

Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Humanitarianism and palliative care share both fundamental goals around easing suffering and upholding dignity, and a moral root in the recognition of our common suffering, fragility and humanity.

'Dying individuals and suffering populations: Applying a population-level bioethics lens to palliative care in humanitarian contexts: Before, during and after the COVID-19 pandemic' (p.7), in *Journal of Medical Ethics*.

Canada

Pandemic exposes need to overhaul funding of hospice care

ONTARIO | *Healthy Debate* – 23 June 2020 – The COVID-19 global pandemic has led to many paradigm shifts in the delivery of healthcare. Virtual care is probably the most visible and stark change. Overnight, Canadian healthcare transformed itself from a heavy reliance on face-to-face encounters to a majority of interactions occurring via secure video-conferencing or telephone support, accelerating a change that had been years, if not decades, in the making. Now, most feel virtual care is here to stay. But there is another change requiring a paradigm shift that has not yet happened: how Ontario funds hospice care. Palliative and hospice care are often used synonymously and interchangeably. For clarity, palliative care is the umbrella term that refers to the care provided to patients with a life-threatening illness, preferably from the time of diagnosis (when resources permit) until end of life (EoL). Hospice care is synonymous with EoL care. This typically occurs in either a residential hospice or a patient's home. Some residential hospices have commu-

nity outreach programs that provide home hospice care with the residential hospice available as a backstop. Residential hospices are built through philanthropic giving and fundraising. While the government partially funds the clinical operation of hospices, it is estimated that more than 50% of the overall operating expenses must be raised year-after-year to make up for shortfalls. Hospices survive due to the generosity of their communities and the unfailing commitment of staff. COVID-19 pandemic has exposed many shortcomings in our healthcare system and our funding of hospices is no exception. <https://bit.ly/3fRUbQp>

Specialist Publications

'Are you prepared for end-of-life care? A content review of Canadian end-of-life care standards and competencies for Saskatchewan' (p.9), in *Journal of Palliative Care*.

Cont.

N.B. Selected articles and reports on the provision and delivery of palliative care and hospice in Ontario noted in 29 July 2019 issue of Media Watch (#624, pp.1-2).

[U.S.A.](#)

Prevalence of living wills in U.S. up slightly

GALLUP | Online – 22 June 2020 – Forty-five percent of Americans say they have a living will, a slight increase from 40% in 2005, when Gallup last asked this question. The increase has come among those of higher socio-economic status, with double-digit increases among college graduates and upper- and middle-income adults. These results are based on Gallup's annual Values & Beliefs poll conducted May 1-13 amid the Coronavirus pandemic, which has resulted in the deaths of more than 100,000 Americans, the vast majority of whom are elderly. Gallup first asked about living wills in 2005, in response to a highly publicized right-to-die legal case involving Terri Schiavo, a Florida woman whose husband sought to remove life support for her despite opposition from her parents, and ultimately, some state and federal elected officials. Asked about their own experience with end-of-life (EoL) issues, 25% of U.S. adults say they have been in a situation in which they had to make a decision about whether to remove life support for a family member. In 2005, 22% said they had been in such a situation. Fifty-eight percent of Americans who have had to decide about removing life support for a family member have a living will, compared with 40% who have not had to make such a decision. The poll also included Gallup's annual update on Americans' views of euthanasia. Seventy-four percent of U.S. adults

say doctors should be allowed to EoL of a patient with an incurable disease “by some painless means” if the patient and the patient's family requests it. This puts current support for euthanasia at the higher end of the historical range, just below the all-time high of 75% recorded twice previously -- in 1996 and 2005. <https://bit.ly/3dmrFVx>

[COVID-19: End-of-Life Care](#)

'Bereavement care in the wake of COVID-19: Offering condolences and referrals' (p.8), in *Annals of Internal Medicine*.

'The alleviation of suffering during the COVID-19 pandemic' (p.8), in *Palliative & Supportive Care*.

'Goals of care and COVID-19: A GOOD framework for dealing with uncertainty' (p.9), in *Palliative & Supportive Care*.

[Specialist Publications](#)

'Understanding the core principles of primary and specialty surgical palliative care' (p.7), in *Journal of the American College of Surgeons*.

