

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

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Compiled & Annotated by Barry R. Ashpole

Electronic records and computer-based treatment algorithms have reduced the amount of face-to-face personal interactions so vital to understanding the emotions of cancer and patient/family dynamics.

'End-of-life and goals-of-care discussions with cancer patients in the Coronavirus pandemic' (p.7), in *Palliative & Supportive Care*.

Canada

What are we willing to pay for the quality of death we want?

ONTARIO | *Healthy Debate* – 21 August 2020 – Research on the preference for place of death shows most people with a terminal illness prefer to die at home or in other home-like environments such as hospices or palliative care units, where they are comfortable and surrounded by their loved ones. However, a significant concern for patients and their families is the lack of healthcare services and supports at home. Patients in their final months of life need around-the-clock care. Sadly, only one in five Ontarians receive end-of-life (EoL) care through the province's publicly funded home care program in their last year of life. The **COVID-19** pandemic has further limited access through staffing shortages, cancellation of visits and a lack of personal protective equipment. How can we, as a society, improve access to this essential care both now and in a post-pandemic period? Stated bluntly, what is the cost to support a good death? Through the provincial home care program, Ontarians have access to care provided by registered nurses, personal support workers and other healthcare professionals trained in palliative and EoL care. Patients can

receive up to 24-hour nursing support at home in their final weeks of life. This results in better patient outcomes. Patients who receive EoL home care spend fewer days in hospital in their last three months of life and are three times more likely to die at home. A study of 50,000 deceased older adults in Ontario found the cost to enable people to die at home by providing EoL care is an additional \$995 per person over the last three months of life, less than the average cost for one day in a hospital.¹ So, why aren't all Ontarians at the EoL receiving home care? Why is the bulk of EoL care in Ontario still provided in hospitals? <https://bit.ly/2YIWCV0>

Specialist Publications

'An active in-home physician model of palliative care and its resulting performance indicators related to home deaths, unplanned emergency department visits and unplanned hospital admissions' (p.4), in *Journal of Palliative Care*.

Cont.

1. 'Cost-effectiveness of investment in end-of-life home care to enable death in community settings,' *Medical Care*, 2020;58(8):665-673. **Abstract:** <https://bit.ly/31eWzwd>

[U.S.A.](#)

Hospices strategize for longer patient stays

HOSPICE NEWS | Online – 19 August 2020 – A majority of patients continue to experience short lengths of stay in hospice, in many cases limiting their ability to receive the full benefits of those services. Confronted with this reality, providers are seeking new ways to connect with patients further upstream in the course of their illness. Nearly 54% Medicare decedents received hospice care for 30 days or less in 2018, according to a new report.¹ About 28% of those beneficiaries were in hospice for seven days or less, which is considered too short a period for patients to fully benefit... This reality not only interferes with patients' quality of life in their final days, it drives up healthcare costs as individuals who enter hospice later are more likely to receive expensive and aggressive curative treatments that often are unlikely to be effective at their stage of illness. About 80% of people in the U.S. say they would prefer

to die in their homes as opposed to a hospital or other healthcare facility, according to the U.S. Centers for Disease Control & Prevention. The needle has barely moved on this issue from year to year. In 2017, 54% of Medicare decedents received hospice care for less than 30 days, only 0.2% higher than the 2018 numbers. Many providers are fighting this trend by offering a wider range of services to allow for earlier engagement with patients and families and create new revenue streams. <https://bit.ly/31fhTlq>

[Specialist Publications](#)

“Are they saying it how I’m saying it?”: A qualitative study of language barriers and disparities in hospice enrollment’ (p.6), in *Journal of Pain & Symptom Management*.

1. 'NHPCO Facts & Figures,' National Hospice & Palliative Care Organization, August 2020. **Download at:** <https://bit.ly/3hevqPv>

[International](#)

Hospice care adapts to multicultural, multilingual Germany

GERMANY | *Deutsche Welle* (Berlin) – 22 August 2020 – Germany is home to 21 million people whose families have immigrated within the past couple of generations. Hospices and givers of palliative care are adapting their practices to make them more inclusive. About 30,000 people a year spend the last weeks or months of their lives in Germany's palliative care (PC) homes, according to the Federal Statistical Office. Now, the German Hospice & Palliative Care Foundation has highlighted the importance of making volunteers aware of cultural differences when tending to the terminally ill. Lazarus Hospice Berlin is one of several PC providers that specialize in tending to people from different cultural backgrounds. German healthcare insurers cover 95% of the costs for terminally ill patients at hospices, which fund the remaining 5% through donations.

