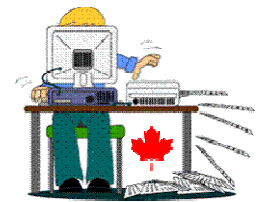


## Media Watch...

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

***We all think there's this massive workforce of nurses and social workers to provide care, but the reality is there isn't. There's the hospice workforce, and there's the home-health workforce, and that's who is around. This is really going to strain serious illness and hospice resources out in the community.***

'Hospice: Demanded but threatened by COVID-19' (p.4), in *Forbes*.

## Canada

### **Coronavirus triage protocols: Hard choices over ventilator shortages shouldn't put doctors at legal risk**

*THE CONVERSATION* | Online – 13 April 2020 – Across Canada, the Coronavirus pandemic is increasing the demand for already scarce critical care resources. In the coming weeks, there is a very real chance that there won't be enough ventilators and critical care beds for everyone who needs them. Difficult decisions will have to be made about who gets what. Sick individuals who might survive if put on a ventilator may be denied access to one, or even removed from one they were already on, in order to save someone else. In anticipation of this, provincial and territorial governments now face the challenge of authorizing triage protocols: documents that spell out the nature and process of allocation decisions. The normal rules for allocating resources just don't work during a pandemic. When critical care units can no longer admit everyone who wants and might benefit from critical care, new rules must be set. Who lives and who dies? Who decides? The best case scenario is that these protocols will not need to be introduced, and it will be possible to meet all clinical needs through mobilization, management and sharing of resources. However, given the uncer-

tainty about the future spread of the virus, we should hope for the best but prepare for the worst. Which means provincial and territorial governments should prepare critical care triage protocols... <https://bit.ly/2yaac3V>

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

'**Pandemic palliative care: Beyond ventilators and saving lives**' (p.10), in *Canadian Medical Association Journal*.

'**Palliative care clinical rotations among undergraduate and postgraduate medical trainees in Canada: A descriptive study**' (p.14), in *CMAJ Open*.

'**Canadian physicians working hard to protect homeless from worst of COVID-19**' (p.12), in *The Medical Post*.

Cont.

Noted in Media Watch 13 April 2020 (#661, p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 April 2020 – ‘**Rapid de-escalation and triaging patients in community-based palliative care.**’ The following are recommendations by the Palo Alto Medical Foundation Palliative Care & Support Services team to help triage and coordinate for timely, safe, and effective palliative care in the community and outpatient setting during the ongoing COVID-19 pandemic. Patients are initially triaged based on location followed by acuity. Interdisciplinary care is implemented using strict infection control guidelines in the setting of limited personal protective equipment resources. Thorough screening for COVID-19 symptoms is implemented at multiple levels before a patient is seen by a designated provider. **Full text:** <https://bit.ly/2RlFoUs>

Noted in Media Watch 23 September 2019 (#632, p.6):

- AUSTRALIA (Victoria) | *Health & Wellbeing* (University of Melbourne) – 16 September 2019 – ‘**Triaging the terminally ill.**’ The Responding to Urgency of Need in Palliative Care (RUN-PC) Triage Tool is expected to change practice internationally.<sup>1</sup> Demand for specialist palliative care (PC) is increasing because of our ageing population, but there are other factors. Earlier integration of PC in cancer care, enhanced involvement of PC in non-cancer diseases and increased community awareness and acceptance of PC are helping to drive demand. So, with a growing workload both in terms of the volume of referred patients and the diversity of those patients’ needs, PC clinicians are facing difficult decisions on a daily basis as to how to allocate their clinical resources. **Full text:** <http://bit.ly/2mdEiNH>

1. ‘Development of the Responding to Urgency of Need in Palliative Care (RUN-PC) triage tool,’ *Journal of Pain & Symptom Management*, published online 14 August 2019. [Noted in 19 August 2019 issue of Media Watch (#627, p.11)] **Abstract (w. link to references):** <http://bit.ly/33HpwAm>

## The Coronavirus palliative care crisis

*MACLEAN’S MAGAZINE* | Online – 13 April 2020 – In some jurisdictions, hospices and long-term medical facilities have, for understandable reasons, closed their doors to COVID-19 patients. Too many Canadians die in acute care hospitals as it is. But that will be the reality for many people in this pandemic. Many others will die in places not well-equipped to address either the medical, emotional, psychological and spiritual needs of the dying and those close to them. Some people will die in nursing homes... Others will die in prison. And many will die in their own homes at a time when palliative home care is already overstretched and the personal protective equipment we are hearing so much about is being rationed mainly to help those on the front-line in acute care hospitals. To be direct: dying of COVID-19 without the support of good palliative care (PC) means a desperate gasping for air – an anguishing end. The disease principally attacks the airways and the lungs, meaning patients are left to suffocate, while agitated and

delirious. Even at the best of times, Canada’s PC system is under-resourced. In this crisis there are particular challenges facing compassionate care at the end of life. One of the most distressing aspects of this disease is that it separates the dying from their loved ones. That makes it even more important that healthcare workers at the bedside of patients understand their medical – as well as their human – responsibilities. <https://bit.ly/2RB73AY>

### [Specialist Publications](#)

‘**Medical assistance in dying: Patients’, families’ and healthcare providers’ perspectives on access and care delivery**’ (p.16), in *Journal of Palliative Medicine*.

‘**Paediatric euthanasia in Canada: New challenges for end-of-life care**’ (p.16), in *Paediatrics & Child Health*.



Media Watch: Access Online

Updated 04.13.2020

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.18.

## U.S.A.

### Hospices encounter barriers to safe opioid disposal

*HOSPICE NEWS* | Online – 14 April 2020 – A number of hospices nationwide are hitting barriers to effectively disposing of medications following a patient's death while remaining in compliance with current law and regulation, according to a report ... by the U.S. Government Accountability Office.<sup>1</sup> Proper disposal of medications is a critical factor to preventing drug diversion. Drug diversion – the transfer of a prescription medication from a lawful to an unlawful channel of distribution or use – is a prevalent issue throughout the healthcare continuum. Hospice providers and other organizations that

provide care in the home face unique challenges due to the potential easy access to the patients' medications. <https://bit.ly/2wGBuHL>

#### Specialist Publications

**'Generalist palliative care in the California Safety Net: A structured assessment to design interventions for a range of care settings'** (p.7), in *American Journal of Hospice & Palliative Medicine*.

1. 'Preventing Drug Diversion: Disposal of Controlled Substances in Home Hospice Settings,' U.S. Government Accountability Office, April 2020. **Download/view at:** <https://bit.ly/2yIQ5av>

Noted in Media Watch 17 February 2020 (#653, p.10):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2020;323(6):566-568. **'Estimates of medication diversion in hospice.'** Given the challenges of symptom management during hospice care, patients require responsive opioid prescribing. Within the context of the national opioid crisis, medication diversion in hospice is an increasing concern. The authors conducted a national survey of hospices (June-September 2018). Using 2015 data on U.S. hospices, they randomly selected 600 agencies, proportionately stratified by state and profit status. The authors surveyed agency representatives by phone or online about practices, policies, and experiences regarding medication diversion. **Abstract:** <http://bit.ly/2uAETxu>

**N.B.** Additional articles on medication diversion in hospices noted in 13 January 2020 issue of Media Watch (#648, p.5).

