

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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Helping parents understand the harms, benefits, burdens and risks of any treatment or intervention is an ongoing dialogue that weighs helping them differentiate between what constitutes good care and care that may be multi-faceted but not holistic.

'Serious illness conversations in pediatrics: A case review' (p.6), in *Children*.

Canada

Raising the bar on our haphazard end-of-life transition from hospital to home

HEALTHY DEBATE | Online – 28 August 2020 – The authors' research demonstrates that hospital-to-home transitions at end of life (EoL) are tremendously fragmented, resulting in patient and caregiver distress, errors, miscommunication and prolonged hospital admissions.¹ These problems have been exacerbated during the **COVID-19** pandemic as caregiver and family presence has been restricted in hospitals despite the fact that family members are essential partners who oversee an often chaotic transition process. There is a critical need to invest resources to restructure transition processes and to support healthcare providers in improving the transition for this vulnerable and often overwhelmed group. Transitioning from hospital-to-home is common toward the EoL as many individuals with terminal illness wish to die at home. Being at home enables patients to spend meaningful time with family members. Transitions across settings can be

challenging for healthcare providers, caregivers and patients. Poor transitions at the EoL can lead to complications and rehospitalisations due to deteriorating health and increased care needs. The authors' research was conducted pre-COVID-19 and it is evident that COVID-19 has magnified existing inequities. <https://bit.ly/3gCH1Xx>

Corrections & Clarifications

An incorrect link was given to the article 'What are we willing to pay for the quality of death we want,' published in *Healthy Debate* 21 August 2020 and highlighted in Media Watch 24 August 2020 (#680, p.1). The correct link is: <https://bit.ly/3b25019>

N.B. Please report any difficulties or problems accessing articles, etc., highlighted in Media Watch. Contact information at the foot of p.14.

1. 'Palliative care transitions from acute care to community-based care: A systematic review,' *Journal of Pain & Symptom Management*, 2019;58(4):721-734. **Abstract:** <https://bit.ly/3gzvXdl>

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Noted in Media Watch 10 August 2020 (#678, p.15):

- *PALLIATIVE MEDICINE* | Online – 8 August 2020 – ‘**Palliative care transitions from acute care to community-based care: A qualitative systematic review of the experiences and perspectives of healthcare providers.**’ The majority of studies focused on the discharge process from acute care; there was a lack of studies exploring the experiences of healthcare providers in the community who receive patients from acute care and provide them with palliative care (PC) at home. The results of this review indicate that healthcare providers experience multiple complex roles during the transition facilitation process and future research should examine how to better assist clinicians in supporting these transitions within the context of PC provision. **Abstract (w. list of references):** <https://bit.ly/2PCMEdb>

Palliative care needs better PR

HEALTHY DEBATE | Online – 25 August 2020 – For decades, we have known about the benefits of palliative care (PC). First, we learned that when a palliative approach is provided to patients earlier, they live longer. Then, we learned it improved the quality of life for patients facing a life-limiting illness. Then we learned it actually saves the healthcare system money and resources that can be reinvested back into other areas of the system. And most recently, a study in Ontario showed how PC can reduce ER visits, hospital and ICU admissions in patients with non-cancer diagnoses.¹ So why are patients not demanding better access to PC and why is government not shoveling money into one of the few areas of medicine that actually simultaneously gives better care and a return on investment? The answer is: PC has a public relations issue. Now most of you in the field will immediately chime in and say “Oh yeah, we are dealing with that. We keep telling people that PC is not just about dying.” So, uh, how’s that working out? The stats in Canada are not so good ... [*vis-à-vis*] ... the federal government’s current (lack of) action plan.² The stats are also not good in Ontario, according to Health Quality Ontario’s 2019 report.³ Clearly, this particular messaging is not resonating well with either the public or government. <https://bit.ly/3hwOYyL>

1. ‘Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: Population based matched cohort study,’ *British Medical Journal*, published online 6 July 2020. [Noted in Media Watch 13 July 2020 (#674, p.8)] **Full text:** <https://bit.ly/2O2Ds0Q>
2. ‘A (lack-of) action plan for palliative care in Canada,’ *The Medical Post*, posted online 23 October 2019. [Noted in Media Watch 4 November 2019 (#638, p.1)] **Access article at:** <http://bit.ly/2Pp0JMs>
3. ‘Palliative Care at the End of Life: Update [of the Network’s 2016 report],’ Health Quality Ontario, 2019. **Download/view at:** <https://bit.ly/2UC0RdX>



[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.14.

U.S.A.

