

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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This new “Cottage Hospice” approach is intended to be resourced largely by volunteers, providing support to family caregivers who continue to provide direct care, with paid staff acting to support and facilitate care.

‘Constructing a new role for family carers and volunteers providing care towards the end of life: An action research approach exploring a new model of hospice care’ (p.9), in *Health & Social Care in the Community*.

U.S.A.

New report calls for universal coverage of long-term care for older adults in U.S.

OREGON | Oregon Health & Science University (Portland) – 18 February 2021 – The COVID-19 pandemic’s heavy toll on older Americans highlights the need to strengthen the nation’s safety net for people in need of long-term services and supports, an Oregon Health & Science University (OHSU) researcher and co-authors argue in a new report published by *Milbank Quarterly*.¹ The report proposes a system of universal coverage to support the long-term care of all older Americans. “This approach would protect against financial catastrophe and end the current system that is based on the need to be financially destitute in order to access coverage via Medicaid,” the authors write. “Such an approach would benefit both individuals and families and would also create a far more stable and more generous funding stream to providers.” Walt Dawson, assistant professor of neurology in the OHSU School of Medicine, said he believes the pandemic could be an inflection point to improve the U.S. system of long-term services and support. The report lays out a series recommendations to repair what it

characterized as a fragmented and patchwork system of long-term services and supports for older Americans living with physical and cognitive impairments. <http://bit.ly/3sdAVD4>

Extract from Oregon Health & Science University report

With anecdotal reports that hospice providers are being barred access to nursing homes, it is critical to fill gaps with telehealth options and accelerate the training of existing nursing force workers in pain management and person-centered principles in the hospice care model to address corresponding gaps in non-COVID-19 and COVID-19 end-of-life care needs.

Specialist Publications

‘Palliative care specialist access is associated with rankings of hospital quality’ (p.10), in *Journal of Pain & Symptom Management*.

1. ‘COVID-19: The time for collaboration between long-term services and supports, healthcare systems, and public health is now,’ *The Millbank Quarterly*, published online 16 February 2021. **Full text:** <https://bit.ly/3aCsADk>

CAPC's Diane Meier: Palliative care demand skyrocketing during COVID

HOSPICE NEWS | Online – 17 February 2021 – Geriatrician and palliative care (PC) specialist Diane Meier MD, founder and executive director of the Center to Advance Palliative Care (CAPC), has been a leading voice in the movement to improve access to PC in the U.S. She is the author of more than 200 articles and several books and has appeared in numerous media outlets, including *Hospice News*. Meier recently announced that she would be stepping down as the leader of CAPC and has made no on-the-record statements about her future plans. She recently sat down with *Hospice News* to discuss her legacy at CAPC and the future of PC in the U.S. and during a pandemic. <http://bit.ly/3u9kdGX>

International

Pressure on hospices “relentless” as patients rise by one-third compared to first COVID wave

U.K. (England) | ITV News (London) – 19 February 2021 – Hospices in England are caring for more than one-third more patients than in the first wave of the coronavirus pandemic, with one in three patients being discharged from National Health Service (NHS) hospitals, ITV News has learned. A survey by Hospice U.K. exclusively for ITV News shows that in the week beginning 8 February, 35% of hospice inpatients came from hospitals, including people with COVID-19. Around 23% of hospice patients being cared for at home also came directly from hospital settings. In June last year hospices were caring for around 200,000 people per month, both inpatient and in the community. In the week beginning 8 February this year, they were caring for 277,140 patients – a rise of 37.5%. Some hospices have set up entire coronavirus wards within their buildings as more patients with COVID-19 are discharged to relieve pressure on the NHS. <http://bit.ly/3dvkcHr>

Specialist Publications

‘Hospice care access inequalities: A systematic review and narrative synthesis’ (p.9), in *BMJ Supportive & Palliative Care*.

‘Do the clinical management guidelines for COVID-19 in African countries reflect the African quality palliative care standards? A review of current guidelines’ (p.10), in *Journal of Pain & Symptom Management*.

‘Community end-of-life care during the COVID-19 pandemic: Initial findings of a U.K. primary care survey’ (p.12), in *medRxiv*.

‘British laypeople’s attitudes towards gradual sedation, sedation to unconsciousness and euthanasia at the end of life’ (p.13), in *Plos One*.

Desire to die among older people often transient, study finds

IRELAND | *The Irish Times* (Dublin) – 18 February 2021 – Researchers from Trinity College have found that the “wish to die” among older people living in the community is often “transient” and is strongly linked to depression and feelings of loneliness. A survey of more than 8,100 people aged over 50 as part of the Irish Longitudinal Study on Ageing (Tilda) found that 4% of people surveyed expressed a wish to die. However, almost three-quarters of those who initially expressed this desire did not feel the same when researchers revisited the issue with them two years later. The Tilda research, which is a large-scale, nationally-representative study, found that 60% of those who reported a wish to die had co-existing depressive symptoms while half of those who stated they wanted to die had been diagnosed with depression. This indicates a “high burden of undetected mental health problems” in the group, the authors said. Almost three-quarters of those with a wish to die were also lonely, the study found. Those who subsequently said two years later that they no longer felt the wish to die reported that their symptoms of loneliness and depression had improved. Some 15% of those who expressed this wish actually died during the study’s six-year follow-up period, it added. <http://bit.ly/2NFwodZ>

N.B. Irish Longitudinal Study on Ageing (Tilda) website: <http://bit.ly/3uf5AC0>

Ending inequalities: Supporting people with no recourse to public funds at the end of life