[Specialist Publications](#)

‘Barriers to the early integration of palliative care in pediatric oncology in 11 Eurasian countries’ (p.5), in *Cancer*.

‘The pathway to comfort: Role of palliative care for serious COVID-19 illness’ (p.5), in *Indian Journal of Medical Sciences*.

‘The dead with no wake, grieving with no closure: Illness and death in the days of Coronavirus in Spain’ (p.6), in *Journal of Religion & Health*.

Cont.

A decade ago, about 50 PC agencies wrote and signed a charter on caring for gravely and terminally ill patients in Germany. The document emphasizes that every patient holds unique value. In 2017, the Family Affairs, Senior Citizens, Women & Youth Ministry convened a panel on the intercultural aspects of PC. In 2019, a group of medical researchers from Göttingen university published a comprehensive report on intercultural hospice and PC.¹ They concluded that people who were born abroad or have at least one parent or grandparent who was tend to use hospice and palliative services less than other Germans. The researchers urged a greater focus on ensuring that medical staff and caregivers possess the relevant language skills, cultural sensitivity and awareness to engage with diverse communities. <https://bit.ly/3gp8T1q>

1. "An odyssey without receiving proper care": Experts' views on palliative care provision for patients with migration background in Germany,' *BMC Palliative Care*, published online 21 January 2019. [Noted in Media Watch 28 January 2019 (#599, p.7)] Full text: <https://goo.gl/MxA4PY>

Major nursing homes report calls for review of staff working conditions in wake of COVID-19 crisis

IRELAND | *The Journal* (Dublin) – 19 August 2020 – A review of the employment terms and conditions of healthcare workers in nursing homes should be carried out, according to a new report on the sector...¹ With a combination of both short-term measures and long-term goals for the sector, the report stressed that the health system and nursing homes ... need to be more closely aligned. The 200-page report, which looks at how nursing homes responded to the COVID-19 crisis, offered a series of wide-ranging recommendations about how the system needs to change to cope with any similar issues in the future. The Nursing Homes Expert Panel, which compiled the report, was launched in the wake of the severe Coronavirus outbreaks in nursing homes. Deaths in nursing homes accounted for 56% of all COVID-19-related deaths. Calling it "200 pages of wisdom," Minister for Health Stephen Donnelly said that the government would be looking carefully at the recommendations but acknowledged that the care of older people needs "systemic reform." This report, he said, should be a key foundation for that reform. Donnelly didn't commit the government to implementing all the recommendations of the report, admitting that some of it

would be a challenge. An implementation group for the report will be established next week, but Donnelly also said that some of the more ambitious measures were matters for the government to discuss. <https://bit.ly/3iU0xQM>

End-of-life care: Extract from Nursing Homes Expert Panel report

If a nursing home does not have adequate numbers of senior nursing staff on duty at all times, there is a risk that end-of-life (EoL) care is compromised. Many nursing homes required assistance from gerontologists and specialist palliative care teams to guide and support staff through EoL care issues. Nursing Homes Ireland stated that their members are used to dealing with and managing residents at EoL, however when COVID-19 arrived in nursing homes, the scale of assistance staff required by some was more than expected. Many, (but not all) required assistance with anticipatory prescribing and assessment of EoL care plans as residents' conditions changed. Communication with relatives of dying residents required a higher level of skill and time as deterioration occurred and death approached at speed. Lack of family visiting may contribute to delayed symptom awareness by staff.