Mount Sinai researchers investigate racial disparities in end-of-life care

NEWSWISE | Online – 24 August 2020 – While hospice care has increased substantially in recent years throughout the U.S., stark racial disparities remain in utilization. The Mount Sinai study of 1,212 participants found that Black decedents were less likely (34.9%) to use hospice than White decedents (46.2%).¹ And Black decedents were far more likely to receive aggressive care at the end of life (EoL). The researchers investigated several manifestations of treatment intensity at the EoL. For example, Blacks required emergency room care more than Whites (59.3% vs. 46.4%, respectively). Disparities in EoL care were most egregious among deaths due to cardiovascular disease. “It is critical that we address disparities in quality of care at the EoL, including use of hospice. Despite impressive growth in palliative care and hospice use in the U.S. in recent years, we continue to find that Blacks are receiving more burdensome care at the EoL. This is unfortunately not surprising and should be a call to action. The medical community must do more to ensure equal access to high quality EoL care including hospice. Current Medicare guidelines for accessing the hospice benefit, including foregoing curative care, is a barrier to those who have been systematically denied quality healthcare. Reducing disparities will require improving communication and education around hospice care and ultimately addressing the systemic racism and bias that drive these disparities,” says

Katherine Ornstein, lead author and associate professor, Geriatrics & Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York. <https://bit.ly/32rOkw2>

COVID-19 and supporting black communities at the end of life

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 26 August 2020 – COVID-19 deaths to date have impacted the lives of Black people and other diverse groups disproportionately, relative to the general population, nationally and internationally. The organization’s Diversity Advisory Council has issued a position paper to help communities at all levels better understand the “why,” with an emphasis on building trust with diverse populations relative to patient care and the pain, misery, grief, and sorrow caused by the pandemic. The topics covered in the position paper include building trust, the impact of mental distress on chronic disease in the Black community, healthcare segregation, and how COVID-19 has affected the grieving process of underserved communities. **Download/view position paper at:** <https://bit.ly/2QpZhZs>

Publishing Matters

‘Responsibility of medical journals in addressing racism in healthcare’ (p.13), in *JAMA Network Open*.

1. ‘Evaluation of racial disparities in hospice use and end-of-life treatment intensity...,’ *JAMA Network Open*, 2020;8(3):e2014639. **Full text:** <https://bit.ly/3laPVzb>

N.B. Selected articles on disparities in the provision and delivery of hospice and palliative care for racial/ethnic minorities in the U.S. noted in Media Watch 3 August 2020 (#677, p.3).

International

Homerton Hospital study shows gender and ethnicity inequity in palliative care

U.K. (England) | *Hackney Citizen* (London) – 26 August 2020 – A Homerton Hospital study has concluded that there is an “urgent need” for further research into its findings showing that Black, Asian and minority ethnic patients, and in particular women, have had to wait longer for palliative care (PC) than white patients, both before and during the pandemic.¹ The research was conducted by the Homerton’s PC team, looking at the first 60 COVID-19 positive inpatients referred to its service between 1 March and 23 April of this year, alongside the 60 inpatients referred in a similar period last year. The results showed that the time of referral

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to PC ... became longer for Black, Asian and minority ethnic patients during the pandemic, with a mean difference of 3.94 days to how long white patients had to wait. Pre-COVID-19, the mean difference was 0.27 days. The study, the first comparative investigation of its kind into referrals to a PC service before and during the pandemic, is a local reflection of widely-reported findings showing that Black, Asian and ethnic minority groups have suffered disproportionately from the pandemic's impact. Data presented by the Homerton Hospital ... also suggested that women from minority ethnic groups are referred later than men, with the report adding: "Evidence suggests that women are less likely to receive pain medications and are more likely to present with advanced illness, assume a caregiver role and experience a PC referral compared to men." <https://bit.ly/2EvdDW8>

1. 'The need for early referral to palliative care especially for Black, Asian and minority ethnic groups in a COVID-19 pandemic: Findings from a service evaluation,' *Palliative Medicine*, published online 31 July 2020. **Full text:** <https://bit.ly/2YWCLwj>

Only 25% of older Australians have an advance care plan. Coronavirus makes it even more important

AUSTRALIA | *The Conversation* – 25 August 2020 – Older adults and those with chronic health conditions share an increased risk of experiencing severe symptoms if they contract COVID-19. But they're not a homogeneous group. In the event they become very sick, one person may want all available treatment, even if this includes intensive care and an extended period of rehabilitation. Another may prefer to avoid life-sustaining but highly invasive medical interventions. If either of these people became suddenly unwell, how likely is it health professionals would know their wishes? Understanding a person's wishes in advance makes it easier for the healthcare system to provide care that matches the person's preferences. Yet research shows 25% of older Australian adults accessing health and aged-care facilities have documented their wishes for future care through advance care planning (ACP).¹ A recent paper makes the case for incorporating ACP into the COVID-19 response.² <https://bit.ly/3hwq1Uf>

Where do advance care plans fall during a pandemic?

ROYAL AUSTRALIAN COLLEGE OF GENERAL PRACTITIONERS | *GP News* – 27 August 2020 – For residential aged care facilities (RACFs), where the majority of Australia's COVID-19 related deaths have occurred, cracks have been exposed in the management of preventing spread of the virus. There has been ambiguity regarding infection prevention and control standards and hospital transfer procedures, with reports suggesting many people of RACFs are not being transferred to the hospital after testing positive to COVID-19. But for those residents who do get transferred to hospital, some general practitioners are expressing frustration about not being involved and, in some cases, being unable to fulfill their patients' advance care plans, particularly if they die in hospital. **Full text:** <https://bit.ly/3gxXxrR>