### How COVID-19 is straining hospice care

*PUBLIC BROADCASTING SERVICE* | Online – 13 April 2020 – Comfort, touch, togetherness: these are among the key elements of hospice care – the kind of care offered at the end of one's life. These same principles are also in direct opposition to the distance and separation asked of us during a pandemic. Yet hospice, available to those with a life expectancy of six months or fewer, remains an essential branch of medical care. Nearly 2,000 Americans die every day due to the Coronavirus, which has just become the number one leading cause of death in 2020. Some terminal patients will receive hospice care. Others will die too quickly for it. Millions of Americans were already on hospice care long before the Coronavirus – mostly in-home, since that's where hospice predominantly takes

place – and many more will enter hospice for reasons unrelated to COVID-19. The hospice care tradition is to rally loving visitors around a dying patient, focusing care on pain management, comfort and peace at the end of life. Hospice is meant to address not only physical care, but also the substantial emotional, social and spiritual needs that arise as death approaches. <https://to.pbs.org/2xkILo0>

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

**'Grief during the COVID-19 pandemic: Considerations for palliative care providers'** (p.11), in *Journal of Pain & Symptom Management*.

Cont.

## Related:

- *HOSPICE NEWS* | Online – 16 April 2020 – ‘**Hospices adopt new strategies to support end-of-life decisions.**’ National Health Care Decisions Day takes on a new significance this year as COVID-19 sweeps ... across the country. With demand for hospice and palliative care services on the rise amid the pandemic, providers are adopting new strategies to highlight the benefits of advance care planning for patients and families. Recently updated data from the U.S. Centers for Disease Control & Prevention reported nearly 25,000 deaths and more than 605,000 confirmed cases throughout the nation. The pandemic has not only increased the volume of patients in need of hospice and palliative services, but also impacted how they are receiving care in their final days. <https://bit.ly/2XJ3EE7>
- *HOSPICE NEWS* | Online – 15 April 2020 – ‘**Hospices hurting from diminished fundraising, philanthropy.**’ Hospices often rely on philanthropic donations and fundraisers to support their programs, but many are taking a financial hit from fallout of the Coronavirus pandemic. Despite federal funding relief efforts, strained donors, increased costs and cancelled fundraising events are impacting hospice bottom lines. Providers are working to address these issues by adapting their methods and outreach efforts. Many are revising their traditional fundraising strategies amid climbing unemployment rates and other economic stressors. Hospices around the country are struggling to balance their budgets while working to prevent the spread of COVID-19. <https://bit.ly/2KaMh6Y>
- *HOSPICE NEWS* | Online – 13 April 2020 – ‘**Facing ethical decisions during the COVID-19 pandemic.**’ The COVID-19 pandemic has brought on a number of unprecedented ethical questions as hospice and palliative care (PC) leaders work to continue providing crucial services to their most vulnerable patients, including the need to limit contact between staff and patients, drawing a line between safety and the traditional hospice care model. Honoring end-of-life goals while caring for patient and family needs can be a delicate balance for hospice and PC providers. Among the most significant of these barriers for hospice and PC leaders is easing staff anxieties and fears as they come into direct contact with patients, especially those with known exposure to COVID-19. <https://bit.ly/3ceKycT>
- *TIME* | Online – 13 April 2020 – ‘**Coronavirus patients who don’t speak English could end up “unable to communicate in their last moments of life.”**’ At the University of Louisville hospital dozens of patients each day need help of an interpreter to understand their medical conditions and make informed choices about their care. Like the estimated 100,000 interpreters who work at hospitals across the country, their services – translating word-for-word between doctor and patient, maintaining patient confidentiality and accounting for cultural nuances – can mean the difference between life or death. It’s a dilemma gripping hospitals across the country that, in order to receive federal assistance, must make their services available to the 65 million Americans who speak limited English. <https://bit.ly/34FuVJ4>
- OHIO | Fox 4 News (Cleveland) – 12 April 2020 – ‘**A plan to save Coronavirus patients from dying at home.**’ A team of researchers at University Hospitals is running a small pilot program designed to help save the lives of Coronavirus patients who run into trouble while battling the virus at home. Patients who come into the emergency department but aren’t sick enough to be admitted to the hospital are sent home with a sensor to wear on their finger. The sensor measures oxygen levels in their blood and sends signals to a wrist monitor that looks like a watch, which then sends signals to their cell phone. That data is then goes to a central monitoring station where doctors and nurses can monitor the patient’s condition minute by minute. <https://bit.ly/2Rz8YpC>
- *FORBES* | Online – 10 April 2020 – ‘**Hospice: Demanded but threatened by COVID-19.**’ Comfort, touch, togetherness: these are among the key elements of hospice care... These same principles are also in direct opposition to the distance and separation asked of us during a pandemic. Yet hospice, available to those with a life expectancy of six months or fewer, remains an essential branch of medical care. Nearly 2,000 Americans die every day due to the Coronavirus, which has just become the number one leading cause of death in 2020. Some terminal patients will receive hospice care. Others will die too quickly for it. Millions of Americans were already on hospice care long before the Coronavirus ... and many more will enter hospice for reasons unrelated to COVID-19. <https://bit.ly/2Xs6FI1>



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## International

### **Families expected to provide palliative care during Coronavirus crisis – National Health Service**

U.K. (England) | *The Guardian* (London) – 18 April 2020 – Families will be expected to provide end-of-life (EoL) care to relatives dying at home during the crisis, according to National Health Service England guidelines that have raised safeguarding concerns among experts.<sup>1</sup> According to the new standard operating procedure for community health services, families will be asked if they can provide care that until now has been provided by GPs, community services and specialist palliative care (PC) teams. “During the Coronavirus pandemic, there will be more people dying of Coronavirus at home who will also require care and support at the end of their lives,” says the guidelines. “The anticipated increase in demand and stretch in workforce availability means that there will have to be a greater reliance on family members, unpaid carers and those who are with these patients, to help provide the care,” it adds. “They may have to administer medication more than they are used to.” To help manage the health needs of people at the EoL, specialist PC advice usually available only to GPs will be made accessible to those caring for loved ones dying at home. Additional information to support family carers is being developed, the guidance says. In the mean-

time, it provide links to two documents, including a toolkit, which give step-by-step instructions to help those caring for someone dying at home. <https://bit.ly/2ynw7EH>

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

**‘Allocation of scarce resources during the COVID-19 pandemic: A Jewish ethical perspective’** (p.10), in *Journal of Medical Ethics*.

