

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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Does it seem sensible that a lay person sitting at their kitchen table or even with a lawyer in their office should make medical treatment decisions when they are ill-informed about medical treatments and more likely driven by emotion and fear with no one to coach or help them deal effectively with their future realities?

'Advance care planning vs. advance serious illness preparations and planning' (p.9), in *Healthcare*, 2020;8(3):E218.

Canada

Editorial

Virus vs. visitors – why long term care needs a palliative approach

ONTARIO | *The Hamilton Spectator* – 27 July 2020 – **COVID-19** has exposed the ills of long term care (LTC), but I hear words like facilities, beds, and dollars when I hear about solutions. What we need to hear are words like people, time, and quality of life (QoL). And, we need to talk about a palliative approach to care because the very words symbolize the QoL we all seek. We call it LTC, but for those living there it is their home, or it should be. And throughout society, what we have failed to face is that it is often a person's last home. A LTC resident is most often elderly and fast approaching the end of their life, with an average time from admission to death of under two years. This is not the time for heroic measures and unnecessary trips to hospitals that often fail to extend life and regularly cause more suffering and complications. It is a time to focus on living as well as possible until the end of life, based on an individual's values and needs. That's what the palliative approach means. It is not a resignation or a giving-in to death; instead, it is embracing life and all that

we are – physically, emotionally, socially, psychologically, and spiritually. And it is not just a checklist of tasks – toileting, bathing, feeding, and medications – instead it focuses on QoL. <https://bit.ly/2P2qfG2>

Highlighting the need for long-term care reform

ONTARIO | *Healthy Debate* – 27 July 2020 – This article is not only a critique of the current system but provides real and tangible solutions for improvement. These include increased access to palliative care (PC) specialists, appropriate staffing levels and education to provide better care, much of which can be provided through a combination of traditional face-to-face patient care as well as virtual care. The pandemic has shown that now is the time for a fundamental culture change in how we view long-term care homes and how we provide care within these facilities. Early integrated PC within these homes is essential to ensure that our aging population has the quality of care it deserves. <https://bit.ly/3fbFVRM>

Cont.

Noted in Media Watch 20 July 2020 (#675, p.1):

- *POLICY OPTIONS* | Online – 16 July 2020 – ‘**Palliative care has been lacking for decades in long-term care.**’ As Canada discusses reforming nursing homes in the wake of COVID-19, it is important that we recognize the need for early, integrated palliative care. What this means is that suffering is monitored and then addressed in a timely fashion when required, not just in the last days or weeks. It means that we attend to the physical and emotional well-being of patients and their families while continuing to learn about what quality of life means for them. This care happens while patients are being treated for their underlying illnesses and continues after they or their doctors decide that treatment is no longer helpful, desirable or necessary. <https://bit.ly/2B5GAXb>

Noted in Media Watch 22 June 2020 (#671, p.1):

- *HEALTHY DEBATE* | Online – 16 June 2020 – ‘**Not scared of dying but of dying scared.**’ COVID-19 has shone a bright light on a flawed system in need of dramatic reform, and on a workforce that must be better supported and empowered to provide meaningful end-of-life (EoL) care. This is not to place blame at the feet of our underpaid and undervalued care workers. These workers are cycling in and out of and in-between long-term care (LTC) settings without proper resources, training and educational supports. This workforce, much like the residents that they care for in an ageist society, has been largely ignored. While COVID-19 has brought this issue into focus, the lack of EoL support in LTC has been an ongoing injustice. <https://bit.ly/37F4bJS>

N.B. Additional articles on EoL care in LTC facilities in Ontario noted in this issue of Media Watch.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GOVERNMENT OF CANADA | Online – 26 July 2020 – ‘**First annual report on medical assistance in dying (MAiD) in Canada, 2019.**’ This report contains information collected from practitioners and pharmacists for the 2019 calendar year on written requests for and cases of MAiD across Canada. The data presented has primarily been drawn from the federal monitoring system for MAiD, which was launched on 1 November 2018. **Download/view at:** <https://bit.ly/39s9Tjt>

U.S.A.

How death doulas have adapted end-of-life care amid COVID-19

VOGUE | Online – 30 July 2020 – For centuries, doulas have been assisting with childbirth, providing emotional, physical, and educational support during pregnancy, labor, and delivery. But there aren’t just doulas for the birthing process: over time, both officially and unofficially, end-of-life (EoL) doulas have emerged to help individuals with palliative care and support their families through the grief that comes with losing someone. A 2017 study found that women who had continuous support during their labor – whether from a nurse, doula, or partner – reported a more positive birth experience. It seems likely that the same kind of constant emotional support from a death doula would have an equally positive effect on processing the grief around passing. In a year when death and grief have become a constant, the palliative care process has reached a new level of complexity amid COVID-19. EoL doulas have always strived

to be a support system for those who are terminally ill, but in 2020 the people who take on that responsibility have been challenged to think outside the box when it comes to caregiving. They’ve had to help their dying clients make unimaginable choices between risking virus exposure and spending their last days alone. They’ve also had their presence questioned at a time when their skills could be most valuable. <https://bit.ly/39JDftw>

Specialist Publications

‘**COVID-19 pandemic response: Development of outpatient palliative care toolkit based on narrative communication**’ (p.6), in *American Journal of Hospice & Palliative Medicine*.