1. 'Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: Multi-centre audit study,' *BMJ Open*, published online 15 January 2019. [Noted in Media Watch 21 January 2019 (#598, p.6)] **Full text:** <https://goo.gl/DAeYyZ>
2. 'Advance care planning in Australia during the COVID-19 outbreak: Now more important than ever,' *Internal Medicine Journal*, 2020;50(8):918-923. [Noted in Media Watch 17 August 2020 (#679, p.2)] **Full text:** <https://bit.ly/2Q1DIUF>

Noted in Media Watch 25 February 2019 (#603, p.10):

- *INTERNAL MEDICINE JOURNAL* | Online – 20 February 2019 – '**Prevalence of advance care directives in the community: A telephone survey of three Australian States.**' Despite long-standing efforts to increase advance care planning, community prevalence of advance care directives (ACDs) remains low, particularly for instructional ACDs. This study [i.e., a telephone survey of adults living in New South Wales, Victoria and Queensland] found some different predictors for instructional ACDs compared with appointing ACDs, and also a potential role for experiential factors in triggering uptake. These findings suggest supplementing general community awareness campaigns with more nuanced and targeted efforts to improve ACD completion. **Abstract:** <http://bit.ly/2U23qTT>

Specialist Publications

Providing end-of-life care in the emergency department: Early experience from Médecins Sans Frontières during the Covid-19 pandemic

AFRICAN JOURNAL OF EMERGENCY MEDICINE | Online – Accessed 24 August 2020 – Médecins Sans Frontières (MSF) has combined research and field-based experience to develop a guidance document for clinicians with limited experience in the provision of palliative care (PC), including those working in emergency services. In this article, the authors describe how evidence-based PC protocols can be adapted to less-resourced contexts at the necessary scale for a rapidly spreading epidemic whilst still respecting the physical and emotional needs of critically unwell individuals and their families. 'Covid-19 Resource Allocation & Palliative Care – Strategic Framework' is based upon the principles of ethical decision-making, management of symptoms, communication with, and psychosocial support for, patients and families, and acknowledges the stress that the provision of this care places on clinicians. Respect for local customs and use of local interlocutors is central to the guidance. The Covid-19 pandemic has meant that areas not traditionally linked to PC, such as emergency departments, are becoming environments where clinical decisions about providing a peaceful and dignified end of life (EoL) are being made and carried out. MSF's practical guide to the provision of PC may be adapted to numerous contexts, and allows clinicians, including those in the emergency department, to use evidence-based tools to provide compassionate EoL care in difficult or lower-resourced settings. **Full text:** <https://bit.ly/2QoiQsg>



N.B. Scroll down to 'Appendix A' to download/view guidance document.

Noted in Media Watch 20 August 2018 (#577, p.12):

- *PALLIATIVE MEDICINE* | Online – 16 August 2018 – 'How do expatriate health workers cope with needs to provide palliative care in humanitarian emergency assistance? A qualitative study with in-depth interviews.' Given the worldwide increase of chronic diseases, expatriate health workers on assignment with humanitarian emergency organisations can face more clinical situations that require advanced pain control or palliative care (PC). Multiple reasons can prevent the provision of this care. Fifteen expatriate health workers took part in individual in-depth interviews after their assignment with the organisation Médecins sans Frontières. Clinical situations requiring advanced pain control or PC do occur during assignments. **Abstract (w. list of references):** <https://bit.ly/2YxoVjA>

Access to inpatient palliative care among cancer patients in France: An analysis based on the national cancer cohort

BMC HEALTH SERVICES RESEARCH | online – 26 August 2020 – The authors present the findings of the first nationwide retrospective cohort study to provide a quantitative description of inpatient palliative care (PC) access in cancer patients in France, irrespective of vital status (i.e., alive or deceased), 3 years after diagnosis. The results revealed that less than one fifth of patients accessed inpatient PC after diagnosis, and that patients who died during follow-up were much more likely to access it. Men, older patients, those with cancer of the nervous system, people with metastatic cancer, and patients with one or more comorbidity were the most likely groups to access inpatient PC. Differences in PC access in terms of social deprivation and regions were also observed. **Full text:** <https://bit.ly/3jkciQV>

Diagnosis to death: Family experiences of paediatric heart disease

CARDIOLOGY IN THE YOUNG | Online – 24 August 2020 – Coronary heart disease (CHD) remains one of the leading causes of mortality of children in the U.S. There is limited research about the experience of parents from the diagnosis of their child with CHD through the death of their child. A prior study has shown that adults with heart failure go through a series of four transitions: 1) Learning the diagnosis; 2) Reframing the new normal; 3) Taking control of the illness; and, 4) Understanding death is inevitable. In this qualitative

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study, the author's performed semi-structured interviews with parents who have a child die of CHD to determine whether the four transitions in adults apply to parents of children with CHD. They found that these four transitions were present in the parents interviewed and that there were two novel transitions, one that proceeded the first Jones *et al* transition ("prenatal diagnosis") and one that occurred after the final Jones *et al* transition ("adjustment after death").¹ It is the authors' hope that identification of these six transitions will help better support families of children with CHD. **Abstract (w. list of references):** <https://bit.ly/31mrner>

1. 'The future as a series of transitions: Qualitative study of heart failure patients and their informal caregivers,' *Journal of General Internal Medicine*, 2015;30(2):176-182. **Full text:** <https://bit.ly/2Ytao8E>