1. COVID-19 Nursing Homes Expert Panel Examination of Measures to 2021, Report to the Minister for Health, Irish Government. Download/view report at: <https://bit.ly/327RftX>



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>

Specialist Publications

Palliative care delivery in residential aged care: Bereaved family member experiences of the Supportive Hospice Aged Residential Exchange (SHARE) intervention

BMC PALLIATIVE CARE | Online – 17 August 2020 – SHARE is a new model of palliative care (PC) education that has been designed for residential aged care. The goal of SHARE is to help clinical staff improve PC within residential aged care facilities and to improve specialist PC nurses' knowledge and skill to care for frail older people. The experiences of 18 bereaved families concerning the PC journey (both at the start and finish of a one-year implementation of SHARE) were explored using semi-structured interviews. Three themes were important to bereaved families' experience: communication with staff, systems of care, and hospice involvement. Sub-themes indicating changes in these three components of care between the start and finish of SHARE was identified. A fourth theme highlighted challenges (relationship with GP, staff shortages, and turnover) that continued across SHARE. Findings indicated that SHARE benefited families (improved communication and support) through the end of life journey of their relatives, but challenges remained. **Full text:** <https://bit.ly/326JfX>

Predictors and trajectories of emergency department visits among patients receiving palliative home care services: Findings from a time series analysis (2013-2017)

BMC PALLIATIVE CARE | Online – 16 August 2020 – The findings of this study, conducted in the Piedmont Region of Northern Italy, have multiple policy implications. First, home care managers should support the decline in emergency department (ED) visits and use ED only when unavoidable. Teams should work with a holistic perspective around the clock, which should include the best palliation of both physical and psychological symptoms. Palliative care (PC) teams should also be sure to offer support through the greater involvement of patients and family members, who must be properly informed and trained on when to use the ED, by providing family members with the skill set necessary to manage an illness and to navigate the healthcare system, and by offering emotional and advocacy support as needed. Previous studies have underlined the complexity of home care, reporting that the resolution of frequent family imbalance and distress must be incorporated into home healthcare services. Second, although the World Health Organization has stated that patients with any advanced progressive disease may benefit from integrated palliative home care, this study confirms previous research showing that PC services are most often used by cancer patients and are used very little by other patients, despite much evidence showing a need among these patients. Policymakers should take initiatives to improve access to PC for all patients with severe disabilities through the strengthening of PC networks and the training of teams to guarantee adequate skills. **Full text:** <https://bit.ly/2E17tgb>

Related:

- *JOURNAL OF PALLIATIVE CARE* | Online – 18 August 2020 – ‘**An active in-home physician model of palliative care and its resulting performance indicators related to home deaths, unplanned emergency department visits and unplanned hospital admissions.**’ The London Home Palliative Care (LHPC) team care model [in Ontario, Canada] is based upon: 1) Physician visit availability; 2) Active patient-centered care with strong physician in-home presence; and, 3) Optimal administrative organization. In the 18 month study period, 354 patients received care from the LHPC team. Most significantly, 88.4% died in the community or at a designated palliative care unit after prearranged direct transfer; no comparable provincial data is available. **Abstract (w. list of references):** <https://bit.ly/2E4dvg3>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.12.

The role of the social worker at the end of life: Paving the way in an academic hospital quality improvement initiative

BRITISH JOURNAL OF SOCIAL WORK | Online – 20 August 2020 – The end-of-life (EoL) experience of patients dying in acute care has been highlighted as an area for quality improvement. Delivering comprehensive care to these patients involves addressing physical symptoms and psychosocial concerns. The social work role offers a range of interventions to address the common domains of EoL care. The authors report on results of an EoL survey evaluating satisfaction with social work interventions for imminently dying patients in acute care. This article is the first phase towards gaining an understanding of the contributions of the social worker in supporting dying patients and their families... **Abstract:** <https://bit.ly/3aU7EpX>

Barriers to the early integration of palliative care in pediatric oncology in 11 Eurasian countries

CANCER | Online – 19 August 2020 – Cultural, structural, and socioeconomic barriers can delay the integration of palliative care (PC) into cancer care, particularly in low-income and middle-income countries. To date, little is known regarding the timing of and barriers to PC integration in Eurasia. The Assessing Doctors' Attitudes on Palliative Treatment survey evaluates physician perceptions regarding PC integration into pediatric oncology in Eurasia. This evidence-based survey was adapted to the regional context; iteratively reviewed by U.S. and regional panelists; and, piloted in English, Russian, and Mongolian. 424 physician responses were received from 11 countries in the Eurasian region. Study findings demonstrated wide variability in access to PC experts across countries, with the majority of providers reporting that the initial PC consultation typically occurs when curative options are no longer available. This study is the first to identify physician perceptions of the delayed timing of PC integration into childhood cancer care and associated barriers in Eurasia. These findings will inform the development of targeted interventions to mitigate local structural and cultural barriers to access and facilitate earlier PC integration in the region. **Abstract:** <https://bit.ly/31dX2ir>

