**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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**18 May 2020 Edition | Issue #666**

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Compiled & Annotated by Barry R. Ashpole

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**Canada**

Action needed to address COVID-19’s hidden tragedy: National grief advocates urge support for grieving Canadians and health workers

*CANADIAN VIRTUAL HOSPICE | Online – 12 May 2020 –* Never in our lifetimes has Canada experienced the volume and complexity of grief as has resulted from the COVID-19 pandemic. Canadians have been robbed of goodbyes with dying relatives and forced to grieve in isolation without funeral rites. They and those working on the front lines of healthcare are at heightened risk for prolonged, complicated grief marked by depression, and the risk of suicide. Existing grief services are fragmented, under-funded and insufficient. Left unaddressed, significant long-term social, health and economic impacts will result. The Canadian Grief Alliance – a coalition of national leaders in grief and bereavement – is urging the Government of Canada and the provinces and territories to bolster the country’s grief services to meet the growing demand. Existing and recently announced mental health initiatives do not include grief services. The Alliance is asking the Federal Government to invest $100 million in grief supports over the next three years and $10 million in research. Download/view at: [https://bit.ly/2ylo5aa](https://bit.ly/2ylo5aa)
Palliative care has become a critical issue for patients and families during this COVID-19 pandemic

HEALTHY DEBATE | Online – 11 May 2020 –

The role of palliative care (PC) is multifaceted and includes symptom management, end-of-life care and expertise in goals-of-care conversations. There has been an effort to develop educational resources during the pandemic to increase PC capacity for clinicians who are not familiar with this area but who might be called upon to provide palliation. The need to educate healthcare workers in the midst of a crisis reveals a weakness in our training of physicians. A recent study… indicates that the majority of undergraduate and postgraduate medical trainees do not complete a PC clinical experience during their training, exposing an interesting dichotomy: although PC is an important part of the pandemic response, the majority of our physician workforce is not trained to provide it. Even outside the confines of a pandemic, access to PC in Canada is woefully inadequate, with fewer than 1 in 6 Canadians able to access home PC in the last year of life. Inequitable access is based on many factors, including geography, culture, socioeconomic status, language and diagnosis. The consequence of this fragmented access is that most patients receive PC only in the last month of life, in an emergency setting or in a hospital, with significant subsequent distress to their caregivers. Although opportunities for PC training have increased over the years, they are still insufficient to address the broad national need. To tackle these access issues, all physicians need to know the basic skills inherent in providing PC…


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

COVID-19: End-of-Life Care


Specialist Publications

‘A modern integration of palliative care into the management of heart failure’ (p.9), in Canadian Journal of Cardiology.

‘Canada’s evolving medicare: End-of-life care’ (p.13), in Journal of Palliative Care.

‘The relationship between caregivers’ perceptions of end-of-life care in long-term care and a good resident death’ (p.14), in Palliative & Supportive Care.

‘Medical assistance in dying in Canada: Implications and considerations for music therapists around the globe’ (p.15), in Music Therapy Perspectives.

‘Medical assistance in dying: A review of Canadian regulatory documents’ (p.16), in Policy, Politics & Nursing Practice.

pg. 2
The pandemic is changing how we die – and not just for COVID-19 patients

TIME MAGAZINE | Online – 13 May 2020 – Hospitals today face an impossible predicament regarding visitors for terminally ill patients. On one hand, a visitor might spread the virus within the hospital or become exposed and bring it home. On the other, depriving people of the chance to make life-and-death decisions and say goodbye in person is cruel and may even influence the choices they make. Many hospitals seek to walk this line by allowing visitors for dying patients, with stringent restrictions. For example, the New York State department of health recommends hospitals permit one visitor for patients expected to die within 24 hours. Some hospitals allow only a single hour-long visit. And even generous policies have unintended consequences: though medical teams don’t intend to coerce families into transitioning patients to comfort-focused care before they feel ready, the fact that they cannot visit until their loved one is dying can seem like an incentive. For families that opt to discontinue ventilators, the calculus becomes more brutal. COVID-19 is especially contagious during the removal of a breathing tube, so many hospitals prohibit visitors during this procedure. If a hospital allows just one visit, families must choose between seeing their loved one before the tube is removed, while she is guaranteed to be alive, and waiting until after – with the uncertain hope of witnessing her final moments. When visits are allowed only for an hour, it may be impossible to time a visit with the moment of death. https://bit.ly/3cx7EMu

Hospice care continues – without the human touch

THE PEW CHARITABLE TRUSTS | Online – 11 May 2020 – If anyone in the healthcare industry might have been expected to be prepared to face the grim toll from COVID-19, it was hospice care providers whose purpose even in normal times is to usher the dying to peaceful, pain-free endings. Yet even hospice care workers have found their professional lives altered in unimagined ways. The pandemic introduces fear and risk into their daily routines while limiting the arsenal of customary tools they wield to bring comfort to the dying and bereaved. Touch is just one of those techniques. “Hugs used to be a big part of my job,” said Luan Biggs, a certified nursing assistant with the southern Wisconsin hospice and palliative care provider Agrace. Skin-on-skin contact – so prevalent, if not essential, in hospice work – is off limits now. Hospice care, which addresses the physical, psychological and spiritual needs of patients and their families, is particularly intimate. Patients develop bonds with hospice caregivers, who include physicians, nurses and nurse assistants, social workers, bereavement counselors and often spiritual care coordinators as well. Unlike elsewhere in healthcare, hospice workers tend to spend prolonged time with patients and their families. Care is often holding a hand or offering an empathetic smile. A premium is placed on physical and emotional presence. https://bit.ly/2YZEpOa

COVID-19: End-of-Life Care


‘Allocating scarce resources and triaging patients during the COVID-19 pandemic’ (p.12), in Journal of the American College of Cardiology.