U.K. | Hospice UK – 18 February 2021 – St. Christopher’s Hospice has launched a toolkit to support people at the end of life (EoL) who have no recourse to public funds (NRPF). The guide has been published to better prepare migrant centre workers, social workers and welfare teams to support people with EoL or palliative care needs with NRPF status, which means they may not be able to access National Health Service hospital treatment and welfare, such as Universal Credit and Disability Living Allowance. People can find themselves with no recourse to public funds when their immigration status is unsettled, such as when their visa expires, or when their claim for asylum is rejected. The new toolkit was put together after 18 months of research, including listening to the experiences of people living with NRPF, and collaborating with partners and specialists working in migrant centres. The toolkit emphasises the importance of partnership working between people with expertise in EoL care and those who feel confident working with people with no recourse to public funds. Neither can help this group of people adequately on their own – each need the other to attend to the double disadvantage facing carers and those they care for. For this reason, the resources are written in a way that brings their two worlds together, with the person who is dying, their families and carers at the centre. <http://bit.ly/2ORSB99>

N.B. Link to ‘Do you see us? Carers with no recourse to public funds who are supporting loved ones at the end of their life. A guide for hospice and palliative care staff’ is embedded in Hospice UK report.

Is the pandemic the conversation opener about death the workplace needed?

U.K. | *theHRDIRECTOR* – 15 February 2021 – The pandemic has prompted conversations across the workplace – from boardrooms and meeting rooms, to locker rooms and virtual offices. Companies have begun to consider what bereavement means for their business, their people strategy and the individuals who are personally affected by loss and grief. Employees have begun to articulate their concerns: how would loss affect their work? Their home life? Their mental health? In a year, we have moved from a workplace culture where death and bereavement are seldom discussed, to an environment where the potential for a staff member to lose a loved one must now be both acknowledged and planned for. Companies not only need to protect their business from the impact of stress and poor mental health due to staff bereavement, they also need to demonstrate to their team that they are a supportive employer that cares. Commercially, strategically and pastorally, the pandemic has been challenging for human resources professionals. Considering an alternative approach to employee benefits can help to address elements of all those responsibilities. <http://bit.ly/3pl6Lfr>

Noted in Media Watch 17 August 2020 (#679, p.8):

- *SOCIAL WORK IN HEALTH CARE*, 2020;59(6):335-350. ‘**The potential impact of bereavement grief on workers, work, careers, and the workplace.** This study sought an understanding of the lived experience of bereavement on the mourner’s ability to work and their work-related experiences following the death of a loved one. Three themes emerged: 1) Grief is universal but individually impactful; 2) Accommodation is needed to assist the return to work and to regain work abilities; and, 3) There are many impediments to working again. These themes highlight the potential for bereavement grief to substantially affect mourners and thus their work, careers, and the workplace. Older workers could be particularly disadvantaged because of workplace ageism. **Abstract (w. link to references):** <https://bit.ly/3gWqhLN>

N.B. Selected articles on bereavement in the workplace noted in Media Watch 28 October 2019 (#637, pp.3-4).



Media Watch: Access Online

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

Poor and terminally ill Mexicans have less chance to get opioids intended for palliative care

MEXICO | *Medical News* – 13 February 2021 – If you're poor and terminally ill in southern Mexico, there's far less chance you'll get the painkillers you need for palliative care (PC) than your cousins in more prosperous regions, particularly those pharmacy-rich areas along Mexico-U.S. border, say University of California, Los Angeles (UCLA), researchers and colleagues who studied opioid dispensing levels across the country.¹ Despite a Mexican government initiative launched in 2015 to improve access to prescription opioids among PC patients, the country has seen only a marginal increase in dispensing levels, and inequities in dispensing have left many of the nation's poorest residents without comfort in their final days, said lead author Dr. David Goodman-Meza... The researchers analyzed data on prescription drug dispensing from August 2015 to October 2019 for all 32 Mexican states and six large metropolitan areas. They compared opioid prescribing levels against the expected need for the drugs based on the burden of disease in each state. While they

found that opioid dispensing had increased overall by an average of 13% per quarter over that period, they also discovered that dispensing levels were nearly 10 times higher in states whose populations had the highest socioeconomic status than in those with the lowest. <http://bit.ly/2Ou7xdi>

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>

1. 'Geographical and socioeconomic disparities in opioid access in Mexico, 2015-2019: A retrospective analysis of surveillance data,' *The Lancet: Public Health*, 2021;6(2):88-96. **Full text:** <https://bit.ly/37dlKRe>

N.B. See commentary on UCLA study, 'Disparities and crisis: Access to opioid medicines in Mexico,' *The Lancet: Public Health*, 2021;6(2):83-84. **Full text:** <https://bit.ly/3phSlra>

Specialist Publications

The potential of personalized virtual reality in palliative care: A feasibility trial

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 15 February 2021 – Virtual Reality (VR) can help alleviate symptoms in a non-palliative care population. Personalized therapy can further alleviate these symptoms. There is little evidence in a palliative care (PC) population. This is a novel study in the U.K. investigating personalized VR, over repeated sessions, for people with a terminal illness. This research suggests it is feasible to recruit people with advanced illness, in a hospice setting, for a repeated VR trial. While preliminary findings suggest a reduction in Edmonton Symptom Assessment System-Revised scores, there were no statistically significant findings. This is comparative to the previous work, and provides the data to inform a future larger trial. Future studies, in a fully powered trial, should explore the structure of VR

(session length and number of sessions) to further understand the clinical benefit to patients under PC services. **Full text:** <http://bit.ly/3bat3LQ>

Research Matters

'Stakeholder perspectives on research enrollment at end of life' (p.14), in *Pediatrics*.

Publishing Matters

'Top health research funders' guidance on selecting journals for funded research' (p.14), in *F1000Research*.

