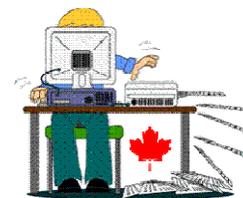


Media Watch...

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

COVID-19: End-of-Life Care

Most of our work is probably going to be through telemedicine and telephone support. That's critical for a couple of reasons. One, it allows us to reach a lot more people. And number two, it allows us to keep our workforce, which is very scarce, healthy.

'Palliative care providers mobilize during COVID-19' (p.2), in *Hospice News*.

Canada

Palliative care in a pandemic: "Patients who are not expected to survive should not be abandoned."

ONTARIO | *The Ottawa Citizen* – 31 March 2020 – Local palliative care (PC) providers are racing to overcome logistical hurdles – acquiring personal protective equipment, training staff, coordinating resources – in order to provide end-of-life care to those people expected to die at home during the COVID-19 pandemic. Ottawa's residential hospices are not accepting COVID-19 patients, but PC is available to people who decide against hospital treatment and want to die at home... PC often involves coordinated visits by home care workers, nurses, family physicians or PC specialists. In the past, those healthcare workers have rarely used personal protective equipment (PPE), but the pandemic makes it a necessity. The problem is that PPE is in short supply, and other homecare and hospital workers are also desperately searching for more protective equipment. Dr. James Downar, head of the division of PC at the University of Ottawa,

called PC a human right for all dying patients. He said it must be maintained – even in the face of a humanitarian crisis. "The current COVID-19 pandemic will likely strain our PC services," said Dr. Downar, a PC physician at The Ottawa Hospital and Bruyère Continuing Care. "But we're not doing our job if we're not preparing for the possibility that we're going to see here what has been seen elsewhere – in places like Italy." Downar and three other physicians offer a plan for hospital-based PC during the pandemic [see below]. <https://bit.ly/39BxFb7>

COVID-19: End-of-Life Care

'Pandemic palliative care: Beyond ventilators and saving lives' (p.9), in *Canadian Medical Association Journal*.

U.S.A.

Palliative care providers mobilize during COVID-19

HOSPICE NEWS | Online – 1 April 2020 – According to the U.S. Centers for Disease Control & Prevention (CDC), people at higher risk for severe illness and complications from COVID-19 are older adults and those with serious underlying medical and comorbid conditions such as cardiac illness, cancer, congestive heart failure, and pulmonary disease. With such diagnoses common among patients who need palliative care (PC), providers are assessing the coronavirus' potential reach and how they can respond to it. "This is our part, our opportunity to deploy our expertise that is the scarce resource of PC," Sean Morrison, MD, chair of the Brookdale Department of Geriatrics & Palliative Medicine at Mount Sinai Medical Center in New York, said in a recent Center to Advance Palliative Care (CAPC) webinar.¹ "We know how to care for these people, and we're going to be called on to do it. We're going to need a frontline workforce that has the knowledge and skills in PC, and we're going to need it right now." With the magnitude of the COVID-19 crisis placing a strain on the healthcare workforce, PC teams nationwide are among the various medical specialties needed now more than ever, according to Diane E. Meier, MD, director of CAPC. "PC care teams are nowhere near large enough to address the suffering in the tens of millions of people who are going to turn to our healthcare sector for help with this virus," Meier said. "Our job is to support our frontline clinician colleagues to gain the core essential skills – whether management of cough, management of shortness of breath, management of anxiety or agitation – in such a manner that even someone who hasn't had any formal PC training can address those sources of suffering effectively." <https://bit.ly/3bVVHPR>

1. 'Briefing: Serious illness, palliative care, and the impact of COVID-19,' Center to Advance Palliative Care, 31 March 2020. **View video at:** <https://bit.ly/3aCEfPL>

Centers for Medicare & Medicaid Services waives hospice rules during pandemic, further expands telehealth

HOSPICE NEWS | Online – 30 March 2020 –The Centers for Medicare & Medicaid Services (CMS) has waived a number of hospice regulations, including temporarily removing the requirement that a nurse conduct a home visit at least every two weeks and expanding the allowable use of telehealth. These flex-

Specialist Publications

'Palliative care skills and new resources for oncology practices: Meeting the palliative care needs of patients with cancer and their families' (p.7), in *American Society of Clinical Oncology Educational Book 40*.

'Developing and testing the feasibility of a culturally based tele-palliative care consult based on the cultural values and preferences of Southern, rural African American and White community members: A program by and for the community' (p.11), in *Health Equity*.

'Forced to choose: When Medicare policy disrupts end-of-life care' (p.12), in *Journal of Aging & Social Policy*.

'Trends in U.S. population interest in palliative care and its association with prevalence of palliative care programs in U.S. states' (p.12), in *Journal of Pain & Symptom Management*.

'Improving medical-legal advance care planning' (p.13), in *Journal of Pain & Symptom Management*.

COVID-19: End-of-Life Care

'Creating a palliative care inpatient response plan for COVID19: The University of Washington Medicine experience' (p.10), in *Journal of Pain & Symptom Management*.

'Goals-of-care in a pandemic: Our experience and recommendations' (p.10), in *Journal of Pain & Symptom Management*.

'Applying palliative care principles to communicate with children about COVID-19' (p.10), in *Journal of Pain & Symptom Management*.