Cont.

Noted in Media Watch 2 September 2020 (#629, p.11):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 25 August 2019 – ‘**The voices of death doulas about their role in end-of-life care.**’ Death doulas have emerged not only as a response to the overwhelming demands on families and carers, but also demands placed on healthcare professionals ... at the end of life. They have identified gaps in health and social care provision, perhaps taking on tasks that health professionals don’t have responsibility for. However, the roles and scope of practice of death doulas is not clear-cut..., which can then make it hard for patients and families when choosing a death doula, especially as a lack of regulation and standardised training means that doulas are working without oversight, and often in isolation. **Full text:** <http://bit.ly/2ZuHcQb>

Noted in Media Watch 1 October 2018 (#583, p.13):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 26 September 2018 – ‘**What role do death doulas play in end-of-life care? A systematic review.**’ Current health and social care systems do not always meet the needs of the dying in our communities. This systematic review has highlighted the paucity of formal investigations into death doulas, and a need to undertake further inquiry. Death doulas are working in end-of-life care, but their role and place within the health and social care systems is not well understood. Death doulas may represent a new direction for personalised care directly controlled by the dying person, an adjunct to existing services, or an unregulated form of care provision without governing oversight. **Full text:** <http://bit.ly/2Ld0Oz8>

Social justice and palliative care policy

SOCIAL WORK HOSPICE & PALLIATIVE CARE NETWORK | Online – Accessed 27 July 2020 – In an effort to engage in social action to address racial inequity, the network’s ‘Statement on Racism and Structural Inequities in Hospice and Palliative Social Work’ is suggesting the bold and necessary step of asking us to critically question how we, as hospice and palliative care (PC) social workers, are contributing to maintaining systems of inequity in the work that we do. These are hard conversations to have, but needed to do the work necessary to correct racial and ethnic disparities inherent in end-of-life care (EoLC). To be anti-racist PC and hospice social workers, we need to examine our own personal biases and the systems of care that pay our salaries and contribute to poorer care provision for people who are not white. Using a lens of intersectionality to examine the market based economy of healthcare in the U.S., having a life-threatening illness and being black or His-

panic unfortunately, leads to poorer EoLC outcomes. As our healthcare system struggles to care for those impacted by COVID-19, we have seen that higher rates of infection and death have occurred in nonwhite communities. PC research also tells us that racial and ethnic minorities experience a higher likelihood of difficulties in managing symptoms from all illnesses, including higher rates of experiences with pain, a higher likelihood of hospitalization in final stages of life, and a higher likelihood of discharge from hospice. **Download/view network’s statement at:** <https://bit.ly/39z9jjS>

[Specialist Publications](#)

‘**Cultivating cultural competence: How are hospice staff being educated to engage racially and ethnically diverse patients?**’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

N.B. Selected articles on disparities and barriers in the provision and delivery of EoLC for racial/ethnic minorities in the U.S. noted in Media Watch 8 June 2020 (#669, p.5).



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International

New framework to address inequity for Māori in hospice care

NEW ZEALAND | TVNZ News 1 (Auckland) – 29 July 2020 – Mauri Mate is a new palliative care (PC) structure, which focuses on the quality, equity and compassion of hospices in Aotearoa.¹ It's the first of its kind, with extensive collaboration between the Te Ohu Rata o Aotearoa (The Māori Medical Practitioners Association), Totara Hospice in South Auckland and Mary Potter Hospice in Wellington. It involves improving the access for Māori whānau, as well as increasing the cultural competence and awareness of staff in PC. Māori clinicians, leaders and academics were brought together to ensure the framework was “by Māori, for Māori.” Research and literature, as well as kōrero between health providers and the community, highlighted the need to improve the cultural safety and cultural value of Māori. Although there's no word at this stage on Mauri Mate being adopted nationally, there's hope the endorsement from Hospice New Zea-

land will help the framework be implemented in across other hospice care systems eventually. <https://bit.ly/3hMM3BT>

Specialist Publications

'A review of the current state of hospice care in China' (p.8), in *Current Oncology Reports*.

'Adapting care for older cancer patients during the COVID-19 pandemic: Recommendations from the International Society of Geriatric Oncology COVID-19 Working Group' (p.6), in *Journal of Geriatric Oncology*.

'The impact of bereavement support on wellbeing: A comparative study between Australia and Ireland' (p.12), in *Palliative Care & Social Practice*.

1. 'Mauri Mate: A Māori Palliative Care Framework for Hospices,' Hospice New Zealand. **Download/view at:** <https://bit.ly/3hJY4YL>

N.B. Aotearoa is the Māori name for New Zealand; whānau is Māori for extended family; and, translated, Kōrero is “to speak, to talk.” Additional articles on Māori beliefs and practices in the context of end of life, and palliative and end-of-life care noted in Media Watch 24 February 2020 (#654, p.8).