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Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 February 2021 – ‘**Virtual reality in specialist palliative care: A feasibility study to enable clinical practice adoption.**’ The authors of this article highlight a number of practical questions to support organisations considering use of virtual reality (VR) in palliative care (PC). Although the clinical use of VR in PC appears feasible and safe, further evidence of its benefit, effectiveness and practicality are required before recommendations can be made about its usefulness. Ten items are identified for organisations to consider ahead of adoption of VR in PC. Further research is needed to examine whether VR can effectively improve symptom management in PC and to ensure its use is practical, meaningful and evidence based. **Full text:** <https://bit.ly/2NeyKAG>

Noted in Media Watch 7 September 2020 (#682, p.10):

- *MORTALITY* | Online – 30 August 2020 – ‘**Addressing fear of death and dying: Traditional and innovative interventions.**’ Virtual reality appears to have the potential to reduce death anxiety, possibly by simulating an out-of-body experience and strengthening belief in an afterlife. Although some interventions appear to have a positive impact on fear of death and dying, the literature does not support a clearly superior therapeutic approach. Fear of death and dying is a multifaceted and prevalent source of human distress that can cause significant psychological and existential distress, especially at the end of life (EoL). Analysing current therapeutic approaches to this issue to identify promising modalities and knowledge gaps could improve EoL experiences and reduce human suffering. **Abstract:** <https://bit.ly/3gHR3qr>

Noted in Media Watch 11 May 2020 (#665, p.10):

- *PALLIATIVE MEDICINE* | Online – 8 May 2020 – ‘**A mixed-methods pilot study of ‘LIFEView’ audio-visual technology: Virtual travel to support well-being and quality of life in palliative and end-of-life care patients.**’ ‘LIFEView’ technology is feasible to integrate into existing care practices as a reminiscence and virtual travel programme for adults receiving inpatient and community palliative care (PC) services. ‘LIFEView’ videos and accompanying music yielded extensive conversation, reminiscence and meaning-making... Previous studies using reminiscence or life review interventions in PC contexts demonstrated reminiscence as an effective method of finding meaning in one’s life experiences and found associated reductions in psychosocial and spiritual distress. **Full text:** <https://bit.ly/3beEsse>

Noted in Media Watch 17 June 2019 (#618, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 June 2019 – ‘**Virtual reality: Endless potential in pediatric palliative care.**’ Pediatric palliative care (PC) deals with the physical, psychosocial, and spiritual concerns of patients and their families. And to do this, clinicians must use all the tools at their disposal, including pharmacological and non-pharmacological modalities. Virtual reality is quickly becoming a useful tool in many areas of medicine, including surgical planning, simulation training, rehabilitation, and pain prevention and treatment. Recently it has been used in the adult PC population for symptom management, and memory and legacy creation. The authors present a case report for, what they believe to be, the first time in the pediatric PC population. **Abstract:** <http://bit.ly/2XbaeDz>

“It made me feel like I didn’t know my own body”: Patient-provider relationships, LGBTQ+ identity, and end-of-life discussions

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 15 February 2021 – LGBTQ+ individuals experience multiple challenges receiving quality care at the end of life (EoL), such as lack of confidence in the healthcare system to address their needs and lack of knowledge about advance care planning. Important gaps remain about the needs of LGBTQ+ individuals in the provider-patient relationship and how critical discussions about the EoL occur or do not occur in that relationship. The purpose of this study is to explore patients’ narratives of their relationship with their provider and their experiences discussing EoL care with their providers, among patients who do and do not identify as LGBTQ+. Survey respondents described wanting to be heard, finding safety and trust, and valuing competency in their relationship with their provider. Respondents who identified as LGBTQ+ additionally: 1) Valued providers who avoided making assumptions; 2) Looked for cues of safety to indicate they would be accepted by the provider: and,

Cont.

3) Sought providers competent in LGBTQ+ care needs. Few respondents had discussed EoL care with their provider, although some assumed that their provider may or may not be able to meet their needs based on aspects of their provider-patient relationship. Strengthening patient-provider relationships may help improve the care of LGBTQ+ populations, particularly for the EoL. **Abstract (w. list of references):** <http://bit.ly/3qprP5I>

N.B. Search back issues of Media Watch for additional articles on palliative and EoL care for LGBTQ+ individuals at: <http://bit.ly/2ThijkC>

Parents' perspectives on conflict in paediatric healthcare: A scoping review

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 16 February 2021 – Conflict in paediatric healthcare is becoming increasingly prevalent, in particular relation to paediatric end of life. This is damaging to patients, families, professionals and healthcare resources. Current research has begun to explore perspectives of healthcare professionals (HCPs), but the parental views on conflict are lacking. The authors review found 10 papers that included parental views on conflict. Data on conflict were categorised into the following themes: 1) Communication breakdown; 2) Trust; 3) Suffering; 4) Different understanding of “best interest”; 5) Disagreements over treatment; 6) Spirituality; and, 7) Types of decision-making. In particular, parental expertise, perspectives on suffering and ways of making decisions were significant themes. A subset of themes mirror those of HCPs. However, parents identified views of conflict unique to their perspective. Parents identified important themes, in particular their perspective of what constitutes suffering and “best interest.” In addition, parents highlight the importance of being recognised as an expert. **Abstract:** <http://bit.ly/37iintB>

Noted in Media Watch 22 April 2019 (#611, p.3, p.5):

