

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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Provision of equitable, compassionate, safe and dignified end-of-life care to people with COVID-19 who are unable to be offered life-saving critical care is fundamental to ensuring the integrity of the Australian social fabric, and the moral and mental welfare of potentially large swathes of the population.

'Public health, health systems and palliation planning for COVID-19 on an exponential timeline: Mass community palliative care' (p.12), in *The Medical Journal of Australia*.

Canada

Miscommunication can lead to unwanted deathbed outcomes in long-term care homes, studies show

ONTARIO | *St. Catharines Standard* – 5 June 2020 – End-of-life (EoL) care communication breakdowns can put long-term care residents at risk for “overtreatment,” two new studies from McMaster and Queen’s Universities show.^{1,2} The findings provide valuable lessons applicable to COVID-related care, says lead McMaster researcher Dr. Henry Siu. The latter study on clinician barriers included a survey asking doctors what their top barriers were to productive “goals-of-care” EoL discussions. Responses showed top barriers included the power of attorney having “difficulty accepting their loved one’s poor prognosis” and “difficulty understanding the limitations and complications of life-sustaining therapies,” along with a lack of sufficient documentation around prior discussions with the resident or their power of attorney. The other study – on advance care planning – included a survey of “substitute decision-makers,” such as residents’ family members. It looked at how the decision-maker’s knowledge of the care their loved one wanted at EoL jived with what was documented as being what they wanted. The survey found a disconnect between the two. <https://bit.ly/3dFP59w>

1. ‘The impact of prior advance care planning documentation on end-of-life care provision in long-term care,’ *Canadian Geriatrics Journal*, 2020;23(2):172-183. **Full text:** <https://bit.ly/2Ud9RFP>
2. ‘A multicenter study to identify clinician barriers to participating in goals-of-care discussions in long-term care,’ *Journal of Post-Acute & Long-Term Care Medicine*, published online 28 October 2019. [Noted in 11 November 2019 issue of Media Watch (#639, p.11)]

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

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

Noted in Media Watch 16 September 2019 (#631, p.9):

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 11 September 2019 – “**My family wants something different**”: **Discordance in perceived personal and family treatment preference and its association with do-not-resuscitate order placement.**’ Patients make treatment decisions based not only on what they want, but what they think their families want. Discordance in such perceived preferences may therefore pose challenges for advance care planning. This study examines discordance in preference for life-extending care versus comfort-focused care and its association with do-not-resuscitate order placement. Approximately 23% of patients perceived discordance between their preference and their families’ preference. **Abstract:** <http://bit.ly/2IN9Xpf>

The Coronavirus pandemic is changing the face of palliative care in Quebec

QUEBEC | GLOBAL TV News (Montreal) – 31 May 2020 – Terminally-ill patients living in palliative care (PC) facilities are especially vulnerable to COVID-19. The country’s largest private PC facility in Kirkland, Quebec, went above and beyond government protocols to keep their patients and staff safe. The move has proven to be successful, but the concern now is that those strict safety measures are changing the face of PC. Since the start of the COVID-19 pandemic, all patients are tested for the novel Coronavirus on-site before admission. It’s one of the measures the West Island Palliative Care Residence (WIPCR) adopted that goes above the required government protocols. Patients are only allowed one visitor in their room at one time, and they must wear a mask and respect social distancing rules. Children, however, aren’t allowed in the building until further notice. Movement within the building is being restricted and common spaces are off limits. But despite all the measures put in place, one patient and one staff member have tested positive and have since recovered from COVID-19. The patient was immediately transferred to hospital, since the WIPCR is a designated cold zone and infected patients can’t remain on site. Patients at the WIPCR are getting everything they need in terms of pain and symptom management. The ratio is still what it was pre-pandemic – 1 nurse to every 3 patients. It’s the psychological, emotional and physical support that PC patients and their families often have to go without. <https://bit.ly/2Xo3od5>

[Worth Repeating](#)

Palliating a pandemic: “All patients must be cared for”

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2010;39(2):291-295. In the event of an overwhelming influenza pandemic, many healthcare systems will implement a triage system that would potentially deny critical care treatment to some seriously ill patients. Although all triage systems have guaranteed palliative care (PC) for those who are denied critical care, no jurisdiction has yet developed a plan to accommodate the anticipated “surge” in demand for PC. The authors present a mathematical and ethical justification for a PC surge plan and outline some of the key elements that should be included in such a plan. PC may have a large role to play in an influenza pandemic, but our scarce resources could easily be overwhelmed, with potentially dire consequences. Although we hope that the present H1N1 influenza pandemic will be less severe than some experts predict, we must plan for the worst. By developing a plan that addresses our “stuff,” staff, space, and systems needs, we can go a long way toward fulfilling our responsibility toward those who are not expected to survive. **Full text:** <https://bit.ly/3cy7gww>

N.B. *Journal of Pain & Symptom Management* article noted in 15 February 2020 issue of Media Watch (#136, p.7). See Table 1, ‘Summary of Palliative Care Pandemic Plan.’

