration within ALD care is still in its infancy. While amassing evidence in ALD, hepatology organizations can promote consensus-based integrated PC models that can guide research and practice efforts to increase supportive care for these patients in need and their family caregivers. **Full text:** <https://bit.ly/3dY4q6p>

Noted in Media Watch 25 May 2020 (#667, p.8):

- **FRONTLINE GASTROENTEROLOGY** | Online – 19 May 2020 – ‘**Palliative care in liver disease: What does good look like?**’ Many factors limit widespread provision of good palliative care (PC), including the unpredictable trajectory of chronic liver disease, the misconception that PC and end-of-life care are synonymous, lack of confidence in prescribing, and lack of time and resources. Healthcare professionals managing these patients need to develop skills to ensure effective delivery of core PC, with referral to specialist PC services reserved for those with complex needs. Core PC is best delivered by the hepatology team in parallel with active disease management ... ensuring discussions about disease trajectory and advance care planning occur alongside active management... **Full text:** <https://bit.ly/3q5jmSY>

Opioids: A “crisis” of too much or not enough – or simply how rich you are and where you live?

EUROPEAN JOURNAL OF PAIN | Online – 6 April 2021 – Worldwide, 83% of countries have low or non-existent access to opioids for pain relief. Over 25 million people are at the end-of-life stage, with eight million people dying annually in unnecessary pain and distress. Ineffectively controlled pain is a global public health issue blighting the lives of billions of people worldwide with immeasurable human and socioeconomic costs. International conventions regulate the trade and use of controlled medications, including many opioids. The goal is to balance widespread access to optimal forms of pain management with

Opioid pain relief in different countries

U.S. gets 30 times more opioid pain relief medication than it needs

Mexico gets only 36% of what it needs

China gets about 16% of what it needs

India gets 4% of what it needs

Source: ‘Alleviating the access abyss in palliative care and pain relief...’ *The Lancet*, 2017;391(10128):1391-1454. [Noted in Media Watch 16 October 2017 (#534, p.14)] **Full text:** <http://bit.ly/2Ww8Cku>

Cont.

restrictions to govern the use and prevent the misuse of controlled substances. Those conventions are failing to meet their goals. International guidelines to inform national legislation have been compromised and withdrawn, thanks to undue interference from U.S.-based opioid manufacturers. The new goal must be to ensure equitable access, for all, to opioids and ensure that optimal pain management becomes a central component of universal health coverage. The opioid crisis is, more accurately, a multicomponent global crisis and one that is not fully apparent or well understood. Regulations of the wealthy and powerful to control a surfeit of opioids, which encourages misuse, cannot be allowed to govern legislation in the majority of countries worldwide where citizens have little or no access to opioids to reduce pain and suffering. International conventions must be revised to ensure an optimal balance that allows access to opioids for all those who need them. **Abstract:** <https://bit.ly/3d5Xk0s>

How do persons with young and late onset dementia die?

JOURNAL OF ALZHEIMER'S DISEASE | Online – 3 April 2021 – End of life (EoL) symptoms and symptom management as well as the quality of dying (QoD) of persons with advanced dementia (PWAD) have not yet been systematically studied in Germany. Undoubtedly there is a need for EoL palliative care (PC) for patients suffering from dementia. The PWADs' needs must be assessed regularly, and supportive treatment strategies should be adapted accordingly. It is important to identify PWAD who suffer from physical or emotional symptoms, and then alleviate those symptoms by establishing, monitoring, and adjusting effective drug and non-drug treatment. Additionally, providing counselling and support to family caregivers of PWAD who live and die at home is crucial. To do so, the incorporation of PC coordinators would be desirable. Likewise, it must be highlighted that a hospital admission before death does not necessarily result in a reduced QoD. Lastly, informing medical and care providers as well as patients' families about the meaning and purpose of advance care documents might increase the number of written therapy goals, contingency plans, and general practitioner orders which will alleviate burdensome treatment and provide certainty and clarity to all involved. **Full text:** <https://bit.ly/3a5D6SG>

Related:

- *BMJ OPEN* | Online – 12 April 2021 – **'Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study.'** Physicians ... who provide long-term and end-of-life care for persons with dementia rated the patient question prompt lists (QPL) to be acceptable and the quality of the contents as good. However, many found the amount of information problematic, and were concerned it could be overwhelming. Importantly, the physicians were divided about whether the QPL would be too difficult for use by persons with dementia themselves due to the cognitive impairment associated with dementia... **Full text:** <https://bit.ly/3dfEmo8>
- *THE HASTINGS REPORT*, 2021;51(2):4-5. **'The limited value of dementia-specific advance directives.'** Many people are worried about developing dementia, fearing the losses and burdens that accompany the condition. Dementia-specific advance directives (AD) are intended to address dementia's progressive effects, allowing individuals to express their treatment preferences for different stages of the condition. But enthusiasm for dementia-specific AD should be tempered by recognition of the legal, ethical, and practical issues they raise. Dementia-specific AD are a simplistic response to a complicated situation. Although they enable people to register their future care preferences, in many cases, those preferences will not, and should not, determine their later care. **Abstract:** <https://bit.ly/3dcT4wu>



Media Watch: Access Online (Updated 04.16.2021)

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.17.

Death and dying in prison: An integrative review of the literature

JOURNAL OF FORENSIC NURSING | Online – 8 April 2021 – Mass incarceration has been a major issue in the U.S., with rates sharply increasing since the 1970s. In the past two decades, the number of older incarcerated persons has grown by 500%, highlighting the importance of end-of-life (EoL) care and decisions among this demographic. Searches yielded 233 articles published after 2000. Following screening, 29 full-text articles were assessed for eligibility, and 7 qualitative studies met criteria and were included in the review. Five main categories were observed across the themes elicited by the studies: 1) EoL services in prison; 2) Social contact and human interactions; 3) Thoughts of death and fear of dying; 4) Wishes and decision-making; and, 5) Guilt and coping. Many of these themes may be considered by correctional nurses who provide supportive “good death” care for incarcerated persons who are dying. **Abstract:** <https://bit.ly/3mGhb9V>

Related:

- *AMERICAN JOURNAL OF PUBLIC HEALTH* | Online – 15 April 20-21 – ‘**Ten Urgent Priorities Based on lessons learned from more than a half million known COVID-19 cases in U.S. prisons.**’ Lessons include: accelerate population reduction coupled with community re-entry support, limit transfers between facilities, strengthen partnerships between public health departments and prison leadership; introduce or maintain effective occupational health programs, ensure access to advance care planning processes for incarcerated patients and delineation of patient healthcare rights, strengthen partnerships between prison leadership and incarcerated people, provide emergency mental health support for prison residents and staff and commit to public accountability and transparency. **Abstract:** <https://bit.ly/3dkZcTc>

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded at the Palliative Care Network website: <http://bit.ly/2RdegnL>

Ethical implications of COVID-19: Palliative care, public health, and long-term care facilities

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2021;23(2):120-127. Outbreaks of COVID-19 among nursing homes, assisted living facilities, and other long-term care facilities in the U.S. have had devastating effects on residents. Restrictions such as banning visitors, sequestering residents, and testing healthcare staff have been implemented to mitigate the spread of the virus. However, consequences include a decline in mental and physical health, decompensation, and a sense of hopelessness among residents. The authors explore a case study at an assisted living facility addressing the ethical issues in balancing the management of the community versus the resident’s right to autonomy and self-determination. A team of palliative care (PC) experts was brought into assisted living facilities to manage patients, care for well residents, and provide input in advance care planning and symptom management. The principles of self-determination and autonomy, stewardship, and distributive justice were explored. The use of nursing skills in triage and assessment, principles in public health, and the eight domains of PC provided a comprehensive framework for structuring emergency operations. Palliative interventions and the role of PC

nurses played an integral part in addressing ethical challenges in the containment of the virus and the deleterious effects of social isolation among the elderly. **Abstract:** <https://bit.ly/2QaavEK>

In this together: Navigating ethical challenges posed by family clustering during the COVID-19 pandemic

THE HASTINGS REPORT, 2021;51(2):4-5. Harrowing stories reported in the media describe COVID-19 ravaging through families. The authors report professional experiences of this phenomenon, family clustering, as encountered during the pandemic’s spread across Southern California. They identify three ethical challenges following from it: family clustering impedes shared decision-making by reducing available surrogate decision-makers for incapacitated patients, increases the emotional burdens of surrogate decision-makers, and exacerbates health disparities for and the suffering of people of color at increased likelihood of experiencing family clustering. t affect patient care and the surrogate experience. **Full text:** <https://bit.ly/2OHLsZe>

Cont.