Cont.

ibilities for hospice are components of a larger initiative intended to reduce regulatory burden across the healthcare continuum as providers battle through the ongoing COVID-19 pandemic. The waiver also applies to the rule requiring a nurse to conduct an onsite visit to evaluate whether aides are providing care consistent with the patient's care plan. Further, the agency has waived the requirement that volunteers provide 5% of patient care hours and extended the timeframe for updating a patient's comprehensive assessment to 21 days. The agency will also allow hospice clinicians to conduct visits and provide services via telehealth as long as those activities are consistent with the patient's plan of care. Less clear is whether physicians can certify patients for hospice via telehealth. <https://bit.ly/2UuiDzw>

It's time to get serious about end-of-life care for high-risk Coronavirus patients

TIME MAGAZINE | Online – 30 March 2020 – According to a report ... published in 2017, in the U.S. just 58% of people have had a conversation with their loved ones about end-of-life (EoL) wishes.¹ Only 25% have documented their EoL wishes in the form of an advance directive (AD), and less than 20% discussed those wishes with their healthcare provider. This often leaves families in the incredibly difficult position of making life and death decisions on behalf of their sick loved ones. Ideally, one engages in advance care planning early in life, before a serious illness or medical crisis ensues. But, the reality is, COVID-19 has taken away our control over many things, including, possibly, our final days. In the absence of an AD, an established healthcare proxy or available next of kin, the default approach is aggressive, invasive treatment in the intensive care unit. This traditionally can include placing a thick, hard, plastic tube down your windpipe, inserting needles into your blood vessels, and using machines to maintain your regular bodily functions (a ventilator to help you breathe, a dialysis machine that filters your blood when your kidneys are damaged). In the new era of COVID-19, the protocols aren't as clear. Some hospitals are considering a do-not-resuscitate policy for all infected patients. Bioethicists have weighed in on the need for hospitals to create triage committees, a team of nurses and doctors that evaluate COVID-19 cases and remove the burden of rationing care from the individual providers. Given that we know only a minority of elderly people and those living with serious illnesses who are put on ventilators will survive this pandemic to leave the hospital, this is a reality that must be discussed now. <https://bit.ly/2wNiChc>

1. 'Views and Experiences with End-of-Life Medical Care in the U.S.,' Kaiser Family Foundation and *The Economist*, April 2017. [Noted in 1 May 2017 issue of Media Watch (#510, p.3)] **Download/view at:** <https://bit.ly/2JodN0r>

International

Palliative care for all when the end is approaching is still the national goal

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 3 April 2020 – In 2016 the Scottish Government set out an ambitious, and very welcome, vision that by 2021 everyone who needs palliative care (PC) will have access to it.¹ We are rapidly approaching that time, and despite great efforts we are unlikely to meet that vision. But it is an almost impossible task. PC can include so much and be delivered by so many. It would be impossible to know if everybody living with a terminal illness received all of the care they need, and it is so easy for the smallest most important thing to be missed. However, the ambition is a worthy one. A society that strives to ensure that everyone who will be affected by dying, death and bereavement has the best possible experience,

is one that Marie Curie believes passionately we should be working for. That experience should reflect what is most important to people. Thanks to recent Marie Curie-led research, we are starting to see a developing picture of what care and support for people living with a terminal ill-

COVID-19: End-of-Life Care

'Palliative care pandemic pack: A specialist palliative care service response to planning the COVID-19 pandemic' (p.10), in *Journal of Pain & Symptom Management*.

Cont.

ness will look like in Scotland by 2040.² The number of people dying in Scotland will increase by 7,000 a year to over 65,000 by 2040, with people living longer into their mid-80s.³ By 2040 45% of all deaths will be people over 85. Our dying population will become increasingly older, frailer and living with multi-health conditions, which will create a new level of complexity in the care they will need. Many more people will die with dementia, cancer and/or frailty, as well as other health conditions. Further Marie Curie-led research has shown if current trends continue then two-thirds of Scots will die in the community, either in a care home, their own home or a hospice, but experts have said that this won't happen without significant investment in community services including social care and PC services. <https://bit.ly/2yr9wqJ>

1. 'Strategic Framework for Action on Palliative & End-of-Life Care: 2016-2021,' Scottish Government, December 2015. [Noted in 21 December 2015 issue of Media Watch (#441, p.8)] **Download/view at:** <https://bit.ly/2JBChU1>
2. 'The impact of population ageing on end-of-life care in Scotland: Projections of place of death and recommendations for future service provision,' *BMC Palliative Care*, published online 19 December 2019. [Noted in 16 December 2019 issue of Media Watch (#644, p.8)] **Full text:** <http://bit.ly/2qKez24>
3. 'End-of-life care in Scotland: Trends in the population in need of palliative care.' *International Journal of Population Data Science*, published online 11 June 2018. [Noted in Media Watch 2 July 2018 (#570, p.9)] **Abstract:** <https://bit.ly/2UWXYmJ>

Noted in Media Watch 29 January 2018 (#548, p.7):

- *BMC PALLIATIVE CARE* | Online – 26 January 2018 – '**Palliative and end-of-life care research in Scotland 2006-2015: A systematic scoping review.**' Research output was strong compared with that reported in an earlier Scottish review (1990-2005) and a similar review of Irish palliative care research (2002-2012). A large amount of descriptive evidence exists on living and dying with chronic progressive illness in Scotland; intervention studies now need to be prioritised. Areas highlighted for future research include palliative interventions for people with non-malignant illness and multi-morbidity; physical and psychological symptom assessment and management; interventions to support carers; and bereavement support. **Full text:** <https://bit.ly/3dLJ8lx>

Children's Hospices Across Scotland launches U.K.'s first virtual children's hospice