Impact of caring for terminally ill children on physicians: A systematic scoping review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 20 August 2020 – Caring for terminally ill children influences nurses' and allied health provider's quality of life, ability to provide personalized, dignified and empathetic care and even their concepts of personhood. In the absence of data this review utilizes the Ring Theory of Personhood to evaluate how a physician's concept of personhood is affected caring for terminally ill children in order to better support them holistically. 13,424 titles and abstracts were retrieved, 188 full texts were evaluated, and 39 articles were included and analyzed. Identical categories and themes identified ... suggest that caring for dying children in pediatric palliative care impacts the physician's professional identity, clinical decision-making, personal well-being and relationships. Data also suggests that the magnitude of these effects depends on the presence of protective and risk factors. Aside from providing a novel insight, this review proffers a unique approach to accounting for the presence, magnitude and influence of incoming catalysts, resultant conflicts, and protective and risk factors upon the physician's personhood. **Abstract (w. list of references):** <https://bit.ly/3aJ0apG>

The pathway to comfort: Role of palliative care for serious COVID-19 illness

INDIAN JOURNAL OF MEDICAL SCIENCES, 2020;72(2):95-100. The COVID-19 pandemic has led to significant distress among people of all age groups. Patients with advanced age and severe life-limiting illnesses are at increased risk of death from COVID-19. Not all patients presenting with severe illness will be eligible for aggressive intensive treatment. In limited resource settings, patients may be triaged for supportive care only. This subset of patients should be promptly identified and receive appropriate palliative care (PC) with adequate symptom control strategies and psychosocial support. Breathlessness, delirium, pain, and noisy breathing are main symptoms among these patients which can add to the suffering at end-of-life. The COVID-19 pandemic also contributes to the psychological distress due to stigma of the illness, uncertainty of the illness course, fear of death and dying in isolation, and anticipatory grief in families. Empathetic communication and holistic psychosocial support are important in providing good PC in COVID-19 patients and their families. **Full text:** <https://bit.ly/2Eo2iqK>

Cont.

Related:

- *JOURNAL OF RELIGION & HEALTH* | Online – 20 August 2020 – ‘**The dead with no wake, grieving with no closure: Illness and death in the days of Coronavirus in Spain.**’ The pandemic caused by the spread of [COVID-19](#) is giving rise to an exceptional social situation because of the great speed of propagation of the illness and the high level of mortality it has occasioned in a very short time. Moreover, the lockdown measures decreed in Spain prohibit the holding of wakes to avoid contagion, and limit funerals to three people plus the officiant. Thus, coronavirus is robbing people of the opportunity of a final farewell, stripping the dead of their dignity and worsening the grief of the living. This article investigates the situation and the social and cultural impact it has provoked. **Full text:** <https://bit.ly/3j03j77>

N.B. Selected articles on grief and bereavement during the COVID-19 pandemic noted in Media Watch 10 August 2020 (#678, pp.3-4).

Controlled substances in hospices after patient death:

A cross-sectional survey of Ontario hospices

INTERNATIONAL JOURNAL OF CLINICAL PHARMACY | Online – 19 August 2020 – Twelve hospices (12/39; 31%) participated in the survey, 25 did not, and two were ineligible. Two (2/12, 17%) hospices served both pediatric and adult patients while 10 (83%) served adults only; 100% indicated that 76-100% of their patients were on controlled substances (CS) at time of death. Eight (67%) had a policy for controlled substances handling, two had policy and standard operating procedures (SOPs) and two had no policies, guidelines or SOPs. Qualitative analysis indicated variability in procedures for obtaining CS (patient’s own supply, other patient’s supply, hospice associated pharmacy), storage and dispensation of CS (location, secure lock, dispensing by staff or family), documentation (dispensing records, double signature, tracking returns and disposal), and disposal of CS (return to pharmacy, disposal at hospice, return to families). Although most of the hospices have a policy, guideline or SOP on the handling of CS, there is considerable variation in practice of dispensing CS to patients, documentation and disposal of CS, which may provide an avenue for inappropriate use, abuse or diversion of CS. **Abstract:** <https://bit.ly/2Q9EFoj>

