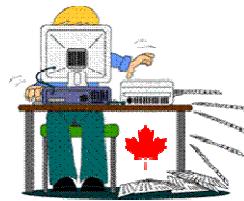


## **Media Watch...**

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.

**25 May 2020 Edition | Issue #667**



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**Compiled & Annotated by Barry R. Ashpole**

**It is well established that people dying from cancer receive better access to specialist palliative care than those with non-cancer conditions, and this diagnosis related inequity extends to the costs of caring.**

'Equity and the financial costs of informal caregiving in palliative care: A critical debate' (p.7), in *BMC Palliative Care*.

## **Canada**

### **COVID-19 Pandemic**

**Social isolation means people aren't being provided the ritual of mourning, with serious mental health implications. A new organization hopes to help**

**POLICY OPTIONS** | Online – 18 May 2020 – It is time we talked about the grief. First, the sheer volume of it. There have been more than 5,400 deaths from COVID-19 in Canada right now. But we know that is an undercount. And we know that the number will grow long after this first peak is passed. We know also that yet more people are dying out of fear: for example, they have been slow getting to the emergency room for a heart condition. We know that more people are going to die, or die sooner because of postponed surgery, chemotherapy or radiation. Except for the most luckless among the dead, each individual leaves behind someone grieving deeply for their loss, and most will leave behind three, four, five, perhaps many more. Second, it is the character of that grief. Many of those who die from COVID-19 do so in a hospital or care home cut off from their loved ones. If they have a chance to say goodbye, it may be on a phone or tablet held briefly aloft by a harried healthcare worker. Things that should have been said will

remain unsaid. If someone is holding their hand at the moment they pass, it will be a nurse, wearing a mask and gloves. The people who love them and would have wanted to be there are instead at home

### **Specialist Publications**

'**Implementing volunteer-navigation for older persons with advanced chronic illness (Nav-CARE): A knowledge to action study**' (p.6), in *BMC Palliative Care*.

'**Palliative care?! But this child's not dying: The burgeoning partnership between pediatric cardiology and palliative care**' (p.7), in *Canadian Journal of Cardiology*.

'**End-of-life care for federally incarcerated individuals in Canada**' (p12), in *McGill Journal of Law & Health*.

Cont.

waiting for the phone to ring. In recent years, we have begun as a society to take matters of mental health much more seriously, if not yet seriously enough. It is not widely known, however, that grief or bereavement are not included in either public or charitable programs for mental health, including in this pandemic. That is why the Canadian Virtual Hospice, a pioneer in dealing with issues of life-ending illness online, has convened the Canadian Grief Alliance. <https://bit.ly/2TkLgOS>

Noted in Media Watch 18 May 2020 (#666, p.1):

- CANADIAN VIRTUAL HOSPICE | Online – 12 May 2020 – ‘**Action needed to address COVID-19’s hidden tragedy: National grief advocates urge support for grieving Canadians and health workers.**’ Never has Canada experienced the volume and complexity of grief as has resulted from the COVID-19 pandemic. Canadians have been robbed of goodbyes with dying relatives and forced to grieve in isolation without funeral rites. They and those working on the front lines of healthcare are at heightened risk for prolonged, complicated grief marked by depression, and the risk of suicide. Existing grief services are fragmented, under-funded and insufficient. Left unaddressed, significant long-term social, health and economic impacts will result. Download/view at: <https://bit.ly/2ylo5aa>

### Will the pandemic finally make us talk about palliative care?

HUFFPOST | Online – 17 May 2020 – To understand the holistic philosophy behind palliative care (PC), imagine three concentric circles with one person, the patient, in the middle. These are all rings of support. Now move outward. The first focuses on pain and symptom management. That’s where a PC doctor’s medical training kicks in. The second ring puts attention on a patient’s network of psychological, social, spiritual and practical support. Emotional support and social engagement from family, friends or religion play a special role here. The last circle is caregiver support. Depending on the severity of the disease, a patient may no longer be able to care for themselves, and become increasingly reliant on support workers for meals and personal care. It’s incredibly demanding work – one in three caregivers report stress and burnout. The pandemic has put strain on all three rings. <https://bit.ly/3bJfPUP>

## U.S.A.

### Discussing serious illnesses more challenging during COVID-19 pandemic

REUTERS HEALTH | Online – 21 May 2020 – Talking about a serious illness such as cancer over the phone or by video during the coronavirus pandemic can be tough, but it’s doable, according to two geriatrics and palliative care (PC) experts. Doctors can have meaningful conversations with their patients and their families with careful planning and by responding to emotion, the two write in the *Annals of Internal Medicine*. “Conversations about serious illness are really hard to have, even when they are done in person,” co-author Dr. Ashwin Kotwal of the University of California, San Francisco, told Reuters Health by email. Emotionally-charged topics can come up, such as negative medical updates, decisions about ventilators or intensive care, and conversations about dying, hospice care and PC. “Now many of these conversations are happening over video or telephone due to hospital visitor restrictions or infection precautions, and this brings unique challenges,” Dr. Kotwal said.

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

‘**Bereavement in the time of Coronavirus: Unprecedented challenges demand novel interventions**’ (p.9), in *Journal of Aging & Social Policy*.

‘**Pandemic palliative care consultations spanning state and institutional borders**’ (p.10), in *Journal of the American Geriatrics Society*.

‘**COVID-19 lessons: The alignment of palliative medicine and trauma-informed care**’ (p.10), in *Journal of Pain & Symptom Management*.