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *The Globe & Mail* (Vancouver) – 3 June 2020 – ‘**Controversy around a Delta, British Columbia, hospice deepens over its refusal to allow medically assisted death.**’ For the dying in Delta, the Irene Thomas Hospice, just down the road from the local hospital, has been a serene refuge where patients can live out their final days. But patients there have never been able to ask for a doctor’s help to end their lives: the Delta Hospice Society, which runs the facility, does not allow medical assistance in dying and the procedure has never been performed at the hospice, even though some patients have wanted it. Back in February, British Columbia Health Minister Adrian Dix put the society on notice – change the policy or lose the provincial funding that flows to the facility. For the year ending 31 March 2019, according to filings with the Canada Revenue Agency, the hospice received the lion’s share of its revenue – \$1.6-million, or 47% of its \$3.4-million budget – from the province. Last week, Dix announced the society’s funding would be cut next February. What happens next will be sure to divide the community even further. Not only does the hospice receive public money, it also sits on public land leased to the society by the Fraser Health Authority. The health authority has not said what it will or can do about the matter. Society president Angelina Ireland pointed out that the organization is only 10 years into a 35-year lease with the authority. Faith-based organizations in the province are not required to provide medical assistance in dying, but they are expected to provide referrals. The Delta Hospice Society is not a faith-based organization. <https://tgam.ca/305L22k>

U.S.A.

Hospice providers strained to support caregivers during pandemic

HOSPICE NEWS | Online – 3 June 2020 – While hospice providers have leveraged telehealth to support caregivers in the home from a distance during the COVID-19 pandemic, evolving safety measures and concerns about program sustainability have created obstacles. Remaining connected to families and caregivers has been an ongoing challenge as providers work to minimize risk of COVID-19 exposure to vulnerable hospice and palliative care patients in the home. While telehealth has allowed hospice providers to remain connected to patients and their families, canceled volunteer services during the pandemic have impacted some forms of caregiver support such as respite care. The pandemic has caused roadblocks in continuing the same level of hands-on education and training support to caregivers as prior to the pandemic. With larger fundraising events on hold or canceled due to social distancing measures, hospices relying on philanthropy and private donations to support caregiver programming have taken a hit amid the economic downturn. Despite funding challenges, education and training for caregivers and families of home hospice patients

remains crucial. While increased availability of telehealth has yielded cost savings for many hospices, providers have struggled to weigh the balance between the limitations of telehealth and the risks associated with in-person visits during the outbreak. <https://bit.ly/3762wwP>

COVID-19: End-of-Life Care

‘**The role of palliative care in COVID-19**’ (p.11), in *Cleveland Clinic Journal of Medicine*.

‘**Early intervention of palliative care in the emergency department during the COVID-19 pandemic**’ (p.11), in *JAMA Internal Medicine*.

‘**Feasibility and acceptability of inpatient palliative care e-family meetings during COVID-19 pandemic**’ (p.11), in *Journal of Pain & Symptom Management*.

‘**A beacon for dark times: Palliative care support during the Coronavirus pandemic**’ (p.12), in *NEJM Catalyst*.

Cont.

Related:

- *HOSPICE NEWS* | Online – 4 June 2020 – ‘**Hospices step up grief care to support providers in other settings.**’ As more clinicians in other healthcare settings, such as hospitals and nursing homes, encounter more patient deaths than ever before due to the COVID-19 pandemic, hospices are bringing their expertise in bereavement to support healthcare workers and their communities at large. These efforts are coming to the forefront at a time when hospices have had to redesign their approach to bereavement care due to sheltering-in-place and social distancing. Many are turning to telehealth to replace in-person counseling, support groups and larger functions such as children’s camps, that could pose exposure risks. <https://bit.ly/2Y9bfds>

Hospice use in assisted living higher than in traditional homes, nursing homes: Study

MCKNIGHT’S SENIOR LIVING | Online – 3 June 2020 – Older adult use of hospice services at the end of life is higher in community-based residential settings, such as assisted living and retirement communities, than in nursing homes and traditional homes, according to ... the first national study of deceased Medicare beneficiaries categorized by residential setting, according to the authors.¹ The study used data from the Medicare Current Beneficiary Survey 2002-2017 and tracked 8,394 older adults representative of the 28.4 million Medicare beneficiaries who died during the study period. According to the study, 9.8% of Medicare beneficiaries spent the end of their lives in community-based residential settings, including assisted living facilities (30.4%), retirement communities (23.2%), continuing care facilities (16.4%) and senior citizen housing (12.3%). Efforts by state Medicaid programs to fund long-term services and supports in home- and community-based settings, rather than for nursing home care, is “a key driver of the growth in community-based residential care,” the authors wrote. State and federal policies also encouraged the use of nursing home alternatives, including assisted living communities, board and

care facilities and adult foster care, they said. “Where people live as they age has implications for healthcare delivery, costs and policy,” the authors wrote. As more people live and die in residential care communities, the need for hospice there increases... <https://bit.ly/2Xrbn92>

[Specialist Publications](#)

‘**A review and considerations on palliative care improvements for African Americans with cancer**’ (p.5), in *American Journal of Hospice & Palliative Care*.