More than half of adult Coronavirus patients at a leading hospital were given do not resuscitate orders or barred from treatment in intensive care, study reveals

U.K. (England) | *The Daily Mail* (London) – 28 July 2020 – More than half of all adult patients treated for Corona-virus at a leading hospital were given do not resuscitate orders (DNR) or barred from treatment in intensive care, a study has revealed.¹ Less than one in five patients ... was admitted to the intensive care unit (ICU). A total of 61% of COVID-19 patients had treatment limitations placed on them on admission to King's College Hospital in London at the peak of the crisis. This meant they were denied access to potentially life-saving care. The study raises new fears about care rationing for elderly and vulnerable patients amid concerns that they were rushed into agreeing DNR. The other National Health Service (NHS) method of limiting life-saving treatments for the most elderly, frail or sick ... was to use treatment escalation plans (TEPs). The study of 429 patients at King's College ... reveals in detail what happened as staff coped with up to nine admissions of critically ill patients to the ICU a day and a further 41 to the wards. Experts from the local NHS trust's Department of Critical Care Medicine said: “Treatment limitations were placed on 61% of patients overall, most commonly on hospital admission. These meant patients agreed not to go into intensive care or be put on a ventilator or any kind of life support, including kidney dialysis, if their organs failed. The study found such TEPs were used for eight out of ten patients on COVID-19 wards, effectively keeping them out of intensive care, and typically went hand-in-hand with DNR orders, which were also agreed by 86% of patients on the wards. <http://dailym.ai/307J2pN>

1. 'Hospital mortality and resource implications of hospitalisation with COVID-19 in London: A prospective cohort study,' *medRxiv* posted 17 July 2020. **Full text:** <https://bit.ly/3gc9152>

N.B. This article is a preprint and has not been peer-reviewed. It reports new medical research that has not been evaluated.

Research into palliative care for COVID-19

U.K. (England) | *Mirage* – 28 July 2020 – The International Observatory on End-of-Life Care at Lancaster University is involved in two new projects exploring aspects of palliative and end-of-life care (EoLC). The first project, CovPall is a rapid evaluation of the COVID-19 pandemic response in palliative and EoLC, exploring national delivery, workforce and symptom management. The team hope the findings will help shape our future palliative care response to COVID-19 or other emergency situations. PC professionals and services are at the fore-front of the response to COVID-19, helping to provide essential care to those seriously ill or dying with COVID-19. The second project – ‘Necessary Conversations’ – is an online tool to help staff in care homes have conversations with families and residents about planning what should happen if a resident got COVID-19 or another condition that might result in an admission. The team is led by Queens University, Belfast, and the project is funded by the Economic & Social Research Council. Alongside the UK Research & Innovation and the National Institute for Health Research, Cicely Saunders International and the National Institute of Health Research Applied Research Collaboration, partners on the project are the European Association for Palliative Care, Marie Curie, Palliative Care Outcome Scale Development Team, Together for Short Lives, Sue Ryder and Hospice UK. <https://bit.ly/30Qyw5n>

N.B. CovPall website: <https://bit.ly/2ANoNDR>

Specialist Publications

Opioids and public health

AMA JOURNAL OF ETHICS, 2020;22(8):E645-750. Manufacturers of prescription opioids offered assurance in the mid-to-late 1990s that these drugs wouldn't make patients with pain into patients with substance use disorders. Some physicians believed them and prescribed these drugs without appropriate regard for their addictiveness, contributing to prescription and street opioid misuse that has reached alarming proportions. This issue of the journal considers ethical questions that contextualize the opioid epidemic from social, cultural, and policy-based perspectives and illuminates potential solutions. **Contents page:** <https://bit.ly/2DcA0z9>

Cultivating cultural competence: How are hospice staff being educated to engage racially and ethnically diverse patients?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 31 July 2020 – Compared to Whites, racial/ethnic minorities are less likely to enroll in hospice and if they enroll, more likely to experience poor quality care. Building cultural competence among hospice staff is a strategy that may reduce disparities. A total of 197 hospices participated in a national survey; most were not-for-profit (80%) with an average daily census less than 100 (47%); 73% offered staff cultural competence training (CCT). There were no differences in characteristics of hospices who offered CCT and those that did not. Of hospices offering CCT, 61% held it annually. Most trainings were 1 hour (60%); content was delivered via web (58%) and/or lecture (58%). While over 90% of staff (i.e., nurses, social workers, chaplains) completed CCT, a smaller proportion of medical directors (64%), senior leaders (71%) and board members (26%) did so. Most common topics were: cross-cultural communication, death/illness beliefs, spirituality's role, and healthcare disparities. The majority focused on African-Americans (83%), Hispanics (76%), and Asians (62%) – the most common U.S. minority groups. Almost 30% reported no effectiveness assessment of CCT, while 51% reported a quiz at the end of training. Most hospices offered some CCT. CCT has been shown to improve healthcare providers' knowledge and skills in caring for diverse patients and it is associated with increased patient satisfaction. Future research should evaluate effectiveness of CCT in improving the ability of hospices to deliver high quality end-of-life care to diverse groups of older adults. **Abstract (w. list of references):** <https://bit.ly/3gmvaO4>

N.B. Selected articles on disparities and barriers in the provision and delivery of EoL care for racial/ethnic minorities in the U.S. noted in Media Watch 27 July 2020 (#676, p.2).