‘**Neuropalliative care during COVID-19: How clinicians help patients and families cope with isolation, fear, and life-limiting illness**’ (p.10), in *Neurology Today*.

Cont.

Dr. Kotwal and Dr. Lynn Flint of the San Francisco Veterans Affairs Medical Center wrote a brief guide to share the strategies they have learned during this time. They provide telepalliative care for patients with serious illnesses, which helps people who live in rural areas and nursing homes or can't leave their home for an appointment. In the guide, they write that the first step is careful preparation. Doctors should understand a patient's ability to participate by phone or video, as well as the possible need for a translator and the patient's preferences for including loved ones. Healthcare providers should also check whether patients can use equipment and if someone on the hospital staff needs to help. <https://reut.rs/36nCpkv>

1. 'The new normal: Key considerations for effective serious illness communication over video or telephone during the Coronavirus disease 2019 (COVID-19) pandemic,' *Annals of Internal Medicine*, published online 14 May 2029. **Full text:** <https://bit.ly/2ZhGZPP>

**Related:**

- REUTERS HEALTH | Online – 19 May 2020 – '**Palliative care may require caution, creativity during COVID-19.**' Although palliative care (PC) may be tough to provide during the pandemic, specialists are finding new ways to help their patients. "We care for patients' minds, bodies and spirits. COVID-19, like other serious illnesses, impacts all of these," said lead author of a new report Dr. Ambereen Mehta of UCLA Health in Los Angeles.<sup>1</sup> "However, our traditional ways of providing excellent PC weren't possible with physical distancing. At the same time, more people were asking for PC services." Instead of spending time at the bedside and holding long in-person meetings with families, they needed a new option. PC doctors held national video calls to discuss their concerns. <https://reut.rs/3bSbAGA>
  1. 'Palliative care for patients with cancer in the COVID-19 era,' *JAMA Oncology*, published online 7 May 2020. [Noted in 11 May 2020 issue of Media Watch (#665, p.7)] **Full text:** <https://bit.ly/3dpErmC>

### **State reports: Palliative care access and recommendations**

CENTER TO ADVANCE PALLIATIVE CARE | Online – 20 May 2020 – As more state-level champions and health officials explore opportunities to expand palliative care (PC) access, data on the current PC landscape can help prioritize efforts. The Center's new state-level reports provide information about PC access in each state, along with recommendations to improve it. Each state report includes state-specific information on: 1) The availability of hospital PC and comparisons to national and regional access; 2) Community PC; 3) The number of certified PC clinicians; and 4) Ways to advance PC access and quality in the areas of workforce, payment, clinician skill building, and public awareness, including available resources. **Download/view at:** <https://bit.ly/2Xdxi2m>

### **International**

#### **Poor communication, discrimination and lack of training: Why LGBT people may face inequalities in palliative care**

U.K. | *THE CONVERSATION* – 21 May 2020 – Palliative or end-of-life care (EoLC) can help people with terminal conditions, such as cancer, live as well as possible for as long as possible – and allow them to die with dignity. But EoLC is not a straightforward process. And for patients from the LGBT community, the process presents a whole host of barriers that they and their families may face. Not only do many people from the LGBT community face difficulties accessing high-quality EoLC, they also may face issues

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

**'Reassessing advance care planning in the light of COVID-19'** (p.9), in *British Medical Journal*.

#### **Specialist Publications**

**'Social work in hospice and palliative care in Europe: Findings from an European Association for Palliative Care survey'** (p.13), in *Palliative & Supportive Care*.

**'Dignity in end-of-life care at hospice: An action research study'** (p.14), in *Scandanavian Journal of Caring Sciences*.

Cont.

with their care. This may sometimes be because of ignorance and prejudice against them during pre-hospital admission. It may also be due to poor communication between patients and care providers about treatment plans, judgement by staff about a patient's family or relationships, and a failure to properly support the spiritual needs of the patient. Many have also experienced victimisation, discrimination and personal hardship as a result of their sexual identity throughout their life, and may feel that telling a health-care professional about their sexual identity would change their interactions or quality of treatment. Staff may also be unaware of an LGBT patient's particular needs or how to meet them. For example, patients who have undergone gender reassignment may have been married previously in their former gender. They might have children and grandchildren. Dealing with current partners, spouses, former spouses and children during EoLC takes particular skills, which requires specialist training. As many in palliative care want to be surrounded by loved ones, healthcare workers need to be trained to deal with these types of situations. <https://bit.ly/2Xj8W7b>

Noted in Media Watch 18 May 2020 (#666, p.13):

- **JOURNAL OF PAIN & SYMPTOM MANAGEMENT** | Online – 10 May 2020 – ‘**LGBTQ+ inclusive palliative care in the context of COVID-19: Pragmatic recommendations for clinicians.**’ Although care for LGBTQ+ individuals is no different and requires careful consideration, there is a concerning literature gap related to the health and palliative care (PC) of these populations in this context. All clinicians must continue to strive toward inclusive, person-centered care in sensitive and respectful ways to improve the quality of care provided and the patient experience, promote social support that alleviates distress, and ensure dignity remains at the forefront of high-quality PC for each and every patient, family, and community. **Full text:** <https://bit.ly/2YTnrRR>

**N.B.** Additional articles on palliative and hospice care for LGBT people noted 13 January 2020 issue of Media Watch (#648, p.10).