Improving paediatric advance care planning: Results of a learning needs analysis and simulation-based education programme

JOURNAL OF PAEDIATRICS & CHILD HEALTH | Online – 19 August 2020 – The author’s assessed clinicians’ experience, attitudes and confidence with advance care planning (ACP) at a quaternary paediatric referral centre using a learning-needs survey, and then applied this information to develop and examine the feasibility of simulation-based education for this topic. Most (75.0%) participants had participated in ACP discussions previously. Only 40.1% of participants felt confident to assess appropriate timing of, and 45.2% felt adequately prepared to participate in ACP discussions. Barriers identified were both clinician and patient/parent related, including clinicians not knowing when to address issues (43.9%) or what to say (21.0%). Participants indicated that ACP discussions are most frequently initiated when death is clearly imminent. Following a pilot of simulation-based education with the oncology department, 90% of participants expressed confidence to participate in ACP discussions. **Abstract:** <https://bit.ly/3l6nKl0>

“Are they saying it how I’m saying it?”: A qualitative study of language barriers and disparities in hospice enrollment

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 20 August 2020 – Language barriers contribute significantly to disparities in end-of-life (EoL) care. However, the mechanisms by which these barriers impact hospice care remains under-examined. Three themes emerged in this study regarding language barriers: 1) Structural barriers inhibit access to interpreters; 2) Variability in accuracy of translation of EoL concepts exacerbates language barriers; and, 3) Interpreters’ style and manner influence communication efficacy during complex conversations about prognosis, goals of care (GoC), and hospice. The authors’

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theoretical model derived from the data suggests that theme one is foundational and common to other medical settings. However, theme two and particularly theme 3 appear especially critical for hospice enrollment and care. Language barriers present unique challenges in hospice care due to the nuance and compassion required for delicate GoC and EoL conversations. Reducing disparities requires addressing each level of this multi-layered barrier. **Abstract (w. list of references):** <https://bit.ly/3gINVAw>

Noted in Media Watch 17 February 2020 (#653, p.8):

- *BRITISH MEDICAL JOURNAL* | Online – 11 February 2020 – ‘**Can patients use family members as non-professional interpreters in consultations?**’ Sofia Sarfraz, senior clinical fellow in paediatrics and medical education, says: “For patients who don’t share your language the gold standard is to use a professional interpreter. We’ve all, however, used patients’ family members or other health professionals (HPs) as interpreters in consultations. It’s hard to see how medicine could function in our multicultural society without them, especially in emergencies. But non-professional interpreters should be used with caution and you should consider the risks. Medical interpreters have training and experience, which family members and other HPs may lack. **Full text:** <http://bit.ly/2SzE401>

Noted in Media Watch 10 April 2017 (#507, p.13):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 3 April 2017 – ‘**Understanding patient needs without understanding the patient: The need for complementary use of professional interpreters in end-of-life care.**’ In linguistically and culturally diverse societies, language discordant consultations become daily practice, leading to difficulties in eliciting patient preferences toward end-of-life care. The case discussed generated a triple-layered ethical dilemma: 1) How to safeguard patient autonomy against paternalistic interventions by family members; 2) How to respect the relational context in which patient autonomy can be realized; and, 3) How to respect the ethno-cultural values of the patient and his family. **Abstract (w. list of references):** <http://bit.ly/2JqsyjL>

Epidemiology of fear, sadness and anger expression in palliative care conversations

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 18 August 2020 – Advancing the science of serious illness communication requires methods for measuring characteristics of conversations in large studies. Understanding which characteristics predict clinically important outcomes can help prioritize attention to scalable measure development. The authors audio-recorded initial palliative care consultations involving 231 hospitalized people with advanced cancer at two large academic medical centers. They coded conversations for expressions of fear, anger and sadness. Nearly 6 in 10 conversations included at least one audible expression of distressing emotion. Among conversations with such an expression, fear was the most prevalent followed by sadness and anger. Anger expression was associated with more disease-focused end-of-life treatment preferences, pre-post consultation improvement in feeling heard and understood and lower 6-month hospice enrollment. Fear was strongly associated with pre-consultation patient ratings of shorter survival expectations. Sadness did not exhibit strong association with patient descriptors or outcomes. **Abstract (w. list of references):** <https://bit.ly/31qi9ka>

