

## 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

**The question is no longer “is palliative care needed?” ...but, “when should it be initiated?” and “what is the best model of palliative care for each community?”**

‘Hastened death due to disease burden and distress that has not received timely, quality palliative care is a medical error’ (p.12), *Medical Hypotheses*.

## Canada

### Brief to the House of Commons Standing Committee on Health

#### **Immediate issues and recommendations regarding provision of palliative care during the COVID-19 pandemic**

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS | Online – 22 April 2020 – The Society’s Board has been working hard to bring palliative care (PC) issues to as many national planning tables as possible. It is actively involved in a variety of advocacy issues, including drug shortages, access to personal protective equipment, and PC standards and education needed for COVID-19. In the context of the COVID-19 pandemic, PC delivery requires additional considerations due to the need for physical distancing, severity and rapid change of symptoms, varied responses to medications used for PC, and visitor bans/restrictions. While this is true for all people who are suffering and dying at this time, we are seeing that some people with COVID-19 can suffer immensely with shortness of breath, pain and delirium; and they may decline and die very rapidly. Symptoms from the virus do not respond predictably to usual PC treatments, which means physicians need to be ready for almost anything – with expertise, rapid response, alternate medications, and alternate medication delivery mechanisms. **Download/view brief at:** <https://bit.ly/2YlhE79>



#### **Urgent needs**

More dedicated community resources for PC in community settings;

Staffing to support primary and specialist PC for COVID-19 patients in all settings;

Access to appropriate medications for management of severe symptoms in all settings; and,

National clinical standards and guidelines across all settings as well as clarity around accountability measures for organisations in all settings – for COVID-19 right now, and more broadly over time.

## U.S.A.

### Hospices focus on staff to cut turnover during pandemic

*HOSPICE NEWS* | Online – 30 April 2020 – Even as COVID-19 puts new staffing pressures on hospice and palliative care (PC) providers, organizations continue to wrestle with ongoing staffing shortages. While organizations respond to the pandemic, the business of hospice continues – including the need to control routine issues such as staff turnover. The U.S. has 13.35 hospice and PC specialists for every 100,000 adults 65 and older, according to a 2018 study.<sup>1</sup> The research estimated that by 2040 the patient population will need 10,640 to 24,000 specialists; supply is expected to range between 8,100 and 19,000. Hospice and PC providers also experience shortages in non-physician disciplines, including chaplains, nurses, and social workers. As far back as 2008, the U.S. Centers for Medicare & Medicaid Service began allowing hospice providers to use contracted nursing staff because not enough nurses were available to fill permanent positions. More than 26% of hospice providers in a recent *Hospice News* poll indicated that staffing would be the greatest challenge they would face during 2020... Numerous factors can impact turnover rates, including persistent problems such as staff burnout and routine staff retirement. <https://bit.ly/2Ss3xt4>

1. 'The growing demand for hospice and palliative medicine physicians: Will the supply keep up?' *Journal of Pain & Symptom Management*, published online 2 February 2018. [Noted in 5 February 2018 issue of Media Watch (#549, p.12)] **Full text:** <http://bit.ly/2CRjxwO>

**N.B.** Additional articles on the status of the PC workforce in the U.S. noted in 13 April 2020 issue of Media Watch (#661, p.13).

## International

### Best investigative journalism of the Coronavirus crises revealed

U.K. | *Press Gazette* – 1 May 2020 – News media investigations have helped shed light on the impact of the Coronavirus on the most vulnerable in society and, in doing so, pushed for action from officials. Among the investigations highlighted in a recent 'Journalism Matters: Excellence in Reporting Coronavirus' survey, undertaken by the trade magazine, is one by ITV, which shed light on the precarious funding of hospices in the U.K.<sup>1</sup> The vast majority of end-of-life care in the U.K. is paid for through fundraising, which stopped overnight more or less when the virus hit. ITV's investigation eventually led to the government giving the sector £200 million to help them through the next three months. <https://bit.ly/2KQaj7G>

1. 'Hospices issue dire warning of closures as coronavirus sparks cutbacks in end-of life-care,' ITV, 28 March 2020. <https://bit.ly/3aVPhPB>

**N.B.** Selected news reports on funding hospice in the U.K. noted in 16 March 2020 issue of Media Watch (#657, p.4).

### COVID-19: End-of-Life Care

'Universal do-not-resuscitate orders, social worth, and life-years: Opposing discriminatory approaches to the allocation of resources during the COVID-19 pandemic and other health system catastrophes' (p.10), in *Annals of Internal Medicine*.

'To face Coronavirus disease 2019, surgeons must embrace palliative care' (p.10), in *JAMA Surgery*.

'COVID-19 – A reminder to reason' (p.10), in *The New England Journal of Medicine*.

### Specialist Publications

'Hospital characteristics associated with palliative care program prevalence' (p.11), in *Journal of Palliative Medicine*.