‘**Palliative care for the Asian American adult population: A scoping review**’ (p.5), in *American Journal of Hospice & Palliative Care*.

‘**Hospice carve-in: Aligning benefits with patient and family needs**’ (p.8), in *Journal of the American Medical Association*.

‘**Geographic variation in palliative care delivery among patients diagnosed with metastatic lung cancer in the U.S.: Medicare population-based study**’ (p.12), in *Supportive Care in Cancer*.

1. ‘Trends in residential setting and hospice use at the end of life for Medicare decedents,’ *Health Affairs*, 2020;39(6):1060-1064. **Abstract:** <https://bit.ly/2MoNUzh>

Noted in Media Watch 18 November 2019 (#640, p.12):

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 5 November 2019 – ‘**Variability in assisted living residents’ end-of-life care trajectories.**’ A growing and increasingly vulnerable population resides in assisted living (AL). States are responsible for regulating AL and vary in their requirements. AL residents’ dying trajectories vary significantly by state. To ensure optimal end-of-life (EoL) outcomes for assisted living residents, state policy makers should consider how their regulations influence EoL care in AL, and future research should examine factors (e.g., state regulations, market characteristics, provider characteristics) that may enable AL residents to die in place and contribute to differential access to hospice services. **Abstract:** <http://bit.ly/2pOZv2Z>

Cont.

Noted in Media Watch 26 November 2018 (#591, p.10);

- *JOURNAL OF AGING*, 2018;47(12):72-83. ‘**Contours of “here.”: Phenomenology of space for assisted living residents approaching end of life.**’ This study, informed by theory from environmental gerontology, investigated how AL residents who are approaching end of life (EoL) navigate and experience space. Findings show that participants experience a neutral theme of shrinking space, negative themes of confinement and vulnerability, and positive themes of safety and intimacy. Findings have implications for interventions to improve place integration in AL and enhance residents’ quality of life at EoL, including developing strategies to promote small meaningful journeys within context of shrinking life space. **Abstract:** <http://bit.ly/31mARTH>

International

Coronavirus changes how doctors deal with death

U.K. | BBC News – 1 June 2020 – During the pandemic, doctors have had to deal with death more often than many are used to, and due to restrictions in place over hospital visitors, they are often the last person to spend time with a terminally ill patient. Filmmaker Paul Myles spoke to five doctors administering end-of-life care during the crisis. <https://bbc.in/2TUiQve>

COVID-10: End-of-Life Care

‘**The role of palliative medicine in ICU bed allocation in COVID-19: A joint position statement of the Singapore Hospice Council and the Chapter of Palliative Medicine Physicians**’ (p.11), in *Asian Bioethics Review*.

‘**Recommendations for the support of suffering, severely ill, dying or grieving persons in the Corona pandemic from a palliative care perspective**’ (p.10), in *Der Schmerz*.

Specialist Publications

A review and considerations on palliative care improvements for African Americans with cancer

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE | Online – 3 June 2020 – Hospice and palliative care (PC) benefits are infrequently realized by African American patients with cancer. With the increasing recognition of the critical role of early utilization of palliative services for optimal and quality patient care, it is important to acknowledge disparities and barriers to access that minority patients may face. The authors discuss the status of PC delivery for African American patients within the structure and framework of the clinical practice guideline domains established by the National Consensus Project for Palliative Care.¹ This perspectives paper describes the different aspects of PC and the interplay with African American culture. The authors also attempt to identify the multi-level barriers (healthcare system and provider level) to PC among African Americans as a required step toward decreasing the disparities in access, coverage, utilization, and benefit of PC. **Abstract (w. list of references):** <https://bit.ly/2XZbzLQ>

1. ‘National Consensus Project’s Clinical Practice Guidelines for Quality Palliative Care,’ National Consensus Project for Quality Palliative Care, 2018. **Download/view at:** <http://bit.ly/2uulDhJ>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE* | Online – 3 June 2020 – ‘**Palliative care for the Asian American adult population: A scoping review.**’ The Asian American (AA) population is rapidly becoming one of the largest racial/ethnic groups in the U.S. Despite this growth and advances in palliative care (PC) programs in the U.S., the scope and nature of the literature regarding PC for AAs remains unclear. This review provides an overview of existing research on PC for AAs, identifies gaps in the research with recommendations for future research and delineates practice implications. A culturally inclusive approach is vital to providing appropriate and accessible PC for AAs. **Abstract (w. list of references):** <https://bit.ly/3cuf42b>

N.B. Selected articles on disparities and barriers in the provision and delivery of PC for racial/ethnic minorities in the U.S. noted in 1 June 2020 issue of Media Watch (#668, pp.11-12).