#### **Specialist Publications**

**‘Collaborative data familiarisation and quality assessment: Reflections from use of a national dataset to investigate palliative care for Indigenous Australians’** (p.11), in *Health Information Management Journal*.

**‘Fully integrated oncology and palliative care services at a local hospital in Mid-Norway: Development and operation of an innovative care delivery model’** (p.9), in *Pain & Therapy*.

1. ‘Novel Coronavirus (COVID-19) standard operating procedure: Community health services,’ National Health Service England, April 2020. **Download/view at:** <https://bit.ly/2KkQq8l>

### **Call for palliative care to be adapted for severely ill COVID-19 patients**

U.K. (England) | About Manchester – 17 April 2020 – Emergency-style palliative care (PC) needs to be implemented to meet the needs of COVID-19 patients who wouldn’t benefit from a ventilator say researchers. This is the first time that PC has been examined in the light of the current global pandemic. The researchers describe the challenges of providing PC where resources are stretched and demand is high, based on their experiences at a hospital in Switzerland close to the Italian border where there are high rates of the illness. Professor Nancy Preston, Co-Director of Lancaster University’s International Observatory on End-of-Life Care said: “Many patients are too unwell to benefit from ventilation but still need their symptoms managing.” In a paper published in the *Journal of Pain & Symptom Management*,<sup>1</sup> the researchers explained how PC needs to adapt to an emergency style in order to help make the best decisions and support families. Professor Preston said: “These people require a conservative approach to their treatment, one which provides maximum support for their physical, emotional and spiritual needs – this is where a recognition that PC is required is crucial.” The team based their recommendation on caring for severely ill patients with COVID-19 in the Swiss hospital where treatment plans have changed dramatically. <https://bit.ly/2xqMsZi>

1. ‘Conservative management of COVID-19 patients – emergency palliative care in action,’ *Journal of Pain & Symptom Management*, published online 7 April 2020. [Noted in 13 April 2020 issue of *Media Watch* (#661, p.8)] **Full text:** <https://bit.ly/3e5tRCn>



## National bereavement charter launched to make Scotland “confident in talking about death, dying and bereavement”

U.K. (Scotland) | *Holyrood* – 15 April 2020 – A national bereavement charter has been launched by a coalition of organisations, with the goal of making Scottish society “more effective at supporting people to grieve.”<sup>1</sup> Good bereavement care is a human right, it says, and the right support “renews and restores, [gives] a sense of purpose and direction, and for many it is what has literally saved their lives.” The charter contains 15 statements that describe what bereavement support should be like across areas of life including the home, workplace and wider community. People should be “treated with compassion, empathy and kindness” and should have their “wishes, choices and beliefs listened to, considered and respected by all,” it says. It describes Scotland as a country where there should be an “open culture” around grief, bereavement and death, where access to emotional, practical, financial, social and spiritual support is seen as a right. <https://bit.ly/3cgllgU>

1. ‘A Bereavement Charter for Children and Adults in Scotland,’ Scottish Care, April 2020. **Download/view at:** <https://bit.ly/2xwvEjt>

## Shelter from the storm: Might the pandemic be a lifeline for the rich world’s homeless?

U.K. | *The Economist* – 12 April 2020 – The advice governments around the world are giving their people has a monotonous consistency: stay at home; shelter in place; maintain social distance; go out only for essential purposes. None of that is much use for people who spend their nights either sleeping rough or in a homeless shelter. To take an extreme example: in a number of cities in France, charities claim, people have been fined for not staying in homes they do not have. And government efforts to help people through the crisis often require fixed abodes. Yet charities working at improving the lot of the homeless have seen the pandemic as, perversely, offering a glimmer of hope – it does at least highlight the urgency of easing their plight. For two reasons, the homeless are especially vulnerable to contracting the COVID-19 virus and hence to transmitting it. The first is to do with their physical state. They are more likely to suffer from underlying health conditions. According to a paper in *The Lancet Public Health* ... homeless people in America and Canada aged younger than 65 years are five to times likelier to die, of any cause, than the general population of the same age.<sup>1</sup> In England, where a survey one

night last autumn found 4,300 people sleeping rough, Pathway, a healthcare charity for the homeless, estimates they are 2.5 times as likely to have asthma as the general population, and 34 times likelier to have tuberculosis, conditions that often make COVID-19 fatal. Homeless men in England have a life expectancy of 44, half the national average. But in many countries, the homeless tend to be older than society as a whole. <https://econ.st/2XAkF35>

### Specialist Publications

‘Life’s hard and then you die: The end-of-life priorities of people experiencing homelessness in the U.K.’ (p.12), in *International Journal of Palliative Nursing*.

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

‘Canadian physicians working hard to protect homeless from worst of COVID-19’ (p.12), in *The Medical Post*.

1. ‘COVID-19: A potential public health problem for homeless populations,’ *The Lancet Public Health*, 2020;5(4):PE186-187. **Full text:** <https://bit.ly/34vuHE6>



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

## COVID-19: National Health Service “score” tool to decide which patients receive critical care

U.K. | *The Financial Times* – 12 April 2020 – Doctors coping with the coming peak of the Coronavirus outbreak will have to “score” thousands of patients to decide who is suitable for intensive care treatment using a COVID-19 decision tool developed by the National Health Service.<sup>1</sup> With about 5,000 Coronavirus cases presenting every day and some intensive care wards already approaching capacity, doctors will score patients on three metrics – their age, frailty and underlying conditions – according to a chart circulated to clinicians. Patients with a combined score of more than eight points across the three categories should probably not be admitted to intensive care, according to the ... although clinical discretion could override that decision. The scale of the pandemic and the speed at which COVID-19 can affect patients, has forced community care workers, GPs and palliative carers to accelerate difficult conversations about death and end-of-life planning among vulnerable groups. <https://on.ft.com/3b1tBSY>

1. ‘COVID-19 rapid guideline: Critical care in adults,’ National Institute for Health & Care Excellence. Download/view at: <https://bit.ly/2ycCJpa>

## Specialist Publications

### **Generalist palliative care in the California Safety Net: A structured assessment to design interventions for a range of care settings**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 April 2020 – Adviser pairs – one from palliative care (PC) and one from a partner service line – from 10 California public healthcare systems conducted assessments at their sites. A steering committee provided educational webinars, best practices, and assessment tools. Partner service lines were primary care, surgery, emergency department, and radiation oncology. Selected gaps were advance care planning and goals-of-care communication, identifying patients with serious illness, and pain management. All sites designed multiple interventions to address gaps, based on factors that predispose, enable, and reinforce a target audience to perform a target behavior.

Advisers reported that the program strengthened relationships between PC and the partner service line. This structured assessment helped busy clinicians develop theory-based generalist PC interventions. **Abstract (w. list of references):** <https://bit.ly/2K7jxvL>

#### Publishing Matters

‘The International Committee of Medical Journal Editors (ICMJE) recommendations: Challenges in fortifying publishing integrity’ (p.17), in *Irish Journal of Medical Science*.