## “A good death” during the COVID-19 pandemic in the U.K.: A report on key findings and recommendations

U.K. (England) | London School of Economics & Political Science – 28 April 2020 – Dealing with death and bereavement in the context of the COVID-19 pandemic will present significant challenges for at least the next three months. The current situation does not allow for families and communities to be involved in the process of death in ways in which they would normally hope or expect to be. In addition, mortality rates will disproportionately affect vulnerable households. The government has identified the following communities as being at increased risk: single parent households; multi-generational Black and minority ethnic groups; men without degrees in lone households and/or in precarious work; small family business owners in their 50s; and elderly households. This report presents a summary of findings and key recommendations by a team of anthropologists who conducted a public survey and 58 cross-community interviews... It explores ways to prepare these communities and households for impending deaths with communications and policy support. Research was focused on “what a good death looks like” for people across all faiths and for vulnerable groups. It examined how communities were already adapting how they dealt with processes of dying, burials, funerals and bereavement during the pandemic, and responding to new government regulations. It specifically focused on five transitions in the process of death, and what consultation processes, policies and communications strategies could be mobilised to support communities through these phases. **Download/view at:** <https://bit.ly/2VOGZ85>

**N.B.** See London School of Economics & Political Science resources to support community and institutional long-term care responses to COVID-19 at: <https://bit.ly/2Yu4FA6>

### Related:

- U.K. (Scotland) | Scottish Government – 27 April 2020 – ‘**Coronavirus (COVID-19): Palliative care toolkit.**’ The purpose of this palliative care (PC) toolkit is to provide Health Board planners with support for local resilience planning during the COVID-19 pandemic. It is not intended to replace existing PC processes and guidance documents but instead it offers a range of practical approaches and tools that can be considered and adapted locally in order to strengthen any local response to the COVID-19 situation. The toolkit has been shared with a range of stakeholders for comment and has been approved by the Scottish Government Professional Advisors Group for application during the COVID-19 outbreak. **Download/view at:** <https://bit.ly/2y1kKIW>

### Coronavirus: The hospice staff working through a pandemic

U.K. (England) | BBC News – 28 April 2020 – The Coronavirus crisis has dramatically changed how hospices operate – including visitor restrictions and social distancing rules, to minimise the risk of the virus being passed on. BBC News finds out the impact on staff, patients and families at East Cheshire Hospice, which thinks hospices like them have been forgotten about in the pandemic. <https://bbc.in/2Si57xw>

### COVID-19: End-of-Life Care

‘**The impact of socio-cultural influences on the COVID-19 measures: Reflections from Singapore**’ (p.9), in *Journal of Pain & Symptom Management*.

‘**Response and role of palliative care during the COVID-19 pandemic: A national telephone survey of hospices in Italy**’ (p.10), in *Palliative Medicine*.

‘**COVID-19: A personal perspective**’ (p.10), in *Palliative Medicine*.

‘**Staying connected and informed: Online resources and virtual communities of practice supporting palliative care during the novel Coronavirus pandemic**’ (p.10), in *Progress in Palliative Care*.



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## Together for Hospice launch the National Hospice Movement

IRELAND | *The Limerick Post* – 27 April 2020 – The launch coincides with an urgent national fundraising appeal. During these unprecedented and difficult times, with such uncertainty surrounding fundraising events and campaigns, hospices nationwide need support now more than ever, and people are being encouraged to donate what they can to support their local hospice. Together for Hospice, The National Hospice Movement consists of 26 independent specialist hospice and palliative care providers working at the heart of local communities all across Ireland. <https://bit.ly/3f1eXxp>

**N.B.** Together for Hospice website.: <https://bit.ly/3bMdXLw>

## Seoul City fosters “well-dying” culture

SOUTH KOREA | Korea Bizwire (Seoul) – 27 April 2020 – Despite growing social interest in “well-dying,” the concept that goes beyond “well-being,” some seniors living in Seoul are not preparing adequately for their death. In a survey of 526 men and women aged between 20 to 79 conducted by the city in September of last year, 44.4% of citizens aged 65 or older said they were not preparing for their death. Analyzing the responses by age group, 53.7% of those in their 60s and 37.9% of those in their 70s were not prepared for death. In addition, while 25.3% were in favor of life-prolonging treatment or care, 74.7% opposed this form of intervention. A considerable number of respondents had negative views of medical treatment and care that merely prolongs the life of patients. The older the age, the more opinions were against life-prolonging treatment. In particular, 81% of those in their 60s opposed the idea. A 2017 survey of senior citizens by the Ministry of Health & Welfare also showed that 91.8% of senior citizens objected meaningless life-prolonging treatment. The results can be interpreted as an indication that the majority of the elderly want to end their lives comfortably and with dignity without relying on mechanical and artificial devices. <https://bit.ly/2W1U3pt>

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

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



### [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

### **General practitioners' perspectives on general and specialized palliative home care in North Rhine, Germany: An explorative focus group study**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 April 2020 –

General practitioners (GPs) are important providers and coordinators of palliative home care (PHC). Through this double role, their perspectives and their treatment decisions influence PHC fundamentally. Participating GPs describe their role in PHC, based on high motivation and positive attitudes toward PHC as a hybrid role: coordinator, provider (mostly in general PHC), and referrer (gateway to palliative care specialists). According to GPs' medical activity, participants describe moderate expertise, demanding tasks, and elaborate PHC provision for GPs. Participants stressed the importance of palliative care (PC) in GPs' work. But also PC is a small field in general practice. GPs' PHC benefits from the deep trust resulting from the often close and long-term GP-patient relationship. Complexity and bureaucracy of PHC structures as well as the lack of resources and multidisciplinary cooperation are named as barriers for providing PHC. The highest level of care is reached in specialized PHC, which only very few, severely impaired patients need. Participating GPs see themselves as important PHC providers as well as referrers and coordinators. Complexity and discontinuity in PC arrangements create challenges for their provision. Therefore, they long for reduced bureaucratic burdens. **Abstract (w. list of references):** <https://bit.ly/2Wfq8u6>