Constructing stability: A classic grounded theory of next-of-kin in palliative cancer care

BMC PALLIATIVE CARE | Online – 5 June 2020 – Being next-of-kin to someone with cancer requiring palliative care (PC) involves a complex life situation. Changes in roles and relationships might occur and the next-of-kin thereby try to adapt by being involved in the ill person's experiences and care even though they can feel unprepared for the care they are expected to provide. The aim of this study was to develop a classic grounded theory of next-of-kin in palliative cancer care. *Constructing stability* emerged as the pattern of behaviour through which next-of-kin deal with their main concern; *struggling with helplessness*. This helplessness includes an involuntary waiting for the inevitable. The waiting causes sadness and frustration, which in turn increases the helplessness. The theory involves; *Shielding, Acknowledging the reality, Going all in, Putting up boundaries, Asking for help, and Planning for the inescapable*. These strategies can be used separately or simultaneously and they can also overlap each other. There are several conditions that may impact the theory *Constructing stability*, which strategies are used, and what the outcomes might be. Some conditions that emerged in this theory are time, personal finances, attitudes from extended family and friends and availability of healthcare resources. The theory shows the complexities of being next-of-kin to someone receiving PC, while striving to construct stability. This theory can increase healthcare professionals' awareness of how next-of-kin struggle with helplessness and thus generates insight into how to support them in this struggle. **Full text:** <https://bit.ly/2MB89Kc>

Related:

- *PALLIATIVE MEDICINE* | Online – 3 June 2020 – ‘**A drive for structure: A longitudinal qualitative study of the implementation of the Carer Support Needs Assessment Tool (CSNAT) intervention during hospital discharge at end of life.**’ Overall, despite practitioner efforts, implementation proved challenging. This study revealed three main findings: 1) An emphasis on structured approaches to work, dominance of outcomes measurement, and performance metrics which framed practitioners' perceptions of the intervention and their implementation decisions; 2) Contradictions in the extent to which specialist practitioners felt that they were the “right” people to implement the intervention; and, 3) Practical implementation challenges of the hospital context. **Full text:** <https://bit.ly/2XyP3KT>
- *PROGRESS IN PALLIATIVE CARE* | Online – 30 May 2020 – “**There for me”: A qualitative study of family communication and decision-making in end-of-life care for older people.**’ Participants preferred not to think about dying as older people trusted others to make decisions for them. This influenced end-of-life (EoL) communication, resulting in family members making decisions during medical crises. Such decisions were complicated by family conflict and denial of dying. Family members were crucial mediators between older people and health services, helping them to navigate the care system and advocating on their behalf. Being treated with respect, remaining independent and socially connected was integral to participants' perception of good EoL care. **Abstract:** <https://bit.ly/2Mge7zL>

Adverse events in deceased hospitalised cancer patients as a measure of quality and safety in end-of-life cancer care

BMC PALLIATIVE CARE | Online – 1 June 2020 – Anticancer treatment given during the last 30 days of life is associated with a significantly increased rate of adverse events with twice the odds of having an adverse event contributing to death. In this retrospective cohort [multi-centre] study, patients receiving specialist palliative care (PC) had significantly fewer adverse events, supporting recommendations of early integration of PC in a patient safety perspective. Identifying these adverse events is clearly warranted to improve clinical practice and avoid overtreatment in end-of life (EoL) cancer care. Doing so with a standardised review method on a limited number of deceased hospitalised cancer patients proved to be efficient, and can provide a pragmatic real time measure of quality and safety in EoL cancer care. **Full text:** <https://bit.ly/3073uHT>



Closing the Gap Between Knowledge & Technology

<http://bit.ly/2DANDFB>

Conceptual barriers to palliative care and enlightenment from Chuang-tze's thoughts

CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS, 2020;29(3):386-394. The authors claim that palliative care (PC) is a suitable approach for offering comprehensive support to patients with life-threatening illness and unavoidable asthenia, to enhance their quality of life in aging and chronic illness. There are however some conceptual barriers to accessing that care on the Chinese Mainland: 1) Death-denying culture and society; 2) Misguidance and malpractice derived from the biomedical model; and, 3) Prejudice against PC and certain deviant understandings of filial piety culture. To counter these obstacles, this study introduces the philosophy of Chinese Taoist Chuang-tze to enlighten the public from ignorance and remove some illusions about death and dying, inspire people to face and accept illness and death calmly, and keep harmony and inner peace of mind to alleviate suffering, with the aim of providing wisdom and a shift of attitude toward life and death. Chuang-tze's thoughts are consistent with the provision of PC, and to a certain degree, can promote its acceptability and delivery, and the conception of good death in practice. **Abstract (w. list of references):** <https://bit.ly/3cv1wDm>

Outcomes associated with a nurse-driven palliative care screening tool in the intensive care unit

CRITICAL CARE NURSE, 2020;40(3):23-29. Access to specialty palliative care (PC) delivery in the intensive care unit is inconsistent across institutions. The intensive care unit (ICU) at the study institution uses a screening tool to identify patients likely to benefit from specialty PC, yet little is known about outcomes associated with the use of screening tools. Records of 112 patients with positive results on PC screening were retrospectively reviewed to compare outcomes between patients who received a specialty PC consult and those who did not. Primary outcome measures were length of stay, discharge disposition, and escalation of care. Sixty-five patients (58%) did not receive a PC consult. No significant differences were found in length of hospital or ICU stay. Most patients who experienced mechanical ventilation did not receive a PC consultation. Patients who were discharged to home were also less likely to receive a consult, whereas patients who were discharged to hospice were more likely to receive a consult. Unmet needs exist for specialty PC. Understanding the methods of identifying patients for specialty PC and providing them with such care is critically important. Future research is needed to elucidate the factors providers use in their decisions to order or defer specialty PC consultation. **Abstract:** <https://bit.ly/2Ao4Nap>