U.K. (Scotland) | *Third Force News* (Edinburgh) – 31 March 2020 – The U.K.'s first virtual children's hospice has been launched to support children with life-shortening conditions and their families during the Coronavirus outbreak and beyond. The innovative service has been set up by Children's Hospices Across Scotland to help families who are self-isolating or unable to visit a hospice. It will offer nursing, medical and pharmacy-related advice over the 'phone or via video call, as well as bereavement support, money and benefits advice and practical information about the Coronavirus. The service will also provide a storytelling service for children at home, letter writing and other activities for children and parents, and virtual visits from hospice "clowndoctors." <https://bit.ly/2yhZsjO>

China's struggle with hospice care

CHINA | *The New Yorker* – 30 March 2020 – Few cultures relish talking about death, but in China the subject remains taboo. Mentioning it is considered so unlucky that dying people are often reluctant to discuss arrangements with their families or even to make wills. As a result, fewer than a hundred and fifty institutions specialize in end-of-life care, in a country where nearly twenty-per-cent of the population – a quarter of a billion people – is sixty or older. The U.S., with some seventy million people over sixty, has more than fifty-five hundred such institutions. In China, the family has traditionally provided care for the vulnerable... Confucian expectations of filial piety remain strong, but for most Chinese they have become increasingly difficult to fulfill. Dizzying economic expansion has made China's population ever more mobile, and the one-child policy, in force from 1979 to 2015, means that many adults have no siblings with whom to share the burden of caring for relatives. Hundreds of millions of workers who have moved to the

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country's booming cities cannot do much more for aging parents back in remote villages than wire whatever money they can spare. Rural areas also lack adequate public health services. Close to half the population lives in the countryside, but about eighty-per-cent of China's medical facilities are concentrated in cities. Healthcare costs have risen sharply in recent years, and Chinese patients must navigate a byzantine system of government coverage. Most people have basic insurance, but anything beyond routine care usually requires steep out-of-pocket payments. <https://bit.ly/2JCdD5X>

Noted in Media Watch 18 November 2019 (#640, p.13):

- *MEDICINE*, 2019;98(45):e17683. '**Knowledge and attitudes toward end-of-life care among community healthcare providers and its influencing factors in China: A cross-sectional study.**' Community healthcare provider (CHP) attitudes toward end-of-life care (EoLC) were predicted by death attitudes, working experience, experiences of the death of relatives, and experiences of caring for the dying. This suggested that CHP attitudes toward EoLC were influenced by a variety of variables that were not included in this study. Public's insufficient knowledge of EoLC, imperfect medical insurance system, imperfect policies, laws and systems of palliative care, and the lack of localized end-of-life models also influenced CHP attitudes toward EoLC. **Full text:** <http://bit.ly/36SV1sG>

N.B. Additional articles on EoLC in China noted in 29 July 2019 issue of Media Watch (#624, p.11).

How health professionals need to discuss end-of-life situations – during Coronavirus and beyond

U.K. | *The Conversation* – 30 March 2020 – Researchers ... analyse human interaction – how it is structured, and how it functions. This means that besides giving evidence-based advice on difficult conversations relating to Coronavirus, we can also provide some general lessons about how phrases work (and fail). Even with evidence-based advice on which phrases to use in difficult conversations, it is important to remember the importance of context and nuance. For example, one phrase currently recommended by many in the field of healthcare for when the medical judgement is that someone's death is imminent is: "sick enough to die." But it's one thing to read a "key phrase" in published guidance, and quite another to say or hear it in an actual conversation. However appropriate the phrase looks on the page or screen, it might fail utterly when spoken out loud. This is because how a phrase is understood depends crucially on when it is said. A written down phrase can stand alone – a spoken phrase never does. We understand spoken words and phrases in context. Our words will inevitably be heard in the light of what has come beforehand within a conversation, and in the light of the broader circumstances. So the phrase "sick enough to die" will be heard and understood very differently if uttered as part of a conversation between a doctor and an acutely unwell patient (or their family member), than if yelled down the phone when a first responder at an accident is trying to persuade the emergency services to dispatch an air ambulance. Even within the conversation between doctor and patient, precisely when the doctor says "sick enough to die" will shape how it is heard and responded to. <https://bit.ly/2xEpfSU>

Noted in Media Watch 21 October 2019 (#636, p.8):

- *BRITISH MEDICAL JOURNAL* | Online – 16 October 2019 – '**What to say when patients are "sick enough to die."**' Most people value discussion and involvement. The National Survey of Bereaved People and the National Audit of End-of-Life Care in Hospital make that clear, as does the Royal College of Physicians...^{1,2,3} Communication failings and insufficient information are a major cause of bad experiences.⁴ Although we should communicate sensitively, vague euphemisms don't work. Unless you say very clearly that someone is dying, or at very high risk, patients and families are left in limbo. To be clear and direct you need to go back and have [the conversation] as many times as needed for people to come to terms with what can be shocking news.⁵ **Full text:** <http://bit.ly/31nZqzM>

1. 'National Survey of Bereaved People (VOICES): England, 2015: Quality of care delivered in the last 3 months of life for adults who died in England,' Office for National Statistics, April 2016. [Noted in 25 April 2016 issue of Media Watch (#459, p.9)] **Download/view at:** <http://bit.ly/2qfpvUJ>

2. 'National Audit of Care at the End of Life: 2018-2019 Report,' Healthcare Quality Improvement Partnership, July 2019. [Noted in 15 July 2019 issue of Media Watch (#622, p.6)] **Download/view at:** <http://bit.ly/2LhXa9J>

Cont.