- *ARCHIVES OF DISEASE IN CHILDREN* | Online – 18 April 2019 – ‘**Achieving consensus: Advice for paediatricians and other health professionals on prevention, recognition and management of conflict in paediatric practice.**’ Conflict is damaging, stressful and emotionally challenging for all involved. Taking the correct early steps may prevent early disagreements reaching conflict. If conflict is reached, families must continue to be supported even if there is a breakdown of trust between families and clinicians. As the voice of the child and what is in their best interest remains paramount, the families’ wishes and needs must also be taken into consideration. External expert advice may be helpful, including ethical and legal services and early involvement of mediation services. **Full text:** <http://bit.ly/2T4Zwd6>
- *PAEDIATRIC RESPIRATORY REVIEWS*, 2019;29(2):1-2. ‘**Integrating ethics and palliative care concepts into pediatric end-of-life care and decision-making: A changing landscape?**’ The ethical dimensions of clinical dilemmas challenge even the best and most experienced of us to negotiate conflicting values, cultures and religious beliefs and their interplay in decision-making; all while adhering to professional standards and setting appropriate medical limits. As medical technology and options continue to evolve, these dilemmas are bound to become even more complex; the evolving autonomy of the patient, the sometimes competing interests of more powerful parental voices and the struggle to promote the child’s best-interests are additional challenges. **Full text:** <http://bit.ly/2vakImU>

Palliative care nurse champions’ views on their role and impact: A qualitative interview study among hospital and home care nurses

BMC PALLIATIVE ONLINE – 18 February 2021 – The authors’ findings show that palliative care (PC) nurse champions in hospital wards and home care think differently about their role and tasks. Nurses have diverging views on PC in these settings. Both PC nurse champions in hospital and home care have the potential to increase the quality of PC. However, because of the complexity of PC, the role of nurse champion may involve a great challenge for nurses. Therefore, nurse champions should be carefully selected, trained and supported, and their role should be formalised. Care organisations should properly embed PC nurse champions in their organisation, offer them ongoing education and ensure that they are structurally supported by the management and by the PC expert team. **Full text:** <http://bit.ly/3qEEJ06>

Applying the knowledge-to-action framework to engage stakeholders and solve shared challenges with person-centered advance care planning in long-term care homes

CANADIAN JOURNAL ON AGING | Online – 15 February 2021 – As they near the end of life (EoL), long term care (LTC) residents often experience unmet needs and unnecessary hospital transfers, a reflection of suboptimal advance care planning (ACP). The authors applied the knowledge-to-action framework to identify shared barriers and solutions to ultimately improve the process of ACP and improve EoL care for LTC residents. They held a 1-day workshop for LTC residents, families, directors/administrators, ethicists, and clinicians from Manitoba, Alberta, and Ontario. The authors identified four themes: 1) Differing provincial frameworks; 2) Shared challenges; 3) Knowledge products; and, 4) Ongoing ACP. Theme 2 had four subthemes: i) lacking clarity on substitute decision-maker (SDM) identity, (ii) lacking clarity on the SDM role, iii) failing to share sufficient information when residents formulate care wishes, and (iv) failing to communicate during a health crisis. These results have informed the development of a standardized ACP intervention currently being evaluated in a randomized trial in three Canadian provinces. **Full text:** <http://bit.ly/3qrvVKW>

Shared decision-making in palliative care: A maternalistic approach

NARRATIVE INQUIRY IN BIOETHICS, 2021;11(2):1-6. During goals-of-care conversations, palliative care (PC) clinicians help patients and families determine priorities of care and align medical care with those priorities. The style and methods of communicating with families and negotiating a care plan can range from paternalistic to entirely patient driven. The authors describe a case in which the PC clinician approached decision-making using a paradigm intuitive to many clinicians and which seems conceptually sound, but which has not been fully explored in the bioethics literature. This paradigm, termed maternalism, allows the clinician to direct decision-making within a relationship such that best interests and autonomy are mutually reinforced, thus reflecting relational autonomy as opposed to individual autonomy. The authors explore whether this method is appropriate in this case and explain how it captures significant ethical features of the case that might be missed by other approaches. **First page view:** <http://bit.ly/3ddpyXC>

Related:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 12 February 2021 – ‘**An advance care planning long-term care initiative in response to COVID-19.**’ The authors describe a systematic approach to address advance care planning (ACP) during a COVID-19 outbreak and its impact on the incidence of new do-not-hospitalize (DNH) directives among long-term care (LTC) residents. There was substantial opportunity to increase the proportion of LTC residents with DNH orders during the COVID-19 pandemic through a systematic ACP initiative which utilized real-time electronic medical record data. New directives to avoid hospitalizations were sustained among the majority of residents beyond the peak of the pandemic. **Abstract:** <https://bit.ly/3u3XGLx>
- *JOURNAL OF APPLIED GERONTOLOGY* | Online – 19 February 2021 – ‘**Examining racial differences in the informal discussion of advance care planning among older adults: Application of the Andersen Model of Health Care Utilization.**’ After accounting for predisposing, enabling, and need factors, Black and Hispanic older adults [i.e., participants in this cross-sectional study] were less likely to discuss end-of-life care (EoLC) and medical power of attorney compared with Whites. These results point to significant racial disparities in advance care planning (ACP) discussions among older adults and call for future examinations of cultural, historical, and systemic factors that could influence the discussion of ACP among this population. **Abstract (w. list of references):** <http://bit.ly/3buOaJc>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 February 2021 – ‘**Top ten tips palliative care clinicians should know about decision-making capacity assessment.**’ Palliative care (PC) clinicians treat seriously ill patients who are at increased risk for compromised decision-making capacity (DMC). These patients face profound and complex questions about which treatments to accept and which to decline. PC clinicians, therefore, have the especially difficult task of performing thorough, fair, and accurate DMC assessments in the face of the complex effects of terminal illness, which may be complicated by fluctuating acute medical conditions, mental illness, or cognitive dysfunction. This study aims to provide expert guidance on best practice for complex DMC assessment. **Abstract:** <https://bit.ly/2NEQ9IV>