COVID-19 pandemic response: Development of outpatient palliative care toolkit based on narrative communication

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 July 2020 – To develop a succinct and practical palliative care (PC) toolkit for use by primary care clinicians during the COVID-19 pandemic, the authors focused on two key elements: 1) Advance care planning communication skills based on the narrative 3-Act Model; and, 2) Comfort care symptom management at the end of life. The toolkit was finalized through an iterative process involving a team of end-users and experts in PC and primary care, including social work, pharmacy, nursing, and medicine. The modules were formatted into an easily navigable, smartphone-friendly document to be used at point of care. The toolkit was disseminated to Johns Hopkins Bayview Medical Center's primary care network with practices spanning the state of Maryland. Early feedback has been positive. While we had been focused primarily on the inpatient setting, the PC team pivoted existing infrastructure and curriculum development expertise to meet the expressed needs of our primary care colleagues during the pandemic. Through collaboration with an interprofessional team including end-users, the authors designed and disseminated a concise PC toolkit within 6 weeks. **Abstract (w. list of references):** <https://bit.ly/3hVsEyT>

We will all be changed: Palliative care transformation in the time of COVID-19

JOURNAL OF PALLIATIVE MEDICINE | Online – 27 July 2020 – Transformation began in early 2020. In December of 2019, a novel respiratory illness was described in China, and the era of the global pandemic caused by severe acute respiratory syndrome Coronavirus 2 began. Coronavirus disease 2019 (COVID-19) has expanded globally to infect millions of people and to cause over half a million deaths – and these numbers are underestimates due to lack of widespread testing. By the time this article is published, this epidemiology will be far out of date, since the number of cases and deaths per day continues to rise globally and in the U.S. People who are presymptomatic and minimally symptomatic will shed and share this virus that is so adapted to our human desire to touch, to interact, and to live in proximity to one another. Although most people who are infected will recover, a significant percentage will die or live on with major chronic effects on lung, renal, or neurologic function. Every facet of ordinary life is affected, from celebrations to funerals, from grocery shopping to employment, from household cleaning to visiting older relatives. And frankly, although research is progressing on treatment and vaccines, we all know this new normal will be sustained for an indefinite amount of time. **Full text:** <https://bit.ly/3hJZwuk>

Related:

- *AMERICAN JOURNAL OF BIOETHICS*, 2020;20(7):202-204. **'Ethical challenges in advance care planning during the COVID-19 pandemic.'** Advance care planning (ACP) is a means of alleviating some uncertainty around end-of-life care preferences and should be utilized for the ethically guided use of limited resources. Proactive conversations with patients prior to diagnosis and hospitalization can be a valuable form of community engagement and education. They can help tailor care and triage decisions that broad strokes of DNR policy can fail to address. ACP can play an important role in contingency planning toward patients most at-risk of severe illness... Several new ethical challenges in the creation of advance directives have emerged due to limited resources... **Full text:** <https://bit.ly/3qn5GjO>
- *JOURNAL OF GERIATRIC ONCOLOGY* | Online – 16 July 2020 – **'Adapting care for older cancer patients during the COVID-19 pandemic: Recommendations from the International Society of Geriatric Oncology COVID-19 Working Group.'** Despite the scarcity of health resources brought on by the pandemic, attention needs to be paid for the provision and maintenance of palliative care services. COVID-19 restrictions and physical distancing guidelines have resulted in reduced access to available information, care and supports from families and friends, as well as social and personal care services that allow older persons, including those living with disabilities, to cope at home. **Full text (click on direct link to journal):** <https://bit.ly/30J6nx4>