3. 'Talking about dying: How to begin honest conversations about what lies ahead,' Royal College of Physicians, October 2018. [Noted in 22 October 2018 issue of Media Watch (#586, p.3)] **Download/ view at:** <http://bit.ly/33zMok9>
4. 'One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in 30 June 2014 issue of Media Watch (#364, p.7)] **Download/view at:** <http://bit.ly/33Cx5HE>
5. 'The Second Conversation Project: Improving training in end-of-life care communication among junior doctors,' *Future Healthcare Journal*, 2019;6(2):129-136. [Noted in 24 June 2019 issue of Media Watch (#619, p.7)] **Full text:** <http://bit.ly/2lqdP8t>

Strategies for improving end-of-life discussions

AUSTRALIA | *Australian Ageing Agenda* – 27 February 2020 – Older people today may be more willing to discuss end-of-life (EoL) treatment preferences than in the past two decades. However, solely focusing on decision-making may burden uninformed patients and distressed caregivers and families. While shared decision-making implies shared responsibility for the best outcome, inadequate communication, complex advance directives and the urge for medicalisation can negatively impact the process. The way forward includes public education on the purpose, harms and benefits of life-sustaining therapies and awareness raising among clinicians about attitudes and interventions that may not be in the patient's best interests. In the absence of a family member or surrogate, clinicians often find themselves having to guess or assume older people's EoL care preferences and goals in non-ideal settings such as the hospital emergency department after flare ups of chronic illness. These discussions tend to manifest as transfer of information about the medical aspects of dying rather than as timely and honest consultations resulting in joint decisions. This means

missed opportunities for timely referral to palliative care, which could minimise preventable harm and preclude the achievement of a good death. <https://bit.ly/33UpDZE>

Extract from *Australian Ageing Agenda* article

Reasons reported in the medical literature for delayed clinician-patient discussions about EoL preferences:

1. Lack of skills or self-confidence in communication;
2. Prognostic uncertainty and lack of recognition of dying trajectory;
3. Apprehension about patient's responses to bad news;
4. Clinicians' lack of time to support patients after sensitive conversations;
5. Perceptions that families cannot accept a poor prognosis; and,
6. Clinicians' sense of failure when patients deteriorate or die under their charge.



[Barry R. Ashpole](#)

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

Specialist Publications

Use of palliative care consultation services for infants with life-threatening conditions in a metropolitan hospital

ADVANCES IN NEONATAL CARE, 2020;20(2): 136-141. Palliative care (PC) is becoming an important component for infants with life-limiting or life-threatening conditions and their families. Yet PC practices appear to be inconsistent and sporadically used for infants. The [patient] population [studied] included 64 infants who were admitted to a level IV neonatal intensive care unit (NICU) and then died during hospitalization between January 2015 and December 2016. Most infants died in an ICU, and only 20 infants (31%) received PC consultation. Most common reasons for consultation were care coordination, defining goals-of-care and end-of-life (EoL) planning, and symptom management. PC consultation at this institution did not change the course of EoL care. Interventions provided by the ICU team to infants surrounding EoL were similar to those in infants receiving PC services from the specialists. The authors' findings may be useful for developing guidelines regarding how to best utilize PC services for infants with

life-threatening conditions who are admitted to an ICU. These findings support continued research in neonatal PC, more specifically the impact of PC guidelines and algorithms. **Abstract:** <https://bit.ly/2yonppN>

Special issue



Neonatal Palliative, End of Life, & Hospice Care Across Multiple Settings

Journal contents page: <https://bit.ly/2UP5r7n>

Palliative care skills and new resources for oncology practices: Meeting the palliative care needs of patients with cancer and their families

AMERICAN SOCIETY OF CLINICAL ONCOLOGY EDUCATIONAL BOOK 40 | Online – 26 March 2020 – In its 2017 guideline, the society challenged members to integrate palliative care (PC) into their standard oncology practices for all patients, throughout their cancer trajectory. However, partnering with PC experts alone will not be enough to achieve that goal; there are too few experts now, and there will not be enough in the future to meet the needs of patients with cancer and their families. Other strategies are required. Oncologists can develop new communication skills that were not included in their fellowship curricula, skills that integrate into their visits the subjects that PC clinicians discuss routinely with patients referred to them. This review offers three questions matched to communication skills that can help oncologists explore key areas: 1) What is happening?; 2) How do you (and I) feel?; and, 3) What is important? ... and discusses the “REMAP” strategy for making urgent medical decisions. The authors review the impact of community-based PC resources and telehealth on care quality, patient centeredness, and reducing costs. **Full text:** <https://bit.ly/3dlpxZl>

Noted in Media Watch 1 May 2017 (#510, p.6):

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 26 April 2017 – ‘**REMAP: A framework for goals-of-care conversations.**’ Conversations regarding goals-of-care with patients who have advanced cancer still occur too late, and oncologists say they lack the training to have these conversations effectively. Experts recommend a number of strategies when having these discussions, including discussing prognosis, responding to patient emotion, exploring values, and often making a recommendation for medical treatments that fit those values. The authors developed a framework with a mnemonic, REMAP: Reframe, Expect emotion, Map out patient goals, Align with goals, and Propose a plan. **Full text:** <https://bit.ly/2QXZV1h>

A mixed methods investigation of end-of-life surrogate decisions among older adults