[International](#)

Forgotten families: Families feel more isolated than ever under lockdown

U.K. | Together for Short Lives – 25 June 2020 – A new study, in collaboration with Martin House Research Centre and the University of Southampton, reveals that most families caring for a child with a life-limiting condition have felt even more isolated and alone than normal during the Coronavirus pandemic, with some parents describing that they feel like a “forgotten group.” 93% of families [i.e., survey respondents] felt

[COVID-19: End-of-Life Care](#)

'Preparing a young palliative care unit for the COVID-19 pandemic in a teaching hospital in Ghana' (p.8), in *Palliative & Supportive Care*.

'Dying patients with COVID-19: What should hospital palliative care teams be prepared for?' (p.9), in *Palliative & Supportive Care*.

Cont.

isolated during the pandemic; 57% said isolation has brought up negative memories; 95% are fearful that their child will catch the virus from their parent; and, 93% fear their child's treatment will be cancelled or delayed. Families are missing out on vital care and support for their child while many services are still suspended. Feelings of isolation were heightened for several reasons, including the need to shield their child at home, worries about carers coming into their home and the loss of some of their formal and informal support. Around 82% of families taking part in the study are supported by their local children's hospice. Many parents, exhausted after months of providing 24/7 care for their child at home, may choose to carry on shielding their child and family long after social distancing ends because they are extremely nervous about the impact that contracting COVID-19 could have on their household. The study reveals negative impacts on the wellbeing of the seriously ill child, the parent and other family members. <https://bit.ly/3i78vq9>

Specialist Publications

To make and execute decisions throughout life: A person-centred model that facilitates self-determination in residential care, developed through participatory research

APPLIED NURSING RESEARCH | Online – 16 June 2020 – Although there are many obstacles to self-determination in residential care, the model "To make and execute decisions throughout life" shows that there are ways to facilitate self-determination throughout the residents' lives. There will probably always be a lack of time and resources in residential care, but the model might help staff to see how they, with fairly simple means, can contribute to increased self-determination for the residents. By combining practical and theoretical knowledge, the model was developed. The core message of "In my way, at my pace, with the help of you" was reinforced by the categories "See me as a competent person," "Show me professional consideration," "Meet me in a trustful relationship," "Give me opportunity to a meaningful and safe day," "Support me in being independent," "Let me have power over my own life," and "Help me to plan my end-of-life care." The model provides a base for a person-centred approach to care. By reflecting on the core message and the different categories in the model, staff can be inspired to see their own contribution to the residents' self-determination and find ways to facilitate it despite the many obstacles. However, it is

crucial that the organization acknowledge the importance of facilitating resident's self-determination and provides sufficient time and training to support the staff in their work. **Full text:** <https://bit.ly/3fBO10a>

Extract from *Applied Nursing Research* article

Help me to plan my end-of-life care

To enable me to have an influence over decisions that deal with deterioration in my health and the end of life, conversations about this must be initiated in time. As staff, you need to pay attention to changes in my health and communicate about this with me as well as within and between your various occupational groups. As I have had a long life and know my body, these questions will probably not come as a surprise to me. You should not wait for me to raise questions about deterioration, life-sustaining treatment, such as cardiopulmonary resuscitation, and dying. It is your responsibility as professionals, and especially as physicians, to offer me information about prognosis, treatment options, and what kind of care can be provided here at the residential care facility in comparison with the hospital.

Related:

- *CMAJ OPEN* | Online – 19 June 2020 – 'Quality of clinicians' conversations with patients and families before and after implementation of the Serious Illness Care Program in a hospital setting: A retrospective chart review study.' In this single-centre retrospective chart review study, the authors found that the quality of documented conversations regarding serious illness after implementation of the Serious Illness Care Program (SICP) was significantly higher than during usual care. In particular, after SICP implementation, the clinician and patient more often discussed patient values and goals, and understanding of prognosis and illness. The authors found conversations about serious illness were more clearly documented and more retrievable after SICP implementation. **Full text:** <https://bit.ly/3dmY6TG>

Conceptions of dignity in the Charlie Gard, Alfie Evans and Isaiah Haastrup cases