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- *PATIENT EDUCATION & COUNSELING* | Online – 18 February 2021 – ‘**Emotional expression in conversations about advance care planning among older adult home health patients and their caregivers.**’ This study provides insight into the emotional contexts that occur during shared decision-making, which provides the foundation for developing future research and interventions to better support emotional coping of patients and families who face serious medical decisions. Study participants’ emotional expression during an advance care planning (ACP) intervention was mostly positive. They had similar depth of emotional expression and similar proportions of positive and negative valence across decisional, relational, and existential topics during ACP discussions. **Abstract:** <http://bit.ly/3qAoi4F>
- *PROGRESS IN PALLIATIVE CARE* | Online – 14 February 2021 – ‘**Strengthening advance care planning in rural residential aged care through multidisciplinary educational case conferences: A hybrid implementation-effectiveness study.**’ Multidisciplinary educational case conferences were reported to be acceptable, effective, and a valuable learning experience. By providing a framework for informed decision-making and joint problem sharing, MuDECCs were effective in facilitating advance care planning... However, MuDECCs were time consuming to organise with disproportionate responsibilities or time commitments borne by several key individuals. The necessary personal and professional capital to implement MuDECCs may be limited or unavailable in some locations. **Abstract:** <https://bit.ly/3u05wpr>

Supporting the needs of adolescents and young adults: Integrated palliative care and psychiatry clinic for adolescents and young adults with cancer

CANCERS | Online – 12 February 2021 – Adolescents and young adults (AYA) cancer patients represent a unique group with distinctive needs, but specialized AYA clinics are uncommon, even in tertiary comprehensive cancer centers. A collaborative approach between palliative care (PC) and psychiatry has demonstrated promising results in improving symptom burden and the aggressiveness of end-of-life care for this population. Further research is needed to explore the PC needs of this unique group, identify the most effective ways to promote early AYA referrals to PC from oncology teams, understand what elements of the Integrated Adolescents & Young Adults Palliative Care & Psychiatry Clinic [at the Princess Margaret Cancer Centre, Toronto, Canada] model are most beneficial to patients and their caregivers as well as to healthcare providers, explore areas for improvement of the current model, and evaluate the clinic’s impact on the healthcare system at our cancer center. These findings will be instrumental in creating specialized AYA

medical training programs and developing clinical practice recommendations. **Full text (click on pdf icon):** <http://bit.ly/37jbVCm>



A 2018 ‘Literature Review’ is part of the “Crossroads of Grief: Understanding Grief & Diversity Project,” published by the Children & Youth Grief Network, Ontario, Canada. The Project addresses the lack of knowledge and resources related to the complex interplay of grief with other sociological barriers. In the ‘Literature Review’ scroll down to ‘End-of-life Care in Children & Adolescents’ (p.9). **Download at:** <http://bit.ly/2OB4Y6C>

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

- *JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK* | Online – 11 February 2021 – ‘**Barriers to optimal end-of-life care for adolescents and young adults with cancer: Bereaved caregiver perspectives.**’ Although interviews with caregivers of adolescents and young adults who died of cancer focused in part on specific care decisions ... most caregivers focused on whether care provided comfort and emotional support to their dying loved one, regardless of the care delivery model. Several caregivers noted that their lack of knowledge of the patient’s prognosis prevented them from focusing on comfort and quality of life at the end of life. With many patients, clinicians provided overly optimistic information or avoided conversations entirely... **Full text:** <http://bit.ly/3pdGZK9>

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Noted in Media Watch 2 November 2020 (#690, p.12):

- *JOURNAL OF PEDIATRICS* | Online – 26 October 2020 – ‘**Improving advance care planning for seriously ill children: Engaging a diverse research population early and often.**’ DeCoursey *et al* describe the development of a new pediatric serious illness communication program to support providers in advance care planning (ACP) conversations with their patients and families.¹ Despite ACP long being considered the standard of care for patients with life-limiting or life-threatening conditions, there is increasing awareness that pediatric providers still have room to improve. To address this meaningful gap, the authors used a step-wise, rigorous approach to adapt an adult communication guide for children. **Abstract (w. list of references):** <https://bit.ly/37PwG9Z>

1. ‘Development of a stakeholder driven serious illness communication program for advance care planning in children, adolescents, and young adults with serious illness,’ *Journal of Pediatrics*, published online 16 September 2020. **Abstract (w. list of references):** <https://bit.ly/34yhCM4>

Constructing a new role for family carers and volunteers providing care towards the end of life: An action research approach exploring a new model of hospice care

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 13 February 2021 – Estimates suggest a rapidly increasing need for palliative and end-of-life care (EoLC) as the population ages and lives longer but perhaps burdened with increasing frailty and chronic ill health. At the same time, moves away from expensive professionalised palliative and EoLC services, allied with a need to relocate death and dying in supportive communities where possible,

drove the development of “Cottage Hospice” as an innovative model of care. This study demonstrated that embarking on such a change in service delivery, relying as is planned on family caregivers and volunteers, is frequently viewed as a threat and resistance to change, particularly among those staffing the established hospice service – but also with caution on the part of local resident stakeholders and some in the local health economy. Service users and volunteers proved more enthusiastic seeing the advantages of a service that provides for a wider group of people in a setting over which they could exercise more control, but with the support of professionals where needed. It remains to be seen how the service will operate in reality and what unforeseen challenges may lie ahead, but “Cottage Hospice” represents a truly new way of attempting to meet the needs of dying people and their families and has the capacity to act as a template for progressive service developments elsewhere in the palliative and EoLC field. **Full text:** <https://bit.ly/3qn9WEJ>



N.B. An abstract of this article was noted in Media Watch 1 February 2021 (#702, p.6).