Serious illness conversations in pediatrics: A case review

CHILDREN | Online – 18 August 2020 – This case review highlights the way that the Serious Illness Conversation Guide-Peds (SICG-Peds) [developed at Canuck Place Children's Hospice in Vancouver, British Columbia, Canada] can be used by pediatric palliative care clinicians to engage with families around sensitive topics. Parents with seriously ill children rely on clinicians' ability to communicate well. Clinicians require competencies that include excellent listening skills along with the ability to delve into themes outlined in the SICG-Peds – seeking permission, assessing understanding, prognosis sharing, and exploration of key topics. This enables the parent-clinician connection to then create a path forward in caring for the child and the family that is centered on underlying knowledge, values, and support through the trajectory of the illness. As outlined, determining goals of care and decision-making is not a one-off conversation. The use of the guide and components of the guide assist with revisiting understanding, hopes and fears within the context of the clinical picture shared through sensitive prognostications. Notably, parents who had the opportunity to engage in advance planning for their child reported that they felt more likely to be prepared for the child's last day and better able to plan for their child's location of death and rated their child's quality of life during end-of-life care as good to excellent. **Full text:** <https://bit.ly/34u02sP>



Noted in Media Watch 23 March 2020 (#658, p.8):

- *EUROPEAN JOURNAL OF PEDIATRICS* | Online – 19 March 2020 – '**Towards advance care planning in pediatrics: A qualitative study on envisioning the future as parents of a seriously ill child.**' Parents prefer open and honest information about their child's illness and prognosis and they value the concept of advance care planning (ACP), while they emphasize the need for an individualized approach. Healthcare professionals, however, see parental factors like unease and emotional burden as key barriers for ACP. When envisioning the future of their seriously ill child, parents tended to stay close to the near future initially, with a focus on disease-related, practical themes. In this study, ongoing conversations uncovered deeper, value-based elaborations towards the future. **Full text:** <https://bit.ly/3bjTb1N>

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

- *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/2vaklmU>



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Assessing physicians' and nurses' experience of dying and death in the ICU: Development of the CAESAR-P and the CAESAR-N instruments

CRITICAL CARE | Online – 25 August 2020 – As an increasing number of deaths occur in the intensive care unit (ICU), studies have sought to describe, understand, and improve end-of-life (EoL) care in this setting. Most of these studies are centered on the patient's and/or the relatives' experience. This study aimed to develop an instrument designed to assess the experience of physicians and nurses of patients who died in the ICU, using a mixed methodology and validated in a prospective multicenter study. The authors described and validated two new instruments for assessing nurses' and physicians' experience of EoL in the ICU. Their study shows factors associated with a better experience that include quality communication, both with family members and inter-professional communication and collaboration; family presence in the ICU; and, avoidance of aggressive care. **Full text:** <https://bit.ly/3hwhKzx>

Palliative and end-of-life care: Vital aspects of holistic diabetes care of older people with diabetes

DIABETES SPECTRUM, 2020;33(3):246-254. Palliative and end-of-life care (EoLC) and advance care planning (ACP) are important components of holistic diabetes management, especially for older people with a long duration of diabetes and comorbidities who experience unpleasant symptoms and remediable suffering. Many diabetes clinicians do not have conversations about ACP with patients, often because they are reluctant to discuss these issues and are not familiar with palliative care. This article outlines palliative, terminal, and EoLC for older people with type 1 or type 2 diabetes and suggests when to consider changing the focus on tight blood glucose control to a focus on safety and comfort. It proposes strategies to incorporate palliative and EoLC into personalized holistic diabetes care, determined with older people with diabetes and their families through shared decision-making. **Abstract:** <https://bit.ly/3jeAALW>

N.B. Additional articles on end-of-life diabetes care noted in Media Watch 20 May 2019 (#614, p.10):

Accuracy in surrogate end-of-life medical decision-making: A critical review

HEALTH & WELL-BEING | Online – 23 August 2020 – Increasing age is accompanied by a greater need for medical decisions, due in part to age-related increases in chronic disease and disability. In later life, medical decisions about end-of-life care in particular are likely. However, a significant percentage of these decisions are made by surrogate decision-makers. "Surrogates" are most often instructed to use the substituted judgment standard and make decisions that patients would choose if they were able. Whether surrogates make decisions that adequately match patients' preferences is a concern. Surrogates are generally poor predictors of patient preferences... However, no critical review of this literature has yet been published. These studies generally concur that patient-surrogate agreement on medical decisions is poor. However, this conclusion is qualified by inconsistencies in methodological quality and the potentially limited generalisability of these findings. Clinical research incorporating standardised hypothetical decision-making protocols, as well as triangulated data collection methods, would bolster confidence in future findings. Investigations prioritising the surrogate decision-making process, rather than solely the decisional outcome, could better identify ways to improve the decision-making process for incapacitated patients. **Abstract:** <https://bit.ly/3gkLgXz>