Noted in Media Watch 1 June 2020 (#668, p.10):

- *DIMENSIONS OF CRITICAL CARE NURSING*, 2020;39(4):219-235. 'Evaluating the outcomes of an organizational initiative to expand end-of-life resources in intensive care units with palliative support tools and floating hospice.' There is evidence that palliative care (PC) and floating (inpatient) hospice can improve end-of-life experiences for patients and their families in the intensive care unit (ICU). However, both PC and hospice remain underutilized in the ICU setting. This study examined palliative consultations and floating hospice referrals for ICU patients during a phased launch of floating hospice, two palliative order sets, and general education to support implementation of PC guidelines. **Abstract:** <https://bit.ly/2M6hJEq>

Noted in Media Watch 11 May 2020 (#665, p.8):

- *PALLIATIVE MEDICINE REPORTS* | Online – 30 April 2020 – 'Best case/Worst case: ICU (COVID-19) – A tool to communicate with families of critically ill patients with COVID-19.' During the COVID-19 pandemic, critically ill patients have been hospitalized and strictly isolated. In March 2020, palliative care clinicians at the University of Wisconsin were asked to bridge a gap in communication between patients' families and critical care teams, as bedside demands overwhelmed the critical care team's capacity to provide consistent communication with family. In response, the authors adapted an established intervention ... to support daily conversations between hospital-based clinicians and out-of-hospital family. **Full text:** <https://bit.ly/2W3sVrk>

Knowledge, attitudes and expectations of physicians with respect to palliative care in Ecuador: A qualitative study

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online – 30 May 2020 – Only two countries in Latin America, Cuba and Uruguay, include palliative care (PC) in their pre-graduate courses as a mandatory discipline in all their medical schools. Medical schools in Argentina, Brazil, Colombia, Cuba, Costa Rica, Mexico, Panama, Paraguay, Uruguay and Venezuela offer PC post-graduate programs for physicians. In Ecuador, however, there is no official training in PC, but five post-graduate programs have included it and several have incorporated care for the end of life in their curricula... The worldwide need for PC is high, especially in mid-income countries like Ecuador, where the percentage of patients receiving such care is very small due to the scarcity of infrastructure and specialized personnel and to the unequal distribution in the country. Strategies are needed which intensify the training of medical professionals in PC, as well as develop the human resources and materials for providing it. **Full text (click on pdf icon):** <https://bit.ly/2TSkrBB>

U.S. Center for Medicare & Medicaid Innovation

Hospice carve-in: Aligning benefits with patient and family needs

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 4 June 2020 – Patient-centered care should be a defining feature of the healthcare system, and no time is more critical for having patients at the center of care than at the end of life (EoL). At this difficult and deeply personal time for patients and their families, it is paramount that the preferences of patients and their families be respected and their experiences prioritized. Compassionate EoL care should be available to the 2.8 million individuals who die every year in the U.S. and should be delivered in a way that is highly coordinated, seamless to patients and their families, and attuned to the patient's goals and wishes. One important step in realizing that goal is the new hospice benefit design proposed by the Center for Medicare & Medicaid Innovation. **Full text:** <https://bit.ly/30nm7aH>

Last months of life of people with intellectual disabilities: A U.K. population-based study of death and dying in intellectual disability community services

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 31 May 2020 – Intellectual disability services are places of living and dying. This study reiterates that the agenda to improve quality of care and experience of people in intellectual disability services must embrace a notion of care “to the end of life.” A failure to do so may ultimately lead only to poor experiences and unnecessary disadvantage at the end of life (EoL). Death appears not to be a common event within intellectual disability services but as this population continues to age, and if “ageing in place” becomes increasingly successful, death will only come to have a greater presence. The data suggest that services can respond successfully to the needs of people with intellectual disabilities at the EoL if dying is recognized in a timely manner and external support is in place. There are areas though where future service development and resources, and research might enable more people with intellectual disabilities to be supported well at the EoL. These involve improving the ability to recognize that death might be likely and determining the challenges that supported living settings face in supporting people whose deaths are anticipated. The benefits may not only be felt by individuals with intellectual disabilities who are dying but also those who care for and about them. If there can be developments in EoL care provision that successfully meet the needs of a population who seem more likely to experience complex dying whilst living in types of residences that are themselves complex, at least to people outside of intellectual disabilities, then one might reasonably expect that this leads to wider developments in EoL care that benefit all. **Full text:** <https://bit.ly/36NZ49S>

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Noted in Media Watch 24 February 2020 (#654, p.8):

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Online – 19 February 2020 – ‘**Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A U.K.-wide survey of intellectual disability support staff.**’ This study investigated the extent to which staff communicate about death with people with intellectual disability facing terminal illness or bereavement. 52.6% of people with intellectual disability who were terminally ill were told about their illness, and 18.1% were told they would die. Of those experiencing an anticipated bereavement, 32.4% of staff said no one talked about this with them beforehand. A quarter of staff had received training on end of life or bereavement. **Abstract:** <http://bit.ly/38KREvq>