Related:

- *JOURNAL OF PRESCRIBING PRACTICE* | Online – 7 April 2021 – ‘**End-of-life care in a pandemic: A primary healthcare perspective.**’ This article shows the new approaches that have been adopted to support people in the community at the end of life (EoL). These new ways of working demonstrated the resilience of healthcare professionals working together with the use of video to ensure that patients received the optimum care and treatment in their home at the end of their lives. It demonstrated that community teams such as district nurses, hospice staff, general practitioners and the lead nurse for EoL care could implement new ways of working to ensure joined up care and treatment. It also shows new models of working in the future. **Abstract:** <https://bit.ly/3a55N21>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 12 April 2021 – ‘**Comfort care homes: Pressures and protocols in end-of-life care during the COVID-19 pandemic.**’ Comfort care homes are community-run, residential homes that provide end-of-life care (EoLC) to terminally ill individuals who lack safe, secure housing and a reliable caregiver system. As non-profit, non-medical facilities, these homes have faced both new and magnified challenges due to the COVID-19 pandemic. This article highlights the value of collaborative interagency partnerships and shares reflections on the unique pandemic pressures faced by comfort care homes. Innovative ideas for improving community-based EoLC and implications for social work practice are included. **Abstract:** <https://bit.ly/3tgNkY0>
- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 12 April 2021 – ‘**Connection, comfort and COVID-19 in palliative care.**’ Across countries and a range of care settings, palliative care services have been forced to quickly and flexibly adapt to pandemic conditions. Such changes have included the development of new protocols and best-practice models of care, the redeployment of key workers to best support people within the community, and the seeking of new and creative ways of supporting patients and families. While clinical practices adapted, and compassion and communication remain at the core of frontline work, the social and relational experiences, for patients, their families and clinicians, remain less well-attended to. **Full text:** <https://bit.ly/3a7pTZv>

What constitutes a palliative care need in people with serious illnesses across Africa? A mixed-methods systematic review of the concept and evidence

PALLIATIVE CARE | Online – 16 April 2021 – This review presents strong evidence and conceptual clarity for the specific palliative care (PC) needs of people with serious illness and their families in Africa. The comprehensive overarching framework developed elaborates on the domains of PC needs highlighted in the World Health Organization (WHO) definition using evidence from Africa and across different serious illnesses. The authors identified critical gaps in evidence of PC needs in west, central and North Africa, in serious illnesses other than HIV/AIDS and cancer and in family caregivers. Thus, to achieve the outcomes improvement and cost-saving effects of PC within universal health coverage in Africa, it is imperative to address total care needs in line with the African evidence-based framework identified in this review. Based on contextual factors driving PC needs, health literacy is a specific and crucial need that must be met to ensure that the benefits of PC can be achieved at the patient-level. The WHO must review and update the recommendations for planners and implementers of PC within primary healthcare to ensure families have access to adequate support for their PC needs. The framework should also inform clinical multidimensional needs assessment of patients with serious illnesses in Africa in a way that encompasses context-driven needs. **Full text:** <https://bit.ly/2Qt7NKO>

Noted in Media Watch 22 February 2021 (#705, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 February 2021 – ‘**Do the clinical management guidelines for COVID-19 in African countries reflect the African quality palliative care standards? A review of current guidelines.**’ The authors set out to critically appraise the case management guidelines for COVID-19 in Africa for their palliative care (PC) content and evaluate the adequacy of this against African Palliative Care Association standards for quality PC provision across Africa. The majority of the countries with specific sections on PC are in Southern and Eastern Africa. This reflects the development of PC in these countries with strong advocacy networks and well-developed services and national policies. **Full text:** <https://bit.ly/3ubMH2J>

N.B. Additional articles on PC in Africa noted in Media Watch 15 June 2020 (#670, pp.7-8).