### **The need for a serious illness digital ecosystem (SIDE) to improve outcomes for patients receiving palliative and hospice care**

*AMERICAN JOURNAL OF MANAGED CARE*, 2020;26(4):SP124-SP126. Due to the national shift [in the U.s.] toward value-based payment models, health systems and payers share a heightened awareness of the need to incorporate palliative and hospice services (P&HC) into their service mix for seriously ill patient populations. During the last decade, a tremendous amount of capital has been invested to better integrate information technology into healthcare. This includes development of technologies to promote utilization of P&HC. However, no coordinated strategy exists to link such efforts together to create a cohesive strategy that transitions from identification of patients through receipt of services. SIDE is the intentional aggregation of disparate digital and mobile health technologies into a single system that connects all of the actors involved in serious illness patient care. A SIDE leverages deployed health technologies across disease continuums and geographic locations of care to facilitate the flow of information among patients, providers, health systems, and payers. Five pillars constitute a SIDE, and each one is critical to the success of the system: 1) Identification; 2) Education; 3) Engagement; 4) Service Delivery; and, 5) Remote Monitoring. **Full text:** <https://bit.ly/2K9w5Dc>

## Development and psychometric evaluation of a new tool for measuring the attitudes of patients with progressive neurological diseases to ethical aspects of end-of-life care

*BMC MEDICAL ETHICS* | Online – 15 April 2020 – In recent decades, research into end-of-life (EoL) care of patients with progressive neurological disease (PND) has flourished. However, in a review of the literature, no evaluation scales identifying views of PND patients on EoL issues were found. For this reason, the authors developed a tool in order to evaluate attitudes towards ethical aspects of EoL care for patients with PND, and their family members. The main finding of this study was to demonstrate the adequate psychometric characteristics of the Attitudes of Patients with PND to End-of-Life Care questionnaire in the population of patients with PNDs, and their family members. Determining opinions on ethical issues to EoL care can help physicians, patients, and family members to develop individual care plans. Due to frequent cognitive, emotional and behavioral disorders in patients with PND, it is advisable to establish these views in the first stages of the disease. **Full text:** <https://bit.ly/2xzFqkX>

### Related:

- *PALLIATIVE MEDICINE* | Online – 14 April 2020 – ‘**The experiences of, and need for, palliative care for people with motor neurone disease and their informal caregivers: A qualitative systematic review.**’ Despite being a terminal neurodegenerative disease, the role of palliative care (PC) is less recognised for motor neurone disease (MND) than for other life-limiting conditions. This review identified a considerable literature exploring the care needs of people with MND and their carers; however, descriptions of PC were associated with the last days of life. Across the disease trajectory, clear points were identified where PC input could enhance patient and carer experience of the disease, particularly at times of significant physical change. **Abstract (w. list of references):** <https://bit.ly/3ckntFB>

**N.B.** Additional articles on PC for patients living with motor neurone disease noted in 17 February 2020 issue of Media Watch (#653, p.16).

## The family talk intervention for families when a parent is cared for in palliative care: Potential effects from minor children’s perspectives

*BMC PALLIATIVE CARE* | Online – 16 April 2020 – To the authors’ knowledge, this is the first study reporting the potential effects of family talk intervention (FTI) with minor children who have a parent with a life-threatening illness, one being cared for in specialized palliative home care. After participating in FTI, the children reported increased knowledge about their parent’s illness and the younger children felt that it became easier to talk to their parents. However, most of the children reported no change in their communication with siblings. Through their participation in FTI, children received help from the interventionists with situations at school and to establish professional counselling. Furthermore, FTI facilitated the beginning of communication between children and their families, helped them to prepare for future illness-related situations, other future events, and to maintain everyday life and minimize conflicts. All of this was appreciated by the children and described as strengthening and helpful. The interviews revealed that learning more about the parent’s illness gave children better control over and a greater understanding of the situation, which they described as a relief. **Full text:** <https://bit.ly/2z1jD5T>

**N.B.** See ‘Parental Illness, Dying and Death’ (pp.13-17), ‘Crossroads of Grief Project: Grieving or Bereaved Children: Literature Review 2015-2018,’ Children & Youth Grief Network, Ontario, Canada, December 2018. **Download/view at:** <http://bit.ly/2OB4Y6C>



### Resources relevant to Palliative Care and COVID-19

The International Association for Hospice & Palliative Care has compiled a list of resources relevant to palliative care and COVID-19 published by academia, civil society organizations, member states and special agencies of the United Nations, with links to all of the websites and documents listed. <https://bit.ly/2QQ1q1t>



## **The desire to die in palliative care: A sequential mixed methods study to develop a semi-structured clinical approach**

*BMC PALLIATIVE CARE* | Online – 15 April 2020 – As health professionals are frequently confronted with desire to die, a semi-standardized communication guide for dealing with desire to die has great potential for clinical practice. The fact that more practitioners participated in the Delphi survey than originally planned shows their great interest in the topic and its particular relevance in palliative care. The semi-structured clinical approach thus became a tool tailored directly towards everyday practice of people working in the field. This can include all professions directly in contact with palliative patients provided they have partaken in the mandatory training course: physicians, nurses, psychologists, social and spiritual care workers as well as volunteers. The authors expect the semi-structured clinical approach in conjunction with their training program to foster multi-professional competencies across all healthcare structures, especially on dealing with desire to die in patients with serious health-related suffering due to severe illness. The major achievement of this study is the creation of the first consensus-based semi-standardized approach for (proactively) assessing and optimally responding towards desire to die based on literature review, patient interviews and expert consent. **Full text:** <https://bit.ly/3ekOyKG>

**N.B.** Additional articles on patient desire to die noted in 13 April 2020 issue of Media Watch (#661, p.10).

## **Palliative care utilization in oncology and hemato-oncology: A systematic review of cognitive barriers and facilitators from the perspective of healthcare professionals, adult patients, and their families**

*BMC PALLIATIVE CARE* | Online – 13 April 2020 – This study systematically reviewed current literature on using palliative care (PC) in oncology and hemato-oncology. The focus was on cognitive barriers and facilitators influencing the use of PC services from the perspectives of health professionals (HPs), adult patients with cancer, and their families. Literature on this topic is very heterogeneous in objectives and focus, mainly addressing PC use, PC provision, and PC service referral. Findings show that barriers and facilitators can be summarized in four areas: 1) Awareness of PC; 2) Collaboration and communication in PC-related settings; 3) Attitudes and beliefs towards PC; and, 4) Emotions involved in disease pathways. Overall, the studies revealed that lacking awareness of PC, having incorrect beliefs, negative attitudes and negative emotions towards PC among HPs or patients and families, as well as lack of collaboration and communication skills among HPs, poor communication and consensus on PC between HPs and PC team, and lack of open communication between HPs and patients and families represented the most common barriers to providing, asking for PC consultations or referring to, and consequently using PC services. In addition, it should be noted that specific barriers in hemato-oncology include HPs' lack of trust re-

garding the appropriateness of PC services for hemato-oncology patients, and lower comfort levels towards PC referrals compared to oncologists. Enhancing HPs' education about and clinical experience of PC as well as patients and families' education could facilitate PC utilization. **Full text:** <https://bit.ly/2xk9Jw0>