Noted in Media Watch 20 July 2020 (#675, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 15 July 2020 – 'What would people think? Perceived social norms, willingness to serve as a surrogate, and end-of-life treatment decisions.' The authors investigated how intrapersonal and social-contextual factors predicted two components of the surrogate decision-making process: individuals' willingness to serve as a surrogate and their tendency to select various end-of-life treatments (EoLT)... Viewing service as a surrogate as a more typical practice in healthcare was associated with greater willingness to serve. Greater decision-making confidence, greater willingness to collaborate with patients' physicians, and viewing intensive, life-sustaining EoLT ... were associated with choosing more intensive EoLT. **Abstract (w. list of references):** <https://bit.ly/2AYWe6u>

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

- *JAMA NETWORK OPEN* | Online – 19 May 2020 – ‘**Assessment of discordance between surrogate care goals and medical treatment provided to older adults with serious illness.**’ Almost half of the patients in this study had at least one medical treatment or code status order that was discordant with the goal of care identified by their surrogates. The most common source of discordance was having a full code status when the surrogate’s preferred goal was comfort measures only or an intermediate goal. There may be many cases where needed discussions with the surrogate do not occur or result in an order change. This study found there may be serious consequences to failing to document preferences for comfort care. **Full text:** <https://bit.ly/2XaaLDw>

N.B. Selected articles on surrogate decision-makers noted in Media Watch 6 April 2020 (#660, p.8).

Hospice employees’ perceptions of their work environment: A focus group perspective

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online – 24 August 2020 – Burnout in healthcare professionals can lead to adverse effects on physical and mental health, lower quality of care, and workforce shortages as employees leave the profession. Hospice professionals are thought to be at particularly high risk for burnout. Findings from the focus groups depicted both rewards and challenges of hospice caregiving. Benefits included intrinsic satisfaction from the work, receiving positive patient and family feedback, and teamwork. Challenges reflected issues with workload, technology issues, administrative demands, travel-related problems, communication and interruptions, difficulties with taking time off from work and maintaining work-life integration, and coping with witnessing grief/loss. Hospice workers glean satisfaction from making meaningful differences in the lives of patients with terminal illness and their family members. It is an expected part of the job that certain patients and situations are particularly distressing; team support and targeted grief support is available for those times. Participants indicated that workload and administrative demands rather than dealing with death and dying were the biggest contributors to burnout. Participants reported episodic symptoms of burnout followed by deliberate steps to alleviate these symptoms. Notably, for all except one of the participants, burnout was cyclical. Symptoms would begin, they would take steps to deal with it (e.g., taking a mental health day), and they recovered. At an organizational level, a multipronged approach that includes both personal and occupational strategies is needed to support professional caregivers and help mitigate the stressors associated with hospice work. **Full text:** <https://bit.ly/2EyZyHc>

N.B. Selected articles on burn-out, compassion fatigue, and the well-being and resilience practices in the hospice and palliative care workforce noted in Media Watch 27 April 2020 (#663, pp.11-12).

At the crossroads of religion and palliative care in patients with dementia

ISRAEL JOURNAL OF HEALTH POLICY RESEARCH | Online – 24 August 2020 – The timing of palliative care (PC) initiation may be more appropriately directed using a needs-based approach, instead of a prognostically driven one. Jewish Law or Halachah (“the way”) upholds a strong commitment to the sanctity of life and teaches that the duty to prolong life supersedes the duty to end suffering prematurely, unless one is expected to imminently die. This intersection of PC and a reliance on prognostic triggers with an individual’s observance of religious traditions complicates matters nearing the end-of-life (EoL). A recent pilot study by Sternberg *et al* of 20 patients with advanced dementia in Israel found that home hospice care significantly reduced distressing symptoms, caregiver burden and hospitalization and teaches us important lessons about some of the essential elements to providing excellent PC at home, including the 24/7 availability of healthcare providers outside of the emergency department.¹ In light of specific religious practices, PC should strive to incorporate a patient’s specific religious observance as part of high-quality EoL care. **Full text:** <https://bit.ly/34wZAKk>

1. ‘Home hospice for older people with advanced dementia: a pilot project,’ *Israel Journal of Health Policy Research*, published online 6 May 2019. **Full text:** <https://bit.ly/32s2j5n>

Systems of care in crisis: The changing nature of palliative care during COVID-19

JOURNAL OF BIOETHICAL INQUIRY | Online – 25 August 2020 – Among the far-reaching impacts of COVID-19 is its impact on care systems, the social and other systems that we rely on to maintain and provide care for those with “illness.” The authors examine these impacts through a description of the influence on palliative care (PC) systems that have arisen within this pandemic. They explore the impact on the meaning of care, how care is performed and identified, and the responses of PC systems to these challenges. The authors also highlight the current and potential future implications of these dynamics within the unfolding crisis of this pandemic. COVID-19 has also influenced the meaning of being a PC provider. PC clinicians’ role satisfaction often corresponds to their sense that they are providing care which is beneficial and appreciated... The constraints encountered when delivering PC in the setting of COVID-19 may result in a compromised form of care that correspondingly influences the meaning of current care roles. Furthermore, new and relatively unfamiliar risks of being a PC provider have emerged which may be influential. Cancer or heart failure are not contagious, but healthcare providers are at increased risk of contracting the COVID-19 virus, particularly when a person is close to dying of COVID-19. Providing PC now places clinicians and their families at risk from the illness itself and from fear-based responses and hostility of the community to healthcare workers. **Full text:** <https://bit.ly/2YvMd9B>