Noted in Media Watch 10 February 2020 (#652, p.7):

- *BRITISH JOURNAL OF LEARNING DISABILITIES* | Online – 31 January 2020 – ‘**Palliative care needs of direct care workers caring for people with intellectual and developmental disabilities.**’ Direct care workers (DCWs) caring for people with intellectual and developmental disabilities (PWIDD) provide palliative care, but research indicates they are ill-equipped to do so. Staff trained as DCWs in organisations that serve PWIDD were surveyed in suburban and rural areas of a U.S. Midwestern state. They reported limited experience in legal matters, yet had substantial experience in assisting PWIDD with pain, distress and bereavement. Training was inadequate but desired for cultural competence, effective communication, post-death logistics and legal matters. **Abstract:** <http://bit.ly/31taXzp>

N.B. See ‘Current thinking on palliative and EoL care for patients living with intellectual and developmental disabilities,’ European Association for Palliative Care blog: <http://bit.ly/300WMRt>

End-of-life care practice in dying patients after enforcement of Act on Decisions on Life-Sustaining Treatment For Patients in Hospice & Palliative Care or at the End of Life: A single center experience

KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE, 2020;23(2):93-102. This study reviews the practices of end-of-life care (EoLC) for patients who withdrew or withheld life-sustaining treatment at a tertiary care hospital, addresses the limitations of the law, and discusses necessary steps to promote patient-centered self-determination. The authors retrospectively analyzed the medical records of patients who died after agreeing to withhold life-sustaining treatment in 2018 at their university hospital. The cause of death, the intensity of EoLC, and other characteristics were reviewed... The decision to stop life-sustaining treatment was made by family members for 178 patients overall (53.3%) and for 101 (43.7%) cancer patients, regardless of the patient’s wishes. When the patient decided to stop life-sustaining treatment, the time from the authorization to withhold life-sustaining treatment to death was longer than when the decision was made by family members... In many cases, the decision to discontinue life-sustaining treatment was made by the family, not by the patient. In order to protect human dignity based on the patients’ self-determination, it is necessary for patients to understand their disease based on careful explanations from physicians. **Abstract:** <https://bit.ly/2MzWw5Z>

Noted in Media Watch 10 February 2020 (#652, p.4):

- SOUTH KOREA | Yonhap News Agency (Seoul) – 4 February 2020 – ‘**Some 85,000 terminal patients opt to die with dignity over two years: Data.**’ More than 85,000 terminally ill South Koreans have chosen to forgo life-prolonging treatment since the legalization of the right to die with dignity two years ago. The law allows terminal patients to sign up to forgo a “meaningless extension of life” by stopping or postponing four life-sustaining treatments – cardiopulmonary resuscitation, artificial respiration, hemodialysis and anti-cancer drug administration. They are only meant to prolong the lives of terminally ill patients without giving any treatment from the start. Slightly over 37,300 terminally ill patients have registered to die with dignity without receiving further treatment. <http://bit.ly/2SfToi8>

Barriers to and strategies for gaining entry to correctional settings for health research

NURSING LEADERSHIP, 2020;33(1):71-80. Challenges to gaining entry to correctional settings to conduct research can impede research productivity, delay the launch of studies and inhibit researchers from proposing health research in corrections. The authors share lessons learned from a large-scale corrections research project designed to develop computer-based learning modules to train front-line corrections personnel about geriatric and end-of-life care. Key lessons learned include the importance of building a team of experts, planning and putting, coordinating with institutional review boards and examining denied applications to inform future planning. To be effective in a correctional setting, leaders in nursing research and corrections nursing must work together within the contextual nature of prisons and jails to advance evidence-based practices for this vulnerable population. These lessons serve to establish best practices on how to access correctional settings and to enable more research in corrections. **Abstract:** <https://bit.ly/3eyKBS0>

Prison Hospice: Backgrounder



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

Photo: Lori Waselchuk. Philadelphia, PA

Recommendations for the support of suffering, severely ill, dying or grieving persons in the Corona pandemic from a palliative care perspective

Recommendations of the German Society for Palliative Medicine, the German Interdisciplinary Association for Intensive & Emergency Medicine, the Federal Association for Grief Counseling, the Working Group for Psycho-oncology in the German Cancer Society, the German Association for Social Work in the Healthcare System, and the German Association for Systemic Therapy, Counseling & Family Therapy.

DER SCHMERZ | Online – 2 June 2020 – The Corona pandemic has led to a number of restrictions and prohibitions, which in turn place large psychosocial or spiritual burdens on patients with COVID-19, their families and relatives and the treating personnel in the healthcare system. Patients with COVID-19 are not allowed to receive visitors and many hospitals and nursing homes have completely banned visitors. Many support services have been reduced or stopped completely. Necessary treatment interventions for other patients with critical and life-limiting diseases have been delayed or suspended in order to free resources for the expected COVID-19 patients; however, these people need to feel social connectedness with their relatives. Palliative care patients should be exempted from any ban on visitors. Families should be able to visit dying patients even on intensive care units or isolation wards, using adequate protective equipment. Alternative options, such as video telephone calls or via social media should be explored for patients in isolation. Families should also be enabled to say goodbye to the deceased with adequate protective equipment or should be offered alternative real or virtual options for remembrance and commemoration. Healthcare professionals coping with the exceptional stress should be continuously supported. This requires clear communication and leadership structures, communication training, psychosocial support, but most of all optimal framework conditions for the clinical work. **Full text:** <https://bit.ly/3eXBhaH>

N.B. German language article.