Noted in Media Watch 19 October 2015 (#432, p.6):

- U.K. (England) | *Crowborough Life* – 16 October 2015 – ‘**Hospice propose “cottage hospices” to care for terminally ill patients.**’ Hospice in the Weald is proposing to open a string of Cottage Hospices to give terminally ill patients access to expert specialist care within their own local community. The new Cottage Hospice is intended as a community hub, with drop-in daycare facilities for patients as well as ground-breaking training courses to teach volunteers, families and carers the skills to look after patients themselves. It will provide residential suites for terminally ill patients where relatives or carers will have the chance to stay with their loved ones round the clock and care... <http://bit.ly/3rZiwdb>

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 19 February 2020 – ‘**Hospice care access inequalities: A systematic review and narrative synthesis.**’ This systematic literature review highlights the persisting unequal access to hospice services for many groups: people with non-malignant disease, the oldest-old, ethnic minorities, living in rural and socioeconomically deprived areas, are consistently reported to be referred to or to die in hospice less frequently. A combination of prognostic uncertainty, institutional cultures, unique needs of particular groups and a lack of public awareness of services exacerbate these problems. Equity of access for all is urgently needed, with innovative and collaborative services developed to meet the diverse needs of the whole community. **Full text:** <https://bit.ly/3qDCSS9>

What's lost in translation: A dialogue-based intervention that improves interpreter confidence in palliative care conversations

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 20 February 2021 – For U.S. patients with limited English proficiency (LEP), diversity of language and culture can create potential healthcare disparities in discussions of prognosis and goals-of-care. Although professional medical interpreters are often thought of as language conduits, they are also trained as clarifiers and mediators of cultural barriers between providers, patients and their families. Identifying interpreter challenges in palliative care (PC) conversations and brainstorming and rehearsing solutions could improve their confidence interpreting PC encounters and being cultural mediators. This dialogue-based intervention eliciting ongoing interpreter challenges, with PC social work facilitation and role-play with PC clinicians in a mutually respectful environment, significantly improved interpreter confidence in partnering with clinicians in PC conversations. **Abstract (w. list of references):** <https://bit.ly/3dwqiOp>

N.B. Additional articles on the role of interpreters in PC conversations noted in Media Watch 14 December 2020 (#696, p.6).

Do the clinical management guidelines for COVID-19 in African countries reflect the African quality palliative care standards? A review of current guidelines

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 19 February 2021 – 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. Also, these countries named their treatment and therapeutic management sections supportive therapy or supportive treatment to recognize the absence of curative treatment for COVID-19 as against other countries. While some case management documents made recommendations for some symptoms, there were no recommendations on other PC problems that may accompany breathlessness in COVID-19 such as delirium, anxiety, and cough. Also, except for guidelines in South Sudan, Ethiopia, Eswatini, and Uganda, there were no clear recommendations for giving patients and families choices regarding care decisions such as the use of mechanical ventilation. In a continent where healthcare delivery has been known to be paternalistic and PC training and education are limited, there is need for explicit recommendations on shared decision-making, fostering autonomy of choice, providing psychosocial care, patient-centred referrals to PC, and encouraging adequate communication with the patient and families at a time of high anxiety. **Full text:** <https://bit.ly/3ubMH2J>

Palliative care specialist access is associated with rankings of hospital quality

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 16 February 2021 – Increasing evidence has shown access to specialty palliative care (PC), particularly outpatient PC clinics, can yield improved health outcomes and be a marker of hospital quality. This study used publicly available data from the Center to Advance Palliative Care (CAPC) Provider Directory to determine access to in-patient and out-patient PC in the 2020-2021 *U.S. News & World Report* (USNWR) Best Hospitals Rankings.¹ 100% of the Top 20 hospitals include hospital-based PC consultation teams, and 95% offered outpatient PC. Of the second cohort of 83 hospitals, 99% offered inpatient PC, and 65% offered outpatient PC. Of the third cohort of 75 hospitals ranked, 96% had inpatient PC services, while only 41.3% offered outpatient PC. This represents a significant association between rank position and access to outpatient PC. Ranked hospitals also have significantly higher access to hospital-based PC teams compared to the national prevalence rate. These findings reflect the association of access to specialty PC with USNWR rankings for hospital quality. Further study is necessary to determine the specific influence of access to PC and USNWR rank position. **Abstract (w. list of references):** <http://bit.ly/3dmnNYc>



1. '2020-21 Best Hospitals Rankings...', *U.S. News & World Report*, July 2020. <http://bit.ly/3bb78Ew>

“We're performing improvisational jazz”: Interprofessional pediatric palliative care fellowship prepares trainees for team-based collaborative practice

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 15 February 2021 – Interprofessional education (IPE) prepares clinicians for collaborative practice, yet little is known about the effectiveness of postgraduate IPE. This is the first study to describe educational outcomes of an interprofessional fellowship in pediatric palliative care. In this mixed-methodology study, the authors surveyed former fellows from 2002 to 2018 about their fellowship experience and perceived change in interprofessional skills. Response rate was 87% (41/47). 51% of respondents were physicians, 29% were social workers, and 20% were nurse practitioners. Respondents reported significant improvement in all 10 competencies, with summed mean scores of 2.8 ± 0.6 pre-fellowship (“not very well prepared”) and 4.4 ± 0.4 post-fellowship (“very well” to “extremely well prepared”). Effect size for each competency was greater than 1.9 (strong positive impact). The fellowship experience was characterized by dynamic educational relationships: peer relationships with interprofessional co-fellows, mentoring relationships with faculty, clinical relationships with patients and families, and collaborative relationships with the healthcare system. Benefits and challenges of IPE were associated with interprofessional roles, teamwork, patient care, and educational needs. This study demonstrates the feasibility and effectiveness of an interprofessional postgraduate fellowship in preparing clinicians for collaborative practice. **Abstract (w. list of references):** <http://bit.ly/3ptSX2w>