Related:

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 25 August 2020 – ‘**Ethics trade-off between hazards prevention and the safeguard of death dignity during COVID-19.**’ Urgent measures established to contain the transmission of COVID-19 and prevent biological hazards included very restrictive interventions on public Holy Masses and funerals. Italy banned any burial procedure and the decision particularly affected both Catholic and Islamic communities. The dignity of death and the religious competence as cultural competence during COVID-19 epidemic represent important aspects of the epidemic preparedness. This article provides relevant considerations about the topic from an ethical perspective. **Abstract (w. list of references):** <https://bit.ly/2QxQ55j>
- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 27 August 2020 – ‘**Racial disproportionality in COVID clinical trials.**’ There are sufficient data demonstrating that coexisting conditions in patients with COVID-19 influence clinical outcomes and that older age and male sex are associated with a greater risk of death. But despite disproportionately higher rates of COVID-19 infection, hospitalization, and death in racial and ethnic minority groups, the direct effects of genetic or biologic host factors remain unknown. As we strive to overcome the social and structural causes of healthcare disparities, we must recognize the underrepresentation of minority groups [most notably, Black, Latino and Native Americans] in COVID-19 clinical trials. **Full text:** <https://bit.ly/2ECMX8>

Overburdened and underprepared: Medical/nursing task performance among informal caregivers in the U.S.

JOURNAL OF GERONTOLOGICAL NURSING, 2020;46(9):25-35. Informal caregivers are increasingly performing medical/nursing tasks in the home for adult care recipients, often without adequate support. The authors examined associations between performing medical/nursing tasks and caregiver well-being (e.g., physical strain, emotional stress, burden of care). 58% of caregivers [i.e., study participants] performed medical/nursing tasks. Compared to those who did not, those performing tasks had higher risk of emotional stress, physical strain, and high burden of care. Among task performers, difficulty performing tasks was associated with higher risk of all outcomes; having no choice in caregiving was independently associated with higher risk of emotional stress and physical strain. Caregivers performing medical/nursing tasks, particularly those who find tasks difficult, are at risk for adverse outcomes. New clinical approaches are needed to ensure meaningful conversations about caregivers’ willingness, availability, and ability to perform medical/nursing tasks and to provide support for this part of the caregiving role. **Abstract:** <https://bit.ly/34R4H8D>



Palliative Care Network
Palliative Care for Everyone, Everywhere

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

The Palliative Care – Promoting Assessment & Improvement of the Cancer Experience (PC-PAICE) Project: A multi-site international quality improvement collaborative

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 August 2020 – Mentors at seven U.S. and Australian academic institutions partnered with seven leading Indian academic palliative care (PC) and cancer centers to undertake a program combining remote and in-person mentorship, didactic instruction, and project-based learning in quality improvement. From its inception in 2017 to 2020, the PC-PAICE program conducted three cohorts for capacity building of 22 Indian PC and cancer programs. Indian leadership established a Mumbai training hub in 2019 with philanthropic support, Quality Improvement Hub (e.g., QI-Hub) India. In 2020 the project which now focuses on both PC and cancer teams as EQuIP-India. EQuIP now leads ongoing Indian national collaboratives and training in quality improvement and is integrated into India's National Cancer Grid. PC-PAICE demonstrates a feasible model of international collaboration and capacity building in PC and cancer quality improvement. It is one of several networked, blended learning approaches with potential for rapid scaling of evidence-based practices. **Full text:** <https://bit.ly/3gmc8GQ>

Advance care planning engagement and end-of-life preference among older Chinese Americans: Do family relationships and immigrant status matter?

JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE | Online – 20 August 2020 – This study sheds light on how immigrant status and family relationships shape advance care planning (ACP) engagement among older Chinese Americans. It was found that immigrant status decreases whereas family conflict increases the likelihood of having ACP contemplation, ACP discussion, and preference in burial planning. Healthcare providers may consider patients' immigrant status and family relationships to better serve ethnically diverse populations. Given that cultural factors play an important role in ACP engagement, ACP should be adapted to be more culturally appropriate among Chinese Americans, especially in a time of Coronavirus and xenophobia, such as framing ACP as a tool to help families reduce stress while fulfilling filial obligations, in order to ensure equitable access to ACP. **Full text:** <https://bit.ly/3lqnlMD>

Virtual volunteers: The importance of restructuring medical volunteering during the COVID-19 pandemic

MEDICAL HUMANITIES | Online – 20 August 2020 – The pandemic has seen a cascade of protocol and personnel changes in healthcare systems across the country in an effort to limit infection transmission, but it is crucial that we recognise the drawbacks of changes like the cessation of medical volunteering. While volunteers are classified as non-essential personnel, they provide essential services to both patients and hospital staff. Although it would prove irresponsible to prematurely reinstate in-person volunteering programmes, restructuring volunteer services and support networks for virtual platforms offers an innovative approach to adapt medical volunteering for the current pandemic. Virtual volunteering minimises the risk of viral spreading and provides patients and families with important psychosocial and educational development. While volunteers should be encouraged to return to their in-person placements once it is safe to do so, virtual volunteering is currently the only safe option, and it will likely remain a prevalent component of medical volunteer programmes even after the pandemic. **Full text:** <https://bit.ly/31jf6aG>