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

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 26 July 2020 – ‘Usage patterns of a web-based Palliative Care Content Platform (PalliCOVID) during the COVID-19 pandemic.’ The authors demonstrate that, even in the midst of a global pandemic, it is possible to rapidly design and implement a digital solution in response to an unprecedented healthcare challenge. They also demonstrate the use of a free, open-access tool such as Google Analytics to evaluate patterns of user behavior, consequences of the dissemination strategy, and aspects of the platform that may be amenable to future improvements. Quantitative data should be combined with qualitative research to provide more accurate interpretations of user behavior. **Full text:** <https://bit.ly/2X0XzBP>
- *PALLIATIVE MEDICINE* | Online – 31 July 2020 – ‘Prioritising workforce wellbeing and resilience: What COVID-19 is reminding us about self-care and staff support.’ To maintain the provision of quality palliative care (PC) in the wake of such challenges [as the COVID-19 pandemic], there is a clear need to prioritise wellbeing and resilience in the PC workforce. It has also been important to offer such opportunities to the broader health workforce who also have been plunged into a steep learning curve to provide PC, outside their usual scope of clinical practice. But whose responsibility is workforce wellbeing and resilience – the individual practitioner or the organisations in which they work? **Full text:** <https://bit.ly/3k2SNNJ>
- *PALLIATIVE MEDICINE* | Online – 31 July 2020 – ‘Learning a palliative care approach during the COVID-19 pandemic: A case study in an infectious diseases unit.’ This study was conducted in the palliative care (PC) unit of the AUSL-IRCCS hospital of Reggio Emilia ... consulting with the infectious diseases unit of the same hospital. Three themes were identified: 1) New answers to new needs; 2) Symptom relief and decision-making process; and, 3) Educational and training issues. Some changes in usual care needed to be made. These included breaking bad news, patients’ use of communication devices, the limited time available for the delivery of care, managing death necessarily only inside the hospital, and relationships with families. **Abstract (w. list of references):** <https://bit.ly/3fkXleO>
- *PALLIATIVE MEDICINE* | Online – 31 July 2020 – ‘The role and response of primary healthcare services in the delivery of palliative care in epidemics and pandemics: A rapid review to inform practice and service delivery during the COVID-19 pandemic.’ Only five studies met the inclusion criteria, highlighting a striking lack of evidence base for the response of primary healthcare services in palliative care (PC) during epidemics and pandemics. All were observational studies. As the COVID-19 pandemic progresses, there is an urgent need for research to provide increased understanding of the role of primary care and community nursing services in PC, alongside hospices and community specialist PC providers. **Abstract (w. list of references):** <https://bit.ly/33fsl3T>

Transition from children’s to adult services for adolescents/young adults with life-limiting conditions: Developing realist programme theory through an international comparison

BMC PALLIATIVE CARE | Online – 30 July 2020 – The “transition issue” relates to young adults experiencing difficulties engaging with adult services after graduating from children’s services, typically when the young adult is 18 years old. A lack of engagement with adult services can result in measurable adverse outcomes such as non-adherence to treatment and loss to follow up, in addition to adverse social and educational outcomes. This may be the result of inadequacies in transition planning or a lack of transition preparation while the adolescent is in pediatric care. The rationale for the transition issue is multifaceted with causes related to a disjointed transition process, adolescents/young adults experiencing difficulties adjusting to differences in the culture between children’s and adult services, the ending of long-standing relationships with children’s service providers, and loss of services. Although a poor transition to adult care may be associated with poor clinical outcomes, higher costs to both the health system and the family as well as low levels of patient and family satisfaction, an international cross-jurisdictional policy scoping review focusing on identifying health system strategies that support transition to adult care in nine countries found that the U.K. and Australia were the only countries which demonstrated efforts to develop transition to adult service strategies. **Full text:** <https://bit.ly/33apFhK>

N.B. A selection of articles that focus on the “current thinking” in paediatric palliative care, including a selection of articles specific to end-of-life care for adolescents and their transition to adult care, posted 8 July 2019 on the European Association for Palliative Care blog at: <http://bit.ly/2XC24jA>

General practice nurses and physicians and end of life: A systematic review of models of care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 26 July 2020 – General practitioners (GPs) and general practice nurses (GPNs) face increasing demands to provide palliative care (PC) or end-of-life care (EoLC) as the population ages. In order to maximise the impact of GPs and GPNs, the impact of different models of care that have been developed to support their practice of EoLC needs to be understood. From 6,209 journal articles, 13 papers reported models of care supporting the GP and GPN's role in EoLC or PC practice. Services and guidelines for clinical issues have mixed impact on improving symptoms, but improved adherence to clinical guidelines. National frameworks facilitated patients being able to die in their preferred place. A single specialist PC-GP case conference reduced hospitalisations, better maintained functional capacity and improved quality of life parameters in both patients with cancer and without cancer. No studies examined models of care aimed at supporting GPNs. Primary care practitioners have a natural role to play in EoLC, and most patient and health system outcomes are substantially improved with their involvement. Successful integrative models need to be tested, particularly in non-malignant diseases. Such models need to be explored further. More work is required on the role of GPNs and how to support them in this role. **Abstract:** <https://bit.ly/39zQFls>

A review of the current state of hospice care in China

CURRENT ONCOLOGY REPORTS | Online – 28 July 2020 – Although the Chinese government has increased its support for hospice care in recent years, however, owing to the lack of education around hospice care and the heavy influence of the traditional Chinese Confucian concept of “filial piety,” many individuals resist hospice care. Moreover, due to impaired patient rights, inadequate composition of hospice care teams, unbalanced geographical distribution, and limited service range, the development of hospice care in China is hindered. Hospice care education and continued training should be popularized and the government should strengthen the legal structure of the medical system to protect the rights of patients, families, and medical staff to promoting social support for hospice care. Through graded diagnosis and referral systems in medical institutions to integrate medical resources and expand the range of hospice care services. **Abstract (w. list of references):** <https://bit.ly/2BzEgI2>

Noted in Media Watch 6 April 2020 (#660, p.4):