### **Fully integrated oncology and palliative care services at a local hospital in Mid-Norway: Development and operation of an innovative care delivery model**

*PAIN & THERAPY* | Online – 9 April 2020 – The authors describe the development and operation of an innovative, fully early integrated one-stop oncology and palliative care (PC) outpatient clinic at a local hospital in a rural region of Mid-Norway. In this fully integrated clinic, cancer and PC were provided by one team of healthcare providers. The fully integrated clinic communicated and collaborated closely with its local hospital, its affiliated tertiary hospital and community health and care services to provide timely referral, enhanced continuity, and improved coordination and quality of care. This model of care is particularly relevant to the early integration of cancer and PC in a smaller hospital and the provision of cancer and PC in a rural district. **Full text:** <https://bit.ly/3eiJ4Qz>

Cont.

Noted in Media Watch 30 March 2020 (#659, p.10):

- *MEDICAL JOURNAL OF AUSTRALIA* | Online – 20 March 2020 – ‘**Managing haematology and oncology patients during the COVID-19 pandemic...**’ The authors present interim guidance for clinicians caring for patients with cancer who may be particularly vulnerable to COVID-19 and to the potential impact of the pandemic on the provision of cancer investigations and treatment. Clinicians must regularly review and implement institutional, local, state-wide and federal/national policies, modifying or adapting the suggestions provided here as needed. They propose that oncologists and haematologists advocate for the timely application of public health measures or treatments that might contain, delay or mitigate the spread of COVID-19 disease. **Full text:** <https://bit.ly/2UfG13H>

### **Pandemic palliative care: Beyond ventilators and saving lives**

*CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2020;192(15):E400-E404. The severe acute respiratory syndrome Coronavirus 2 (SARS-CoV-2) pandemic will likely strain our healthcare system beyond capacity, and palliative care (PC) services will be needed across many different care settings, including intensive care units, hospital wards, emergency departments and long-term care. Shared decision-making between clinicians and patients is a core process in planning for the end of life (EoL); however, in a pandemic, patient autonomy to choose life-prolonging measures or location of death could be severely restricted as a result of public health directives and resource availability, and some patients may necessarily be isolated at EoL. Previous mass casualty events have taught us much about how best to triage patients requiring care, and some of this work can be adapted to PC; but little has been written on how to manage those who are not offered life-sustaining measures. The authors advise acting now to stockpile medications and supplies used in PC, train staff to meet PC needs, optimize our space, refine our systems, alleviate the effects of separation, have critical conversations and focus on marginalized populations to ensure that all patients are cared for equitably. The SARS-CoV-2 pandemic has been tragic for many people worldwide. Failing to provide Canadians with effective PC would compound that tragedy. **Full text:** <https://bit.ly/2z2eH0P>

#### **Related:**

- *DEATH STUDIES* | Online – 16 April 2020 – ‘**Coronavirus anxiety scale: A brief mental health screener for COVID-19 related anxiety.**’ The objective of this study was to develop and evaluate the properties of the Coronavirus Anxiety Scale (CAS), which is a brief mental health screener to identify probable cases of dysfunctional anxiety associated with the COVID-19 crisis. This 5-item scale, which was based on 775 adults with anxiety over the Coronavirus, demonstrated solid reliability and validity. Elevated CAS scores were found to be associated with Coronavirus diagnosis, impairment, alcohol/drug coping, negative religious coping, extreme hopelessness, suicidal ideation, as well as attitudes toward President Trump and Chinese products. **Full text:** <https://bit.ly/3cughqF>
- *INTENSIVE & CRITICAL CARE NURSING* | Online – 2 April 2020 – ‘**End-of-life decisions and care in the midst of a global Coronavirus pandemic.**’ During this pandemic, end-of-life decisions, in the face of finite critical care support such as staff, beds and equipment are necessary now more than ever. The reported global mortality is only an estimate, given not all countries ... are testing all those who are symptomatic. The spread and course of the disease has led to critical care services being overrun in many places across the world. Those who present to critical care with COVID-19 are the most severe cases and much more likely to die in critical care, up to 1 in 2 in the U.K. at present, compared with a usual mortality in critical care of 16%... **Full text:** <https://bit.ly/2wLRqil>
- *JOURNAL OF MEDICAL ETHICS* | Online – 10 April 2020 – ‘**Allocation of scarce resources during the COVID-19 pandemic: A Jewish ethical perspective.**’ The novel COVID-19 pandemic has placed medical triage decision-making in the spotlight. As life-saving ventilators become scarce, clinicians are being forced to allocate scarce resources in even the wealthiest countries. Ethical triage decisions are commonly based on the utilitarian approach of maximising total benefits and life expectancy. The authors present triage guidelines from Italy, the U.S. and the U.K. as well as the Jewish ethical perspective on medical triage. There is disagreement between the rabbis whether human discretion has any role in the allocation of scarce resources and triage decision-making. **Full text:** <https://bit.ly/2wBuPWc>

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- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 April 2020 – ‘**Grief during the COVID-19 pandemic: Considerations for palliative care providers.**’ The COVID-19 pandemic is anticipated to continue spreading widely across the globe throughout 2020. To mitigate the devastating impact of COVID-19, social distancing and visitor restrictions in healthcare facilities have been widely implemented. Such policies and practices, along with the direct impact of the spread of COVID-19, complicate issues of grief that are relevant to medical providers. The authors describe the relationship of the COVID-19 pandemic to anticipatory grief, disenfranchised grief, and complicated grief for individuals, families, and their providers. **Full text:** <https://bit.ly/3aalJ06>

### **Palliative care for dementia: 2020 update**

*CLINICS IN GERIATRIC MEDICINE*, 2020;36(2):329-339. With the increase of the elderly population and increasing burden of dementia care, one may consider the need for palliative and hospice services as an urgent public health priority, particularly given that Alzheimer disease is the fifth-leading cause among those age 65 and older [in the U.S.]. This public health need is underscored by the severe burden of emotional distress endured by family caregivers and the potential for relief afforded by appropriate end-of-life (EoL) services in dementia, which have been historically created for the context of cancer care, with less of a focus on dementia, although this has changed considerably in recent years. For example, in 1995, fewer than 1% of hospice patients were observed to have a primary diagnosis of dementia, whereas almost 18% of all hospice enrolments in 2017 were in the context of dementia care. Despite this reassuring rapid increase, there remain challenges in ensuring that patients with dementia are given the chance for the best possible care at the EoL. **First page view (w. link to references):** <https://bit.ly/3edWZYc>

Noted in Media Watch 23 March 2020 (#658, p.3):

- U.S. | *The Washington Post* – 16 March 2020 – ‘**Alzheimer’s affects 5.8 million people 65 and older. In 2050, that number may be close to 14 million.**’ Alzheimer’s disease, the most common dementia among older adults, now affects about 5.8 million U.S. residents 65 and older – 10% of that age group, according to a new report from the Alzheimer’s Association.<sup>1</sup> By 2050, the number of U.S. adults 65 and older with Alzheimer’s is expected to reach 13.8 million, with about half of them 85 or older. The association’s report attributes the growing number of Americans with Alzheimer’s to the projected aging of the U.S. population, with the West and Southeast regions of the country expected to experience the largest increases in the next five years. <https://wapo.st/39ZPD89>

1. ‘2020 Alzheimer’s Disease Facts & Figures,’ Alzheimer’s Association, March 2020. **Download/view at:** <http://bit.ly/33oL84F>

**N.B.** Additional articles on hospice and EoL care for people living with dementia noted in the 9 March 2020 issue of Media Watch (#656, p.12).