End-of-life and goals of care discussions with cancer patients in the Coronavirus pandemic

PALLIATIVE & SUPPORTIVE CARE | Online – 20 August 2020 – Honest discussions with patients and their families to outline realistic goals-of-care and, when appropriate, end-of-life (EoL) care are important. Unfortunately, for many years and even still today, these conversations have been minimized or even omitted. There are many explanations for this deficiency. Training in palliative care (PC) and delivery of bad news is often a minor part of the education program for many clinicians, even oncologists. Electronic records and computer-based treatment algorithms have reduced the amount of face-to-face personal interactions so vital to understanding the emotions of cancer and patient/family dynamics. New therapies, while advancing survival, have caused patients and clinicians to feel that there are still potential “curative” or disease-remitting options, even after multiple lines or futile therapy. PC and EoL conversations, especially if brought upon late in the course or a patient’s disease, after multiple different treatments, may be seen as “giving up.” These conversations are difficult and uncomfortable. As a result, they are often deferred for a later appointment, or to a colleague or PC specialist. **First page view:** <https://bit.ly/34enFFP>

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Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 August 2020 – ‘**What if I get seriously ill? A virtual workshop for advance care planning during COVID-19.**’ The authors describe the implementation and evaluation of a novel, public-facing, two-part virtual advance care planning (ACP) workshop. Participants were recruited through electronic communication, and evaluations were collected through surveys administered after each part of the workshop. They found that utilizing a virtual format allowed us to reach a large, geographically diverse audience. Participants were likely to recommend the workshop to friends and family. There was no change in ACP engagement between the post-session surveys between the first and second parts of the workshop. **Full text:** <https://bit.ly/2F11nln>

Noted in Media Watch 10 August 2020 (#678, p.14):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 July 2020 – ‘**MVP (Medical situation, Values & Plan): A memorable and useful model for all serious illness conversations.**’ Serious illness conversations (SIC) are integral to the optimal care of the vast and growing population of seriously ill patients, but they are under-taught in health professions training and widely feared, delayed or altogether avoided by clinicians. Experts have published a variety of communication models designed to aid and promote SIC facilitation. The authors of this article ... are among their many beneficiaries. Yet despite their value, their experience in communication education and clinical encounters has revealed three recurring impediments to their instruction, retention and usefulness. **Full text:** <https://bit.ly/3gmQov9>

Noted in Media Watch 29 June 2020 (#672, p.3):

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

Working at the intersection of palliative end-of-life and mental healthcare: Provider perspectives

JOURNAL OF PALLIATIVE CARE | Online – 18 August 2020 – The most prominent issues pertained to assessment of patients and differential diagnosis of chronic and persistent mental illness, and preparedness of caregivers to deliver mental health interventions, given the isolation of palliative care from other agencies. Among the assets mentioned, informal relationships with frontline caregivers were seen as the main support structure, rather than the formal policies and procedures of the practice settings. Strategies to improve mental healthcare in palliative and end-of-life care (PEoLC) centered on holistic roles and interventions benefiting the entire palliative population, illustrating the participants saw little point in compartmentalizing mental illness, whether diagnosed or not. Continuity of care and personal advocacy can significantly improve quality of life for end-of-life patients with mental health challenges, but bureaucracy and disciplinary siloing tend to isolate these patients and their caregivers. Improved interdisciplinary connectivity and innovative, hybridized roles encompassing palliation and psychiatry are two strategies to address this disconnect, as well as enhanced training in core mental healthcare competencies for PEoLC providers.