- U.S. | *The New Yorker* – 30 March 2020 – ‘**China’s struggle with hospice care.**’ Few cultures relish talking about death, but in China the subject remains taboo. Mentioning it is considered so unlucky that dying people are often reluctant to discuss arrangements with their families or even to make wills. As a result, fewer than a hundred and fifty institutions specialize in end-of-life care, in a country where nearly twenty-per-cent of the population – a quarter of a billion people – is sixty or older. The U.S., with some seventy million people over sixty, has more than fifty-five hundred such institutions. In China, the family has traditionally provided care for the vulnerable... Confucian expectations of filial piety remain strong, but for most Chinese they have become increasingly difficult to fulfill. <https://bit.ly/2JcD5X>

Noted in Media Watch 18 November 2019 (#640, p.13):

- *MEDICINE*, 2019;98(45):e17683. ‘**Knowledge and attitudes toward end-of-life care among community healthcare providers and its influencing factors in China: A cross-sectional study.**’ Community healthcare provider (CHP) attitudes toward end-of-life (EoL) care were predicted by death attitudes, working experience, experiences of the death of relatives, and experiences of caring for the dying. This suggested that CHP attitudes toward EoL care were influenced by a variety of variables that were not included in this study. Public’s insufficient knowledge of EoL care, imperfect medical insurance system, imperfect policies, laws and systems of palliative care, and the lack of localized EoL models also influenced CHP attitudes toward EoL care. **Full text:** <http://bit.ly/36SV1sG>

N.B. Additional articles on EoLC in China noted in 29 July 2019 issue of Media Watch (#624, p.11).

Prisons and COVID-19: A desperate call for gerontological expertise in correctional healthcare

THE GERONTOLOGIST | Online – 24 July 2020
– The large and continued growth of the older adult population within U.S. prisons affects not only criminal justice policy and correctional health practice, but also gerontology. Amidst the unfolding COVID-19 crisis, associated knowledge and skills surrounding older adulthood will be critical to assuring the needs of older adults incarcerated in prisons are met during their detention, while undergoing off-site intervention in community settings, and when preparing for release. The authors outline several key areas for which gerontologists and associated practitioners are especially well-suited in the effort to curtail morbidity and mortality driven by the disease caused by the novel Coronavirus. Critical gerontological knowledge and skills needed in prison healthcare include awareness regarding the unusual clinical presentations of COVID-19 among older adults, deconditioning among older adults due to immobility, challenges in prognostication,

and advance care planning with older adults. Specific, targeted opportunities for gerontologists are identified to reduce growing risks for older adults incarcerated in prisons. **Full text (click on pdf icon):** <https://bit.ly/2WUQ7YA>

Extract from *The Gerontologist* article

The increased burden of disease among persons in prisons has dire consequences for prison infirmaries which have limited acute care capacity and rely on transfer to outside community hospitals for care of patients with serious illness. Such transfers can quickly overwhelm nearby community hospitals (many of which are small and rural). Worse, few prison healthcare professionals have specialty training in geriatrics or palliative care, knowledge and skills needed desperately to combat the COVID-19 emergency.

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 15 June 2020) can be downloaded from the Palliative Care Network website at: <http://bit.ly/2RdegnL>

Advance care planning vs. advance serious illness preparations and planning

HEALTHCARE, 2020;8(3):E218. **COVID-19** has highlighted the reality of an impending serious illness for many, particularly for older persons. Those faced with severe COVID-19 infection or other serious illness will be faced with decisions regarding admission to intensive care and use of mechanical ventilation. Past research has documented substantial medical errors regarding the use or non-use of life-sustaining treatments in older persons. While some experts advocate that advance care planning (ACP) may be a solution to the problem, the author argues that the prevailing understanding and current practice of ACP perpetuates the problem and results in patients not receiving optimal patient-centered care. Much of the problem centers on the framing of ACP around end-of-life care, the lack of use of decision support tools, and inadequate language that does not support shared decision-

making. A new approach and new terminology is needed. Advance Serious Illness Preparations & Planning consists of discrete steps using evidence-based tools to prepare people for future clinical decision-making in the context of shared decision-making and informed consent. **Full text:** <https://bit.ly/30GUkAc>

Extract from *Healthcare* article

Most of the care plans or instruction directives are framed around conditions of certainty, “If I am dying, I don’t want this or I do want this....” However, most of the clinical scenarios where we need to make preference-sensitive decisions regarding the use of life-sustaining treatments are situated early in the clinical course where the outcomes are uncertain.

Cont.