Specialist Publications

‘Improvements needed in palliative care services’ (p.9), in CA: A Cancer Journal for Clinicians.

‘Framework for planning the delivery of psychosocial oncology services: An American Psychosocial Oncology Society Task Force report’ (p.14), in Psycho-Oncology.
Many lay people lack clear understanding of “futile treatment”

REUTERS HEALTH | Online – 5 May 2020 – When patients are terminally ill, shared decision-making is often complicated by the public’s lack of understanding of what is meant by “futile” or “potentially inappropriate” treatment, coupled with the belief that the patient or family should have the final say, a focus-group study suggests.1 “Although it is difficult to recommend the discontinuation of life-sustaining treatment, it is crucial that physicians communicate to families when treatments are non-beneficial, will not change patient outcomes, and potentially prolong suffering,” said Dr. Thanh H. Neville of David Geffen School of Medicine at University of California, Los Angeles. “It is important that physicians have the courage to make recommendations. These recommendations should be explained not in the context of resource limitations, but in the context of patient-centered care...” The medical community perceives aggressive treatment that may keep a patient alive but not result in meaningful benefit as being inappropriate or futile. But how the general public perceives and understands the terms “potentially inappropriate” and “futile” remains unclear. https://wb.md/3bmqNiJ


N.B. Click on pdf icon to access full text.
Poll reveals importance of being able to visit terminally ill family and friends during lockdown

U.K. | ITV News – 10 May 2020 – A majority of people believe not being able to see someone before they died would cause a lasting sadness, amid confusion about the government’s “right to say goodbye” policy. The finding came from a poll by Opinium which also suggested that 48% feel that not being able to attend a funeral or see someone before they died would make it harder. Adrienne Betteley, end-of-life care strategic adviser at Macmillan Cancer Support, said: “Many people struggle to understand the rules around [Secretary of State for Health & Social Care] Matt Hancock’s recent announcement on ‘the right to say goodbye,’ making the unbearably difficult situation of saying final farewells to loved ones during the pandemic even harder. Without delay, the government must clarify the guidance surrounding this proposal, particularly whether it applies beyond care homes and hospices and would allow family members to visit someone before they die in their own home. To be told that you may be reaching the end of your life is fraught with difficulties. It’s understandable that many people will be anxious about what happens next, while also feeling sad, angry and unsure about how to cope with their emotions.”

https://bit.ly/3fzIgHX


Noted in Media Watch 11 May 2020 (#665, p.3)

- U.K. (England) | The Guardian (London) – 5 May 2020 – ‘Dying surrounded by family “a fundamental right” says U.K. judge.’ Being allowed to die surrounded by your nearest relatives is a fundamental part “of any right to private or family life,” a senior judge has ruled. Delivered in the middle of the Coronavirus crisis, the Court of Protection ruling could have an immediate effect at a time when families have been deterred from saying goodbye to people dying in care homes and hospitals due to fears over spreading the infection. In her judgment, in a case involving a terminally ill woman who has since died, Mrs. Justice Lieven said: “The ability to die with one’s family and loved ones seems to me to be one of the most fundamental parts of any right to private or family life…” https://bit.ly/2yB1pbz

COVID-19: End-of-Life Care

‘Who gets the ventilator? Important legal rights in a pandemic’ (p.12), in Journal of Medical Ethics.


Specialist Publications

‘Preferred and actual place of death in haematological malignancies: A report from the U.K. haematological malignancy research network’ (p.8), in BMJ Supportive & Palliative Care.

‘Death, loss and community-perspectives from children, their parents and older adults on intergenerational community-based arts initiatives in Sweden’ (p.11), in Health & Social Care in the Community.

‘Mapping paediatric palliative care development in the WHO-European region: Children living in low-middle income countries are less likely to access it’ (p.11), in Journal of Pain & Symptom Management.
Conceptually redefining neonatal palliative care

ADVANCES IN NEONATAL CARE | Online – 6 May 2020 – The purpose of this article is to suggest a conceptual definition of neonatal palliative care (NPC) that encompasses all the essential concepts as a way of moving NPC forward by having a consistent approach. Following a review of the NPC literature, a thematic analysis as a method for identifying, analyzing, and interpreting patterns of meaning in the definitions (“themes”) within the literature was undertaken. The major themes identified included philosophies of care, support, culture and spirituality, the team, and clinical management. At the heart of NPC is the primacy of maintaining quality of life, while providing ethical and humane care that supports a “good death.” The extensive elements presented in this article are considered essential to a comprehensive and conceptual definition of NPC proposed here. Abstract: https://bit.ly/2LsFvKJ

N.B. The focus of the current issue of Advances in Neonatal Care is neonatal palliative, end-of-life and hospice care across multiple settings. Journal contents page: https://bit.ly/2UP5r7n

Lack of truth-telling in palliative care and its effects among nurses and nursing students