### **COVID-19 has made majority rethink dealing with death, survey finds**

IRELAND | *The Irish Times* (Dublin) – 20 May 2020 – A large majority of people believe the COVID-19 pandemic has made the public rethink the way it deals with death and bereavement, a new survey by the Irish Hospice Foundation has found. The survey ... found that 68% of people felt that the virus had made people rethink how it deals with death. The charity has called for “a national response” in the wake of the pandemic and for the next government to develop a new “whole of government strategy” to “end of life care.” Among the proposals in a seven-point policy document published by the charity is a suggestion that end of life and palliative care services be set up in nursing homes, the sector worst hit by the pandemic, and that people be allowed to die at home or their place of preference. The foundation wants the government to introduce a new national mortuaries programme, to provide community supports on bereavement and to start a new “national dialogue on dying, death and bereavement.” <https://bit.ly/36icvyx>



**N.B.** Foundation’s seven-point policy document can be download/view at: <https://bit.ly/2AlZp1H>



### **Barry R. Ashpole**

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>

## COVID-19 Pandemic

### The uncertain future facing our hospices

U.K. (England) | ITV News – 18 May 2020 – Hospices across the Midlands have told ITV News Central that they have many concerns for their futures. ITV News spoke to 12 hospices whose end-of-life care is vital to many families and also relieves pressure on the National Health Service. COVID-19 has brought their fundraising to a standstill. Shops across the country have closed and events to generate cash have been cancelled. The Government has stepped in with a £200 million cash injection for hospices across the U.K., but it is not yet clear what will happen when that runs out. <https://bit.ly/36elK1W>

#### Related:

- U.K. (England) | *The Daily Mirror* – 20 May 2020 – ‘**Children’s hospice backed by royal family shuts after £2 million Coronavirus losses.**’ A children’s hospice backed by the Royal Family has been forced to close after COVID-19 blew a £2 million hole in its finances. Sophie, Countess of Wessex, patron of Shooting Star Children’s Hospices, has been left “incredibly saddened” after it shut one of two sites dedicated to helping 800 seriously ill kids. But a *Mirror* probe has discovered it is one of dozens of hospices, which rely on the public’s generosity, facing unprecedented hardship. Shooting Star was awarded £480,000 in emergency government funding last month, but with services costing £30,000 a day ... it has “merely papered over the cracks.” <https://bit.ly/2Xc1DhK>

### Is COVID-19 exacerbating inequities in end-of-life experience?

U.K. (Scotland) | *The Herald* (Glasgow) – 18 May 2020 – National Records of Scotland data has revealed that people living in the most deprived areas of Scotland are more than twice as likely to die with COVID-19 than those living in the least deprived areas. Whilst data are yet to emerge, it seems probable that the pandemic is exacerbating existing inequities at the end of life (EoL). We know that people who live in areas of high deprivation are less likely to access specialist palliative care services such as hospice. They may be less likely to get GP support because, as the inverse care law shows, GPs in deprived areas are much busier. They are also less likely to die at home which is where most people in the U.K. would prefer to die. Evidence of these inequities has provided the impetus to the current research project – Dying in the Margins – which looks at how experiences of poverty can affect people’s ability to die at home. The School of Interdisciplinary Studies at the University of Glasgow is partnering with the Deep End Group, a network of GP surgeries serving the 100 most deprived areas in Scotland. Currently, policymakers and the public have very little insight into what it is like to be dying while also experiencing serious financial hardship and living in a deprived area. Health service access is only one aspect of EoL experience. Most of the care we receive at the end of our lives is provided by family members. However, carers in families experiencing poverty are more likely to be suffering ill health themselves. Family members whose work is low paid and insecure, or who have been made unemployed as a result of the lock down, may find the pressures of looking after a dying family member too much to bear. <https://bit.ly/2TdCTnV>

Noted in Media Watch 17 September 2018 (#581, p.4):

- U.K. (Scotland) | Press Association (Glasgow) – 13 September 2018 – ‘**People in most deprived areas 24% more likely to die alone – research.**’ The research says those living in the most deprived neighbourhoods are 24% more likely to die alone at home than those in the least deprived areas. They were also less likely to die in a hospice or care home, two researchers from Edinburgh Napier University found. The findings have led academics to call for more insight into the circumstances of people nearing the end of their lives. Dr. Anna Schneider said: “Our research shows that neighbourhood deprivation has an influence on how people spend their last months of life in Scotland. End-of-life care has received much attention from policy makers in the last years... <https://bit.ly/2WEcqSG>



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

Representative sample of recent news media coverage:

- AUSTRALIA (Queensland) | *The Brisbane Times* – 21 May 2020 – ‘**Palaszczuk puts voluntary euthanasia reform on hold.**’ Assisted dying for the terminally ill in Queensland will not be legislated before the state heads to the polls on 31 October. In March, the government’s health committee recommended legislation be debated in parliament, following a year long inquiry. But Queensland Premier Anastacia Palaszczuk believes the scheme needs “further consideration.” She has asked for draft legislation backed by the committee to be sent to the Law Reform Commission for review. The commission will report back to the government by 1 March 2021. “Voluntary assisted dying is a very complex and deeply personal issue, in which competing interests and views of Queenslanders and experts have to be carefully balanced, and the lives of our elderly and most vulnerable people protected,” Ms Palaszczuk said. “It is absolutely critical that the government’s final response to the committee reports is informed by the views and experiences of aged care and palliative care providers. We need to give the sector and community time to consider the reports in detail and we know that the focus in these areas is currently on addressing the risk of COVID-19.” <https://bit.ly/2TrCVJ2>

## **Specialist Publications**

### A palliative, public-health approach in hospice

#### **Implementing volunteer-navigation for older persons with advanced chronic illness (Nav-CARE): A knowledge to action study**