Related:

- *JAMA NETWORK OPEN* | Online – 28 July 2020 – ‘**Assessment of bereaved caregiver experiences of advance care planning for children with medical complexity.**’ The study adds to a growing body of literature in the area of pediatric advance care planning (ACP) that no longer focuses only on typically developing adolescents who are capable of participating in their own ACP but also considers younger or noncommunicative children whose caregivers are faced with making decisions on their children’s behalf ... decisions in the context of a chronic disease course without a predictable trajectory. Perspectives from parents who have experienced the full life and death of their child are crucial for improving our understanding of optimal ACP for children with medical complexity. **Full text:** <https://bit.ly/30agYIO>
- *PALLIATIVE MEDICINE* | Online – 28 July 2020 – ‘**The preferences of patients with chronic obstructive pulmonary disease are to discuss palliative care plans with familiar respiratory clinicians, but to delay conversations until their condition deteriorates: A study guided by interpretative phenomenological analysis.**’ Patients deferred discussions to the future, usually once their condition had deteriorated significantly or planned to wait for clinicians to initiate conversations. This was not rooted in patient preferences, but related to clinicians’ lack of time, absence of an established relationship and belief that appointments were for managing current symptoms, exacerbations and disease factors rather than future care and preferences. **Abstract (w. list of references):** <https://bit.ly/39wXvyG>

Improving the integration of palliative care in heart failure – it’s hard to hit a moving target

JAMA INTERNAL MEDICINE | Online – 27 July 2020 – Bakitas and colleagues report the results of their nurse-led trial to improve outcomes in patients with advanced heart failure (HF).¹ This study builds on their previous work on project ENABLE (Educate, Nurture, Advise, Before Life Ends), a palliative care (PC) telehealth intervention for patients with advanced cancer, which has been shown to improve quality of life and mood. The investigators have adapted their original cancer-based ENABLE intervention to create ENABLE CHF-PC (Educate, Nurture, Advise Before Life Ends Comprehensive Heartcare for Patients and Caregivers) to help patients with advanced HF cope with their serious illness. The intervention involves a combination of in-person PC consultations, nurse coaching sessions via telehealth using a structured workbook as a guide, and ongoing monthly follow-up telephone calls to reinforce the content. Topics covered include improving patients’ understanding of their illness, delivering self-care, addressing physical and emotional symptoms, advance care planning, and creating legacy materials. They enrolled 415 patients who were randomized to the intervention or usual care control. The participants were followed up for 48 weeks to determine whether the intervention improved the primary outcomes of quality of life and mood as well as the secondary outcomes of overall global health, including scales associated with pain, and resource use (numbers of hospital days and emergency department visits). Their intention-to-treat analysis demonstrated that the intervention had no significant effects on the quality of life or mood outcomes in the overall population, but there was a significant improvement in pain intensity and pain interference. There were no changes in resource use. **Introduction:** <https://bit.ly/30dppwt>

1. ‘Effect of an early palliative care telehealth intervention vs usual care on patients with heart failure: The ENABLE CHF-PC randomized clinical trial,’ *JAMA Internal Medicine*, published online 27 July 2020. **Abstract:** <https://bit.ly/3ffzv4q>

End-of-life care among nursing home residents with dementia varies by nursing home and market characteristics

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 28 July 2020 – Nursing homes (NHs) are critical end-of-life care (EoLC) settings for 70% of Americans dying with Alzheimer’s disease/related dementias (ADRD). Whether EoLC/outcomes vary by NH/market characteristics for this population is unknown but essential information for improving NH EoLC/outcomes. Decedents with ADRD in NHs that were nonprofit, had Alzheimer’s units, higher licensed nurse staffing, and in more competitive markets, had better EoLC/outcomes. Modifications to state Medicaid NH payments may promote better EoLC/outcomes for this population. Future research to understand NH care practices associated with presence of Alzheimer’s units is warranted to identify mechanisms possibly promoting higher-quality EoLC. **Abstract (w. list of references):** <https://bit.ly/33bKAAU>

Attitudes on palliative care for adults with developmental disabilities

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 July 2020 – Little is known about the end-of-life needs of adults living with intellectual and developmental disabilities (IDD), and existing literature does not examine attitudes of Canadian providers. The authors examined attitudes of Canadian pediatric palliative care (PC) practitioners on caring for adults with IDD to identify components of care, which could be improved. Major themes covered communication and decision making, lack of resources (including access to appropriate services), and knowledge/skill/experience gaps among adult PC and generalist practitioners. Gaps included complex medical conditions of IDD patients, trajectories, and related management. Pediatric PC practitioners are comfortable being consulted by adult PC and generalist colleagues. However, frequency of consults varied dramatically... **Abstract:** <https://bit.ly/2DbFPwB>

Noted in Media Watch 22 June 2020 (#671, p.10):

- *PALLIATIVE MEDICINE* | Online – 17 June 2020 – ‘**The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review.**’ There is a lack of research into strategies to improve practice. Identified needs included physical needs, psychosocial and spiritual needs, and information and communication needs. Barriers and facilitators were associated with education (e.g., staff knowledge, training and experience), communication (e.g., staff skill in assessing and addressing needs of people with communication difficulties), collaboration (e.g., importance of sustained multidisciplinary approach), and, health and social care delivery (e.g., staffing levels, funding and management support). **Abstract (w. list of references):** <https://bit.ly/2CaEISs>

N.B. Additional articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in this issue of Media Watch and also in the 8 June 2020 issue of the weekly report (#669, pp.8-9).