BEHAVIOURAL SCIENCES | Online – 11 May 2020 – The authors’ research allowed some fundamental issues that are still critical in the relationship between nurses and patients to be highlighted, especially concerning sincere communication of the patient’s diagnosis and prognosis (truth-telling). This is a particularly delicate issue, since nurses are not allowed to give a patient information concerning his/her condition without a doctor’s approval, and, even though the importance of sincere communication with a patient is now generally well recognized, doctors still very often opt for incomplete or totally absent sharing of information, most of the time because they lack the psychological skills needed to manage these situations, and because it is very common for family members to ask a doctor not to tell their relative the truth. Since this important issue can actually be considered part of a widespread conspiracy of silence (even inside healthcare contexts), the main element on which it would be fundamental to take action is the professional curricula useful in understanding and approaching death and dying in health profession degrees. It appears fundamental to adopt a completely new attitude toward death and dying, especially while dealing with terminally ill patients. Extract: https://bit.ly/3fQm1xc

N.B. Click on pdf icon to access full text.

Related:

- DEATH STUDIES | Online – 13 May 2020 – ‘The language of dying: Communication about end-of-life in residential aged care.’ This article explores implications of language used in communicating death and dying in residential aged care, which increasingly emphasizes a “family-centered” approach to end-of-life (EoL) care. Findings of this study reveal a persistent clinical culture that resists frank discussions of dying, with many staff preferring to use euphemisms for dying. Results emphasize the importance of EoL education for families, which families acknowledged was lacking. Cultural change in institutional control over disclosing dying is imperative in order to gain family trust and support in professional care and promote death literacy. Abstract: https://bit.ly/35Z5Mtj
An exploration of the experiences of professionals supporting patients approaching the end of life in medicines management at home. A qualitative study

*BMC PALLIATIVE CARE* | Online – 11 May 2020 – Healthcare professionals reported a variety of ways in which they tried to support patients to take medications as prescribed. While this article presents some solutions and strategies reported by professional respondents it is clear from both professional and patient/family caregiver accounts in the wider study that rather few professionals provided this kind of support. Standard solutions offered included: rationalising the number of medications; providing different formulations; explaining what medications were for and how best to take them. Dose administration aids were also regularly provided, and while useful for some, they posed a number of practical difficulties for palliative care. More challenging circumstances such as substance misuse and memory loss required more innovative strategies such as supporting ways to record medication taking; balancing restricted access to controlled drugs and appropriate pain management and supporting patient choice in medication use. **Full text:** [https://bit.ly/2xWPdBR](https://bit.ly/2xWPdBR)

Noted in Media Watch 18 February 2019 (#602, p.13):

- *MEDSCAPE* | Online – 13 February 2019 – *‘Dying at home: The burden of medication management.’* The management of medications in patients with late stage disease is becoming a major area of concern. A recent literature review explored the experiences and perspectives of family caregivers in managing medications for a family member being cared for and dying at home. The authors reviewed 15 studies in this area and synthesized the findings into five key themes that provide a framework to improve support for these caregivers: These concepts provide important perspectives on caregiver fears, such as over-medicating the patient, and challenges in understanding instructions, particularly with multiple medications. **Full text:** [https://wb.md/2X43MeD](https://wb.md/2X43MeD)


Palliative care in Finland

The required competencies of physicians within palliative care from the perspectives of multi-professional expert groups: A qualitative study

*BMC PALLIATIVE CARE* | Online – 9 May 2020 – The findings of this study describe the perspective of Finnish multi-professional groups of representatives from working life who qualitatively described the required competencies of physicians working within different levels of palliative care. The competencies described emphasize decision-making, social interactions and networking. Symptom management, which is often emphasized in curricula, also appeared in this study, but with a smaller emphasis. This may have been due to the informants considering symptom management so self-evident that they did not name it, or because the lack of competence in it may not be such a big problem in working-life, compared with the lack of the aforementioned competences. It is important to listen to the voices of the working-life representatives when planning curricula. Their views inform how the competences gained during education meet the challenges of the ordinary work. **Full text:** [https://bit.ly/35PR0VH](https://bit.ly/35PR0VH)

Architecture and well-being in a hospice unit: A qualitative exploration

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 14 May 2020 – This study explored how built space plays out in palliative care (PC), focusing on spatial aspects that could support or hamper patients’, relatives’ and caregivers’ well-being. It was conducted in a freestanding small-scale hospice combining a residential part for eight guests with a day-care part for groups of about five persons. The most important spatial aspects that impact on physical and social well-being in PC turned out to be the building scale and physical proximity. The small-scale setting counters the (often negative) association of PC with hospital environments. When the medical condition of the guest allows, it makes communal or outdoor spaces...
reachable, which enhances emotional and social well-being. In worse conditions, it still makes that care and nature are always nearby. The compactness of communal spaces intensifies social contacts. The building scale and physical proximity play out in the relationship between the building and its surroundings, between the residential and the day-care parts and among people within the building. Future research could investigate to what extent these spatial aspects are relevant in more conventional PC units or even in general hospital wards. **Abstract:** [https://bit.ly/2Wwngu2](https://bit.ly/2Wwngu2)

**N.B.** Selected articles on the relationship between the architecture of healthcare facilities and the quality of end-of-life care noted in 18 November 2019 issue of Media Watch (#640, p.3).