#### **Related:**

- *BMC FAMILY PRACTICE* | Online – 29 April 2020 – '**Primary care service use by end-of-life cancer patients: A nationwide population-based cohort study in the U.K.**' The authors found that most cancer patients managed by GPs have complex care needs... GPs maintain active contacts with terminal cancer patients towards the very end of their lives, their involvement reaching a peak at the penultimate month before a sharp drop in the last month. Polypharmacy is common. Patients over 70 years have fewer GP consultations but more prescriptions and a higher chance of referral to other specialties, suggesting their care needs may not be sufficiently met by primary care teams. Having palliative care (PC) needs recognised increases the use of GP services... **Full text:** <https://bit.ly/2WuzQJd>

### Authors' Retraction

In 'Prevalence and predictors of burnout among hospice and palliative care professionals,' published in the *Journal of Pain & Symptom Management* in 2016, the authors reported the findings of a survey of members of the American Academy of Hospice & Palliative Medicine regarding burnout and related issues.<sup>1</sup> They reported a burnout rate of 62% among survey participants. In the Fall of 2018, the authors conducted another burnout survey among several membership organizations of the National Coalition for Hospice & Palliative Care and found a burnout rate much lower than was reported in 2016.<sup>2</sup> Understanding that dramatic shifts in burnout prevalence are not often found, particularly across short time intervals, the authors reran the analysis of the 2016 survey and found a critical error. **Download/view retraction notice at:** <https://bit.ly/2Y8ZDJd>

1. 'Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S.,' *Journal of Pain & Symptom Management*, 2016; 51(4):690-696. [Noted in 25 April 2016 issue of Media Watch (#459, p.11)]
2. 'Policy changes key to promoting sustainability and growth of the specialty palliative care workforce,' *Health Affairs*, 2019;38(6):910-918. [Noted in 10 June 2019 issue of Media Watch (#617, p.1)] **Full text:** <http://bit.ly/2QMAU7N>

**N.B.** Selected articles on burn-out, compassion fatigue, and the well-being and resilience practices in the hospice and palliative care workforce noted in 27 April 2020 issue of Media Watch (#663, pp.11-12).



Closing the Gap Between Knowledge & Technology

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

## Perceptions of facilitators and barriers to measuring and improving quality in palliative care programs

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 April 2020 – The authors surveyed team members in diverse U.S. and Canadian palliative care (PC) programs using a validated survey addressing teamwork and communication and constructs for educational support and training, leadership, infrastructure, and prioritization for quality measurement and improvement. They surveyed 103 respondents in 11 programs; 45.6% were physicians and 50% had leadership roles. Key facilitators across sites included teamwork, communication, the implementation climate (or environment), and program focus on quality improvement. Key barriers included educational support and incentives, particularly for quality measurement, and quality improvement infrastructure such as strategies, systems, and skilled staff. In multivariable analyses, perceptions did not differ by leadership role, but physicians and nurse practitioners/nurses/physician assistants rated most constructs statistically significantly more negatively than other team members, especially for quality improvement... Although participants rated quality improvement focus and environment highly, key barriers included lack of infrastructure, especially for quality measurement. Building on these facilitators and measuring and addressing these barriers might help programs enhance PC quality initiatives' acceptability, particularly for physicians and nurses. **Abstract (w. list of references):** <https://bit.ly/2SgAGHV>

## The community perspective on potentially inappropriate treatment

*ANNALS OF THE AMERICAN THORACIC SOCIETY* | Online – Accessed 1 May 2020 – Medical interventions that prolong life without achieving an effect that the patient can appreciate as a benefit are often considered futile or inappropriate by healthcare providers. In recent years, a multi-center guideline has been released with recommendations on how to resolve conflicts between families and clinicians in these situations and to increase public engagement. Although lay-people are acknowledged as important stakeholders, their perceptions and understanding of the terms “potentially inappropriate” or “futile” treatment have received little formal evaluation. When asked to describe “futile,” or “inappropriate” treatment, community members [i.e., study participants] found the concept difficult to understand and the terminology inadequate, though when presented with a case describing inappropriate treatment, most participants recognized it as the provision of inappropriate treatment. Several themes emerged regarding participant difficulty with the concept, including inadequate physician-patient communication, lack of public emphasis on end-of-life (EoL) issues, skepticism that medical treatment can be completely inappropriate, and doubts and fears that medical futility could undermine patient/family autonomy. Participants also firmly

believed that in situations of conflict, families should be the ultimate decision-makers. Public engagement in policy development and discourse around medical futility will first require intense education to familiarize the lay-public about use of inappropriate treatment at the EoL. **Abstract:** <https://bit.ly/2WhBwWg>



### **AMA Journal of Ethics: Sharing health decisions**

Decision sharing is an important evolution from informed consent in clinical ethics practice. Patients do not always comprehend their diagnoses or treatments, clinicians can define successful outcomes differently than patients, and patients sometimes don't have enough information to set priorities and choose wisely. So, what exactly should be shared between clinicians and patients in shared decision making? The current issue of the journal investigates key clinical and ethical features of this question. **Journal contents page:** <https://bit.ly/3bWzzVR>

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

Cont.