BIOETHICS | Online – 19 June 2020 – In 2017 and 2018, the English courts were asked to decide whether continued life-sustaining treatment was in the best interests of three infants: Charlie Gard, Alfie Evans and Isaiah Haastrup. Each infant had sustained catastrophic, irrecoverable brain damage. Dignity played an important role in the best interests assessments reached by the Family division of the High Court in each case. Multiple conceptions of dignity circulate, with potentially conflicting implications for infants such as Charlie, Alfie and Isaiah. The judgements do not explicate the conceptions of dignity upon which they rely. This article reconstructs the conceptions of dignity invoked in these judgements, finding that a broadly Kantian, agential conception dominates, under which human dignity requires the prospect of agency. This conception is situated within the broader body of thought on dignity, and the potentially adverse implications of applying the reconstructed conception in best interests assessments for infants with severely restricted consciousness are discussed. **Abstract:** <https://bit.ly/2V47Mfv>

Noted in Media Watch 21 October 2019 (#636, p.13):

- *JOURNAL OF MEDICAL ETHICS* | Online – 15 October 2019 – ‘**Worth living or worth dying? The views of the general public about allowing disabled children to die.**’ Decisions about withdrawal of life support for infants have given rise to legal battles between physicians and parents creating intense media attention. It is unclear how we should evaluate when life is no longer worth living for an infant. Public attitudes towards treatment withdrawal and the role of parents in situations of disagreement have not previously been assessed. An online survey was conducted with a sample of the U.K. public to assess public views about the benefit of life in hypothetical cases similar to real cases heard by the U.K. courts (e.g., Charlie Gard, Alfie Evans). **Full text:** <http://bit.ly/2Bf1HTh>

N.B. Selected articles on the Charlie Gard and Alfie Evans cases and related issues noted in 12 August 2019 issue of Media Watch (#626, pp.11-12).

Related:

- *BRITISH MEDICAL JOURNAL* | Online – 22 June 2020 – ‘**Judge rules that baby should be removed from ventilator and given palliative care.**’ An eight week old baby should no longer be kept alive on a ventilator and should be given palliative care (PC) to spare him the risk of a “painful, agonising death,” a High Court judge has declared. The judge was satisfied that intensive care was futile and that it had “come to place an insupportable burden” on the child. Hayden granted Sheffield Teaching Hospitals National Health Service Foundation Trust a declaration that it would be in the best interests of the baby to leave intensive care and to have PC only. The trust had hoped to reach agreement with the child’s Muslim parents and avoid a court application. **Introductory paragraphs:** <https://bit.ly/319bZmf>

A qualitative study to explore healthcare providers’ perspectives on end-of-life patients’ dignity. How can dignity be defined, and which strategies exist to maintain dignity?

JOURNAL OF CANCER EDUCATION | Online – 25 June 2020 – This study aimed to explore various healthcare professionals’ perspectives on end-of-life patients’ dignity by collecting different testimonies about what dignity entails and which strategies healthcare professionals use to maintain patients’ dignity. Participants were interviewed using two open questions to collect qualitative data. Regarding the first question (“What comes to your mind when I say ‘dignity’ in relation to your patients?”), nine themes emerged. The majority sampled stated that dignity means respecting the patient by considering him/her as a person in his/her entirety. Two other themes frequently emerged: “Respect the patient’s will/wishes/needs” and “self-determination/self-expression.” Concerning the second question (“Which strategies do you use to maintain patients’ dignity?”), seven themes emerged. The “caring skills” theme was most frequently identified, followed by “empathic skills” and “professional strategies.” **Abstract (w. list of references):** <https://bit.ly/3eCtNKa>



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Palliative care in its own discourse: A focused ethnography of professional messaging in palliative care