*BMC PALLIATIVE CARE* | Online – 22 May 2020 – Establishing how to adapt hospice societies to the changing face of palliative care (PC) has become a central question arising from this study. If PC is indeed everyone’s business (the public health approach) and if it needs to happen early on (the palliative approach), how might the longstanding and revered culture of hospice need to adapt? Older persons in this study were immediately discouraged from taking advantage of a service offered by an organization traditionally thought to care for the actively dying. Further, in keeping with a palliative approach to care, much of care is now being assigned to interdisciplinary chronic illness management teams. The strong relationships developed between hospice societies and PC practitioners may no longer give hospice access to the upstream palliative population. Organizations in this study were feeling the effects of these changes. There is an urgent need to re-envision the role of hospice, and how to language its services, in light of these developments. In this study, hospice boards were already actively considering their long-term vision in consideration of these changes. Indeed, the dedication of these sites to Nav-CARE sustainability suggested that they see this new role for hospice as a top priority. However, these issues also need to be tackled beyond the local level through a policy approach. **Full text:** <https://bit.ly/2ZwJ0l0>



#### Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.17.



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

## **Equity and the financial costs of informal caregiving in palliative care: A critical debate**

*BMC PALLIATIVE CARE* | Online – 19 May 2020 – The financial costs of informal caring for a person approaching the end of life (EoL) can be significant, and a small but expanding evidence base reflects the range and scope of these costs. A 2014 systematic review of literature on financial costs incurred by informal caregivers identified a very limited evidence base.<sup>1</sup> Nonetheless, there was evidence to suggest that these costs are significant. Costs can be broadly categorised into three main areas: 1) Work related costs (costs related to changes in employment); 2) Carer time costs (cost related to time investment required by carers); and, 3) Out-of-pocket costs (direct outlays of money). A 2015 qualitative study of bereaved carers confirmed that the costs of caring at the EoL are significant and include a range of both direct (e.g., transport, food, medication) and indirect costs (e.g., related to employment, carer time, carer health).<sup>2</sup> The palliative care context was also found to increase costs, as meeting the ill person's needs was prioritised over cost. Over recent years a growing number of international studies have confirmed that the financial costs of caring are a serious issue across the developed world. Furthermore, evidence suggests that informal carers make a huge financial contribution to the wider healthcare system, with studies estimating that informal caregiving accounts for up to 70% of total healthcare costs. **Full text:** <https://bit.ly/2LGFzqh>

1. 'Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature,' *Palliative Medicine*, 2014;28(5):375-390. **Abstract (w. list of references):** <https://bit.ly/36eyDtI>
2. "No matter what the cost": A qualitative study of the financial costs faced by family and whānau caregivers within a palliative care context,' *Palliative Medicine*, 2015;29(6):518-528. **Full text:** <https://bit.ly/2TEnXjh>

**N.B.** The authors of the *BMC Palliative Care* article are members of the European Association for Palliative Care taskforce on costs of family caregiving: <https://bit.ly/2AJX6vj>

## **Palliative care?! But this child's not dying: The burgeoning partnership between pediatric cardiology and palliative care**

*CANADIAN JOURNAL OF CARDIOLOGY* | Online – 10 May 2020 – The field of pediatric cardiology has witnessed major changes over the past few decades that have considerably altered patient outcomes, including decreasing mortality rates for many previously untreatable conditions. Despite this, some pediatric cardiology programs are increasingly choosing to partner with their institutional palliative care (PC) teams. Why is this? The field of PC has also experienced significant shifts over a similar period of time.

### **The healthcare cost of palliative care for cancer patients: A systematic review**

*SUPPORTIVE CARE IN CANCER* | Online – 21 May 2020 – Several delivery models of palliative care (PC) are currently available: hospital-based, outpatient-based, home-based, nursing home-based, and hospice-based. Weighing the differences in costs of these delivery models helps to advise on the future direction of expanding PC services. The objective of this review is to identify and summarize the best available evidence in the U.S. on cost associated with PC for patients diagnosed with cancer. The initial search identified 748 articles, of which 16 met the inclusion criteria. Eight studies (50%) were inpatient-based, four (25%) were combined outpatient/inpatient, two (12.5%) reported only on home-based palliative services, and two (12.5%) were in multiple settings. Most included studies showed that PC reduced the cost of healthcare by \$1,285-\$20,719 for inpatient PC, \$1,000-\$5,198 for outpatient and inpatient combined, \$4,258 for home-based, and \$117-\$400 per day for home/hospice, combined outpatient/inpatient PC. Receiving PC after a cancer diagnosis was associated with lower costs for cancer patients, and remarkable differences exist in cost saving across different PC models. **Abstract (w. list of references):** <https://bit.ly/2ATJAFF>

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Today's PC is focused on improving quality of life (QoL), for any patient with a serious or life-threatening condition, regardless of where they might be on their disease trajectory. Research has clearly demonstrated that improved outcomes can be achieved for a variety of patient cohorts through early integration of PC; recent evidence suggests that the same may be true in pediatric cardiology. All pediatric cardiologists need to be aware of what pediatric PC has to offer their patients, especially those who are not actively dying. The authors review the evolution of PC and provide a rationale for its integration into the care of children with advanced heart disease. Readers will gain a sense of how and when to introduce PC to their families, as well as insight into what pediatric PC teams have to offer. Additional research is required to better delineate optimal partnership between PC and pediatric cardiology so that we may promote maximal QoL of patients concurrently with continued efforts to push the boundaries of quantity of life. **Abstract:** <https://bit.ly/2ZwASHI>