Suffering

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 25 July 2020 – Suffering – in its various forms – has always been a fundamental concern in philosophy, theology and literature. More recently, it has become the subject matter of highly contextualized analyses in medical end-of-life (EoL) decision-making. Three articles scheduled for publication in an upcoming issue of this journal contribute to this strand of research. More specifically, they focus on the following questions: 1) What is suffering?; 2) What should medicine do about suffering?; 3) What is the role of suffering when justifying medical decisions at the EoL? Svenaeus develops a broad phenomenological account of suffering in terms of embodied moods and shared being-in-the-world.¹ Streeck accepts the way suffering has been conceptualised in palliative care from its early days, i.e., as a complex phenomenon involving bodily, psychological, social and spiritual or existential dimensions.² Ahlzen regards authenticity as essential for a better understanding of suffering.³ **Full text:** <https://bit.ly/2X7i1B3>

1. ‘To die well: The phenomenology of suffering and end of life ethics,’ *Medicine, Health Care & Philosophy*, published online 28 August 2019. [Noted in Media Watch 2 September 2019 (#629, p.13)] **Full text:** <http://bit.ly/2ztuT8a>
2. ‘Death without distress? The taboo of suffering in palliative care,’ *Medicine, Health Care & Philosophy*, published online 6 September 2019. [Noted in Media Watch 16 September 2019 (#631, p.11)] **Abstract (w. list of references):** <http://bit.ly/2IEQMxE>
3. ‘Suffering, authenticity, and physician assisted suicide,’ *Medicine, Health Care & Philosophy*, published online 13 July 2019. **Full text:** <https://bit.ly/2EwBBA7>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.13.

The impact of bereavement support on wellbeing: A comparative study between Australia and Ireland

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 27 July 2020 – This comparative study is valuable in identifying similarities or differences in the bereavement experience between two English-speaking countries though in two different continents. Currently, there are no national standards for bereavement service provision in either Ireland or Australia. As a result, bereavement care varies across settings and locations. Service provision is more structured in some settings due to the introduction of standards or guidelines, such as palliative care, hospice settings, and maternity services. The majority of bereavement care is provided by voluntary organisations and relies on the ability of the organisation to raise awareness of their services among possible referral sources and the public. Statutory mental health services are in charge with dealing with severe complications of grieving. Despite the different recruitment methodologies in the two studies and the different age distribution of the bereaved and their relationship to the deceased, the vast majority of bereaved people relied on informal supporters, particularly family and friends, than community or professional support. **Full text:** <https://bit.ly/2CVjXFD>

Noted in Media Watch 20 July 2020 (#675, p.7):

- *BEREAVEMENT CARE*, 2020;39(2):69-78. **'Bereavement support in the U.K. – a rapid evidence assessment.'** This assessment was undertaken to evaluate the provision and effectiveness of bereavement support in the U.K. and to identify gaps in service provision and areas of need with regard to bereavement services. The provision of bereavement support is extremely varied and there is no conclusive evidence for its effectiveness. There is widespread recognition of the potentially negative impact of bereavement on people, and a plethora of recommendations focused on raising awareness and ameliorating these effects have been made. However, the evidence for how best to support people experiencing bereavement is limited and contested. **Abstract (w. link to references):** <https://bit.ly/2ZDiMDj>

Noted in Media Watch 13 April 2020 (#661, p.4):

- *DEATH STUDIES* | Online – 6 April 2020 – **'The value of implementation science in bridging the evidence gap in bereavement care.'** There is a gap in the use of evidence in bereavement care. Implementation science is a field focused on moving evidence into practice and therefore may help close the gap. Implementation science advances the design, relevance, and dissemination of research and the adoption, implementation, and maintenance of evidence-based practices. The authors of this article provide an overview of implementation science, describe five implementation frameworks. These advancements will promote high-quality bereavement care that improves the lives of bereaved people. **Abstract:** <https://bit.ly/2wmMqRF>

End-of-life care for homeless people in shelter-based nursing care settings: A retrospective record study

PALLIATIVE MEDICINE | Online – 30 July 2020 – This retrospective record study shows that at the end of life (EoL), homeless people have multiple somatic, psychiatric, addiction and social problems, for which those residing in shelter-based nursing care settings receive care from a variety of healthcare and social care disciplines. Yet, their EoL trajectories are uncertain and EoL care is fragmented, with transitions to other institutions being rather the rule than the exception. Overall, findings paint a worrisome picture of acute and structural shortages in capacity to serve this vulnerable population at the EoL. Multilevel EoL care improvements, including increased interdisciplinary collaboration and more palliative care facilities and expertise within shelter-based nursing care settings, are needed to reduce unwanted transitions and suffering among homeless people at the EoL. To the authors' knowledge, this is the first European study that provides a thorough overview of shelter-based care for homeless people at the EoL. While most studies have used cross-sectional data from interviews and focus groups, they examined real-world medical and nursing record data that were documented during the full EoL period. The authors included two of the largest shelter-based nursing care settings in The Netherlands. Still, generalisability of our results remains limited to homeless people who use such facilities. **Full text:** <https://bit.ly/3393N6p>

N.B. Additional articles on EoL care for the homeless noted in past issue of Media Watch: in Canada and the U.S., 20 April 2020 (#662, p.6, p.12); and, in the U.K., 15 April 2019 (#610, p.6).



[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>

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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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