BMC PALLIATIVE CARE | Online – 22 June 2020 – Despite 50 years of modern palliative care (PC), a misunderstanding of its purpose persists. The original message that PC is focused on total care, helping to live until the person dies, is being replaced and linked to feelings of fear, anxiety and death, instead of compassion, support or appropriate care. Society is still afraid to speak its name, and specialized units are identified as “places of death” as opposed to “places of life” meant to treat suffering. This issue is prohibitive to the implementation and development of PC policies worldwide. It is imperative to identify what message PC professionals are relaying to patients and other healthcare specialists and how that message may condition understandings of the right to access PC. The findings of this study reinforce the complexity of professional messaging. It seems that there is a common culture, based on the same values, on what messages PC professionals transmit to patients and their families. The PC health professionals sacrifice being identified more readily by their profession for the sake of what they perceive as their patients’ wellbeing. PC professionals forgo self-interest to care for the patient in order throughout the trajectory of their illness, to alleviate suffering and to support the patient’s family. These messages are transmitted through availability, disposition and acceptance towards the ill person. However, not naming and not openly discussing the purpose of PC and its usefulness to patients and their families can perpetuate the myths, misunderstanding and lack of awareness of PC. The conclusions of this study are potentially transversal to other European countries. **Full text:** <https://bit.ly/2YnJ8sm>

Cross-sectional survey of the wish to die among palliative patients in Spain: One phenomenon, different experiences

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 25 June 2020 – Data show that the experience of the wish to die (WTD) is common in patients with advanced illness, and talking about it in a sensitive way proves harmless. The results of this study may encourage professionals to explore systematically the experience of WTD without fear that this could be harmful for the patient. Concerning family and patients, this commonality may contribute to a certain normalisation of the experience, enabling more sincere and open communication about this experience between them. Moreover, the different experiences within the same phenomenon uncovered in this study provide deeper knowledge of the overall phenomenon. More profound insights into different experiences of this kind may help care professionals to achieve a greater understanding of the patients’ experience and thus provide better follow-up. This also may improve the comprehensive support for the patient’s relatives, who may suffer as a consequence of being exposed to the patients’ WTD. **Full text:** <https://bit.ly/2BEsYly>

Strategies used to establish palliative care in rural low- and middle-income countries: An integrative review

HEALTH POLICY & PLANNING | Online – 24 June 2020 – Globally, 40 million people need palliative care (PC); about 69% are people over 60 years of age. The highest proportion (78%) of adults are from low- and middle-income countries (LMICs), where PC is still developing and is primarily limited to urban areas. This review describes strategies used by LMICs to establish PC in rural areas. Thirty papers published in English from 1990 to 2019 were included. They were appraised for quality and extracted data subjected to analysis using a public health model (policy, drug availability, education and implementation) as a framework to describe strategies for establishing PC in rural areas. The methodological quality of the reviewed papers was low, with 7 of the 30 being simple programme descriptions. Despite the inclusion of PC in national health policy in some countries, implementation in the community was often reliant on advocacy and financial support from non-government organizations. Networking to coordinate care and medication availability near-patient homes were essential features of implementation. Training, role play, education and mentorship were strategies used to support health providers and volunteers. Home- and community-based PC services for rural LMICs communities may best be delivered using a networked service among health professionals, community volunteers, religious leaders and technology. **Abstract:** <https://bit.ly/383nT2j>

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Noted in Media Watch 1 June 2020 (#668, p.9):

- *BMJ GLOBAL HEALTH*, 2020;5(5):e002368. ‘**Community health workers in palliative care provision in low-income and middle-income countries: A systematic scoping review of the literature.**’ Despite the limited evidence base, the authors found community health workers (CHWs) have several roles in palliative care provision in low-income and middle-income settings. These include raising awareness in the community, provision of pain management services, home-based care delivery and visitation, and provision of psychological support and spiritual guidance. Several areas of weakness were identified: a lack of details surrounding the training and ongoing support of CHWs, as well as the financial costs associated with deploying CHWs in the provision of PC... **Full text:** <https://bit.ly/3d61K5i>

Factors associated with overall satisfaction with care at the end-of-life: Caregiver voices in New Zealand