### Palliative care in liver disease: What does good look like?

*FRONTLINE GASTROENTEROLOGY* | Online – Accessed 19 May 2020 – Many factors limit widespread provision of good palliative care (PC) ... including the unpredictable trajectory of chronic liver disease, the misconception that PC and end-of-life care are synonymous, lack of confidence in prescribing and lack of time and resources. Healthcare professionals managing these patients need to develop the skills to ensure effective delivery of core PC, with referral to specialist PC services reserved for those with complex needs. Core PC is best delivered by the hepatology team in parallel with active disease management. This includes ensuring that discussions about disease trajectory and advance care planning occur alongside active management of disease complications. Liver disease is strongly associated with significant social, psychological and financial hardships for patients and their carers; strategies that involve the wider multidisciplinary team at an early stage in the disease trajectory help ensure proactive management of such issues. This review summarises the evidence supporting PC for patients with advanced chronic liver disease, presents examples of current best practice and provides pragmatic suggestions for how palliative and disease-modifying care can be run in parallel, such that patients do not miss opportunities for interventions that improve their quality of life. **Abstract (via PubMed):** <https://bit.ly/3cNSHpl>

### Assessment of discordance between surrogate care goals and medical treatment provided to older adults with serious illness

*JAMA NETWORK OPEN* | Online – 19 May 2020 – Almost half of the patients in this study had at least one medical treatment or code status order that was discordant with the goal of care identified by their surrogates. The most common source of discordance was having a full code status when the surrogate's preferred goal was comfort measures only or an intermediate goal. Given that the default order for code status is full code, there may be many cases where needed discussions with the surrogate do not occur or result in an order change. This finding is distinguished from a recent study conducted in nursing homes where 98% of patients whose surrogates preferred comfort care had a directive for DNR, but similar to a recent study in which many patients or surrogates who highly valued comfort had orders for CPR.<sup>1,2</sup> The longer time frame of nursing facility admissions may allow for higher-quality discussions, or facilities may have a more standard approach to addressing code status uniformly. This study found there may be serious consequences to failing to document preferences for comfort care. For example, ten patients in this study had surrogates who did not select a goal of life-sustaining treatment but who received CPR. Overall, using a narrower definition of discordance that focused on resuscitation, ICU care, and surgery, nearly 1 in 5 still had discordant treatments. **Full text:** <https://bit.ly/2XaaLDw>

1. 'Concordance between proxy level of care preference and advance directives among nursing home residents with advanced dementia: A cluster randomized clinical trial,' *Journal of Pain & Symptom Management*, 2019;57(1):37-46. **Full text:** <https://bit.ly/2Zh3OmS>
2. 'Discordance between patients' stated values and treatment preferences for end-of-life care: Results of a multicentre survey,' *BMJ Supportive & Palliative Care*, published online 6 October 2016. [Noted in 17 October 2016 issue of Media Watch (#483, p.10)] **Abstract:** <https://bit.ly/2ZkRtOs>

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

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

### **Congruence gaps between adolescents with cancer and their families regarding values, goals, and beliefs about end-of-life care**

**JAMA NETWORK OPEN** | Online – 19 May 2020 – Families had a poor understanding of their adolescent’s values regarding their own end-of-life (EoL) care with respect to when to initiate EoL conversations and preference for being off machines that extend life, if dying. Pediatric advance care planning (ACP) could minimize these misunderstandings, potentially affecting the broader domain of clinical practice guidelines for quality palliative care. Access to pediatric ACP to increase congruence for interested and ready adolescent-family dyads may be more beneficial than simply asking adolescents about their EoL treatment preferences by helping families with the burdens of making EoL decisions, ensuring that adolescents’ preferences are heard, and opening up conversations on topics that both the adolescent and family member may be thinking about, but avoiding. Ultimately, what is at stake here is excessive and unwanted treatment, leading to unnecessary and avoidable suffering. **Full text:** <https://bit.ly/36glmRI>

#### **Related:**

- **ACTA PÆDIATRICA** | Online – 20 May 2020 – ‘**Evaluation showed that stakeholders valued the support provided by the Implementing Pediatric Advance Care Planning Toolkit**’ Key elements of paediatric advance care planning (ACP) were defined using a systematic review, a survey of 168 paediatricians and qualitative studies of 13 children with life-limiting conditions, 20 parents and 18 paediatricians. The Implementing Pediatric Advance Care Planning Toolkit provided a holistic, caring approach to ACP, gave children a voice and cared for their parents. It provided information on ACP for families and clinicians, manuals to structure ACP conversations and training for clinicians in communication skills and supportive attitudes. **Abstract:** <https://bit.ly/2ZvbQJ3>

### **Bereavement in the time of Coronavirus: Unprecedented challenges demand novel interventions**

**JOURNAL OF AGING & SOCIAL POLICY** | Online – 18 May 2020 – The COVID-19 pandemic has dramatically altered how older adults live, die, and mourn. Persons dying of the virus spend their final days in hospitals and nursing facilities, separated from their families. Their bereaved kin must mourn the loss without the comforting embrace of loved ones, or the support of mourners who show their respect for the deceased at funerals. The symptoms of grief, sadness, and anger experienced by bereaved family members will ultimately diminish, a reflection of human resilience in the face of loss. The recovery process will require innovative modes of support from professionals, family members, and community volunteers who come together to nurture the most vulnerable in their time of need. **Full text:** <https://bit.ly/3cOOu4Y>