Abstract (w. list of references): <https://bit.ly/31fr7hr>

Noted in Media Watch 20 January 2020 (#649, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 January 2020 – ‘**Mental healthcare and palliative care: Barriers.**’ Psychological symptoms are common among palliative care (PC) patients with advanced illness, and their effect on quality of life can be as significant as physical illness. The demand to address these issues in PC is evident, yet barriers exist to adequately meet patients’ psychological needs. This article provides an overview of mental health issues encountered in PC, highlights the ways psychologists and psychiatrists care for these issues, describes current approaches to mental health services in PC, and reviews barriers and facilitators to psychology and psychiatry services in PC, along with recommendations to overcome barriers. **Abstract:** <http://bit.ly/35YIN1e>

Bereavement care interventions for children under the age of 18 following the death of a sibling: A systematic review

PALLIATIVE MEDICINE | Online – 17 August 2020 – Childhood bereavement after sibling death is common, often unrecognized. The psychosomatic and socioeconomic outcomes of bereaved children can be compromised if appropriate care is unavailable during the formative years leading into adulthood. This review describes the methods, structures and procedures of bereavement care for children and adolescents after the loss of a sibling, and the impact on the families benefiting from these interventions. Bereavement care was most often accessed by children ages 6-18 who lost a sibling to cancer 6-12 months prior. Interventions were typically group sessions or weekend camps, run predominantly by unpaid staff from a variety of backgrounds. Some staff members received specific training. Grief education is taught through mediated discussion and bereavement-centered activities balanced with playful and relaxed activities. Several services have effectuated evaluations of their interventions, and preliminary results show a positive effect for families. Existing literature most likely gives an incomplete picture of appropriate childhood bereavement care, and many interventions possibly remain unpublished or published in other

non-scientific sources. An effective response to childhood grief would involve collaboration between medical resources and community services, reinforced through the development of outreach and training programs. **Abstract (w. list of references):** <https://bit.ly/2Q5reWx>



The Crossroads of Grief:
Understanding Grief & Diversity
<http://bit.ly/2OB4Y6C>

N.B. See 'Death of a Sibling,' Section 3, p.24, of 'Grieving or Bereaved Child: Literature Review 2015-2018.'

The pervasive relevance of COVID-19 within routine paediatric palliative care consultations during the pandemic: A conversation analytic study

PALLIATIVE MEDICINE | Online – 16 August 2020 – Guidelines released for inpatient and outpatient care during the COVID-19 pandemic provide recommendations for framing a specific conversation about COVID-19 with patients. While these guidelines are valuable, this study has shown that talk about the COVID-19 pandemic was pervasively raised by both parents (45%) and clinicians (55%) throughout actual consultations. Routine questions and recommendations from the doctor often inadvertently raised the relevance of the COVID-19 pandemic and the associated changes to care and lifestyle. It appears helpful to have direct and specific questions to ask about COVID-19 (e.g., "What have you been thinking about COVID and your situation?"). At the same time, parents and patients often raised the topic themselves or in response to indirect questioning such as a check-in type question ("How are you doing with all of this?"). The holistic and comprehensive nature of a paediatric palliative care consultation can also facilitate conversation on a variety of topics ranging from school to family functioning. More serious health related conversations also occurred around pain and symptom management, and how to manage deterioration of the child if this were to occur. The importance of maintaining emotional support, empathy and compassion during such sensitive conversations is critical. As shown in the reported data..., families who might otherwise physically attend consultations shifted to telehealth consultations during the pandemic. Virtual and telehealth technologies present extra challenges to providing psychosocial support, but do not preclude it. **Full text:** <https://bit.ly/3kOLk5o>



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Toward a consensus on the nature of empathy: A review of reviews

PATIENT EDUCATION & COUNSELING | Online – 19 August 2020 – This study addresses the existing gap and confusion regarding the concept of empathy in the literature. While most articles and books on empathy start out by stating that there is far from a consensus on how empathy should be defined, this article reveals a movement toward four themes in empathy upon which most authors tend to agree. Although definitions of empathy do vary, it seems that they share the view that it involves understanding, feeling, sharing, and maintaining self-other differentiation. Based on these four themes, empathy can be defined as follows: “Empathy is to understand, feel, and share what someone else feels, with self-other differentiation.” The clarification of the content of empathy that the authors’ analysis has generated may assist practitioners and researchers in avoiding confusion regarding the meaning of the concept, as well as in avoiding misunderstandings when discussing empathy. The results of this study may guide practitioners and researchers in developing and measuring the relevant aspects of the concept. The findings may also inspire practitioners and researchers to reflect on the relationship between closeness and distance, feeling and cognition, and body and mind in empathy. **Full text:** <https://bit.ly/34mHo6a>