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 21 June 2020 – In New Zealand, as in other industrialised societies, an ageing population has led to an increased need for palliative care services. A cross-sectional postal survey of bereaved carers was conducted in order to describe both bereaved carer experience of existing services in the last 3 months of life, and to identify factors associated with overall satisfaction with care. Eight hundred and twenty-six completed questionnaires were returned... The majority of respondents (83.8%) rated their overall satisfaction with care (taking all care during the last 3 months into account), as high. However, satisfaction varied by care setting. Overall satisfaction with care in hospice was significantly higher compared to other settings. Additionally, patients who died in hospice were more likely to be diagnosed with cancer and under 65 years of age. The factors associated with overall satisfaction with care in the last 2 days of life were: 1) Caregiver perceptions of treatment with dignity and respect; 2) Adequate privacy; 3) Sufficient pain relief; and, 4) Decisions in line with the patient's wishes. A more in-depth exploration is required to understand the quality of, and satisfaction with, care in different settings as well as the factors that contribute to high/low satisfaction with care at the end-of-life. **Abstract (w. list of references):** <https://bit.ly/3fMypxx>

Extended-hours palliative care service with a hospital-avoidance and enhanced-care approach: Report of a quality improvement project

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2020;26(5):222-228. A community palliative care service (CPCS) identified its after-hours support as sub-optimal in avoiding acute hospitalisation and supporting patients to remain at home. It created and conducted a pilot of an extended hours palliative care service (EHPCS) using current resources. The EHPCS, compared with usual care, showed an almost 50% decrease in acute hospitalisation, nearly doubled after-hours palliative care unit admission and a 17% increase in patients staying in their home. EHPCS was positively received by CPCS staff, despite cost and workforce impact. **Abstract:** <https://bit.ly/2Z9ccDm>

Experiences of relatives with outpatient palliative care: A cross-sectional study

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2020;26(5):230-237. The authors aimed to evaluate the experiences of the relatives of dying people, both in regard to benefits and special needs, when supported by a mobile palliative care bridging service (MPCBS), which exists to enable dying people to stay at home and to support patients' relatives. Many relatives (62.5%) reported that their dying relations when discharged from a facility to stay at home were not symptom-free. The MPCBS helped relatives maintain home care, and this was reported to be helpful. Support provided by the MPCBS made it easier for 77.6% of relatives to adjust care as soon as situations changed, and helped ensure that symptoms could be better controlled, at least for 68.2% of relatives. Younger relatives felt more encouraged by the MPCBS to care for their relatives dying at home. **Abstract:** <https://bit.ly/2BIXN8A>



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

Understanding the core principles of primary and specialty surgical palliative care

JOURNAL OF THE AMERICAN COLLEGE OF SURGEONS, 2020;231(1):185-186. Timely palliative care (PC) consultations have been shown to improve the quality of care, reduce overall costs, and sometimes even increase longevity. The increasing tendency and theoretical appeal of having palliative medical specialists take over all components of patient suffering, however, has many potential negative consequences and includes concerns that: the supply of PC specialists cannot meet demand; adding another specialty team to address all components of PC may unintentionally undermine existing and vital therapeutic relationships; and, care may become even more fragmented as clinicians begin to believe that symptom management and supportive care are not their concern, even though many core elements of PC should be routine elements of good patient care. Although the current literature has clearly established the benefits of specialty consultations in the overall processes of PC, the common reliance (often analyzed retrospectively) on the presence or absence of the “palliative consult” as an outcome measure is methodologically problematic because it does not substantially enhance our understanding of what elements of PC are most important to the individual patient. Other than calling for the assistance of specialists, these reports unfortunately offer limited insight into the strengths or deficiencies of our care. Subsequently, our ability to provide meaningful progressive research and education in this important arena has remained limited. **Abstract:** <https://bit.ly/3fLAPN2>

Noted in Media Watch 4 May 2020 (#664, p.10):

- *JAMA SURGERY* | Online – 28 April 2020 – ‘**To face Coronavirus disease 2019, surgeons must embrace palliative care.**’ Despite evidence palliative care (PC) improves surgical outcomes and publication of practice guidelines, surgical patients are less likely than medical patients to receive PC. COVID-19 presents structural, ethical and clinical challenges forcing a fundamental re-evaluation of how we care for patients. This crisis presents surgeons with an unprecedented opportunity to embrace PC to face this pandemic. Four aspects of PC are instructive to surgeons during this crisis: 1) Using serious-illness communication strategies to disclose prognosis and establish goals of care; 2) Treating total pain; 3) Caring for the family unit; and, 4) Supporting clinicians. **Full text:** <https://bit.ly/2WcKmVd>