#### **Related:**

- **BRITISH MEDICAL JOURNAL** | Online – 18 May 2020 – ‘**Reassessing advance care planning in the light of COVID-19.**’ Older people and those with frailty are more likely to die from acute infections, such as COVID-19, and less likely to survive intensive care. This has prompted calls internationally for advance care planning (ACP) in these vulnerable populations, focusing on documenting individuals’ preferences for resuscitation and hospital admission. The benefits of ACP derive more from its process than from the plans it produces, and that recognising this is essential for provision of optimum care for patients and their families. Moreover, an overemphasis on achieving individual choice, the stated purpose of advance care plans, may paradoxically undermine good care. **Full text:** <https://bit.ly/2TmrFOe>

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- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 22 May 2020 – ‘**Pandemic palliative care consultations spanning state and institutional borders.**’ Many critically ill patients with COVID-19 need specialty level palliative care (PC) to manage symptoms, conduct goals of care conversations, and facilitate medical decision making in ethically and emotionally charged situations. During the apex of the COVID-19 crisis in New York, the Adult Palliative Care Service at Columbia University Irving Medical Center/NewYork-Presbyterian received a 7-fold increase in consultation requests. The authors describe the rapid development and implementation of a scalable virtual consultation model staffed by out-of-state PC specialist volunteers. **Abstract:** <https://bit.ly/2XoR7nu>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 May 2020 – ‘**COVID-19 lessons: The alignment of palliative medicine and trauma-informed care.**’ Trauma-informed care (TIC) is a crucial framework that can be implemented across system levels, clinical specialties, and care settings. It was not until recently that TIC became a focus within the field of palliative care (PC). The integration of TIC principles with the National Consensus Project (NCP) for Quality Palliative Care<sup>1</sup> are a demonstration of the inherent alignment between these two frameworks of care. By rigorously implementing these core trauma-informed interventions ... PC teams can help reduce the long-term psychological impact of the COVID-19 pandemic. **Full text:** <https://bit.ly/2ylk8YM>
  1. ‘National Consensus Project’s Clinical Practice Guidelines for Quality Palliative Care,’ National Consensus Project for Quality Palliative Care, 2018. [Noted in 1 April 2019 issue of Media Watch (#608, p.11)]  
**Download/view at:** <http://bit.ly/2uulDhJ>
- *NEUROLOGY TODAY* | Online – 18 May 2020 – ‘**Neuropalliative care during COVID-19: How clinicians help patients and families cope with isolation, fear, and life-limiting illness.**’ Neurologists who specialize in palliative care (PC) have been engaging in many gut-wrenching conversations with patients and families saddled with the complexities of chronic and terminal conditions. In the context of COVID-19, neurologists, neuro-oncologists, and palliative medicine physicians are improvising health-care delivery, acquiring new know-how and applying telemedicine to delicately broach the subject of advance care planning... Just as the pandemic has accelerated the demand for telemedicine, it has escalated the need for PC skills to manage COVID-19 patients... **Full text:** <https://bit.ly/2LGhu2Q>



Would the articles above on COVID-19 be of interest to a colleague?



#### **Improving palliative care for people affected by the COVID-19 pandemic by sharing learning –the national and international response**

CovPall is a new project that is trying to understand more about how palliative care services and hospices are responding to the COVID-19 pandemic, the problems that services and patients and families/those affected by COVID-19 are facing, and how to best respond. **CovPall website:** <https://bit.ly/2ANoNDr>

### Advance care planning and advance directives

#### **Worry as a mechanism to motivate information seeking about protective end-of-life communication behaviors**

*JOURNAL OF HEALTH COMMUNICATION* | Online – 18 May 2020 – Making known one's end-of-life (EoL) care wishes via the processes of advance care planning (ACP) and advance directive (AD) completion is associated with many positive outcomes for patients including lower healthcare costs, greater patient-provider relationship satisfaction, increased quality of life, and more. Despite these benefits, fewer than 30% of patients in the U.S. engage in ACP or complete ADs. These low numbers are most likely due to several causes, including low self-efficacy and low motivation to engage in the process. Several researchers have examined the persuasive power of using worry to motivate patients to engage in preventive health behaviors. The present study expands upon this body of literature by examining patient intentions to seek information related to ACP and AD after being exposed to stimuli intended to arouse differing levels of worry regarding bad EoL outcomes. Participants were randomly assigned to either the high worry, low worry, or control group and asked to complete a questionnaire examining beliefs and information seeking intentions regarding ACP and AD completion. Results of the experiment indicate worry is associated with greater motivation to engage in information seeking about ACP and AD. This study contributes to the literature on worry as a persuasive mechanism to motivate patients to engage in important preventative health behaviors. **Abstract:** <https://bit.ly/2X89FrV>

#### **Related:**

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 15 May 2020 – ‘**Advance care planning: The future.**’ The authors summarize the evidence about what advance care planning (ACP) is and how it should be conducted. They address its barriers and facilitators and discuss current and future models of ACP, including a wider look at how to best integrate those who have diminished decisional capacity. Different models are analysed, including new work in Wales (future care planning which includes best interest decision-making for those without decisional capacity)... While ACP is a joint responsibility of patients, relatives and healthcare professionals, more clarity on how to apply best ACP practices to include people with diminished capacity will improve patient-centred care. **Abstract:** <https://bit.ly/3fXLtBa>