### **Collaborative data familiarisation and quality assessment: Reflections from use of a national dataset to investigate palliative care for Indigenous Australians**

*HEALTH INFORMATION MANAGEMENT JOURNAL* | Online – 27 March 2020 – The role of external researchers in data quality assessment remains ill-defined in the context of secondary use for research of large, centrally curated health datasets. In order to investigate equity of palliative care (PC) provided to Indigenous Australian patients, researchers accessed a now-historical version of a national PC dataset developed primarily for the purpose of continuous quality improvement. The dataset comprised 477,518 records of 144,951 patients ... collected from participating specialist PC services during a period (1 January 2010-30 June 2015) in which data-checking systems underwent substantial upgrades. Progressive improvement in completeness of data over the study period was evident. The data were error-free with respect to many credibility and consistency checks, with anomalies detected reported to data managers. As the proportion of missing values remained substantial for some clinical care variables, multiple imputation procedures were used in subsequent analyses. In secondary use of large curated datasets, data quality assessment by external researchers may both influence proposed analytical methods and contribute to improvement of data curation processes through feedback to data managers. **Abstract (w. list of references):** <https://bit.ly/3bc3l8s>

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**N.B.** Additional articles on palliative and end-of-life care for Australia's Indigenous peoples noted in 2 December 2019 issue of Media Watch (#642, p.15). A selection of articles focusing on the critical importance of sensitivity to cultural distinctions and linguistic differences, and respect for beliefs, values and end-of-life practices, are highlighted in the January 2020 issue of the International Association for Hospice & Palliative Care newsletter. **Download/view at (scroll down to 'Media Watch: Indigenous Peoples')**: <http://bit.ly/2sMI2JY>

### **Life's hard and then you die: The end-of-life priorities of people experiencing homelessness in the U.K.**

*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 10 April 2020 – People experiencing homelessness consistently fail to access palliative care (PC) services. They are dying young, with very little dignity and without adequate support. This study ... represents the first attempt to explore the end-of-life (EoL) concerns, fears, preferences and priorities of people experiencing homelessness in the U.K. Findings are presented within eight themes to tell the stories of participants' concerns, fears, preferences and priorities regarding EoL: 1) Spiritual concerns; 2) Practical concerns; 3) Fear of needing care; 4) Fear of being forgotten; 5) Preference for dying suddenly; 6) Preference for being somewhere comfortable where people know me; 7) Prioritising autonomy and self-determination; and, 8) Prioritising authenticity. Discussion of the findings exposed four key messages: 1) The pauper's funeral is a real but previously unreported concern for homeless people in the U.K.; 2) The "face of care" is more important than the "place of care"; 3) Traditional PC services are possibly an unattractive resource for this population so new approaches to care are required; and, 4) A strengths-based, trauma-informed, person-centred, collaborative, "compassionate community" approach to care is recommended. This is where the hostel is established as the hub of a compassionate PC community within a local neighbourhood and where the development of peer support workers, with lived experience of homelessness, is actively encouraged and supported. **Full text:** <https://bit.ly/3caHoqv>

**N.B.** Additional articles on EoL care for the homeless in the U.K. noted in 15 April 2019 issue of Media Watch (#610, p.6).

### **Canadian physicians working hard to protect homeless from worst of COVID-19**

*THE MEDICAL POST* | Online – 11 April 2020 – Healthcare workers and cities across the country are currently executing on plans to protect people who are homeless during the COVID-19 pandemic. But, given the close quarters in which this population lives, and the prevalence of pre-existing conditions, many physicians say a significant outbreak in this community is inevitable and will have an impact on the larger population. In Calgary, Dr. Simon Colgan is a palliative care (PC) doctor and lead physician with the Calgary Allied Mobile Palliative Program, which delivers end-of-life PC to some of Calgary's most vulnerable people. "COVID-19 has just added another layer of difficulty for them. So, I'd say the struggle is widespread and it's really causing havoc with how we deal with the most vulnerable." Dr. Naheed Dosani, a PC physician who provides healthcare to people experiencing homelessness in Toronto, tells the story of a man he met at a regional assessment centre, who was told that he needed to go home and self-isolate. "He said, 'I'd love to self-isolate but I'm homeless. I live in a shelter. But I don't want my friends to get sick, so I'll go live on the street so they don't get sick.' While I was moved by his concern, I was distraught at the inequity associated with that," [added] Dr. Dosani... **Full text:** <https://bit.ly/2XIBKlr>

**N.B.** Selected articles on end-of-life care for the homeless in Canada from past issues of Media Watch noted in December 2019 issue of the International Association for Hospice Palliative Care newsletter (scroll down to 'Media Watch: The Homeless'): <http://bit.ly/2OVQyP3>

## Effects of a telehealth early palliative care intervention for family caregivers of persons with advanced heart failure

*JAMA NETWORK OPEN*, 2020;3(4):202583. In an effort to address national priorities to develop models of support for family caregivers (FCGs) of individuals with serious illness, the authors conducted the largest, most racially diverse randomized clinical trial to date of an intervention to support FCGs of community-dwelling persons with advanced heart failure. The results showed that a nurse-led, early palliative care telehealth intervention did not demonstrate significant differences in quality of life, mood, and burden compared with usual care over sixteen weeks. Pre-specified secondary outcomes including global health and positive aspects of caregiving were also not significantly different at 16 weeks. While the intervention does not demonstrate benefit to these particular outcomes over a 16 week time frame, the results nonetheless reveal essential insights to advancing future intervention testing and to guiding clinical services for heart failure FCGs. **Full text:** <https://bit.ly/2XEsYeu>