Noted in Media Watch 27 April 2020 (#663, p.9):

- *JOURNAL OF AMERICAN THE AMERICAN COLLEGE OF SUR-GEONS* | Online – 17 April 2020 – ‘**Identifying core principles of palliative care consultation in surgical patients and potential knowledge gaps for surgeons.**’ Previous studies demonstrated that surgeons tend to underuse palliative care (PC) in comparison with medical services. Furthermore, little is known about the specific use of PC services among surgical oncology practices. The authors evaluated the use of PC in cancer patients undergoing major oncologic surgery. Surgical patients were less likely to undergo PC consultation for assistance with symptom management and more likely to undergo consultation for assistance with end-of-life discussions than were medical oncology patients. **Abstract:** <https://bit.ly/3cBMNqM>

Dying individuals and suffering populations: Applying a population-level bioethics lens to palliative care in humanitarian contexts: Before, during and after the COVID-19 pandemic

JOURNAL OF MEDICAL ETHICS | Online – 19 June 2020 – Humanitarian crises and emergencies, events often marked by high mortality, have until recently excluded palliative care (PC)... In the COVID-19 pandemic, PC received unprecedented levels of societal attention. Unfortunately, this has not been enough to prevent patients dying alone, relatives not being able to say goodbye, and PC being used instead of intensive care due to resource limitations. Yet global guidance was available. In 2018, the World Health Organization (WHO) released a guide on ‘Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises’ – the first guidance on the topic by an international body.¹ The authors of this article argue that while a landmark document, the WHO guide took a narrowly clinical bioethics perspective and missed crucial moral dilemmas. They argue for adding a population-level bioethics lens, which draws forth complex moral dilemmas arising from the fact that groups having differential innate and acquired resources in the context of social and historical determinants of health.

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The authors discuss dilemmas concerning: limitations of material and human resources; patient prioritisation; euthanasia; and legacy inequalities, discrimination and power imbalances. Implications In parts of the world where opportunity for preparation still exists, and as countries emerge from COVID-19, planners must consider care for the dying. Immediate steps to support better resolutions to ethical dilemmas of the provision of PC in humanitarian and emergency contexts will require honest debate, concerted research effort, and international, national and local ethical guidance. **Full text:** <https://bit.ly/2AMaRdx>

1. 'Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises,' World Health Organization, October 2018. [Noted in 1 October 2018 issue of Media Watch (#583, p.6)]
Download/view at: <http://bit.ly/2T4AScC>

Related:

- *ANNALS OF INTERNAL MEDICINE* | Online – 23 June 2020 – '**Bereavement care in the wake of COVID-19: Offering condolences and referrals.**' Coronavirus disease 2019 has resulted in disturbing circumstances of death known to heighten risk for pathologic grief reactions. Physicians are well positioned to comfort and create a critical link to bereavement services for those who may need it. The authors offer brief guidance on how to assess risk and when to make a referral to a mental health provider, providing a road map for physicians who are navigating these challenging conversations and giving crucially needed support to bereaved family members in the wake of this pandemic. **Full text:** <https://bit.ly/3hXdmdx>
- *COLLEGIAN*, 2020;27(3):248-249. '**COVID-19 and what it means for end-of-life care in ICU: Balancing the priorities.**' ICU nurses must have courage to be creative in addressing end-of-life challenges rather than adopting a purely risk-averse approach, such as that created by COVID-19. To support ICU nurses in this, the Australian College of Critical Care Nurses and the Australasian College of Infection Prevention & Control have collaborated to produce a position statement,¹ which outlines how family presence for COVID-19 positive patients dying in the ICU can be facilitated, where adequate resources, including PPE and staffing permit. Balancing the priorities for family presence, duty of care for ICU patients which extends to family ... is possible. **Full text:** <https://bit.ly/3hRwjQQ>
 1. 'Facilitating next-of-kin presence for patients dying from COVID-19 in the ICU,' Joint Statement of the Australian College of Critical Care Nurses and the Australasian College for Infection Prevention & Control, May 2020. **Download/view at:** <https://bit.ly/3ep9boL>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 25 June 2020 – "'**Are you wearing your white coat?": Telemedicine in the time of pandemic.**' The potential benefits of telemedicine are many and easy to appreciate during normal times... But, there is no doubt that the virtual visit is a fundamental alteration to the patient-physician encounter. Recent weeks have brought a massive and hurried adaptation that risks changing the ancient and sacrosanct practice of medicine. And as news, discoveries, ideas, and policies spin around in a flurry, now more than ever we must anchor ourselves in and cherish the wisdom of personal interactions. The place where it all starts. **Full text:** <https://bit.ly/2VjM4nY>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 24 June 2020 – '**Preparing a young palliative care unit for the COVID-19 pandemic in a teaching hospital in Ghana.**' The emergence of the COVID-19 pandemic has necessitated an interim restructuring of the healthcare system in accordance with public health preventive measures to mitigate spread of the virus while providing essential healthcare services to the public. This article discusses how the palliative care (PC) team of the Komfo Anokye Teaching Hospital in Ghana has modified its services in accordance with public health guidelines. It also suggests a strategy to deal with PC needs of critically ill patients with COVID-19 and their families. **Abstract (w. list of references):** <https://bit.ly/2YtnAur>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 23 June 2020 – '**The alleviation of suffering during the COVID-19 pandemic.**' Burnout, moral distress, and existential anxiety are well documented among palliative care clinicians. However, the sequelae of COVID-19 likely heightens this vulnerability. These providers are impacted by the heightened cumulative loss experienced with increased patient mortality, complex patient-family dynamics, inability to be present physically to support patients at the time of death, moral injury in challenging ethical circumstances, sub-optimal symptom management amid medication shortages, and no opportunities to clarify patient/family values or establish trusting relationships. **First page view:** <https://bit.ly/3duK6HA>

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- *PALLIATIVE & SUPPORTIVE CARE* | Online – 23 June 2020 – ‘**Dying patients with COVID-19: What should hospital palliative care teams be prepared for?**’ COVID-19 patients [i.e., study participants] who are not eligible for intensive care unit treatment may have a particularly high need for palliative care (PC). Since beds in specialist PC units are limited, the hospital PC team should be prepared to care for these patients. They may offer support in decision-making, optimize symptom control, and provide psychosocial care for patients and their families. Visiting restrictions aimed to protect the general public must be weighted against the patient's and family's suffering. **Abstract (w. list of references):** <https://bit.ly/2Bu47km>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 23 June 2020 – ‘**Goals of care and COVID-19: A GOOD framework for dealing with uncertainty.**’ As the pandemic continues, more patients will require palliative and end-of-life care. In order to ensure goal-concordant care when possible, clinicians should initiate goals-of-care conversations among the most vulnerable patients and, ideally, among all patients. Many non-palliative care clinicians face deep uncertainty in planning, conducting, and evaluating such interactions. Specialists within palliative care are aptly positioned to address such uncertainties, and in this article offer a relevant update to a concise framework for clinicians to plan, conduct, and evaluate goals-of-care conversations... **Abstract (w. list of references):** <https://bit.ly/2NIHPDU>

Are you prepared for end-of-life care? A content review of Canadian end-of-life care standards and competencies for Saskatchewan

JOURNAL OF PALLIATIVE CARE | Online – 22 June 2020 – The provision of end-of-life care (EoLC) is receiving attention locally, provincially, and nationally in Canada. It is important to ensure that interprofessional standards and competencies are in place to provide quality EoLC that meets the needs of patients and their families. The purpose of this content review was to identify core standards and competencies essential to an interprofessional team providing EoLC. The researchers conducted a review of health professional associations and registration bodies that support professionals providing EoLC to identify existing standards and competencies. Key concepts were reviewed and organized using thematic analysis; relationships were developed; and, core themes for interprofessional EoLC were identified. Four themes essential to the provision of EoLC were common across all health professions: 1) Access to care; 2) Professional practice; 3) Person-centered care; and, 4) The process and delivery of care. Health professional associations need to ensure EoLC standards and competencies are in place for the provision of appropriate and holistic care. **Abstract (w. list of references):** <https://bit.ly/2Bz63YI>

Death relics and reflections: Engaging palliative staff to respond creatively to death experiences in hospice settings