## Related:

- *CMAJ OPEN* | Online – 28 April 2020 – ‘**A novel decision aid to help plan for serious illness: A multi-site randomized trial.**’ Although there are many existing tools for advance care planning available, there are several features of the Plan Well Guide that make it particularly useful for patients and clinicians. In the experience of the authors, patients have difficulty discriminating between planning for terminal care and planning for medical care when seriously ill, and their decision support tool specifically addresses these differences. One of the key observations from the development process was the difficulty patients had linking their underlying values to their preferences for medical treatments **Full text:** <https://bit.ly/3aPthWp>

N.B. Plan Well Guide website: <http://bit.ly/2ObLJiz>

## When to integrate palliative care in the trajectory of cancer care

*CURRENT TREATMENT OPTIONS IN ONCOLOGY* | Online – 23 April 2020 – To date, several studies support the use of early, integrated palliative care (PC) for patients with cancer, based upon documented improvements in quality of life, symptoms, mood, satisfaction, utilization, and even overall survival. Despite this, patients with cancer continue to have unmet PC needs, and PC services are often engaged late in their care, if at all. Amid this under-utilization, questions remain about the optimal timing and nature of PC integration. The authors briefly review the evidence based for PC in oncology, and discuss three approaches to optimizing the timing of PC integration: 1) Prognosis-based; 2) Needs-based; and; 3) Trigger-based models. Prognosis-based models most closely mirror the approach of randomized trials to date, but are overly dependent on prognostication, and may miss patients with unmet needs who do not meet standard definitions of poor-prognosis disease. Needs-based models may better capture patients in a personalized manner, based on actual needs, but require sophisticated screening systems to be integrated into routine care processes, along with clinician buy-in. This may lead to excessive referrals, which strain the already limited PC workforce. As such, a blended, trigger-based approach may be best, allowing one to utilize certain disease-based and prognosis-based triggers for referral, plus screening of unmet needs, to identify those patients most likely to benefit from integrated PC when they need it most. **Opinion statement (w. list of references):** <https://bit.ly/2VS5Cza>

Noted in Media Watch 17 February 2020 (#653, p.13):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 12 February 2020 – ‘**Triggered palliative care consults: A systematic review of interventions for hospitalized and emergency department patients.**’ No standards exist to guide trigger design or implementation. Trigger processes and composition were heterogeneous, although frequently utilized categories such as cancer, dementia, and chronic comorbidities were identified. The authors present a range of trigger tools spanning different hospital settings and patient populations. Common themes in implementation and content arose but the limitations of these studies are notable and further rigorous randomized comparisons are needed to generate standards of care. **Abstract (w. link to references):** <http://bit.ly/37ttdKk>

Noted in Media Watch 9 December 2019 (#643, p.17):

- *SUPPORTIVE CARE IN CANCER* | Online – 2 December 2019 – ‘‘**Triggers**’’ for early palliative care referral in patients with cancer: **A review of urgent unplanned admissions and outcomes.**’ Many triggers have been proposed, but are not commonly used. This study reviewed the timing of palliative care (PC) involvement for patients in a tertiary referral oncology hospital, and whether the use of a trigger tool prior to admission would have facilitated earlier referral. A total of 159 patients were identified. Forty-six percent were referred to PC prior to terminal admission. Application of 6 out of 7 trigger tools would have resulted in the majority of patients referred to PC prior to admission; 52.2% were referred only during their terminal admission. **Abstract (w. list of references):** <http://bit.ly/34GKMgp>

Cont.

## Related:

- *NATURE REVIEWS: CLINICAL ONCOLOGY* | Online – 30 April 2020 – ‘**Palliative care services at cancer centres – room for improvement.**’ Evidence of quality of life improvements in patients with advanced-stage cancer has spurred a move towards early integration of palliative care (PC) into the outpatient setting. As discussed by the authors, meaningful and sustained improvements in timely access to PC requires commitments to funding, encouraging integration and routinizing referral across care settings. More palliative medicine training positions as well as broader education of clinicians and the public about the benefits of PC throughout the disease course are also needed. **Abstract (w. list of references):** <https://go.nature.com/2SqLNy0>

## Proactive integration of geriatrics and palliative care principles into practice for chronic obstructive pulmonary disease

*JAMA INTERNAL MEDICINE* | Online – 27 April 2020 – Half of adults with chronic obstructive pulmonary disease (COPD) in the U.S. will be 75 years or older by 2030. Patients with COPD often have years of debilitating symptoms that accelerate their loss of independence and well-being. COPD is progressive and incurable; many patients are frail and socially isolated and struggle with long lists of medications. Their care is often chaotic and fragmented, with frequent emergency department visits and hospitalizations. Given the limited numbers of geriatricians and palliative care (PC) specialists, clinicians who routinely care for patients with COPD should proactively integrate geriatrics and PC principles into their daily practice. **Abstract:** <https://bit.ly/2S9Fb7h>

Noted in Media Watch 10 February 2020 (#652, p.8):

- *JOURNAL OF APPLIED GERONTOLOGY* | Online – 2 February 2020 – ‘**The overlap between geriatric medicine and palliative care: A scoping literature review.**’ This article provides a scoping literature review on the relationship between geriatric medicine (GM) and palliative care (PC) within the U.K.. The review encompassed literature written between 1997 and 2019. Three themes were identified: 1) Unclear boundaries between specialties; 2) Communication within and between specialisms; and, 3) Ambiguity of how older people fit in the current healthcare system. The authors suggest that more empirical research is conducted about the overlap between PC and GM to understand how inter-professional working and patient care can be improved. **Abstract:** <http://bit.ly/31pTQib>

**N.B.** Additional articles on the potential overlap of GM and PC noted in 6 January 2020 issue of Media Watch (#647, pp.6-7).