**Preferred and actual place of death in haematological malignancies:**

**A report from the U.K. haematological malignancy research network**

**BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 11 May 2020 – Having a preferred place of death discussion, and the decision documented, is important if patient preferences at the end-of-life (EoL) are to be achieved. Ensuring all patients have the opportunity to discuss this in a supportive, pragmatic and compassionate way is therefore paramount. This could be facilitated by strengthened training for medical professionals to improve their ability and confidence in EoL discussions. The increased likelihood of preference discussions, and of death in hospice in those with specialist palliative care (SPC) input suggests further haematology/SPC integration can also be beneficial. Greater support may also be required for haematology staff providing EoL care and advance planning; while some consider this a necessary skill and a rewarding experience, issues are reported with providing adequate emotional and psychological support for patients and families on busy acute wards. Regarding documentation of discussions and decisions, the introduction of the Electronic Palliative Care Coordinating Systems (EPaCCS) in England may facilitate recording between care settings, though challenges implementing EPaCCS remain. **Full text:** [https://bit.ly/3fLduM3](https://bit.ly/3fLduM3)

**Electronic palliative care coordination systems (EPaCCS): A systematic review**

**BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 8 May 2019 – The studies described in this systematic review highlight the important potential benefits of EPaCCS for improving the end-of-life care. However, observational studies can overestimate the effect of interventions, and the lack of strong evidence is of concern. All interventions may have benefits and harms, some of which are more predictable than others. **Full text:** [http://bit.ly/2Jvp5kQ](http://bit.ly/2Jvp5kQ)

**N.B.** BMJ Supportive & Palliative Care article noted in 20 May 2019 issue of Media Watch (#64, p.8).

Noted in Media Watch 11 May 2020 (#665, p.9):

- **THE LANCET HAEMATOLOGY, 2020;7(5):e418-e424.** ‘Patients with haematological malignancies should not have to choose between transfusions and hospice care.’ Although reasons for low and late hospice use in this population are multifactorial, a key barrier is limited access to blood transfusions in hospice programmes. In this Viewpoint, the authors discuss the relationship between transfusion dependence and hospice use for patients with blood cancers. They suggest that rather than constraining patients into either transfusion or hospice models, policies that promote combining palliative transfusions with hospice services are likely to optimise end-of-life care for patients with haematological malignancies. **Summary:** [https://bit.ly/3f7quLi](https://bit.ly/3f7quLi)

Noted in Media Watch 4 March 2020 (#604, p.8):

- **BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 26 February 2019 – ‘Haematologists and palliative care: A multi-centric qualitative study.’ This study identifies haematologists’ perceptions of palliative care (PC). This study highlights four key themes: 1) The aim of PC was clearly identified as alleviating severe suffering; 2) PC was identified as a separate specialty, and participants expressed the need for collaboration; 3) Early intervention was perceived as beneficial to avoid certain situations such as hospitalisation or emergency department visits at the end of life (EoL); 4) The main barrier to PC referral remained the negative connotations associated with the term “palliative,” which was overwhelmingly associated with the EoL... **Abstract:** [http://bit.ly/2H5PTH2](http://bit.ly/2H5PTH2)
Improvements needed in palliative care services

CA: A CANCER JOURNAL FOR CLINICIANS | Online – 8 May 2020 – A new study in Cancer that compared data from a 2009 national study with a similar study conducted in 2018 investigated trends in palliative care (PC) facilities at cancer centers in the U.S.¹ PC program leaders reported some significant improvements in the structures and processes for their outpatient clinics. However, according to senior author Dr. Eduardo Bruera, chair of the palliative, rehabilitation, and integrative medicine department at The University of Texas MD Anderson Cancer Center in Houston, says the study also reported some alarming results. For example, although there has been significant growth in the number of outpatient PC programs, “The vast majority of community cancer centers and a considerable proportion of the National Cancer Institute (NCI) elite cancer centers in the nation do not have inpatient PC units,” he says. In addition, Dr. Bruera notes that the growth of inpatient PC beds has been much slower than the growth of outpatient programs. “This raises concerns about the quality of care when an inpatient dies in many cancer centers.” Another disturbing observation was that the recommended early integration of supportive and PC is not taking place in the majority of cancer centers. Moreover, says Dr. Bruera, “We found that oncology fellows in most cancer centers do not have access to mandatory rotations in supportive and PC and are therefore unable to acquire the necessary training on how to manage physical and psychosocial suffering in their patients.” Perhaps the most concerning finding, according to Dr. Bruera, was the lack of supportive and PC research by most cancer centers, including comprehensive NCI cancer centers, “since better medical care is associated with active research on how to assess and manage the different aspects of suffering associated with cancer.” Full text: https://bit.ly/2WJmLLT


Related:

- CANCER | Online – 8 May 2020 – ‘Bereaved parents’ views on end-of-life care for children with cancer: Quality marker implications.’ End-of-life quality markers in adult oncology include home death and intensive care unit avoidance. Corresponding markers are lacking in pediatric oncology. This is the first qualitative study to identify quality makers for children dying of cancer from bereaved parents’ perspectives. Natural death is generally preferred, and quality measures that address barriers to parents’ spending time with their children, a lack of preparation for the events surrounding death, and feelings of abandonment are critical. Future studies need to validate these findings and develop targeted interventions. Abstract: https://bit.ly/2SSYXnL

- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 11 May 2020 – ‘Experiencing the sublime in a palliative care unit.’ All of us, without exception, must sooner or later face the inevitability of death. However, as comparative studies of different cultures show, the idea that death is something to be feared, denied or hidden away is far from universal. Indeed, it was only during the nineteenth century that the denial of death and the metaphor of illness as a shadowy country began to emerge as narratives. In the works of Leo Tolstoy (1828-1910) and Gustave Flaubert (1821-1880), for example, dying was portrayed, for the first time, as something dirty, obscene, degrading. Abstract (w. link to references): https://bit.ly/2WqmaY