#### **Mediation effects of compassion satisfaction and compassion fatigue in the relationships between resilience and anxiety or depression among hospice volunteers**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2020;22(3):246-253. To the best of the authors' knowledge, this is the first study to examine the effects of compassion satisfaction and fatigue as mediators in the relationship between resilience and psychological symptoms. The finding that compassion fatigue acted as a mediator in the relationship between resilience and anxiety should prompt healthcare system administrators to focus on developing compassion fatigue-reducing and resilience-building strategies to reduce psychological distress in hospice volunteers. Thus, there is a need for further investigation of the relationship between resilience and psychological distress in hospice volunteers and robust evaluation of the impact of intervention to promote resilience in hospice practice. **Full text:** <https://bit.ly/2yVDDal>

#### **An integrative framework of appraisal and adaptation in serious medical illness**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 20 May 2020 – Multiple randomized clinical trials have demonstrated that palliative care (PC) improves the quality of life (QoL) of individuals with serious medical illness. Research also suggests that in patients with advanced cancer, PC's focus on symptom management, coping with illness, goals-of-care, and treatment decisions may be associated with improved patient QoL in part by increasing patients' use of active (versus passive) and approach-oriented (versus avoidant) coping strategies. However, without a framework outlining the process that individuals with serious medical illness and their loved ones undergo, it is challenging to discern exactly where, how, and why PC may affect the serious medical illness experience. To address this gap, the authors propose

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a clinically applicable framework, derived from existing theory and research in the social and behavioral sciences. 'Integrative Framework of Appraisal & Adaptation in Serious Medical Illness' describes how patients and their loved ones cognitively and emotionally process the various events that may occur as they navigate serious medical illness and the end of life. The framework also describes how individuals and their loved ones use that event processing to determine next steps, while considering the impact of their surrounding external environment, their individual social roles and their connections on this decision making. The framework presented in this article is intended to improve the ability to understand and to care for individuals with serious medical illness and their loved ones, while stimulating further discussion and research to test and refine these ideas. **Abstract (w. link to references):** <https://bit.ly/2yjTp8>

### **Developing unique insights from narrative responses to bereaved family surveys**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 May 2020 – Although bereaved family surveys are routinely used quantitatively for quality assessment, open-ended, narrative responses are rarely systematically analyzed. Analysis of narrative responses may identify opportunities for improving end-of-life (EoL) care delivery. Thematic findings clustered into three domains: 1) Patient needs; 2) Family needs; and, 3) Facility and organizational characteristics. Patient needs include maintenance of personal hygiene, appropriately prescribing medications, adhering to patient wishes, physical presence in patient's final hours, and spiritual and religious care at EoL. Family and caregiver needs included enhanced communication with the patient's care team, assistance with administrative and logistical challenges after death, emotional support, and displays of respect and gratitude for the patient's life. Facility and organizational characteristics included care team coordination, optimal staffing, the importance of non-clinical staff to care, and optimizing facilities to be welcoming, equipped for individuals with disabilities, and able to provide high quality food. Systematic analysis of narrative survey data yields unique findings not routinely available through quantitative data collection and analysis. Organizations may benefit from the collection and regular analysis of narrative survey responses, which facilitates identification of needed improvements in palliative and EoL care that may improve the overall experiences for patients and families. **Abstract (w. link to references):** <https://bit.ly/2ZdfRlg>

#### **Related:**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 May 2020 – '**The impacts and effectiveness of support for people bereaved through advanced illness: A systematic review and thematic synthesis.**' Bereavement interventions were wide ranging and included bereavement support and social groups, psychological and counselling interventions and other types of support such as arts-based, befriending and relaxation interventions. Good quality randomised controlled trial evidence was only available for targeted family therapy and a non-targeted group-based therapy intervention, both of which were introduced during the caregiving period and found to be partially effective. **Full text:** <https://bit.ly/2LQxCPr>

### **End-of-life care for federally incarcerated individuals in Canada**

*MCGILL JOURNAL OF LAW & HEALTH*, 2020;14(1):1-50. The authors review the current legislation, policies, and practices related to end-of-life care (EoLC) for federally incarcerated individuals as set out in statutes, guidelines, and government reports and documents that were either publicly available or obtained through Access to Information requests from the Parole Board of Canada and Correctional Service of Canada (CSC). Based on this review, they describe the *status quo*, identify gaps, and offer reflections and raise concerns regarding EoLC for federally incarcerated individuals. The authors conclude that there are significant information gaps about the number of people seeking EoLC and about how CSC is managing the provision of such care. The sparse information available is nonetheless sufficient to support the conclusion that there are good reasons to be concerned about EoLC is regulated, monitored, recorded, and provided. Significant reforms are needed. **Full text (click on pdf icon):** <https://bit.ly/3cQVH4t>

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

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Noted in Media Watch 4 March 2019 (#604, p.1):

- CORRECTIONAL INVESTIGATOR OF CANADA & COMMISSIONER OF THE CANADIAN HUMAN RIGHTS COMMISSION – 28 February 2019 – ‘**Aging and dying in prison: An investigation into the experiences of older individuals in federal custody.**’ Some older, long-serving offenders are being warehoused behind bars well past their parole eligibility dates. There is no legal or policy recognition that older individuals represent a vulnerable population in prison or that they have unique characteristics, needs and rights which must be respected and met. Their health, safety, dignity and human rights are not adequately protected. Federal penitentiaries were never intended or physically designed to accommodate an aging inmate population. **Abstract:** <http://bit.ly/2TmgIND>