## Palliative care benefits patients with Parkinson disease

*JOURNAL OF AMERICAN MEDICAL ASSOCIATION*, 2020;323(16):1543. Outpatient palliative care (PC) improved quality of life (QoL) and symptoms among patients with Parkinson disease and related disorders in a trial in *JAMA Neurology*.<sup>1</sup> The study’s 210 patients and 175 caregivers were randomly assigned to outpatient integrative PC or to standard care. Every 3 months for a year, participants received PC visits either in person or via telemedicine from a neurologist, social worker, chaplain, and nurse with guidance from a palliative medicine specialist. Standard care was provided by a neurologist and a primary care clinician. At 6 months, the intervention group had better QoL and 35% experienced clinically significant benefits compared with 20% in the standard-care group. Caregivers in the intervention group did not report less burden at 6 months but did at 12 months. None of the benefits from standard care alone surpassed PC outcomes. **Full text:** <https://bit.ly/2KJtlwx>

1. ‘Comparison of integrated outpatient palliative care with standard care in patients with Parkinson’s disease and related disorders: A randomized clinical trial,’ *JAMA Neurology*, published online 10 February 2020. [Noted in 17 February 2020 issue of Media Watch (#653, p.9)] **Full text:** <http://bit.ly/2Sde7o6>



Would this article be of interest to a colleague?

## Terminally ill cancer patients' emotional preparedness for death is distinct from their accurate prognostic awareness

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 April 2020 – Emotional preparedness for death (hereafter called death preparedness) and prognostic awareness (PA), a distinct but related concept, each contributes to patients' practical, psychological, and interpersonal preparation for death. However, the distinction between these two concepts has never been investigated. Participants [in this study] who were male, older, reported financial sufficiency, had fewer distressing symptoms, and perceived higher levels of social support were more likely to report death preparedness. Participants who were female, had greater than high-school educational attainment, and endured higher levels of functional dependence were more likely to report accurate PA. The distinction between death preparedness and accurate PA was supported by their poor agreement, lack of reciprocal associations, and two different sets of predictors. Healthcare professionals should not only cultivate cancer patients' accurate PA, but also facilitate emotional preparation for death to achieve a good death and improve end-of-life-care quality. **Abstract (w. link to references):** <https://bit.ly/2Ype9gc>

## The impact of socio-cultural influences on the COVID-19 measures: Reflections from Singapore

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 April 2020 – The COVID-19 pandemic has resulted in tremendous strain on healthcare systems globally. The discipline of palliative medicine prides itself on patient autonomy and fulfilment of personal care preferences. We believe that each patient is unique with needs based on personal experiences and cultural, familial and social influences. These considerations impact how we communicate and treat each patient. Similarly, for policymakers drafting infection control measures in the COVID-19 pandemic, cultural and societal norms warrant special consideration to ensure that measures implemented are acceptable and feasible to the general public. Singapore is a city-state with a population of about 5 million in Southeast Asia. Although it was one of the first countries to institute measures to tackle the COVID-19 epidemic, it had at one point of time the highest number of confirmed COVID-19 patients outside of China where the infection was first reported. Since then, it has reported more than 9,000 infected patients despite tightening of infection control measures that include the shutting of non-essential businesses and schools. Confucianism is the prevailing social model in Singapore, where family-centric obligations and practices are important pillars of the Singaporean identity. These include obligations to provide financial and physical support for the elderly

and sick, the reciprocal obligations of the elderly to provide care for the young and the need for a familial consensus in healthcare decisions. As COVID-19 worsens in the country, the impact of these values on the success of national disease containment policies is becoming increasingly apparent. **Full text:** <https://bit.ly/3cZsDr8>

### Extract from *Journal of Pain & Symptom Management* article

Palliative care (PC) providers have a role in supporting national efforts while equipped with the knowledge of the unique challenges our patients and family members face. Individual patient discussions help to address distress from perceived challenges to personhood, while family conferences facilitated by the multi-disciplinary PC team provide a safe platform for patients and family members to communicate with each other. Financial and caregiving limitations can be tackled with relevant assistance schemes by the PC social workers according to individual circumstances. While there is strong incentive for the implementation of strict measures in the COVID-19 pandemic, awareness and compassion goes a long way in ensuring that these measures remain effective and acceptable. There is no better time than now to illustrate the importance of the PC approach, where understanding the socio-cultural factors relevant to patients and their families is integral to what we do.

Cont.