Related:

- *JCO ONCOLOGY PRACTICE* | Online – 19 February 2021 – **‘Feasibility, acceptability, and education of pediatric oncology providers before and after an embedded pediatric palliative oncology clinic.’** The authors explored whether an embedded pediatric palliative oncology clinic is associated with improved pediatric oncology provider palliative care (PC), knowledge, and attitudes toward pediatric PC, and if the model is feasible for both clinical care and education of providers of all levels. This model was feasible, acceptable, and highly rated by responding oncology clinicians, but was insufficient as a sole method of educating multidisciplinary oncology providers. Methods of combining clinical and formal education are needed to impart sustained educational change. **Abstract:** <http://bit.ly/2ZyVwpi>

Definitions of palliative care terms: A consensus-oriented decision-making process

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 February 2021 – Lack of consistency in palliative care (PC) language can serve as barriers when designing, delivering, and accessing high-quality PC services. The aim of this study was to develop a consensus-driven and evidence-based PC glossary for the Health Standards Organization (HSO) Palliative Care Services National Standard of Canada. Content analysis of the Palliative Care Services standard was used to refine a list of terms. Environmental scan and rapid review were used for identification of concepts and definitions. Two meetings of consultation based on the modified Delphi approach took place among a working committee consisting of 12 healthcare providers, administrators, academics, and patient/family representatives. Palliative approach to care, quality of life, pain and symptom management, caregivers, PC, life-limiting illness, and serious illness were defined by modification/adoption of existing definitions. A glossary of key PC terms was developed and included in the HSO Palliative Care Services standard, which will facilitate communication using consistent language across care settings. **Abstract:** <https://bit.ly/3bi5xwl>

Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 February 2021 – **‘Process quality measures to achieve patient- and family-centred palliative and end-of-life cancer care.’** Quality measures of palliative and end-of-life care relevant to patients with advanced cancer have been developed, but few are in routine use. It is unclear which of these measures are most important for providing patient- and family-centered care and have high potential for improving quality of care. A panel of expert stakeholders helped prioritize 64 measure concepts into a shortlist of 20. Half of the shortlisted measures were related to communication about patient preferences and decision-making, and half were related to symptom assessment and treatment. **Abstract:** <https://bit.ly/3aCz4BQ>

Community end-of-life care during the COVID-19 pandemic: Initial findings of a U.K. primary care survey

MEDRXIV | Online – 16 February 2021 – During the first wave of the COVID-19 pandemic, community nurses and GPs experienced a substantial increase in the need and complexity for palliative and end-of-life care (EoLC). Specific palliative care (PC) activities increased, with community nurses taking greater responsibility in most areas of care including symptom control and the provision of support to family members. GPs reported an increase in advance care planning. Working hours changed to meet rising demands for care at home through a mainly “ad hoc” approach. Changes in the mode of service delivery, including increased virtual consultations, resulted in reports of disconnection within and between teams. Community nursing team members particularly described a sense of abandonment and perceived that other services, including general practice and specialist PC, had withdrawn. GPs reported feeling that the use of virtual consultations was limited in the EoLC context. A significant

emotional toll was experienced due to the impact of providing care during COVID-19 with fears relating to uncertainty and loss of the usual mechanisms of interdisciplinary and collegial support.

Full text: <https://bit.ly/3k4GaT1>



A selection of recent journal articles focused on the COVID-19 pandemic from the perspective of palliative and end-of-life care noted in the February issue of the newsletter of the International Association of Hospice & Palliative Care. **Access (scroll down to Media Watch: COVID-19) at:** <http://bit.ly/3q2Jlgb>

Related:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 17 February 2021 – ‘**A review of web-based COVID-19 resources for palliative care clinicians, patients, and their caregivers.**’ Palliative care (PC) organizations have responded to the growing demand for the rapid dissemination of research, clinical guidance, and instructions for care to clinicians, patients with COVID-19, and their caregivers by creating COVID-19 resource Web pages. These Web pages, however, can be variable in what resources they offer and for whom they are designed (clinicians, patients, caregivers). Therefore, this project was conducted to consolidate these resources via summary tables of specific contents available through each Web page grouped by PC domains and to identify the target audience. **Abstract:** <https://bit.ly/3aAOu9Q>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 February 2021 – ‘**Does integration of palliative care and infection management reduce hospital transfers among nursing home residents?**’ An estimated 50% of nursing home residents [in the U.S.] experience hospital transfers in their last year of life, often due to infections. Hospital transfers due to infection are often of little clinical benefit to residents with advanced illness, for whom aggressive treatments are often ineffective and inconsistent with goals of care. Integration of palliative care (PC) and infection management – i.e., merging the goals of PC – and infection management at end of life may reduce hospital transfers for residents with advanced illness. **Abstract:** <https://bit.ly/2ZFNrit>
- *NURSING IN CRITICAL CARE* | Online – 15 February 2021 – ‘**End-of-life care during the COVID-19 pandemic: What makes the difference?**’ During this pandemic, rapid and constantly evolving end-of-life (EoL) decisions are needed. These decisions are influenced by factors such as judicious allocation of ICU beds due to scarce resources, acute life-threatening illnesses, unknown COVID-19 disease progression, and unexpressed EoL wishes. Due to severely restricted visitation policies, it is more difficult to involve relatives directly. This has a major impact on the relatives’ EoL involvement and their consequent grieving process, resulting in mental health problems, such as depression, anxiety, complicated grief, and symptoms of post-traumatic stress disorder. **Full text:** <https://bit.ly/2ZoPTKh>