Noted in Media Watch 1 June 2020 (#668, p.17):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 May 2020 – '**National outreach of telepalliative medicine volunteers for a New York City safety net system COVID-19 pandemic response.**' The authors successfully implemented a telepalliative medicine response within a large safety-net system without a pre-existing telehealth infrastructure. Within just 72 hours of the initial outreach, over 400 volunteers enlisted, reflecting a rapid and robust response. To the authors' knowledge, this is the first model to leverage external telepalliative medicine volunteers from across the country for an institutional COVID-19 pandemic response. Several concepts resonated through our process, which may aid other institutions in future efforts. **Full text:** <https://bit.ly/3gtEUXn>

Hospital patients' perspectives on what is essential to enable optimal palliative care: A qualitative study

PALLIATIVE MEDICINE | Online – 28 August 2020 – The majority of expected deaths in high income countries occur in hospital where optimal palliative care (PC) cannot be assured. In addition, a large number of patients with PC needs receive inpatient care in their last year of life. International research has identified domains of inpatient care that patients and carers perceive to be important, but concrete examples of how these might be operationalised are scarce, and few studies conducted in the southern hemisphere. The authors sought the perspectives of Australian patients living with PC needs about their recent hospitalisation experiences to determine the relevance of domains noted internationally to be important for optimal inpatient PC and how these can be operationalised. Twenty-one participants [recruited through five hospitals in New South Wales] took part. Results confirmed and added depth of understanding to domains previously identified as important for optimal hospital PC, including: effective communication and shared decision making; expert care; adequate environment for care; family involvement in care provision; financial affairs; maintenance of sense of self/identity; minimising burden; respectful and compassionate care; trust and confidence in clinicians; and, maintenance of patient safety. Two additional domains were noted to be important: nutritional needs; and, access to medical and nursing specialists. Taking a person-centred focus has provided a deeper understanding of how to strengthen inpatient PC practices. Future work is needed to translate the body of evidence on patient priorities into policy reforms and practice points. **Abstract (w. list of references):** <https://bit.ly/2D8EGpC>

Poor physical and mental health predicts prolonged grief disorder: A prospective, population-based cohort study on caregivers of patients at the end of life

PALLIATIVE MEDICINE | Online – 23 August 2020 – End-of-life (EoL) caregiving may affect the physical health in the caregivers, but the role of physical health status as a predictor of prolonged grief disorder remains unclear. Previous studies have revealed poorer mental health in caregivers of EoL patients than in the general population and several aspects of poor mental health have been shown to predict prolonged grief disorder. Cross-sectional studies have indicated a link between health status and prolonged grief disorder, but the association has not been examined prospectively. Caregivers (i.e., study participants) providing EoL care were limited in the daily activities due to their physical health compared to the general population. Poor physical health during caregiving predicted prolonged grief disorder. The mental health was worse in caregivers than in the general population, and poor mental health during caregiving predicted prolonged grief disorder. Early identification of caregivers in need of support may provide new opportunities for early prevention. **Full text:** <https://bit.ly/2EoBl6p>

Advancing research and evidence for compassion-based interventions: A matter of the head or heart?

PALLIATIVE MEDICINE | Online – 28 July 2020 – In recent years the term “compassionate care” has become part of common parlance in healthcare. Currently, a search of PubMed yields nearly 3000 articles. Searching Google Scholar retrieves over 250,000 hits, and results of the same search from the more generic search engine counterpart exceed 71 million. But conflation of compassion with empathy is evident, with these terms often used interchangeably, and there also appears general confusion about so-called “compassion fatigue,” commonly referred to as the “cost of caring.” Although the growing focus on compassionate care is largely beneficial, without rigorous research there is a risk that it becomes reduced to a buzzword lacking substance, merely occupying a place on a health service’s values statement. High quality evidence to better understand what compassion is, and how best to foster it in practice, is essential if compassionate care is to be seen as more than rhetoric in palliative care (PC). As an awareness of suffering, coupled with intentional action to alleviate it, compassion is a complex phenomenon that can, at times, be taken for granted by healthcare professionals and services. Given the various challenges encountered by PC providers, there is a need to cultivate both compassion and self-compassion at the individual level. It is equally important, however, that the flow of compassion is enabled in practice at team and organisational levels, because it is highly unlikely that compassionate care can be sustained without these factors working in synergy. **Full text:** <https://bit.ly/3j9LZwB>

What contributes to family carers' decision to transition towards palliative-oriented care for their relatives in nursing homes? Qualitative findings from bereaved family carers' experiences