BMC PALLIATIVE CARE | Online – 2 April 2020 – Participants were more inclined to accept a life-saving treatment for others than for themselves... This is concurrent with participants reporting they did not want to lose their partner and felt that they should give them a chance of living. The authors found discrepancies between surrogates' choices and those made by the recipient, indicating evidence of surrogate inaccuracy. However, these results alone do not indicate whether participants intended to go against their partner's wishes: some might have made a best-informed guess from their knowledge of their partner but got it wrong, whereas others could have known what their partner wanted but chose to make a different decision. Indeed, surrogates reported taking a variety of perspectives to inform their decision-making. Nevertheless, the majority of surrogates intended to decide according to their partner's wishes and held beliefs that aligned with the ethical underpinnings of the substituted judgment standard. Most participants held the view that they would rather die than end up with a severely compromised quality of life, and showed that they knew their partner did too. Crucially, this indicates that the source of surrogate inaccuracy might not reside in the fact that surrogates misjudged their partners' preferences concerning the choice outcomes, but rather that they misjudged their risk preferences. **Full text:** <https://bit.ly/34eOWWE>

Related:

- *PALLIATIVE MEDICINE* | Online – 1 April 2020 – **'Managing uncertainty and references to time in prognostic conversations with family members at the end of life: A conversation analytic study.'** Requests for prognostic information were initiated by families in the majority of conversations. Clinicians responded using categorical time references such as "days," allowing the provision of prognostic estimates without giving a precise time. Explicit terms such as "dying" were rare during prognostic discussions. Instead, references to time were understood as relating to prognosis. Relatives displayed their awareness of prognostic uncertainty when requesting prognostic information, providing clinicians with "permission" to be uncertain. **Abstract (w. list of references):** <https://bit.ly/2JwY15>

Noted in Media Watch 9 March 2020 (#656, p.2):

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 24 February 2020 – **'Factors associated with physician moral distress caring for hospitalized elderly patients needing a surrogate decision-maker: A prospective study.'** When working with surrogate decision-makers, physicians often encounter ethical challenges that may cause moral distress which can have negative consequences for physicians. Moral distress occurs more frequently when the physician is male, the patient is older or requires decisions about life-sustaining treatments. These findings may help target interventions to support physicians. Prior discussions about patient wishes is associated with lower distress and may be a target for patient-centered interventions. **Abstract (w. list of references):** <https://bit.ly/38kb8Pu>

Noted in Media Watch 3 February 2020 (#651, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 January 2020 – **“Please keep mom alive one more day.”: Clashing directives of a dying patient and her surrogate.** Medical care providers are legally and ethically bound to respect their patient's wishes. As patients lose decision-making capacity at end of life, families or surrogates, who are confronted with grief, fear, self-doubt, and/or uncertainty, may ask physicians to provide treatment which contradicts the patients' previously-stated wishes. The authors discuss the legal and ethical issues surrounding such requests, and provide guidance for clinicians to ethically and compassionately respond – without compromising their professional and moral obligations to their patients. **Abstract (w. link to references):** <http://bit.ly/2Ui35iW>

Young adults with life-limiting or life-threatening conditions: Sexuality and relationships support

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 2 April 2020 – The research project addressed the need to support young adults with issues relating to sexuality and relationships through the development of guidance and standards for practice. Sixteen young adults with life-limiting or life-threatening conditions aged 21-33 years participated in the study. Three significant themes were identified: 1) Sexuality and the

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transition to adulthood; 2) Recognising the significance of sex and relationships; and, 3) Realising sexual rights. Sexuality and relationships play an important role in the transition to adulthood for people with life-limiting or life-threatening conditions living in the U.K. While young adults with these conditions may have considerable support needs, it is important to balance this with the freedom to exercise choice and to make independent decisions. Sex negativity can have an adverse impact on the experiences of young adults and creates barriers. Improved ongoing access to sex education and the provision of enabling environments that afford privacy and safety are important to support young adults with sexuality and relationships. **Abstract:** <https://bit.ly/345fJVg>

U.K. palliative medicine trainees and multisource communication skills feedback: An educational tool?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 31 March 2020 – Multisource feedback provides ratings of a trainee doctor's performance from a range of assessors and enables 360 degree feedback on communication skills and team working behaviours. It is a tool used throughout palliative medicine training in the U.K. There are limited data, however, on the value of multisource feedback from a palliative medicine trainee perspective. A multimodal study encompassing a focus group and questionnaire was mailed to all deanery palliative doctors. Over half of responding trainees thought multisource feedback had little or no impact on their clinical practice. Improvements in delivery of multisource feedback to maximise learning were identified, including skilled feedback and facilitation by educational supervisors. **Abstract:** <https://bit.ly/3blVi35>

Hospice advice and rapid response service for ambulance clinicians

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 27 March 2020 – Patients in the last year of life experience medical emergencies which may lead to an emergency attendance by ambulance clinicians and some patients having a transfer to hospital even when this is unwanted by patients, carers or professionals. The authors report the patient characteristics and outcomes of a 24-hour hospice nursing telephone advice service to support an ambulance service. Forty-five attendances of 44 acutely ill people with palliative care (PC) needs resulted in a telephone call. Thirty-two attendances (71%) were managed without a transfer to hospital, with telephone advice from the hospice and in some cases arrangements for another clinician to visit. Seven attendances (16%) resulted in a transfer to hospital, of which at least five led to an admission. Six attendances (13%) resulted in a notification of the patient's death. This preliminary study shows the feasibility, outcomes and acceptability of telephone advice to support ambulance clinicians attending patients with PC needs. The service was associated with low rates of subsequent transfer to hospital. Further controlled research is needed to assess the clinical and cost-effectiveness of the service. **Abstract:** <https://bit.ly/2V0bE0z>

COVID-19

Pandemic palliative care: Beyond ventilators and saving lives

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 31 March 2020 – The severe acute respiratory syndrome Coronavirus 2 (SARSCoV-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