A modern integration of palliative care into the management of heart failure

CANADIAN JOURNAL OF CARDIOLOGY | Online – 12 May 2020 – As people with heart failure (HF) experience functional decline during periods of deterioration in their HF status, or with aging, their needs for palliative care (PC) increase. This review considers the palliative aspects of evidence-based HF care, which benefit patients while also addressing the underlying etiology of the HF. The authors also identify symptoms common to patients with HF and management beyond evidence-based HF care. Prognostic
models and tools to identify patients appropriately evaluated by HF specialty experts might help clinicians understand the patient’s status. Rather than trying to identify a point at which PC should be included in care for a patient with HF, the authors suggest that identifying specific needs of the patient and family is a better way to target PC interventions. They review available publications that have explored integration of PC into HF care, and propose an outpatient clinic model that assesses needs and symptoms and directs HF specialist or PC based on this assessment. **Abstract (w. List of references):** [https://bit.ly/3fUc9Tb](https://bit.ly/3fUc9Tb)

**Noted in Media Watch 11 May 2020 (#665, p.6):**

- **JOURNAL OF PALLIATIVE MEDICINE | Online – 7 May 2020 – ‘The first steps taken to implement palliative care in advanced heart disease: A position statement from Denmark.’** The statement delivers practical guidance on clinical aspects and managing symptoms during the three stages of advanced heart disease (AHD). It recommends a targeted effort on organizational strategies using high-quality assessment tools and emphasizes multidisciplinary and inter-sectoral collaboration. Cardiologists supported by allied professionals acknowledge the importance of palliative care (PC) in AHD. This national position statement intended to inform and influence policy and practice and can hopefully inspire other countries to take action toward implementing PC in AHD. **Abstract:** [https://bit.ly/3bdb05S](https://bit.ly/3bdb05S)

**Noted in Media Watch 30 March 2020 (#659, p.7):**

- **GIORNALE ITALIANO DI CARDIOLOGIA, 2020;21(4):303-305. ‘Palliative care and heart failure: Some remarks about cost-effectiveness and clinical results.’** Early palliative care (PC) clearly demonstrated its efficacy in patients with heart failure, reducing symptom burden, mainly pain and depression, improving quality of life, and reducing the access to the healthcare system. However, there are not conclusive data on economic cost reduction. The reasons are related to the few patients involved in the studies dedicated to this topic, to the different clinical settings, different modalities of provision and funding of PC, and different timing of PC implementation. PC was not shown to reduce mortality nor hospital readmissions in randomized trials. **Abstract:** [https://bit.ly/3bkbdo8](https://bit.ly/3bkbdo8)

**N.B.** Italian language article.

- **GIORNALE ITALIANO DI CARDIOLOGIA, 2020;21(4):272-277. ‘Selection criteria to palliative care implementation in advanced heart failure.’** Barriers to implementation exist: perception that palliative care is opposite to “life-prolonging” therapies or is involved only in cancer disease and in end of life, prognostic difficulties in advanced heart failure, comorbidities, discrepancy between patient-reported symptom burden and objective measures of disease severity. This is why it is necessary to focus on patient and caregivers “needs” instead of exclusively numerical-objective measures, in order to emphasize clinical but also psychological, existential and spiritual elements contributing to quality of life. It is important to recognize triggers to initiate a PC approach... **Abstract:** [https://bit.ly/3abaxBn](https://bit.ly/3abaxBn)

**N.B.** Italian language article.

**Case study**

**Communication and cultural sensitivity for families and children with life-limiting diseases:**

An informed decision-making ethical case in community-based palliative care

**JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 13 May 2020 –** The healthcare decisions of families of children who have life-limiting genetic diseases are impacted by multiple factors including religious and ethical values, education and knowledge, emotional trauma, availability of support, and accessibility of care. Palliative care (PC) nurses must practice the highest standards by delivering non-biased, nonjudgmental support to patients and families; however, nurses may experience moral distress if their personal values conflict with a family’s decisions and needs. This case focuses on a family receiving community-based PC for a child with a genetic life-limiting disease. They had a family history of this disease, which had caused the deaths of previous children, and the mother had a current unplanned pregnancy. The care team overcame language barriers and cultural obstacles to establish a trusting relation-
ship with the vulnerable pregnant mother. They were able to support her decision to terminate her pregnancy safely by helping her to navigate a complex healthcare system. Using 5 crucial pillars to assist health care members with the delivery of non-judgmental family-centered PC is recommended: 1) Identification of biases; 2) Utilization of a culturally safe approach; 3) Effective communication; 4) Assessment and support; and, 5) Knowledge of community resources. Abstract: https://bit.ly/3dOP82i

Related:

- **CHILDHOOD** | Online – 9 May 2020 – ‘Smart, vulnerable, playful or just disturbing? A discourse analysis of child involvement in palliative care.’ In Scandinavian countries, health professionals (HPs) are legally obliged to involve patients’ minor children. A growing field of research focuses on the support to, and needs and experiences of, these children. The authors of this article add to previous research by analysing discourse in qualitative interviews with nurses and doctors in Norwegian public palliative healthcare. The analysis identifies four interpretative repertoires picturing the child in different ways and defining possibilities for what HPs can say and do regarding child involvement. Abstract (w. list of references): https://bit.ly/3fFlo8L