Cont.

Related:

- *ASIAN BIOETHICS REVIEW* | Online – 1 June 2020 – ‘**The role of palliative medicine in ICU bed allocation in COVID-19: A joint position statement of the Singapore Hospice Council and the Chapter of Palliative Medicine Physicians.**’ With 5-15% of infected patients likely to require intensive care units (ICU) support and Singapore facing nearly 20,000 active cases, it is possible that access to ICU beds may become limited. Facing the possibility of a surge of COVID-19-infected patients requiring ventilatory support in ICU, the Singapore Hospice Council and the Chapter of Palliative Medicine Physicians present its position on the guiding principles that ought to drive the allocation of ICU beds and its role in care of these patients and their families. **Full text:** <https://bit.ly/37eQkdr>
- *CLEVELAND CLINIC JOURNAL OF MEDICINE* | Online – 29 May 2020 – ‘**The role of palliative care in COVID-19.**’ Many healthcare systems are experiencing an increased demand for palliative care (PC). The PC team at Cleveland Clinic designed an enterprise-wide response plan organized around four domains: 1) Staff (educational resources and tools); 2) Staff (medications and supplies); 3) Space (recommendations for optimizing physical space and facilities); and, 4) Systems to facilitate high-quality PC delivery to patients. To mitigate isolation during end-of-life care, the clinic offers “compassionate exceptions” to strict visitation policies, provides personal protective equipment to visitors of these patients, and facilitates virtual visitation via electronic devices. **Full text:** <https://bit.ly/2XJ0777>
- *FUTURE HEALTHCARE JOURNAL* | Online – 1 June 2020 – ‘**Care of the dying person before and during the COVID-19 pandemic: A quality improvement project.**’ This report details how a plan, do, study, act approach was taken to implementing improved, standardised multidisciplinary documentation of individualised care and review for people who are in the last hours or days of life, both before and during the COVID-19 pandemic. The documentation and training produced is subject to ongoing review via the specialist palliative care team’s continuously updated hospital deaths dashboard... The authors hope sharing the experiences and outcomes of this process will help others to develop their own [care] pathways... **Full text (click on pdf icon):** <https://bit.ly/2Mz2Cn6>
- *INTERNATIONAL NURSING REVIEW* | Online – 4 June 2020 – ‘**Coronavirus disease 2019 (COVID-19): Strengthening our resolve to achieve universal palliative care.**’ The authors strongly advocate for universal palliative care (PC) access during the COVID-19 pandemic. The delivery of universal PC services has been called for by leading global health organizations and experts. The authors undertook a review of the COVID-19 and PC literature and drew on their experiences. Investment in nurses is needed to ensure appropriate PC services now and into the future. Avoiding futile interventions and alleviating suffering is an ethical imperative... Multi-level practices and policies to foster the delivery of safe, high-quality PC for all are urgently needed. **Full text:** <https://bit.ly/2Mzik1L>
- *JAMA INTERNAL MEDICINE* | Online – 5 June 2020 – ‘**Early intervention of palliative care in the emergency department during the COVID-19 pandemic.**’ During the novel coronavirus disease 2019 (COVID-19) pandemic, it is particularly critical to ensure that life-sustaining treatment (LST) such as intubation and resource-intensive cardiopulmonary resuscitation (CPR) are aligned with a patient’s goals and values, and to avoid LSTs in patients with a poor prognosis that are unlikely to be beneficial, but have a high risk of causing additional suffering. The authors implemented an ED-based COVID-19 palliative care response team focused on providing high-quality goals-of-care conversations in time-critical situations. **Full text:** <https://bit.ly/2Y7eFgS>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 4 June 2020 – ‘**Feasibility and acceptability of inpatient palliative care e-family meetings during COVID-19 pandemic.**’ During the COVID-19 pandemic ... the authors demonstrated the efficient deployment of telemedicine for e-family meetings that was both feasible and effective for decision-making for patients who were near end of life and their families. Family meetings likely happened sooner and with far more participants than would have been possible without the use of the technology. While providers expressed limitations in the use of technology ... they reported key benefits including observation of prayer rituals and promoting understanding to the family of the patient’s condition. **Full text:** <https://bit.ly/2U8B78j>