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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 (click on pdf icon):** <https://bit.ly/3437WY7>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 April 2020 – ‘**Palliative care pandemic pack: A specialist palliative care service response to planning the COVID-19 pandemic.**’ The Waikato DHB Palliative Care Pandemic Pack has been developed to aid colleagues in providing essential palliative care (PC) ... in a variety of locations. It may be useful as an example to the wider specialist PC services community to support enhanced PC provision in this global challenge. There is limited information on the role of specialist PC services in this crisis, and even less information on how to practically support non-PC medical colleagues. This tool provides a starting point to enable colleagues to develop similar resources in their own communities. **Full text:** <https://bit.ly/2UXojkB>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 March 2020 – ‘**Creating a palliative care inpatient response plan for COVID19: The University of Washington Medicine experience.**’ The COVID19 pandemic has driven rapid change management for many healthcare settings nationally. These rapid changes have caused many healthcare systems ... to move from conventional capacity, to contingency capacity delivery in a matter of weeks. It is important to develop a strategy for delivery of palliative care in both the contingency capacity and crisis capacity. This document details the University of Washington Medicine’s experience with Palliative Care Response Planning and offers this approach for other institutions to adopt and adapt to their local setting. **Full text:** <https://bit.ly/3bJNfTC>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 March 2020 – ‘**Applying palliative care principles to communicate with children about COVID-19.**’ Children are seeing rapid changes to their routines and facing an unpredictable future. Palliative care (PC) teams may consider expanding their communication training and skill sets to help families consider caring ways to communicate with their children and grandchildren about the coronavirus. PC teams are wise to encourage families to ground their communication with children on key values: honesty and trust, self-compassion, safety, sensitivity, connection, preparedness, community-building, recognition of death as a part of the lifecycle, and legacy. **Full text:** <https://bit.ly/39yA2vh>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 March 2020 – ‘**Goals-of-care in a pandemic: Our experience and recommendations.**’ The authors propose that the palliative care (PC) team response will occur in two waves: first communication and second symptom management. Their experience with discussing goals-of-care with the family of a COVID positive patient highlights some expected and unexpected challenges. They describe these challenges along with recommendations for approaching these conversation ... [and] ... also propose a framework for proactively mobilizing the PC workforce to aggressively address goals of care in all patients, with the aim of reducing the need for rationing of resources. **Full text:** <https://bit.ly/2Jsy18d>
- *PULSE* | Online – 30 March 2020 – ‘**End-of-life care during COVID-19: Tips for GPs.**’ The aims of a COVID-19 palliative care plan in primary care are to: 1) Continue to support non-COVID-19 patients at the end of life in the community; 2) Anticipate the discharge of, and provide care to dying patients with COVID-19 in their preferred place of care; 3) Support families and communities who may need enhanced support including bereavement; and, 4) Play a part in supporting local health economies and specialist colleagues and to ensure a safe approach for staff by minimising the risk of infection during home visits when absolutely essential. The key message is: Think ahead – be proactive: create, update, and share more advance care plans for vulnerable patients. **Full text:** <https://bit.ly/3aviPUW>

When can Muslims withdraw or withhold life support? A narrative review of Islamic juridical rulings

GLOBAL BIOETHICS, 2020;31(1):29-46. When it is ethically justifiable to stop medical treatment? For many Muslim patients, families, and clinicians this ethical question remains a challenging one as Islamic ethico-legal guidance on such matters remains scattered and difficult to interpret. In light of this gap, the authors conducted a systematic literature review to aggregate rulings from Islamic jurists and juridical councils on whether, and when, it is permitted to withdraw and/or withhold life-sustaining care. A total of 16 *fatwās* were found, 8 of which were single-author rulings, and 8 represented the collective view of a juridical council. The *fatwās* are similar in that nearly all judge that Islamic law, provided certain conditions are met, permits abstaining from life-sustaining treatment. Notably, the justifying conditions appear to rely on physician assessment of the clinical prognosis. The *fatwās* differ when it comes to what conditions justify withdrawing or withholding life-sustaining care. The authors' analyses suggest that while notions of futility greatly impact the bioethical discourse regarding with holding and/or withdrawal of treatment, the conceptualization of futility lacks nuance. **Full text:** <https://bit.ly/2Jor1KQ>

N.B. Additional articles on the Islamic perspective on end of life, and on palliative and end-of-life care, noted in 2 March 2020 issue of Media Watch (#655, p.3).

Developing and testing the feasibility of a culturally based tele-palliative care consult based on the cultural values and preferences of Southern, rural African American and White community members: A program by and for the community

HEALTH EQUITY, 2020;4(1):52-83. The aim of this study was to develop a culturally based palliative care tele-consult for and by rural, southern African American, and White communities and to test the feasibility of implementation. The program was feasible to both develop and implement. The main implementation challenge was the lower than expected referral by hospitalists. Although this improved after a change in protocol in which they were texted when a patient was eligible, it is clear that getting full buy-in from hospitalists, in addition to leadership and nurses, is essential in conducting hospital-based studies in small, rural hospitals. This study is the first in the U.S. to have developed an ethnic-group specific, culturally based palliative consult intervention by and for rural, southern White and Africans elders with serious illness. **Full text:** <https://bit.ly/2wHWXal>

Better understanding the importance of palliative care for pediatric patients

JAMA ONCOLOGY | Online – 2 April 2020 – Pediatric and adult palliative care (PC) programs have seen tremendous growth in the last two decades. We are beginning to understand critical aspects of adult PC delivery, namely that it matters how, when, and why PC is delivered. Temel *et al* showed increased survival for patients receiving PC for non-small cell lung cancer.¹ In 2019, Sullivan and colleagues demonstrated that PC services were associated with prolonged survival when the first date of services was 31 to 365 days after a patient's diagnosis.² The ensuing discussion and editorials critically explored how patients, families, and clinicians value quantity vs quality of life. A key question of interest: is quantity of life necessarily the goal?