PALLIATIVE & SUPPORTIVE CARE | Online – 24 August 2020 – Family carers (FCs) reported four types of “trigger events” that made them doubt that their relative would recover: 1) Physical deterioration (e.g., stopping eating/walking or swallowing problems); 2) Social confirmation (e.g., confirming their relative's condition with friends); 3) Multiple hospitalizations; and, 4) External indicators (e.g., medical examinations by external consultants). A “resident-centered environment” helped FCs recognize trigger events and “raise awareness of the possibility of death”; however, the “need for reassurance” was pivotal to a “gradual transition towards palliative-oriented care”. When participants did not recognize the trigger event, their relative continued to receive curative-oriented care. Nursing homes that referred residents to palliative care services discussed palliative-oriented care more frequently with FCs, had a lower nurse-to-resident and nurse aide-to-resident ratio, and administered more palliative-oriented care. Trigger events represent an opportunity to discuss residents' prognosis and are the starting point for a gradual transition towards palliative-oriented care. Adequate staffing, teamwork, and communication between FCs and healthcare professionals contribute to a sensitive, timely shift in care goals. **Abstract (w. list of references):** <https://bit.ly/3j6xhqz>



Pediatric palliative care when COVID-19 positive adults are dying in a children's hospital

PEDIATRICS | Online – 27 August 2020 – The presence of a pandemic does not mean that a children's hospital needs to halt or cut back services. In <3 weeks, the Children's Hospital at Montefiore, a 130-bed facility attached to an adult hospital [in New York City, New York], admitted >150 COVID-19 positive adults to our hospital. All received the services of the deployed pediatric palliative care (PC) team. Before 30 March, there was only 1 PC pediatrician providing service to an entire children's hospital. In the model the authors describe, one specialist was able to provide training and oversight to an entire deployed team and quickly expand services. The team completed >150 new consultations, 700 supportive calls were made, and 38 families received bereavement counseling over 6 weeks. During calls, families often expressed gratitude for our services. The team worked to combat the isolation caused by visitor restrictions, the fear created by an incompletely understood illness, and the heightened demands placed on the standard system of care. This approach may be useful for other children's hospitals that may have similar situations in the near or distant future. PC remains essential to alleviate the suffering of our patients, their families, and frontline providers during this time of great uncertainty and loss. **Full text:** <https://bit.ly/3lqHyzo>



Assisted (or facilitated) death

Representative sample of recent journal articles:

- *MEDICAL JOURNAL OF AUSTRALIA* | Online – 23 August 2020 – ‘**Navigating the complexities of voluntary assisted dying in palliative care.**’ Specialist palliative care (PC) services can help patients who elect voluntary assisted dying, as they are well placed to provide specialist support within clear boundaries of engagement. This can include optimal symptom management as well as psychosocial and spiritual support. The Royal Australasian College of Physicians, the Royal Australasian College of Physicians, the Australia and New Zealand Society of Palliative Medicine and Palliative Care Australia have all emphasised the need for greater access and resourcing for specialist PC. The perception of specialist PC services in cases where voluntary assisted dying has been requested will remain problematic. Collaboration with families and treating teams is essential and should involve the recognition of specialist PC involvement separate from voluntary assisted dying. The challenge remains to educate the public and healthcare professionals about PC and how it differs from voluntary assisted dying, amidst a new background of mixed messages. Regardless of the end-of-life choice made, holistic care and good communication skills are not solely related to our specialty, these are skills that can be, and need to be, routine for all areas of medicine. **Full text:** <https://bit.ly/2YxoVJA>

Cont.

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 24 August 2020 – ‘**Perception of medical assistance in dying among Asian Buddhists living in Montreal, Canada.**’ In the Western world including Canada, grievous and irredeemable health conditions, which cause unbearable suffering, has given support to the legalization of medical aid in dying (MAiD). It is unknown how Asian Buddhists who are in contact with the Western culture perceive MAiD. In this qualitative study, 16 Asian Buddhists living in Montreal took part in a semi-structured interview. Contrary to general findings in the literature, religious affiliation do not always determine moral stances and practical decisions when it comes to MAiD. Some participants were willing to take some freedom with the doctrine and based their approval of MAiD on the right to self-determination. Those who disapproved the use of MAiD perceived it as causing unnatural death, creating bad karma, and interfering with a conscious death. end-of-life care (EoLC) providers have to remain sensitive to each patient’s spiritual principles and beliefs to understand their needs and choices for EoLC. **Abstract (w. list of references):** <https://bit.ly/34rUdMt>

[Publishing Matters](#)

Responsibility of medical journals in addressing racism in healthcare

JAMA NETWORK OPEN, 2020;3(8):e2016531. Racism, as a health, public health, and healthcare issue has received important attention in recent medical journals. However, while racial and ethnic health disparities have been the subject of research for decades, racism has received comparatively little attention in research published in medical journals. Recent protests across the U.S. and beyond in response to the horrific death of George Floyd, an unarmed Black man, at the hands of a police officer in Minneapolis, have drawn renewed attention to the consequences of systemic racism on the health of Black, Hispanic, indigenous, and other people of color. Defined as a “system of structures, policies, practices, and norms that construct opportunities and assigns values based on one’s phenotype,” racism was identified 30 years ago as an underlying cause of health inequities. Since then, the role of structural pillars of racism such as employment discrimination, mass incarceration, redlining, substandard public education, exposure to environmental hazards, differential treatment in health care settings, and poor access to quality health care have been extensively documented as social determinants of health. These structural pillars of racism foster an insidious and pervasive environment that promotes the persisting racial gap in morbidity and mortality. Given this context, it is important to reassess the role of medical journals in addressing the health effects of systemic racism. **Full text:** <https://bit.ly/2QjRYTf>

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