Noted in Media Watch 1 April 2019 (#608, p.15):

- *SOCIETY* | Online – 22 March 2019 – ‘**Empathy as care: The model of palliative medicine.**’ This article elaborates the ascent of what the authors call the empathy as care model in contemporary medicine. They make the following arguments: First, does empathy mean care? The authors examine this question in the context of medicine and argue that empathy may not mean care throughout all medical practice, as findings from the medical education field show. However, empathy as care is rising in one specialty, palliative and hospice medicine. This specialty best represents the ideal-typical traits of the empathy as care model. This work contributes to the sociology of health and illness literature and to interpretivist sociological theorizing... **Abstract (w. list of ‘Further Reading’):** <http://bit.ly/2WjVnCk>

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 21 August 2020 – ‘**Do you need compassion to work in palliative medicine?**’ Compassion stands apart from other forms of interpersonal engagement as a deeply human recognition of another’s suffering, which inherently motivates action to do something about this. There are two inextricable elements here: the role of suffering, and the resultant call to action it motivates. The role of compassion pivots on suffering, and thus, our interpretation of suffering and what we consider its upstream cause: the problem to be fixed. Palliative medicine here stands apart, priding itself on the holistic care of what is important to the patient; thus, the symptoms problematic to the patient are the problem, rather than the underlying cause *per se*. **Abstract:** <https://bit.ly/3hktgxP>

The roles and responsibilities of community pharmacists supporting older people with palliative care needs: A rapid review of the literature

PHARMACY | Online – 12 August 2020 – This review by researchers at Flinders University in South Australia aimed to identify the roles and responsibilities of pharmacists supporting older people living in a community setting with their palliative care needs and to synthesise key themes emerging from the data, as well as any gaps in knowledge. The search included all international articles and any date of publication. Fourteen studies met the inclusion criteria. Selected papers predominantly focused on care provided by the pharmacists supporting people receiving residential aged care services. Clinical review, supply of medicines, and clinical governance were identified as key pharmacist roles. Pharmacists’ communication skills, personal behavioural approach, and positive attitude emerged as supportive characteristics for effective person-centered care. Minimal, or no information, were available related to pharmacists located in general medical practices and in Aboriginal health services sector, respectively. The multifaceted role of pharmacists presents an opportunity to provide comprehensive healthcare for older populations at the end of their life. **Full text:** <https://bit.ly/315FdBM>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BIOETHICS* | Online – 19 August 2020 – ‘**Public reasoning about voluntary assisted dying: An analysis of submissions to the Queensland Parliament, Australia.**’ This study does not exhaust the possible reasons, arguments or rhetorical strategies used by the public in supporting or opposing voluntarily assisted dying (VAD). It does, however, help to characterize the main approaches of the two sides: Individualist Pathos vs Communal Ethos. Importantly, it underscores the complexity of reasons and reasoning, and that it is not clear whether this complexity is understood by the public. In particular, in the case of those supporting VAD the authors see potentially contradictory principles invoked, which, when applied, could have quite different implications for what the resulting “assisted dying regime” might look like. This reiterates the need for caution in relying on surveys of public opinion to make laws concerning VAD. Sound normative reasoning remains vital. **Full text:** <https://bit.ly/3ld9SWb>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 August 2020 – ‘**How we can improve the quality of care for patients requesting medical assistance in dying: A qualitative study of health care providers.**’ There is little consensus [in Canada] as to what constitutes high-quality care in medical assistance in dying (MAiD). The authors conducted an exploratory, multi-centre, qualitative study at four Canadian centres. They identified three major themes. 1) Improving access and patient experience: clinicians described struggles in ensuring equitable access to MAiD and supporting MAiD patients and their families; 2) Supporting providers and sustainability: clinicians described managing MAiD workload, remuneration, educational needs, and the emotional impact of participating in assisted dying; and, 3) Institutional support: descriptions of MAiD communication tools and training, use of standardized care pathways, inter-professional collaboration, and human resource planning. Suggestions were described for clinical practice to improve quality of care. **Abstract (w. list of references):** <https://bit.ly/3hkPgZn>

[Media Watch: Editorial Practice](#)

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INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/31q4XrN>

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

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