Abstract: <https://bit.ly/345XqPy>

Sustainable care for children with cancer: A Lancet Oncology Commission

THE LANCET ONCOLOGY, 2020;21(4):e185-e224. The authors estimate that there will be 13.7 million new cases of childhood cancer globally between 2020 and 2050. At current levels of health system performance (including access and referral), 6.1 million (44.9%) of these children will be undiagnosed. Between 2020 and 2050, 11.1 million children will die from cancer if no additional investments are made to improve access to healthcare services or childhood cancer treatment. Of this total, 9.3 million children (84.1%) will be in low-income and lower-middle-income countries (LMICs). Most LMICs do not have properly developed and implemented palliative care programmes. Inadequate pain control is at the core of deficient palliation in LMICs, where pain management can be available in less than 50% of paediatric oncology units and high-potency opiates and adjuvant medications for neuropathic pain are available in less than 15% of LMICs. **Full text:** <https://bit.ly/2QZeBgF>

Cont.

1. 'Prolonged survival with palliative care. It is possible, but is it necessary?' *JAMA Oncology*, published online 19 September 2019. [Noted in 23 September 2019 issue of Media Watch (#632, p.11)] **Abstract:** <http://bit.ly/2m6ddfh>
2. 'Association of early palliative care use with survival and place of death among patients with advanced lung Cancer receiving care in the Veterans Health Administration,' *JAMA Oncology*, 2019;5(12):1702-1709. **Abstract:** <https://bit.ly/2V1nffs>

Related:

- *PALLIATIVE MEDICINE* | Online – 31 March 2020 – ‘**A mixed-methods systematic review and meta-analysis of barriers and facilitators to paediatric symptom management at end of life.**’ Sixty-four studies of medium-low quality were included. Themes were generated encompassing barriers/facilitators experienced by carers (treatment efficacy, treatment side effects, healthcare professionals’ attitudes, hospice care, home care, families’ symptom management strategies) and healthcare professionals (medicine access, treatment efficacy, healthcare professionals’ demographics, treatment side effects, specialist support, healthcare professionals’ training, health services delivery, home care). Only one study included patients’ views. **Abstract (w. list of references):** <https://bit.ly/3bJV1wv>

Forced to choose: When Medicare policy disrupts end-of-life care

JOURNAL OF AGING & SOCIAL POLICY | Online – 29 March 2020 – In the last six months of life, 30% of Medicare beneficiaries [in the U.S.] use the skilled nursing facility (SNF) benefit for post-acute care after a hospital stay. Frequently, the circumstances that indicate a need for SNF care are the same as those of a worsening illness trajectory such as functional decline and falls, unstable health conditions, and pain and other symptoms. The following case example and narrative discussion describes the national implications of this issue and the need for Medicare policy changes that allow for concurrent rehabilitative care and hospice services. **Abstract:** <https://bit.ly/2UTP2hW>

Trends in U.S. population interest in palliative care and its association with prevalence of palliative care programs in U.S. states

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 30 March 2020 – Since the authors published the article about the knowledge of palliative care (PC) in the U.S.,¹ there has been increased attention to the inadequate public awareness and need of promotion strategy to improve the use of PC. In the U.S., the utilization of PC programs has increased significantly since the implementation of the Benefits Improvement & Protection Act and now more than 70% of US hospitals have PC programs.^{2,3} Despite this impressive growth, it has been reported that millions of Americans with serious illnesses still experience difficulty in access to PC in their communities. **Abstract (w. link to references):** <https://bit.ly/3awAjA5>

1. 'Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey,' *Journal of Pain & Symptom Management*, published online 25 March 2019. [Noted in 1 April 2019 issue of Media Watch (#608, p.12)] **Abstract (inc. link to references):** <http://bit.ly/2JCTteG>
2. 'Utilization pattern and service settings of palliative care for patients with metastatic non-small cell lung cancer,' *Cancer*, 2019;125(24):4481-4489. **Abstract:** <https://bit.ly/3aAatLF>
3. 'America's Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals,' Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. [Noted in 5 October 2015 issue of Media Watch (#430, p.14)] **Download/view at:** <https://reportcard.capc.org/>



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 beginning on p.15.

Improving medical-legal advance care planning

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 30 March 2020 – The importance of advance care planning (ACP) has been increasingly recognized by health systems. However, 46-76% of patients report engaging in ACP with lawyers, while only a minority report doing so with physicians. In the U.S., ACP with lawyers focuses on advance directive documents, naturally occurs outside of healthcare contexts, and is often uninformed by the clinical context, such one's prognosis and clinical trajectory. These forms are regularly stored at home or at a lawyer's office and not available at the bedside when needed in a medical crisis. Yet, in contrast to clinicians, lawyers hold sophisticated knowledge about their states' advance directive law. Lawyers may also understand clients' socio-economic context and plans more broadly, which are known to be critical for contextualizing and personalizing patient care but are often not well-captured in healthcare. Aligning medical and legal approaches to ACP is important to ensuring the quality and value of those efforts. As an important first step toward this goal, the authors convened an interprofessional panel of medical and legal experts to elucidate the state of medical-legal ACP and begin to identify strategies to improve and align practices within and across professions. This article describes the historical disconnects between the medical and legal practice of ACP, recommendations and products of the interprofessional panel, and recommendations for future medical-legal collaboration. **Abstract (w. link to references):** <https://bit.ly/3bJSQsP>