Completion of advance directives among African Americans and Whites adults

PATIENT EDUCATION & COUNSELING | Online – 31 March 2021 – This study used data from the Survey of California Adults on Serious Illness & End-of-Life 2019.¹ The authors compared correlates of completion of advance directives (AD) among a sample of 1,635 African American and White adults. Whites were 50% more likely to complete an ad than African Americans. The major differences between African Americans and Whites were mainly explained by the level of mistrust and discrimination experienced by African Americans and partially explained by demographic characteristics. This study shows that at both bivariate and multivariate levels, participation in religious activities was associated with higher odds of completion of an AD for both African Americans and Whites. Culturally appropriate multifaceted, theoretical- and religious-based interventions are needed that include minority healthcare providers, church leaders, and legal counselors to educate, modify attitudes, provide skills and resources for communicating with healthcare providers and family members. **Abstract:** <https://bit.ly/3mGWkmB>

1. 'Help Wanted: Californians' Views and Experiences of Serious Illness and End-of-Life Care,' California Health Care Foundation, October 2019. **Download at:** <https://bit.ly/3g3BoFp>

N.B. Selected articles on engaging African Americans in discussions regarding end-of-life care noted in Media Watch 25 January 2021 (#701, p.5).

Related:

- *JOURNAL OF CLINICAL NURSING* | Online – 7 April 2021 – “‘The woman gives’”: **Exploring gender and relationship factors in HIV advance care planning among African American caregivers.** This study is one of few studies exploring advance care planning (ACP) among caregivers in African American populations hardest hit by HIV. Results suggest that ACP skill building and education are critical for African Americans living with HIV to promote ACP discussions with their caregivers. Knowledge about ACP topics was low overall even when healthcare had recently been accessed. Support reciprocity and gender-specific communication skill building may facilitate ACP in African American HIV informal caregiving relationships. **Abstract:** <https://bit.ly/3a7yCLI>

Facilitating inter-professional integration in palliative care: A service ecosystem perspective

SOCIAL SCIENCE & MEDICINE | Online – 9 April 2021 – A paradigm shift toward healthcare inter-professional collaboration is leading to searches for ways to better facilitate integration. However, policy rhetoric often fails to acknowledge the complexity of healthcare service systems, and the difficulties involved in achieving successful collaborations. Consequently, more research is called for. The authors utilize the concept of a service ecosystem, a perspective currently prominent in service science, which is transforming the ways service systems are studied. This research aims to examine palliative care (PC) provision through a service ecosystem lens in order to uncover previously unidentified insights and opportunities for improvement. The PC ecosystem under study encompasses a defined geographical area of the U.K. Data comprises pathographies (i.e., narratives of illness) with patients and their families and in-depth interviews with a variety of PC providers, collected between 2017 and 2018. Capability issues comprising collaboration, coordination, and resource integration, together with communicating value all emerged as common themes impacting PC services. Taking a service ecosystem perspective, the authors also found shared intentionality for better integration and collaboration, with a desire among PC providers for the ecosystem's hospice organization to take the role of leader and facilitator. Acting on these findings, the authors demonstrate the ways new institutional arrangements provide a foundation for value cocreation. They make a contribution to the burgeoning service ecosystem literature which currently lacks empirical insights, particularly in health. The authors argue that in complex service systems such as healthcare, the focus must be on service design rather than organizational design, approached from the perspective of aggregation of service providers. Reconfiguring resources and developing new institutional arrangements at the meso level can change micro-macro level interaction, enabling the emergence of new and enhanced value cocreation in PC. **Abstract:** <https://bit.ly/3mDFAN6>

Cont.

Noted in Media Watch 23 November 2020 (#693, p.14):

- *SCANDINAVIAN JOURNAL OF CARING SCIENCES* | Online – 17 November 2020 – ‘**Taking care of dying patients through an “interprofessional ecosystem”**: A grounded theory study on the experience of an interprofessional team in palliative care.’ The interprofessional approach is part of the philosophy in palliative care (PC)... However, there is no evidence regarding the process through which the interprofessional team faces the process of the patient’s end-of-life and how this experience might be of value for the team’s development itself. The aim of this study was to analyse and understand the psychosocial processes that occurs when an interprofessional team accompanies patients and their families to death in PC ... to develop a theory to describe this phenomenon. **Abstract:** <https://bit.ly/2UB7IDw>

Research Matters

Mapping an agenda for psychedelic-assisted therapy research in patients with serious illness

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 April 2021 – Medicine and society are witnessing a resurgence of interest in the effects and applications of psychedelic-assisted therapies in a wide range of settings.