## Pediatric concurrent hospice care: A scoping review and directions for future nursing research

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 8 April 2020 – In 2010, forgoing curative therapies were removed as a hospice eligibility criterion for children through section 2302 of the [U.S.] Patient Protection & Affordable Care Act called Concurrent Care for Children. Given that concurrent care is a federally mandated option for children and their families, no review of the science has been conducted. The purpose of this study was to systematically collect the evidence on concurrent hospice care, critically appraise the evidence, and identify areas for future nursing research. Of the 186 articles identified for review, 14 met the authors' inclusion and exclusion criteria. Studies in this review described concurrent hospice care from a variety of perspectives: policy, legal, and ethics. However, only one article evaluated the impact of concurrent hospice care on outcomes, whereas several studies explained clinical and state-level implementation. There is a need for further studies that move beyond conceptualization and generate baseline and outcomes data. Understanding the effectiveness of concurrent hospice care might provide important information for future nursing research. The approaches used to disseminate and implement concurrent hospice care at state, provider, and family levels should be explored. **Abstract:** <https://bit.ly/2VrCjDA>

## Building a medical undergraduate palliative care curriculum: Lessons learned

*JOURNAL OF PALLIATIVE CARE* | Online – 13 April 2020 – Previous literature demonstrates that current palliative care (PC) training is in need of improvement for medical students in global, European and Canadian contexts. The training of medical undergraduates is key to ensure that the ongoing and increasing need for enhanced access to PC across all settings and communities is met. The authors describe building a comprehensive palliative and end-of-life care (EoLC) curriculum for medical undergraduates at their university. As with recent European and U.S. studies, they found that the process of university curriculum renewal provided a critical opportunity to integrate PC content, but needed a local PC champion already in place as an energetic and tireless advocate. The development and integration of a substantive bilingual (English and French) palliative and EoLC curriculum over the 4-year medical undergraduate program at the authors' university has occurred over the course of 14 years, and required multiple steps and initiatives. Subsequent to the development of the curriculum, there has been a 13-fold increase in students selecting our PC clinical rotations. Critical lessons learned speak to the importance of having a team vision, interprofessional collaboration with a focus on vision, plans and implementation, and flexibility to actively respond and further integrate new educational opportunities within the curriculum. Future directions for our PC curriculum include shifting to a competency-based training and evaluation paradigm. Findings and lessons learned may help others who are working to develop a comprehensive undergraduate medical education curriculum. **Abstract (w. list of references):** <https://bit.ly/3a1Yqpg>



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## Related:

- *CMAJ OPEN* | Online – 14 April 2020 – ‘**Palliative care clinical rotations among undergraduate and postgraduate medical trainees in Canada: A descriptive study.**’ This study shows that, among Canadian medical trainees at the undergraduate and postgraduate levels, completion of palliative care (PC) clinical rotations is limited and inconsistent. Basic palliative competencies are essential for the provision of care in family medicine and in many specialties and subspecialties. It is well recognized that, without dedicated clinical exposure to PC, many trainees will enter practice without these vital competencies required for optimal care of the growing population of patients with chronic incurable illnesses and at the end of life. **Full text:** <https://bit.ly/3eiEIP3>

## Top ten things palliative care clinicians should know about caring for Hindus

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 April 2020 – Hinduism is one of the five major world religions with >1 billion followers worldwide and encompasses a diversity of belief systems. As of 2010, an estimated 1.8 million Hindus lived in the U.S., and this number is expected to increase to 4.8 million by 2050, making the U.S. home to the largest Hindu population outside of South Asia. As this population continues to grow, it will become increasingly important that clinicians of all disciplines develop a basic understanding of their beliefs and practices to address their palliative care needs. This article highlights 10 considerations for Hindu patients and their families relevant to inpatient care, symptom management, and advance care planning. **Abstract:** <https://bit.ly/3bfx130>

Noted in Media Watch 23 September 2013 (#324, p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 19 September 2013 – ‘**End-of-life care beliefs among Hindu physicians in the U.S.**’ Studies from the U.S. and Europe indicate that physicians’ religiosity is associated with their approach to end-of-life (EoL) care. No such studies have focused on Hindu physicians practicing in the U.S. Most of the 293 surveyed believed their religious beliefs do not influence their practice of medicine and do not interfere with withdrawal of life support. The practice of discussing EoL issues with the patient, rather than primarily with the family, seems to have been adopted by Hindu physicians in the U.S. **Abstract (w. list of references):** <https://bit.ly/2Vm1KYt>

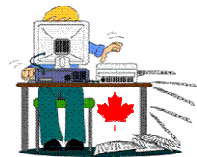
**N.B.** *The Lancet’s* 2005 7-part series of viewpoints explores contrasting end-of-life perspectives (i.e., Hindu, Islamic, Jewish, Buddhist, Christian, Catholic, and Humanist): <https://bit.ly/2xHdN9v>

## Exploring compassion from the perspective of healthcare professionals working in palliative care

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 15 April 2020 – Despite the body of literature regarding the varying definition of compassion, there appears a lack of literature pertaining to the meaning of compassion from the perspective of healthcare professionals (HCPs) working in palliative care (PC) settings. This study presents a novel understanding of the components of compassion from the perspective of HCPs working in PC. While there is need for future research, important areas of improvement include increased resourcing, reducing time pressures, and education within PC settings. This will enable the fostering of compassionate care to patients, as well as enhanced well-being both professionally and personally for HCPs delivering such care. **Abstract:** <https://bit.ly/2xBY3EG>

### [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>



## Congruence between preferred and actual place of death for those in receipt of home-based palliative care

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 15 April 2020 – Understanding the factors that affect the congruence between preferred and actual place of death may help providers offer clients customized end-of-life care settings. Little is known about this congruence for cancer patients in receipt of home-based palliative care (PC). In this study, the overall congruence between preferred and actual place of death was 71.72%. Home was the most preferred place of death. The intensity of home-based nursing visits and hours of care from personal support workers increased the likelihood of achieving death in a preferred setting. This finding highlights the importance of formal care providers in signaling and executing the preferences of clients in receipt of home-based PC. **Abstract:** <https://bit.ly/3ekytom>

Noted in Media Watch 23 March 2020 (#658, p.7):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 16 March 2020 – “**I want to go home.**”: **How location at death influences caregiver well-being in bereavement.**’ Congruence between a dying person’s preferred and actual locations at death has been considered good care and may influence the quality of bereavement. Yet, the preferred location for end-of-life care may be unaddressed. There has been little focus on the reciprocity between caregiver-patient wishes. Discussing preferences about the place of end-stage care may not make location congruence possible, but it can foster shared understanding and support for caregivers’ sense of coherence and well-being in bereavement. **Abstract (w. list of references):** <http://bit.ly/2vZtV5D>

## What consumers say about hospices in online reviews

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 13 April 2020 – Until recently, consumers [in the U.S.] have had limited resources to assess quality of hospices agencies, contributing to growing numbers of consumers turning to online review sites, such as Yelp. However, little is known about the content of hospice Yelp reviews and how these relate to recently available Center for Medicare & Medicaid Services’ Hospice Compare (HC) site data. The authors examined 692 consumer Yelp reviews of 67 hospices in California and compared identified themes with quality measures presented on the HC site. The authors found that overall Yelp comments were positive, however Yelp themes were more extensive and diverse than those on HC. **Abstract:** <https://bit.ly/3a7eB4L>