End-of-life care's ongoing evolution

PROFESSIONAL CASE MANAGEMENT, 2020;25(3):111-131. Continuing shifts in society's cultural landscape, ongoing emphasis on value versus volume, and other industry fiscal imperatives continue to evoke an evolution in end-of-life care (EoLC). The attainment of successful outcomes by professional case managers with those populations will be dependent on awareness and comprehension of regulations, legislation, and reimbursement; the influences of ongoing industry trends; availability of emerging resources; and, ongoing technological advances. Ethical excellence remains at the core of case management across the interprofessional workforce and the transitions of care. The professional case management workforce is tasked to effectively intervene across diverse client populations, with their caregivers and support systems. This action spans every life stage and illness course. With EoLC treatment and processes continuing to receive prime industry attention, case managers must be knowledgeable of the moving parts of this arena. Awareness of the ethical edges of each professional's sandbox is essential to quality-driven case management practice. **Abstract:** <https://bit.ly/2X5fzeW>

Challenges in conducting a multiple qualitative case study approach of communication experiences in the care of children with palliative care needs

RESEARCH METHODS CASES: MEDICINE & HEALTH | Online – Accessed 29 March 2020 – This study is unique as it applies a qualitative collective case study approach that yields a rich and in-depth understanding of the experiences of communication from more than one perspective. It was underpinned by the interpretative constructivist approach that guided the analysis and accepts more than one interpretation of reality as viewed by the participants. The study was conducted in three pediatric units in a Jordanian hospital. Each case comprised a child aged 1-12 years, their most involved family carer (mothers), physician(s), and nurse(s). Two data collection methods were employed, participant observation and semi-structured interviews, with three categories of participants: mothers, physicians, and the nurses who cared for the children that participated in this study (children were involved in the participant observation; however, they were not interviewed). The author decided to avoid interviewing children in this study to avoid any potential harm to them. **Abstract:** <https://bit.ly/2QVImib>



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“My life’s properly beginning.”: Young people with a terminally ill parent talk about the future

SOCIOLOGY OF HEALTH & ILLNESS | Online – 3 April 2020 – The author argues that young people are able to move imaginatively beyond the death of a parent, and in doing so, to maintain a sense of biographical continuity. While thinking about the future, most [participants in this study] were able to generate an alternative to the “harm story” typically associated with parental loss. Furthermore, the facility to engage with parental absence in the present enabled young people to make sense of living with dying, and gave meaning to their imagined futures. These findings suggest that young people’s narratives of the future may act as a symbolic resource to draw on, albeit one requiring adequate material and social resources to construct. The author extends the notion of continuing bonds derived from post-bereavement accounts to suggest that relational experiences of the dead begin prior to bereavement, and may facilitate everyday living in anticipation of significant loss. Enabling young people to imaginatively explore the future may support them in getting by when they are living in these difficult family circumstances. **Full text:** <https://bit.ly/2X6arr1>

Caregiving and bereavement in palliative care: A cross-cultural study between Brazil and Portugal

TRANSCULTURAL PSYCHIATRY | Online – 26 March 2020 – Caregiving and bereavement outcomes are strongly influenced by socio-cultural context. This study compared Brazilian and Portuguese family caregivers (FCGs) in palliative care to identify differences in psychological morbidity and caregiver burden and their relationship with psychosocial factors such as socio-demographic variables, circumstances of end-of-life care and dying, social support, family functioning, and perception of quality of care. In both countries, FCGs devoted most of their day to taking care of their sick relatives and reported a lack of practical support. Portuguese caregivers had higher levels of burden than Brazilian caregivers, and in both populations a greater burden was associated with more psycho-pathological symptoms. Higher caregiver burden among Portuguese caregivers was associated with the circumstances of death and the perceived lack of emotional support. Among Portuguese caregivers, symptomatology persisted during bereavement, reaching significantly higher levels of anxiety, somatization, and peritraumatic symptoms compared to the Brazilian sample. Understanding the underlying cultural patterns and mechanisms requires future research. **Abstract (w. list of references):** <https://bit.ly/3ayO7tU>

Publishing Matters

Faculty knowledge and attitudes regarding predatory open access journals: A needs assessment study

JOURNAL OF THE MEDICAL LIBRARY ASSOCIATION, 2020;108(2):208-218. The purpose of predatory open access (OA) journals is primarily to make a profit rather than to disseminate quality, peer-reviewed research. Publishing in these journals could negatively impact faculty reputation, promotion, and tenure, yet many still choose to do so. Therefore, the authors investigated faculty knowledge and attitudes regarding predatory OA journals. 183 faculty completed the survey: 63% were university and 37% were medical faculty. Nearly one-quarter (23%) had not previously heard of the term “predatory OA journal.” Most (87%) reported feeling very confident or confident in their ability to assess journal quality, but only 60% correctly identified a journal as predatory, when given a journal in their field to assess. Survey results show that faculty recognize predatory OA journals as a problem. To date, most of the literature on predatory OA journals has been opinion-based (editorials, commentaries, news items, and so on), aimed at raising awareness of and cautioning against publishing in predatory OA journals. Numerous investigations of faculty attitudes regarding OA in general have been published, many revealing a general skepticism toward legitimate OA journals. Only a handful of investigations have focused on predatory OA journals specifically, often assessing faculty attitudes; fewer still have tested faculty knowledge of predatory OA journals directly. Libraries currently do and will continue to play a pivotal role in educating users about predatory OA journals. **Full text:** <https://bit.ly/2xPYB9G>

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.

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