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Harnessing social support for bereavement now and beyond the COVID-19 pandemic

PALLIATIVE CARE IN SOCIAL PRACTICE | Online – 17 February 2021 – The current milieu of loss and grief underscores the urgent need to understand substantially more about how to promote social support for grieving persons. Such knowledge is underdeveloped yet increasingly relevant in the wake of “everyday” tragedies and large-scale events such as terrorism, newsworthy tragedies, natural disasters, and pandemics. Most bereavement care intervention efforts are targeted to addressing the needs of people with mental health concerns. However, health services are not necessarily well-equipped to identify bereaved individuals or provide appropriate bereavement care to the rising number of persons in need. The COVID-19 crisis provides the opportunity to focus on developing social support, now and in the future, so that our communities are equipped to provide responsive, timely, and sustainable social support. Understanding the giving, seeking, and accepting of social support is critical to investigate how social support can be bolstered to benefit griever, their supporters, and communities. The time is right for considerable investment in research to understand how social support can be optimised as part of the rapidly developing public health palliative care movement that aims to reclaim dying and death in the everyday lives of individuals and communities. **Full text:** <http://bit.ly/3azPxa9>

British laypeople’s attitudes towards gradual sedation, sedation to unconsciousness and euthanasia at the end of life

PLOS ONE | In print – Accessed 16 February 2021 – The use of sedation in end-of-life care (EoLC) remains controversial. While gradual sedation to alleviate intractable suffering is generally accepted, there is more opposition towards deliberate and rapid sedation to unconsciousness (so-called “terminal anaesthesia” – TA). However, the general public’s views about sedation in EoLC are not known. The authors performed two anonymous online surveys of members of the U.K. public, sampled to be representative for key demographic characteristics. Participants were given a scenario of a hypothetical terminally ill patient with one week of life left. The authors sought views on the acceptability of providing titrated analgesia, gradual sedation, terminal anaesthesia, and euthanasia. They asked participants about the intentions of doctors, what risks of sedation would be acceptable, and the equivalence of terminal anaesthesia and euthanasia. Of the 509 total participants, 84% and 72% indicated that it is permissible to offer titrated analgesia and gradual sedation (respectively); 75% believed it is ethical to offer TA. Eighty-eight percent of participants indicated that they would like to have the option of TA available in their EoLC (compared with 79% for euthanasia); 64% indicated that they would potentially wish for TA at the end of life (52% for euthanasia). Two-thirds indicated that doctors should be allowed to make a dying patient completely unconscious. More than 50% of participants believed that TA and euthanasia were non-equivalent; a third believed they were. These novel findings demonstrate substantial support from the UK general public for the use of sedation and TA in EoLC. More discussion is needed about the range of options that should be offered for dying patients.

Abstract: <http://bit.ly/37jrb26>



[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>

Research Matters

Stakeholder perspectives on research enrollment at end of life

PEDIATRICS | Online – 17 February 2021 –The current systematic review by Hasan and colleagues helps to answer this question, summarizing the perceptions and experiences of children, parents, and health professionals regarding end-of-life (EoL) research.¹ The authors identify 24 published manuscripts utilizing a mix of both qualitative and quantitative methods and focusing on stakeholder experiences in this area. Following thematic analysis and synthesis, primary themes are concisely described in the text. In addition, specific quotations provided by the authors from these studies further illustrate the identified themes and highlight notable differences in perception/experience by child, parent, and health professional report. For example, the authors highlight the delicate balance between family and provider perception of “wanting choices.” Notably, they contrast a) parental belief that EoL research enrollment is the only option to b) provider belief that multiple choices are offered, including palliative care (PC). Given American Academy of Pediatrics’ recent endorsement of the Clinical Practice Guidelines for Quality Palliative Care,² EoL research enrollment may be a critical transition point in the disease trajectory, ripe for PC involvement. **Full text:** <http://bit.ly/3bcGwTu>

1. ‘End-of-life childhood cancer research: A systematic review ’ *Pediatrics*, 2021;147:e2020003780. **Abstract:** <http://bit.ly/3qyNGrE>
2. ‘National Consensus Project’s Clinical Practice Guidelines for Quality Palliative Care’ (4th Edition), National Consensus Project for Quality Palliative Care, 2018. [Noted in Media Watch 1 April 2019 (#608, p.11)] **Download/view at:** <http://bit.ly/2uulDhJ>

Publishing Matters

Top health research funders’ guidance on selecting journals for funded research

F1000RESEARCH | In print – Accessed 16 February 2021 – Most large health research funders mandate open access to funded research outputs, typically by way of open access journal publication and by deposition of published research in digital repositories. Few funders provide guidance on what constitutes a journal (or an open access journal) or are checking to ensure that published research that they have funded is indeed meeting specified requirements about how research should be shared. Health research funding organizations have an obligation to support researchers in meeting their mandates so that research can, as intended, contribute to the broader evidence base. The publishing community needs to provide guidance to funders and researchers on universally acceptable and transparent standards for journal operations. Many solutions to improve policies, facilitate adherence, monitor compliance and work with other funders on large-scale improvements exist and should be implemented. Journals that fail to make research discoverable breach the basic trust that researchers and their funders have in the current publishing system. Most funded researchers publish their work under the basic assumption that their journal or publisher is following best practices to ensure future use. Bodies funding health research have a responsibility to protect their investments and even more importantly, to ensure that funded research is not wasted by being published in non-credible and non-discoverable sources. **Full text:** <http://bit.ly/2LY9I8c>

Media Watch: Editorial Practice

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Something Missed or Overlooked?

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

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/3q2Jlgb>

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

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

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

South America

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

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