## Related:

- *ANNALS OF INTERNAL MEDICINE* | Online – 24 April 2020 – ‘**Universal do-not-resuscitate orders, social worth, and life-years: Opposing discriminatory approaches to the allocation of resources during the COVID-19 pandemic and other health system catastrophes.**’ During a public health catastrophe, although the physician’s responsibility remains with the health and welfare of individual patients under his or her care, the well-being of the community must also be considered, including in institutional and other guidelines. Prioritization of resources becomes critical, but prioritization does not mean discrimination against groups. Fairness does not require that everyone be treated identically, but it does require giving each person his or her due. **Full text:** <https://bit.ly/2VNsv8l>
- *JAMA SURGERY* | Online – 28 April 2020 – ‘**To face Coronavirus disease 2019, surgeons must embrace palliative care.**’ Despite evidence palliative care (PC) improves surgical outcomes and publication of practice guidelines, surgical patients are less likely than medical patients to receive PC. COVID-19 presents structural, ethical and clinical challenges forcing a fundamental re-evaluation of how we care for patients. This crisis presents surgeons with an unprecedented opportunity to embrace PC to face this pandemic. Four aspects of PC are instructive to surgeons during this crisis: 1) Using serious-illness communication strategies to disclose prognosis and establish goals of care; 2) Treating total pain; 3) Caring for the family unit; and, 4) Supporting clinicians. **Full text:** <https://bit.ly/2WcKmVd>
- *THE NEW ENGLAND JOURNAL OF MEDICINE* | Online – 28 April 2020 – ‘**COVID-19 – A reminder to reason.**’ Thus far in the COVID-19 pandemic, we’ve observed that therapeutic management has often been initiated and altered on the basis of individual case reports and physician opinion, rather than of randomized trials. In these uncertain times, physicians fall prey to cognitive error and unconsciously rely on limited experiences, whether their own or others’, instead of scientific inquiry. Physicians should be acting in concert with clinical equipoise. We should be skeptical of any purported therapeutic strategy until enough statistical evidence is gathered that would convince any “open-minded clinician informed of the results” that one treatment is superior to another. **Full text:** <https://bit.ly/2WbonxZ>
- *PALLIATIVE MEDICINE* | Online – 29 April 2020 – ‘**Response and role of palliative care during the COVID-19 pandemic: A national telephone survey of hospices in Italy.**’ The hospice sector is able to respond flexibly and rapidly to the COVID-19 pandemic. However, the potential of hospices in supporting the COVID-19 pandemic will be undermined unless the sector has access to appropriate protective equipment and setting-specific guidance. Governments must urgently recognise the necessity of hospice and palliative care to the COVID-19 pandemic and ensure these services are both protected and integrated into the healthcare system response. Hospices may also need to reach out to offer support in creative ways during the response. **Full text:** <https://bit.ly/2SCWLkr>
- *PALLIATIVE MEDICINE* | Online – 29 April 2020 – ‘**COVID-19: A personal perspective.**’ In the U.K., the media mostly discusses testing, ventilators and intensive care “surge” capacity. Death is noted and mourned in the daily statistical updates, but the contribution of palliative care (PC) to managing dying is not so prominent. Indeed, as services are rapidly reconfigured to address growing numbers of patients with COVID-19 there are reports of PC teams being dismantled to provide care in other areas of the healthcare system, rather than recognising the importance of their PC expertise. However, there are also those arguing strongly that PC should be an essential component of care systems, and that the need to plan for PC “surge” capacity is equally important. **Full text:** <https://bit.ly/3d3dy7T>
- *PROGRESS IN PALLIATIVE CARE* | Online – 28 April 2020 – ‘**Staying connected and informed: Online resources and virtual communities of practice supporting palliative care during the novel Coronavirus pandemic.**’ Those actively involved in palliative care (PC) have rallied to share critical information and mobilise the supports necessary to ensure the evolving needs for palliative and end-of-life care are responded to. One such way this active sharing is occurring is through new and established online networks and social media. In this current context, the authors briefly revisit the concept of virtual communities of practice in PC and overview some of the online resources and strategies shared during the COVID-19 pandemic to date. **Full text (click on pdf icon):** <https://bit.ly/2YqtEH3>

## Palliative care in the U.S.

### Hospital characteristics associated with palliative care program prevalence

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 April 2020 – This study analyzes the availability of palliative care (PC) in U.S. hospitals and examines the variation by hospital characteristics, community-level socioeconomic demographics, healthcare markets, and geographic characteristics. Seventy-two percent of hospitals with 50 or more beds had PC programs. Hospital and geographic characteristics were significantly associated with the presence of PC. Most notably, non-profit hospitals were 24.5% points more likely than for-profit hospitals to have PC, and metropolitan areas were 15.4% points more likely than rural areas, controlling for other variables. The availability of PC in U.S. hospitals is determined by where patients live and the type of hospital to which they are admitted. **Abstract:** <https://bit.ly/3aRIINO>

Noted in Media Watch 30 September 2019 (#633, p.3):

- CENTRE TO ADVANCE PALLIATIVE CARE & NATIONAL PALLIATIVE CARE RESEARCH CENTRE | Online – 26 September 2019 – ‘**America’s Care of Serious Illness: 2019 State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals.**’ The new report demonstrates that access to palliative care (PC) continues to remain variable and depends more upon accidents of geography, whether a hospital is for-profit or non-profit, and hospital size than it does upon the needs of patients living with a serious illness, and their families. The U.S. shows continued growth in the overall number of hospital PC teams: 72% of U.S. hospitals with fifty or more beds report a PC team. This is up from 67% in 2015, 53% in 2008, and 7% in 2001. **Download/view at:** <http://bit.ly/2lrJOWl>