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- *THE LANCET CHILD & ADOLESCENCE HEALTH* | Online – 4 June 2020 – ‘**Talking to children about illness and death of a loved one during the COVID-19 pandemic.**’ In the midst of the devastating death toll and hospitalisations from COVID-19, the psychological effect of this unfolding pandemic on children has been unconscionably overlooked. The ... media coverage and barrage of public health messages sustain a high level of physical and emotional threat within our communities, which is intensely observed by children. Age-appropriate explanations are paramount to ensure children have a coherent narrative and emotional support for their experiences. This need is magnified when someone in the family is hospitalised for or dies from COVID-19. **Full text:** <https://bit.ly/2Y8York>
- *THE MEDICAL JOURNAL OF AUSTRALIA*, 2020;212(10):440-442. ‘**Public health, health systems and palliation planning for COVID-19 on an exponential timeline: Mass community palliative care.**’ Provision of equitable, compassionate, safe and dignified end-of-life care to people with COVID-19 who are unable to be offered life-saving critical care is fundamental to ensuring the integrity of the Australian social fabric, and the moral and mental welfare of potentially large swathes of the population. Up to 40% of older women and 22% of older men live alone, complicating how to achieve what is necessary and right. Planning for this worst case outcome is underway, but requires significant resources, personnel, government support and a national approach. **Full text:** <https://bit.ly/2zlbUuu>
- *NEJM CATALYST* | Online – 12 May 2020 – ‘**A beacon for dark times: Palliative care support during the Coronavirus pandemic.**’ Palliative care (PC) physicians can provide critical expertise in communication and symptom management to help seriously ill patients in the Coronavirus disease 2019 pandemic. However, with an existing shortage of PC specialists, the surge of COVID-19 cases in New York City required rapid expansion of PC services... In response to these needs, the Icahn School of Medicine at Mount Sinai developed and adapted a 24-7 Palliative Care Help line which focused in-person ED supports to serve 873 of the sickest patients with COVID-19 over 4 weeks... The authors describe key principles and lessons learned from this process. **Full text:** <https://bit.ly/2MtFBSC>

Geographic variation in palliative care delivery among patients diagnosed with metastatic lung cancer in the U.S.: Medicare population-based study

SUPPORTIVE CARE IN CANCER | Online – 4 June 2020 – The U.S. has observed a significant increase in the use of palliative care (PC) for patients diagnosed with advanced cancer. However, it is unknown how geographic variation affects patients’ use of PC services. The authors examined temporal and demographic trends in receipt of and timing of PC by state and region. The proportion of metastatic lung cancer patients who received PC ranged from 16.4% in Washington and 16.3% in Connecticut to 6.4% in Louisiana. From 2001 to 2015, use of PC increased from 3.2% to 29.8% in the West region, from 3.3% to 31.9% in the Northeast region, from 3.8% to 36.2% in the Midwest region, and from 0.9% to 23.3% in the South region... The median time from the date of cancer diagnosis to the date of first PC visit varied geographically, from 44 days in Utah to 66 days in California. Hospital-based PC was most common in these states. The substantial geographic variation in the use of PC suggesting a need for additional research on geographic disparities in PC and strategies that might improve state-level PC delivery. **Abstract (w. list of references):** <https://bit.ly/3eS8x2N>



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>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN JOURNAL OF PSYCHIATRY* | Online – 19 May 2020 – ‘**Irremediable psychiatric suffering in the context of physician-assisted death: A scoping review of arguments.**’ Irremediability of suffering is an important aspect of any justification for physician-assisted death (PAD). Whether psychiatric suffering can and should be classified as irremediable has been an issue of debate for over 20 years. This systematic review showed that arguments about irremediability evolve around three main themes and provide suggestions for empirical research and normative deliberation. The first theme is uncertainty about irremediability. This calls for empirical research in order to diminish the level of uncertainty about irremediability as well as deliberation on what level of certainty is necessary for PAD of patients with a psychiatric disorder (PDD) to be acceptable. The second theme is hope. This calls for more research on the relationship between the option of PAD of PDD and the phenomenon of hope in patients and the need for deliberation in individual patient cases. The third theme concerns treatment refusal. This calls for further empirical investigation into which treatments are being refused, and why, and normative deliberation on the justification of decisions to forego treatment in the context of the physician–patient relationship. Finally, this review showed the lack of thorough empirical studies and basic epidemiological data on PPD who request and receive PAD. **Full text:** <https://bit.ly/2XLkyQD>
- *BMC MEDICAL ETHICS* | Online – 3 June 2020 – ‘**Ethical arguments against coercing provider participation in MAiD (medical assistance in dying) in Ontario, Canada.**’ It has historically been a crime in Canada to provide assistance to someone in ending their own life, however, this paradigm was inverted in 2015 when the Supreme Court of Canada ruled that restrictions on this practice, within certain defined parameters, violated the right to life, liberty, and security of the person. Subsequently, recent legal and policy decisions have highlighted the issue of how to balance the rights of individuals to access MAiD with the rights of care providers to exercise conscience-based objections to participation in this process. We argue that there is significant harm and ethical hazard in disregarding individual and institutional rights to conscientious objection and since measures less coercive than the threat of regulatory or economic sanctions do exist, there should be no justification for such threats in Canada’s healthcare systems. **Full text:** <https://bit.ly/2MD0gnz>

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.

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

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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Cont.

Something Missed or Overlooked?

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

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International



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Australia

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

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

Canada



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

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

Europe



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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