- **HEALTH & SOCIAL CARE IN THE COMMUNITY** | Online – 15 May 2020 – ‘Death, loss and community-perspectives from children, their parents and older adults on intergenerational community-based arts initiatives in Sweden.’ Studio DöBra is a community-based initiative in which children and older adults engage with topics related to dying, death and loss through shared arts activities. In an ageing society, Sweden’s end-of-life (EoL) care is increasingly professionalised and specialised, but there is little community involvement. One goal of Studio DöBra is, therefore, to support community engagement with EoL-related topics. Studio DöBra participants act as individuals with agency in creating spaces to connect across generations and engage with EoL-topics. Full text: https://bit.ly/2WAfCir

- **JOURNAL OF PAIN & SYMPTOM MANAGEMENT** | Online – 10 May 2020 – ‘Mapping paediatric palliative care development in the WHO-European region: Children living in low-middle income countries are less likely to access it.’ Approximately 170,000 children in need of palliative care (PC) die every year in Europe without access to it. This field remains an evolving specialty with unexplored development. The authors conducted the first regional assessment of paediatric PC development and provision using data from the European Association for Palliative Care Atlas of Palliative Care 2019. Many countries have recognised the importance of developing services for children in need of PC. Full text: https://bit.ly/35RlFCg


Noted in Media Watch 27 April 2020 (#663, p.12):

- **MEDICAL SCIENCES** | Online – 17 April 2020 – ‘Advances and challenges in European paediatric palliative care.’ Children’s palliative care (PC) is a specialty that differs from PC for adults in many ways. The authors discuss some of the challenges, and some of the recent advances in paediatric PC. Developing responsive services requires good epidemiological data, as well as a clarity on services currently available and a robust definition of the group of children who would benefit from PC. Once a child is diagnosed with a life-limiting condition or life-limiting illness, parents face a number of complex and difficult decisions; not only about care and treatment, but also about the place of care and ultimately, place of death. Full text: https://bit.ly/3bqg2N7

**Meaningful messages from grief workshop participants: A constructivist grounded theory study**

**JOURNAL OF HOSPICE & PALLIATIVE NURSING,** 2020;22(3):180-187. A brief, professionally led workshop on grief support for healthcare professionals (HCPs) facilitated a relational process of learning bereavement knowledge and consequential application of grief support. Participants voiced the importance of having end-of-life content in their training before going out into practice as gaps exist in basic educational programs regarding formal grief and loss education. In light of this and the reality that HCPs will be facing death and dying more frequently with an aging population, it is recommended that other health authorities, areas, and disciplines consider providing this type of training to sustain HCPs in the process and potentially to protect against burnout, lessen attrition rates, and provide long-lasting impacts on personal, emotional, and spiritual well-being. Full text: https://bit.ly/35LF7QJ
Development and implementation of a clinician-facing prognostic communication tool for patients with COVID-19 and critical illness

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 10 May 2020 – The authors have developed and implemented a point-of-care prognostic communication tool for clinicians caring for critically ill patients with COVID-19. Although this tool will need to be updated as additional evidence emerges, the authors present the tool and its development as a model of one approach to promote consistent and high-quality prognostic communication across a healthcare system. Their hope is that the tool will help clinicians develop an approach to communication about prognosis that is practical and patient- and family-centered. The best-case, worst-case, most likely scenario approach supports this tool by prompting clinicians to be objective and descriptive about likely clinical trajectories, providing patients and families with the information they need to imagine the implications of COVID-19 related critical illness and participate in informed decisions about values-based care. Studies to evaluate the utility of prognostic communication tools like this are needed. Full text: https://bit.ly/2SUuxlB

Related:

- CANADIAN JOURNAL OF ANESTHESIA | Online – 11 May 2020 – ‘End-of-life care in patients with a highly transmissible respiratory virus: Implications for COVID-19.’ Symptom management and end-of-life care are core skills for all physicians, although in ordinary times many anesthesiologists have fewer occasions to use these skills. The current Coronavirus disease (COVID-19) pandemic has caused significant mortality over a short time and has necessitated an increase in provision of both critical care and palliative care. For anesthesiologists deployed to units caring for patients with COVID-19, this narrative review provides guidance on conducting goals of care discussions, withdrawing life-sustaining measures, and managing distressing symptoms. Full text: https://bit.ly/2AqiF68

- JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY | Online – 11 May 2020 – ‘Allocating scarce resources and triaging patients during the COVID-19 pandemic.’ The COVID-19 pandemic and its sequelae have created scenarios of scarce medical resources, leading to the prospect that healthcare systems have faced or will face difficult decisions about triage, allocation and reallocation. These decisions should be guided by ethical principles and values, should not be made before crisis standards have been declared by authorities, and, in most cases, will not be made by bedside clinicians. Transparent and clear communication is crucial, coupled with dedication to provide the best possible care to patients, including palliative care. Abstract: https://bit.ly/2y9BriMk

- JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2020;323(18):1771-1772. ‘The importance of addressing advance care planning and decisions about do-not-resuscitate orders during novel Coronavirus 2019 (COVID-19).’ The novel Coronavirus disease 2019 (COVID-19) pandemic is challenging healthcare systems worldwide and raising important ethical issues, especially regarding the potential need for rationing healthcare in the context of scarce resources and crisis capacity. Even if capacity to provide care is sufficient, one priority should be addressing goals-of-care in the setting of acute life-threatening illness, especially for patients with chronic, life-limiting disease. Full text: https://bit.ly/2wMhZnU