## 50 years ago in the *Journal of Pediatrics*

### Residents still struggle when children die

*JOURNAL OF PEDIATRICS*, 2020;220(5):138. Schowalter illustrates the complexities and personal struggles that resident physicians navigate in caring for dying pediatric patients.<sup>1</sup> He describes a trajectory, from the “period of impact” (disclosure and potentially volatile responses), through the “period of battle” (curative treatment fails), to the “period of defeat” (terminal phase and death). Although advancements in medical knowledge, education, and technology necessitate an evolution of these constructed periods and reframing of success and failure, pediatric residents continue to struggle when faced with life lost. Medical education has made strides in addressing the consequences of caring for dying patients, with curricula that highlight self-care and burnout. In addition, a transition away from paternalism toward a family-centered care model in conjunction with the growth of pediatric palliative care and clinical ethics has ushered in the concept of a “good death.” This reinforces that a child dying need not be considered the “indisputable failure” Schowalter suggests. When cure is no longer possible, success should be defined as responsible use and withdrawal of potentially inappropriate treatment, minimizing suffering, and providing a supportive presence. Ultimately the death of a child, whether sudden or after prolonged illness, invokes a flurry of emotional, psychological, and physical responses in residents. Inevitably, these traumatic events will occur, and each resident physician will cope and process the experiences uniquely. Considering the epidemic of physician suicide, it is imperative that we continue to improve upon current education and available resources to support trainees when children die. **Full text:** <https://bit.ly/2S6TDNc>

1. ‘Death and the pediatric house officer,’ *Journal of Pediatrics*, 1970;76(5):706-710. **Abstract (w. link to references):** <https://bit.ly/3blj8fM>

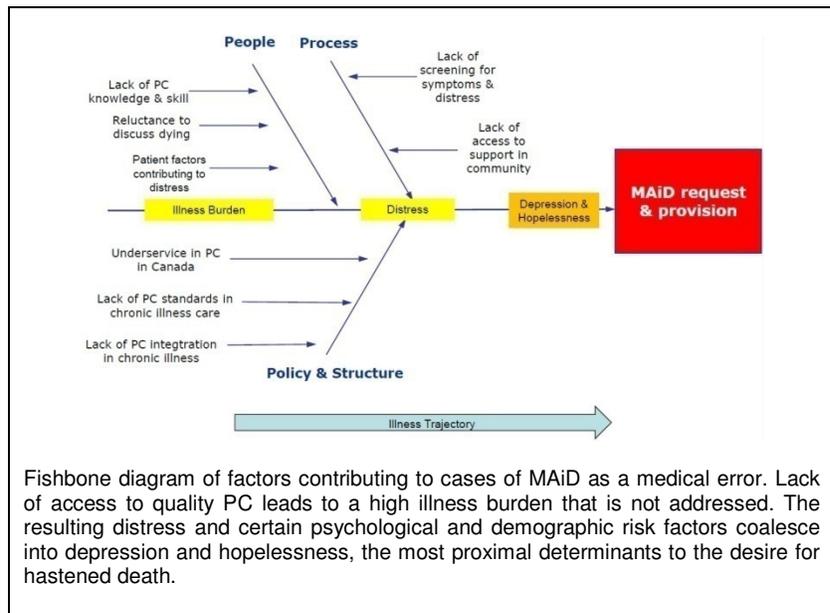
#### Related:

- *JOURNAL OF PEDIATRICS*, 2020;220(5):48. ‘**Shifting attitudes toward the disclosure of serious illness.**’ Arguments for disclosure include: 1) Children already know they are seriously ill or dying; and, 2) Lying is difficult and children may learn their diagnosis in an unintentional and non-supportive way that causes great distress; whereas an honest and safe communication environment provides needed support. Disclosure is tempered by cultural and familial values, although there is broad consensus that if asked directly children should not be lied to regardless of parental preferences. The position to disclose only to children who directly ask, however, is less accepted. Children’s silence may not mean they do not want to know, but rather, they do not feel it is safe to ask. **Full text:** <https://bit.ly/2yON8rq>

## Hastened death due to disease burden and distress that has not received timely, quality palliative care is a medical error

*MEDICAL HYPOTHESES*, 2020;142:109727. Measuring the quality of palliative care (PC) has many challenges due to its presence across multiple health sectors, variable skill and experience of providers and lack of defined processes for providing services. In Canada there is screening for symptoms and distress in most cancer centers, but not in non-cancer diseases. Screening for distress and disease burden can identify suffering, that when properly addressed, improves quality of life (QoL) and reduces depression and hopelessness that can lead to requests for hastened death. The authors' hypothesis is that some requests for hastened death (known as Medical Assistance in Dying or MAiD in Canada) are driven by lack of access to PC or lack of quality in the PC attempting to address disease burden and distress such that the resulting provision of hastened death is a medical error. The root cause of the error is in the lack of quality PC in the previous weeks, months and years of the disease trajectory – a known therapy that the system fails

to provide. The evidence for PC addressing symptoms and improving QoL and mood as well as providing caregiver support is established. Early evidence supporting the use of psycho-therapeutics in emotional and existential distress is also considered. The authors present three cases of request for assisted death that could be considered medical error. The paper references preliminary evidence from a review of previous access to PC in a limited number of MAiD cases showing that only a minority were identified as having PC needs prior to the admission where MAiD was provided. The evidence linking disease burden to hopelessness, depression and hastened death is provided. The many studies revealing the inequity or under-servicing of the Canadian population with regards to PC are reviewed. The authors examine a recent framework for PC in Canada and point out the need for more aggressive use of standards, process and policies to ensure that Canadians are receiving quality PC and that it is equitably accessible to all.<sup>1</sup> **Full text:** <https://bit.ly/2YdajXr>