Dana-Farber
Cancer Institute

This article suggests key opportunities for research in psychedelic-assisted therapies for those affected by serious illness. The authors convened researchers representing palliative care, psychosocial oncology, spiritual care, oncology, and psychedelic-assisted therapies ... to define priorities and envision an agenda for future research on psychedelic-assisted therapies in patients with serious illness. Identified were seven key opportunities to advance the field of psychedelic-assisted therapies in serious illness care. Four opportunities were related to the science and design of psychedelic-assisted therapies: clarifying indications; developing and refining therapeutic protocols; investigating the impact of set and setting on therapeutic outcomes; and understanding the mechanisms of action. The other three pertained to institutional and societal drivers to support optimal and responsible research: education and certification for therapists; regulations and funding; and diversity and inclusion. **Abstract:** <https://bit.ly/32bYxgI>

Noted in Media Watch 18 November 2019 (#640, p.8):

- *CURRENT ONCOLOGY*, 2019;26(4):225-226. ‘**Psychedelics for psychological and existential distress in palliative and cancer care.**’ A so-called psychedelic renaissance is underway, with research programmes at major academic institutions worldwide conducting basic and clinical research into the potential therapeutic effects of psychedelic medicines for a variety of psychiatric conditions. These compounds were first studied in the 1950s, but by the mid-to-late 1960s, clinical research began to be curtailed and was almost fully terminated by the mid-1970s. Those early experiments and their contemporary counterparts invite the questions: Is there a role for psychedelics for treating patients in palliative medicine and cancer care today? And, if so, where? **Full text:** <http://bit.ly/2qK9gj2>

Noted in Media Watch 4 March 2019 (#604, p.13):

- *JOURNAL OF PSYCHOACTIVE DRUGS* | Online – 1 March 2019 – ‘**Psychedelics and dying care: A historical look at the relationship between psychedelics and palliative care.**’ As researchers in the 1950s began exploring different applications for psychoactive substances ... dying care came into clearer focus as a potential avenue for psychedelics. Before that application gained momentum in clinical or philosophical discussions, psychedelics were criminalized and those early discussions were lost. This article looks back at historical discussions about LSD’s potential for easing the anxiety associated with dying, and considers how those early conversations might offer insights into today’s more articulated discussions about psychedelics in palliative care. **Abstract (w. link to references):** <http://bit.ly/2Ta1k7V>

Cont. next page

Noted in Media Watch 29 January 2018 (#548, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 January 2018 – ‘**Taking psychedelics seriously.**’ Even with an expanding evidence base confirming safety and benefits, political, regulatory, and industry issues impose challenges to the legitimate use of psychedelics. Given the prevalence of persistent suffering and growing acceptance of physician-hastened death as a medical response, it is time to revisit the legitimate therapeutic use of psychedelics. This paper overviews the history of this class of drugs and their therapeutic potential. Clinical cautions, adverse reactions, and important steps related to safe administration of psychedelics are presented, emphasizing careful patient screening, preparation, setting and supervision. **Full text:** <http://bit.ly/2tOtJBa>

[Publishing Matters](#)

Opinion: The rise of preprints is no cause for alarm

THE SCIENTIST | Online – 14 April 2021 – The COVID-19 pandemic has led to a cultural shift in the way that science is communicated and shared. Traditional scientific publishing is a slow process and so, needing a faster route of disseminating vital new findings, scientists turned to preprint platforms, which host non-peer reviewed articles on specialized servers. My colleagues and I reported this month that researchers shared more than 35% of the early COVID-19 literature as preprints. But scientists aren’t the only people who have turned to preprints; we found that members of the general public and journalists have been sharing and accessing preprints at unprecedented levels. With this sharing and use of preprints by nonexperts, their coverage by news outlets, and the fact that they have been cited as direct influences on contentious public health interventions, it becomes crucial that we assess the quality of the preprint literature and ask: Can we trust preprints? **Full text:** <https://bit.ly/3sjanQE>

[Media Watch: Editorial Practice](#)

EACH LISTING IN MEDIA WATCH represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

[Distribution](#)

MEDIA WATCH IS DISTRIBUTED AT NO COST to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

[Links to Sources](#)

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

Cont.

Something Missed or Overlooked?

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

Media Watch: Access on Online (Updated 04.16.2021)

International



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

[Scroll down to 'Media Watch']

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

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

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

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

Asia



Asia Pacific
Hospice Palliative
Care Network

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

[Scroll down to 'Media Watch']

Australia

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

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health: <https://bit.ly/3g82uuS>

[Scroll down to 'General Resources' and 'Media Watch']

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://bit.ly/3tby3b3>

Europe



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

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

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

South America

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