- JOURNAL OF MEDICAL ETHICS | Online – 11 May 2020 – ‘Who gets the ventilator? Important legal rights in a pandemic.’ If a ventilator triage policy is going to be based on the principle of “save the most lives,” it must pay close attention to the legal rights that might be violated by this approach. This article identifies ten ways in which the withholding or withdrawal of a clinically indicated ventilator might violate a patient’s rights, along with recommendations on how to avoid doing so. While our analysis is based on U.K. law, it is relevant for other countries with similar legal systems. If the issues we identify are not addressed, doctors may act unlawfully. Worse, patients may die unlawfully. Full text: https://bit.ly/2yHt76R

Would these articles on COVID-19 be of interest to a colleague?
Canada’s evolving medicare: End-of-life care

**JOURNAL OF PALLIATIVE CARE** | Online – 13 May 2020 – A challenging issue in contemporary Canadian medicare is the evolution of end-of-life care (EoLC). Utilizing data from the 2016 and 2018 Health Care in Canada (HCIC) surveys, the authors compare the support and priorities of the adult public, health professionals (HPs), and administrators regarding key components for EoLC just prior to and post legalization of medical assistance in dying (MAiD) in Canada. In 2016 and 2018, the public, HPs and administrators strongly supported enhanced availability of all proposed EoLC options: pain management, hospice and palliative care (PC), home care supports, and medically assisted death. In 2018, when asked which option should be top priority, the public rated enhanced medically assisted death first (32%), followed by enhanced hospice and PC (22%), and home care (21%). Enhanced hospice and PC was the top priority for HPs (33%), while administrators rated enhanced medically assisted death first (26%). Despite legalization and increasing support for MAiD over time, HPs have increasing fear of legal or regulatory reprisal for personal involvement in medically assisted death, ranging from 38% to 84% in 2018, versus 23% to 42% in 2016. While administrators fear doubled since 2016 (40%-84%), they felt the necessary system supports were in place to easily implement medically assisted death. Optimal management of EoLC is strongly supported by all stakeholders, although priorities for specific approaches vary. Over time, professionals increasingly supported MAiD but with a rising fear of legal/regulatory reprisal despite legalization. To enhance future EoLC patterns, continued measurement and reporting of implemented treatment options and their system supports, particularly around medically assisted death, are needed. **Abstract (w. list of references):** [https://bit.ly/2LttoNf](https://bit.ly/2LttoNf)
The relationship between caregivers’ perceptions of end-of-life care in long-term care and a good resident death

PALLIATIVE & SUPPORTIVE CARE | Online – 15 May 2020 – Seventy-eight participants whose relative or friend died in one of five long-term care (LTC) homes in Canada completed self-administered questionnaires on their perceptions of end-of-life care (EoLC) and perceptions of a good resident death. Overall, caregivers reported positive experiences with EoLC and perceived residents to have died a good death. However, communication regarding what to expect in the final days of life and attention to spiritual issues were often missing components of care. Further, when explored alongside direct resident care, family support, and rooming conditions, staff communication was the only aspect of EoLC significantly associated with caregivers’ perceptions of a good resident death. The findings of this study suggest that the critical role staff in LTC play in supporting caregivers’ perceptions of a good resident death. By keeping caregivers informed about expectations at the very end of life, staff can enhance caregivers’ perceptions of a good resident death. By addressing spiritual issues staff may improve caregivers’ perceptions that residents were at peace when they died. Abstract (w. list of references): https://bit.ly/3cDyBOz

N.B. Additional articles on EoLC in LTC homes noted in 27 April 2020 issue of Media Watch (#663, p.8).

Palliative care skills in cystic fibrosis (CF): Perspectives of adults with CF, caregivers, and CF care team members

PEDIATRIC PULMONOLOGY | Online – 8 May 2020 – The role of CF care team members in delivering palliative care (PC) remains undefined. CF care team members (“clinicians”), adults with CF (“patients”), and family caregivers (“caregivers”) rated the ability of CF clinicians to provide aspects of PC using a five-point scale (“poor” to “excellent”). Seventy patients, 100 caregivers, and 350 clinicians participated. Clinicians consistently rated their PC skills higher than patients or caregivers rated them, particularly for advanced PC skills. While clinicians, patients, and caregivers rated clinicians as “very good” at basic pain assessment and “good” at discussing prognostic uncertainty, clinicians rated themselves more highly at providing most skills, including simultaneous PC and standard CF care, basic depression assessment, and discussing transplant, advance directives (ADs), end of life (EoL), code status, and hospice. Respondents affiliated with adult CF care teams rated clinicians more highly than respondents affiliated with pediatric CF care teams at discussing lung transplant, EoL, ADs, code status, and hospice. Most patients (69%) and caregivers (60%) felt CF clinicians should receive more PC training. Discrepancies exist among patient/caregiver and clinician perceptions of PC skills in CF, and skills of adult and pediatric teams may differ. Patients and caregivers feel clinicians’ more advanced PC skills are lacking. CF clinicians may benefit from PC training to enhance skills and to understand how and when to utilize specialty PC services. Abstract: https://bit.ly/3bhu9Dt

N.B. Additional articles on the PC needs of people living with cystic fibrosis noted 27 April 2020 issue of Media Watch (#663, p.10).