Noted in Media Watch 17 February 2020 (#653, p.9):

- *JAMA NETWORK OPEN* | Online – 12 February 2020 – ‘**Content analysis of negative online reviews of hospice agencies in the U.S.**’ As online reviews of healthcare become increasingly integral to patient decision-making, understanding their content can help healthcare practices identify and address patient concerns. Of 100 hospice agencies in the study sample, 67 (67.0%) had 1-star reviews; 33 (49.3%) were for-profit facilities and 34 (50.7%) were non-profit facilities. Of 137 unique reviews, 68 (49.6%) were for for-profit facilities and 69 (50.4%) were for non-profit facilities. Five themes emerged: 1) Discordant expectations; 2) Suboptimal communication; 3) Quality of care; 4) Misperceptions about the role of hospice; and, 5) The meaning of a good death. **Full text:** <http://bit.ly/38tia5p>

## Palliative Care: Too good to be true?

*RAMBAM MAIMONIDES MEDICAL JOURNAL* | Online – 22 March 2020 – Although palliative care (PC) has traditionally been seen as a last resort, it is now being embraced as a necessary treatment in the early stages of both malignant and non-malignant chronic life-limiting illnesses. Education and open discussion play essential roles in the early integration of PC into treatment options. The growing need for improved access and equity in PC programs results from both an aging population and the widespread nature of chronic illnesses. Since the purpose of PC is to diminish suffering associated with life-threatening illnesses, it is imperative to advocate the associated benefits to the public and to healthcare providers. In addition to summarizing the previous research on PC for improving end-of-life care, the findings from this

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narrative review highlight several potential avenues for future research. Healthcare professionals must enhance their PC knowledge to better meet patients' needs. The core competencies of PC, including communication and symptom management, have not received wide attention in most medical school training programs. Improved faculty capability in modeling and teaching state-of-the-art PC in academic health centers has been proposed to meet the teaching needs. Moreover, the PC needs of older adults with multiple coexisting conditions have yet to be well described. Better understanding of the needs of this patient population and their caregivers is required to develop a well-established PC model and allocate the specialist-level PC workforce efficiently. Lastly, a better transition to PC will ensure its coordination and continuity. The newly emerging concept [in Florida] of the mobile integrated healthcare (MIH) aims to facilitate the coordination of PC by closing unaddressed gaps (i.e., access to transportation, declining functional status, community support). Another type of gap the MIH model aims to close is poor care coordination causing failure to transmit patient information, harmful drug interactions, and conflicting treatment plans that may be presented by primary care providers or specialists. **Full text (click on pdf icon):** <https://bit.ly/2VqlokP>

### **Bereaved parents, hope, and realism**

*PEDIATRICS*, 2020;145(4):e20192771. Parents of children with serious illness often maintain hope across a child's illness journey. Historically, the conflict between parental hope and prognostic acceptance has been described as a pendulum oscillating between antithetical states of awareness. In this commentary, bereaved parents partner with interdisciplinary pediatric palliative care clinicians to discuss and challenge the conventional theory in which hope and realism exist as diametrically opposing spaces within which parents vacillate. As parents and clinicians, we offer a reconceptualized model that validates a parent's ability to experience hope and prognostic awareness simultaneously, avoiding assumptions that conflate hope as misinterpretation or denial. The authors advocate for healthcare professionals to consider this framework when partnering with patients and families who carry co-existing hope and prognostic awareness in the context of a child's progressive illness. **Abstract:** <https://bit.ly/34tjrs1>

### **Assisted (or facilitated) death**

Representative sample of recent journal articles:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 April 2020 – '**Medical assistance in dying: Patients', families', and healthcare providers' perspectives on access and care delivery.**' Patients, families, and healthcare professionals (HCPs) [i.e., study participants] highlighted access and delivery concerns regarding program sustainability, care pathway ambiguity, lack of support for care choices, institutional conscientious objection (CO), navigating care in institutions with a CO, and post-death documentation. Patients and families expressed additional concerns regarding lack of ability to provide advanced medical assistance in dying (MAiD) consent, and the requirement of independent witnesses on MAiD request forms and consent immediately before MAiD administration. HCPs were additionally uncertain about professional roles and responsibilities. Ten recommendations to improve regional MAiD care and the resultant practice change are presented. Quality improvement (QI) processes are essential to devise an accessible dignified patient- and family-centered MAiD program. **Abstract:** <https://bit.ly/3blnDN5>
- *PAEDIATRICS & CHILD HEALTH* | Online – 15 April 2020 – '**Paediatric euthanasia in Canada: New challenges for end-of-life care.**' Canadians are looking to expand their Medical Assistance in Dying program to include mature minors. Yet, little evidence exists to support this expansion. The Council of Canadian Academies released a report in December 2018 indicating that little is known about how mature minors make meaning of end of life (EoL) care. To address this knowledge gap, research is needed to understand how mature minors make meaning of the dying process in the first place. Since social perceptions drive Canadian healthcare, practice, and EoL mentalities, the question that needs to be asked is: "What is the Canadian perception of a good death for mature minors?" To answer this question it is first necessary to examine the meaning that death and dying hold for mature minors, as voiced by mature minors themselves. **Full text:** <https://bit.ly/3bdhZMX>

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1. 'Medical Assistance in Dying,' Expert Panel on Medical Assistance in Dying, Council of Canadian Academies, December 2018. [Noted in 17 December 2018 issue of Media Watch (#594, p.2)] **Download/view at:** <http://bit.ly/3bExMov>

**N.B.** See 'Children's understanding of dying & death' (pp.5-7), 'Crossroads of Grief Project: Grieving or Bereaved Children: Literature Review 2015-2018,' Children & Youth Grief Network, Ontario, Canada, December 2018. **Download/view at:** <http://bit.ly/2OB4Y6C>

## Publishing Matters

### **The International Committee of Medical Journal Editors (ICMJE) recommendations: Challenges in fortifying publishing integrity**

*IRISH JOURNAL OF MEDICAL SCIENCE* | Online – 5 April 2020 – In December of 2019, the ICMJE updated its recommendations. As occurs regularly with the ICMJE recommendations, this document was edited and tweaked, and thus fortified and verified. At least one new fortifying positive element was introduced, namely that peer reviewers who relied on the assistance of others during peer review need to declare this to editors. This fortifies publishing integrity, via transparency, in the peer review process in biomedical science. However, a new clause was introduced: "Authors should avoid citing articles in predatory or pseudo-journals." This is controversial because the precise nature of "predatory" publishing venues, either journals or publishers, is unclear and several parameters used by existing blacklists are unreliable and thus debatable. It is concerning that these edited recommendations were simultaneously published in 13 medical journals. **Abstract:** <https://bit.ly/2XKw3K2>

### 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> ]

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

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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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