MORTALITY | Online – 26 June 2020 – ‘We die as we live’ is an art in health research project that positions palliative care staff, working in a myriad of capacities in hospital and hospice settings, as “death elders” because of their expert knowledge and accumulated experience of death and dying. The authors speculate on the commemorative dimensions of death, dying and bereavement as embodied in socially-engaged artistic processes. The weekly art workshops they organise ... are designed to solicit meaningful reflection about death and its impact on the staff, using craft materials, mediums and processes that engaged the participants’ senses, and encouraged open discussion about mortality and impermanence. The workshops illustrated that every death is unique and every experience of death is unique... **Abstract:** <https://bit.ly/2A4YulX>

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>

Associations between unmet palliative care needs and cognitive impairment in a sample of diverse, community-based older adults

PALLIATIVE & SUPPORTIVE CARE | Online – 25 June 2020 – Given a large number of community-based older adults with mild cognitive impairment, it is essential to better understand the relationship between unmet palliative care (PC) needs and mild cognitive impairment in community-based samples. Participants in this study consisted of adults ages 60+ receiving services at senior centers located in New York City. The Montreal Cognitive Assessment (MoCA) and the Unmet Palliative Care Needs screening tool were used to assess participants' cognitive status and PC needs. The authors results revealed a quadratic relationship between unmet PC needs and mild cognitive impairment, controlling for gender, living status, and age. Participants with either low or high MoCA scores reported lower PC needs than participants with average MoCA scores... This study is a first step toward elucidating the relationship between cognitive impairment and PC needs in a diverse community sample of older adults. More research is needed to better understand the unique PC needs of older adults with cognitive impairment living in the community. **Abstract (w. list of references):** <https://bit.ly/2BfBqaZ>

What matters when doctors die: A qualitative study of family perspectives

PLOS ONE | Online – 23 June 2020 – In this study, the authors explored how family members of deceased physicians understood the end-of-life (EoL) preferences of their loved ones. Specifically, families identified the importance of honoring the physicians' preferences for who would care for them and where they would receive care. To advocate for these preferences, families divided tasks among family members and united to offset the impersonal aspects of the healthcare setting. Several families prioritized respecting the dignity of the physician-patients by respecting their preferences regarding symptom management, other goals-of-care and legacy-making. Physician family members felt empowered when they worked together to understand the physician's care preferences regarding difficult decisions made before death and this collaboration seemed to bring an element of peace to the family when reviewing their decisions after the physician's death. The findings of this study have implications for EoL conversations. What matters to the families of physicians when the physician is dying and after his/her death should directly challenge healthcare providers to be more clear in conversations about their own EoL preferences. Suggestions for clinical practice are provided... **Full text:** <https://bit.ly/2zZDuU5>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 20 June 2020 – **'Physician attitudes to voluntary assisted dying: A scoping review.'** Voluntary assisted dying (VAD) became legal in the Australian state of Victoria on 19 June 2019 and will be legal in Western Australia from 2021. Other Australian states are progressing similar law reform processes. In Australia and internationally, doctors are central to the operation of all legal VAD regimes. It is broadly accepted that doctors, as a profession, are less in favour of VAD law reform than the rest of the community. To date, there has been little analysis of the factors that motivate doctors' support or opposition to legalised VAD in Australia. Twenty-six publications detailing 19 studies were identified. Three overarching themes emerged: 1) Attitudes towards regulation' encompassed doctors' orientation towards legalisation, the shortcomings of binary categories of support or opposition and doctors' concerns about additional regulation of their professional practices; 2) Professional and personal impact of legalisation described tensions between palliative care and VAD, and the emotional and social impact of being providers of VAD; and, 3) Practical considerations regarding access considered doctors' concerns about eligibility criteria and their willingness to provide VAD. A detailed understanding of medical perspectives about VAD would facilitate the design of legislative models that take better account of doctors' concerns. This may facilitate their greater participation in VAD and help address potential access issues arising from availability of willing doctors. **Abstract:** <https://bit.ly/2BuCF5P>

Media Watch: Editorial Practice

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

Distribution

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

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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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Updated 06.23.2020

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

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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTP://BIT.LY/300WMRT>

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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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