Framework for planning the delivery of psychosocial oncology services: An American Psychosocial Oncology Society Task Force report

PSYCHO-ONCOLOGY | Online – 10 May 2020 – While screening for psychosocial distress is now standard of care in oncology, little guidance is available for how best to deliver services in response to identified needs. The American Psychosocial Oncology Society convened a task force with the goal of creating a framework which could aid in planning services and justifying requests for resources. Ten experts from multiple disciplines within psychosocial oncology served on the task force, first meeting together as a larger group over two days to set an agenda and then subsequently working in smaller teams to execute the goals. The task force used consensus methods for developing recommendations. Three principles were identified for the framework. First, psychosocial oncology is a key component of population health, and population-based approaches to care delivery are required. Second, several key parameters shape
psychosocial oncology services: resources, aims, and scope. To guide resource allocation, example priorities were identified for the aims and scope of services. Finally, cancer care centers should strive to ensure the delivery of high quality psychosocial oncology care across all components of care. A range of practices were ranked by their potential contributions to achieving that goal. This framework may aid in planning, evaluating, and refining the delivery of responsive psychosocial oncology services. Abstract: https://bit.ly/3czzWpm

Related:

- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 11 May 2020 – ‘Caring for the patient with cancer: Body and soul.’ Is oncology a spiritual practice? As a medical oncology fellow, the author has engaged in existential questions that patients dying from cancer often ask. What is the meaning of my illness? Why am I suffering? Recognizing illness as a spiritual event did not come from any classroom experience, but from experiential learning. The transcendent, spiritual nature of medicine is found in the crevices of daily practice. The spiritual nature of medical care begins when we acknowledge how much patients and healthcare professionals suffer. Abstract (w. link to references): https://bit.ly/2SVCogz

The quality of care of the dying in hospital: Next-of-kin perspectives

SUPPORTIVE CARE IN CANCER | Online – 9 May 2020 – The ‘Care of the Dying Evaluation’ (CODE™) questionnaire, validated in German in 2018 (CODE-GER), examines quality of care for the patient and support of next-of-kin, allocating values between 0 (low quality) and 4 (high quality). The total score (0–104) is divided into sub-scales which indicate support/time given by doctors/nurses, spiritual/emotional support, information/decision-making, environment, information about the dying process, symptoms, and support at the actual time of death/afterwards. Next-of-kin of patients with an expected death in specialized palliative care (PC) units and other wards in two university hospitals between April 2016 and March 2017 were surveyed. Most of 237 analyzed CODE-GER questionnaires were completed by the patient’s spouse (42.6%) or children (40.5%) and 64.1% were female. Patients stayed in hospital for an average of 13.7 days. Half of the patients died in a specialized PC unit (50.6%). Full text: https://bit.ly/3fC6nN

Assisted (or facilitated) death

Representative sample of recent journal articles:

- MUSIC THERAPY PERSPECTIVES | Online – 2 May 2020 – ‘Medical assistance in dying in Canada: Implications and considerations for music therapists around the globe.’ Physician-assisted suicide and voluntary euthanasia are two procedures of Medical Assistance in Dying (MAiD) that are readily requested by patients internationally. In April 2016, the legalization of these procedures occurred in Canada after the pursuit of many jurisdictional cases. Known as Bill C-14, this legislation aims to balance patient autonomy at end-of-life (EoL) with revised standardizations for medical and healthcare professionals. Music therapists may be included in the medical and healthcare team that can be recommended by patients considering MAiD. At present, there are no written guidelines that empirically outline the role of music therapists in this area. The authors explore the global history of MAiD as well as MAiD in the Canadian healthcare system and its implications. Information on the legislation Bill C-14 is explained, along with a discussion on the current practices of music therapy at EoL and the potential scope of a music therapist during the MAiD procedure. Ethical issues and future research are also presented as recommendations to healthcare and music therapy professionals. Abstract: https://bit.ly/2L55nsD

Cont. next page
Medical assistance in dying: A review of Canadian regulatory documents. Canada became the first jurisdiction where medical assistance in dying (MAiD) may be delivered by nurse practitioners as well as physicians. Experience has revealed significant public demand for the service, and Canadians expect nurses to advocate for safe, high-quality, ethical practice in this new area of care. Pesut et al offer a superb analysis of the related Canadian nursing regulatory documents and the challenges in creating a harmonized approach that arise in a federation where the Criminal Code is a federal entity and the regulation of healthcare providers and delivery of care fall under provincial and territorial legislation. Organizations like the Canadian Nurses Association contribute to the development of good legislation by working with partners to present evidence to help legislators consider impacts on public health, healthcare, and providers. Nursing regulators across Canada responded quickly to the unfolding policy landscape as the federal legislation evolved and will face that task again: In February 2020, the federal government tabled legislation to relax conditions related to MAiD requests that will force regulators and professional associations back to public advocacy and legislative tables. The success of the cautious approach exercised by nursing bodies throughout this journey should continue to reassure Canadians that their high trust in the profession is well placed.


International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://bit.ly/2YJJzQt

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[Scroll down to ‘Media Watch by Barry Ashpole’, also ‘Media Watch: Behind the Scenes’ at: http://bit.ly/2MwRRAU ]

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

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

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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

HUNGARY | Magyar Hospice Alapítvány: http://bit.ly/2RgTvYr

U.K. | Omega, the National Association for End-of-Life Care: http://bit.ly/2MxVir1

South America


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