### Internet disruptions in the doctor-patient relationship

*MEDICAL LAW REVIEW* | Online – 17 May 2020 – The ubiquitous access by patients to online information about health issues is disrupting the traditional doctor-patient relationship in fundamental ways. The knowledge imbalance has shifted and the last nails are being hammered into the coffin of medical paternalism. Ready access to Dr Google has many positive aspects but the risk of undiscerning acceptance by patients of unscientific, out-of-date or biased information for their decision-making remains. In turn this may feed into the content of the legal duty of care for doctors and contribute to a need for them to inquire sensitively into the sources of information that may be generating surprising or apparently illogical patient treatment choices. In addition, patients, those related to patients, and others have the potential to publish on the Internet incorrect and harmful information about doctors. A number of influential decisions by courts have now established the legitimacy of medical practitioners taking legal proceedings for defamation and injunctive relief to stop vituperative and vindictive online publications that are harming them personally, reputationally and commercially. Furthermore, disciplinary accountability has been imposed on doctors for intemperate, disrespectful online postings. All of these factors are contributing to a disruptive recalibration of the dynamics between doctors and their patients. **Abstract:** <https://bit.ly/2TdazID>

### Social work in hospice and palliative care in Europe: Findings from an European Association for Palliative Care survey

*PALLIATIVE & SUPPORTIVE CARE* | Online – 18 May 2020 – Social work is considered to be a key player in hospice and palliative care (PC). To prove this claim, the Social Worker Task Force within the European Association for Palliative Care (EAPC) decided to carry out a survey ... to generate basic data and thus to create a basis for further development of PC social work (PCSW) in Europe. Thirty-two collective members of the EAPC completed an online questionnaire. Social workers (SWs) can be found in all of the PC settings, but there are considerable differences between the countries concerning the prevalence of SWs. Only five countries (20%) reported specialized qualification training in PCSW and just around half of the responding SWs had such a specialized training. The responding SWs were quite content with their working conditions. Tasks concerning patient and family and tasks concerning the interprofessional team were most prominent. There is a significant role overlap with other professions. This study reveals a very mixed picture of PCSW in Europe. **Abstract (w. list of references):** <https://bit.ly/2AGfk0T>



Noted in Media Watch 27 April 2020 (#663, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 April 2020 – ‘**Creating a seat at the table: How family meetings elucidate the palliative care social work role.**’ Palliative care social workers (PCSWs) play a crucial role in optimizing communication and family-centered care for seriously ill patients. However, PCSWs often struggle to demonstrate and receive open acknowledgment of their essential skill set within medical teams. This case discussion focuses on the care of patients and families surrounding family meetings to highlight the crucial role of the PCSW in: 1) Preparing the family; 2) Participating in the provider meeting; 3) Participating in the family meeting; and, 4) Following up after the meeting. **Abstract:** <https://bit.ly/353MYZi>

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Noted in Media Watch 30 May 2020 (#659, p.12):

- **SOCIAL WORK IN HEALTH CARE** | Online – 18 March 2020 – ‘**Hospice social workers’ perception of being valued by the interdisciplinary team and the association with job satisfaction.**’ This study examined the degree to which hospice social workers feel valued by other members of the interdisciplinary team... A non-probability sample of 203 hospice social workers completed an online survey assessing job satisfaction, perception of feeling valued by each of the professionals on the interdisciplinary hospice team, interdependence of team members, and professional and personal characteristics. The final regression model for intrinsic job satisfaction included feeling valued by doctors and by other social workers and interdisciplinary interdependence. **Abstract:** <https://bit.ly/3aa9Xnf>

Noted in Media Watch 25 March 2019 (#607, p.12):

- **SOCIAL WORK IN HEALTH CARE** | Online – 19 March 2019 – ‘**Sitting with silence: Hospital social work interventions for dying patients and their families.**’ Controversy around hospital end-of-life (EoL) care highlights the vulnerability of dying patients and their families. Little is known about how social workers provide support and intervention at the EoL in the hospital. Eight hospital social workers provided qualitative descriptions of their clinical practice for adult patients and their families. Highlighting a theoretical orientation towards a person-in-environment approach, social workers develop unique interventions to contribute to multidisciplinary care. Findings emphasize the need to prepare social work students and clinicians for the reality of working with EoL issues. **Abstract:** <http://bit.ly/2Y9jcyC>

**N.B.** Additional articles on the role of social workers in EoL care noted in this issue of Media Watch.

### Dignity in end-of-life care at hospice: An action research study

**SCANDANAVIAN JOURNAL OF CARING SCIENCES** | Online – 17 May 2020 – Safeguarding the dignity of patients at the end of life (EoL) is a key objective in palliative care practice in Denmark. The concept of dignity and how it influences a dying persons’ quality of life is thus influential in EoL care at hospices. However, what is meant by dignity, how dignity is understood and practiced by healthcare professionals in Danish hospices and whether this relates to the patients’ understandings and needs concerning dignity remains unanswered. Three themes emerged: 1) Being understood; 2) Contributing; and, 3) Holistic care. Deeper analysis indicated that staff understandings of dignity mostly focused on preserving patients’ autonomy, whereas patients expressed needs for relational and spiritual aspects of dignity. Staff were mostly concerned about preserving patients’ autonomy when providing dignity in care, however, through the action-in-praxis they increased their awareness on their own praxis and patients’ needs and understanding concerning dignity. The theoretical model on dignity presented in this study also worked as a map to guide staffs’ reflections on dignity in praxis and facilitated a broader focus on supporting and caring for patients’ dignity in care. **Abstract:** <https://bit.ly/3cKra86>

### 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.

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### 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/2YJZzQt>

[Scroll down to 'Media Watch']

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

PALLIATIVE CARE NETWORK: <http://bit.ly/2Uidk2S>

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?']

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/2RqTvYr>

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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