1. 'Framework on Palliative Care in Canada,' Health Canada, 2018. [Noted in 10 December 2018 issue of Media Watch (#593, p.1)] **Download/view at:** <http://bit.ly/2AVEghF>

Noted in Media Watch 24 September 2018 (#582, p.1):

- CANADA | *The Globe & Mail* – 19 September 2018 – '**Almost all Canadians would benefit from palliative care. Only one in seven can actually access it at end-of-life.**' An estimated 89% of Canadians could benefit from palliative care (PC) in the last year of life. But only 15% are actually getting it. That's a pretty damning commentary on the state of end-of-life care in this country, and it only tells part of the story. New data reveals that even those who get PC tend to get it late, and that far too many dying patients are shuffled around mercilessly between home, hospitals and nursing homes in their final days.<sup>1</sup> In short, the report confirms what far too many people who have accompanied a loved one in their final days know – that Canada is not a very good place to die. <https://tgam.ca/2kpqzTv>

Cont.

1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, Ottawa, Ontario, September 2018. [Noted in 24 September 2018 issue of Media Watch (#582, p.1)] **Download/view at:** <http://bit.ly/2MqmCYO>

### **Evaluating a palliative care education programme for domiciliary care workers**

*NURSING OLDER PEOPLE* | Online – 29 April 2020 – Many domiciliary care (DC) workers have reported low confidence and isolation when delivering end-of-life care (EoLC) in patients' homes. Project Extension for Community Healthcare Outcomes (ECHO) is an initiative that has demonstrated success in increasing confidence and knowledge of EoLC in U.K. nursing home and community hospice workers, but it has not been evaluated with DC workers. This study tested the acceptability of Project ECHO to DC workers as a means of increasing their knowledge of, and confidence in, delivering palliative care (PC), and its effectiveness in reducing their isolation by developing a community of practice. PC education for DC staff using ECHO methodology was well received, relevant and accessible, and may have the potential to improve self-assessed knowledge and confidence. However, finding an ideal time for as many staff to attend as possible may be challenging. **Abstract:** <https://bit.ly/2yUWnGM>

### **Caregiving at the margins: An ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end of life**

*PALLIATIVE MEDICINE* | Online – 27 April 2020 – Emerging research has begun to suggest strategies for enhancing access to palliative care (PC) for structurally vulnerable populations by meeting them "where they are at," not only geographically in shelters, on the streets, and in housing units that may be traditionally deemed "unsafe" by the formal healthcare sector, but also socially, to ensure they feel safe and are surrounded by care providers capable of providing them with comfort. Considering this, family caregivers (FCGs) have the potential to play a pivotal role, yet they must first be recognized as valuable members of the care team. Engaging with FCGs of the structurally vulnerable emerged as a missing and necessary PC practice, confirming the need to re-evaluate PC models and acknowledge issues of trust to create culturally relevant approaches for successful interventions. What is meant by "family" in the context of structurally vulnerability needs to be further examined to describe more fully who these caregivers are. Further research is also needed to better understand the varying complexities of how this population is cared for at the end of life and what tools may be utilized to better support FCGs of structurally vulnerable populations. **Full text:** <https://bit.ly/3eS7uRg>

### **A qualitative study of nurses' perspective about the impact of end-of-life communication on the goal of end-of-life care in nursing home**

*SCANDINAVIAN JOURNAL OF CARING SCIENCES* | Online – 28 April 2020 – With a growing nursing home population suffering from chronic progressive illnesses and evolving patterns of comorbidities, end-of-life (EoL) communication takes on a critical role to enable healthcare professionals to gather information about the resident's wishes for care at the EoL and organise the care plan accordingly. This study provides insight into the nursing perspective of EoL communication between healthcare professionals and bereaved family carers of nursing home residents. Twelve themes described how EoL communication may contribute to adjust the care plan in nursing home according to the nurses' perspective. Five antecedents (i.e., life crisis or transitions, patient-centered environment, arising the question of possible dying, quality of relationships and culture of care) influenced the establishment and quality of communication, and five attributes depicted the characteristics and potential mechanisms of EoL communication (i.e., healthcare professional-resident and healthcare professional-family carers communication, knowledge of family carers' preferences, knowledge of residents' preferences, family carers and residents understanding, and shared decision-making), while curative-oriented and palliative-oriented care goals emerged as consequences. **Abstract:** <https://bit.ly/3f0NWdF>

**N.B.** Additional articles on EoL and palliative care in long-term care facilities, nursing homes and residential care noted in 27 April 2020 issue of Media Watch (#663, p.8).

## Media Watch: Editorial Practice

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

## Distribution

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

## Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

## Something Missed or Overlooked?

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

## Media Watch: Access on Online

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3a0zlpf>

[Scroll down to 'Media Watch: COVID-19']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU> ]

### **Australia**

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

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

### **Canada**



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

[Scroll down to 'Are you aware of Media Watch?']

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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**

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

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