

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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It is imperative that we capture, understand, and learn from this work, and ensure that evidence informs policy for end-of-life care through the next phases of COVID-19 and beyond.

'End-of-life care during COVID-19: The central role of primary care must not be overlooked' (p.5), in *BJGP Life*.

Canada

The financial case for palliative care

BRITISH COLUMBIA | *The BC Catholic* (Vancouver) – 5 November 2020 – The federal Parliamentary Budget Office (PBO) recently examined Bill C-7, which would amend the Criminal Code of Canada by further expanding euthanasia access to pretty much anyone who wants it – proximity to death no longer being a prerequisite. The PBO report notes that while the Criminal Code is federal jurisdiction, the costs of healthcare delivery are provincial and there is money to be saved by expanding access to euthanasia by cutting healthcare costs for the provincial governments.¹ The report is quick to point out it's not making the case for cost-cutting through death, since the savings would be negligible considering the staggering size of provincial healthcare budgets. To its credit, the report also has quite a bit to say about palliative care (PC) and how much money could be saved if it were more widely available. It cites medical literature that says PC could reduce end-of-life healthcare costs by 40-70%. The

report also notes the difficulty of getting information on how many patients are receiving PC when they request euthanasia. Sadly, despite the report's numerous references to PC, mainstream news coverage contained not a word about end-of-life care. Instead, the typical news story resembled a cost-benefit analysis, focusing on the number of increased deaths versus the savings. Not that this should come as any surprise. Not a single media outlet outside of Canada's Catholic press has yet reported on Canada's 'First annual Report on Medical Assistance in Dying in Canada 2019.'² <https://bit.ly/3p25MSm>

Specialist Publications

'Burnout and resilience among Canadian palliative care physicians' (p.6), in *BMC Palliative Care*.

1. 'Cost Estimate for Bill C-7: Medical Assistance in Dying,' Parliamentary Budget Officer, October 2020. [Noted in Media Watch 26 October 2020 (#689, p.1)] **Download/view at:** <https://bit.ly/3ocsk2D>
2. 'First annual report on medical assistance in dying (MAiD) in Canada, 2019,' Government of Canada, July 2020. [Noted in Media Watch 3 August 2020 (#677, p.2)] **Download/view at:** <https://bit.ly/39s9Tjt>

U.S.A.

Study examines trends in symptoms experienced at the end of life

CONNECTICUT | *Medical Xpress* – 4 November 2020 – A new analysis ... indicates that fewer older adults may be experiencing certain symptoms that can restrict their activity at the end of life (EoL).¹ The analysis examined information on 665 individuals in Connecticut who were aged 70 years or older when they died between 1998 and 2019. Investigators assessed the occurrence of 16 restricting symptoms within 6 months of death during monthly interviews. From 1998 to 2019, rates decreased for 5 restricting symptoms (difficulty sleeping, chest pain or tightness, shortness of breath, cold or flu symptoms, and nausea, vomiting, or diarrhea), increased for 3 (arm or leg weakness, urinary incontinence and memory or thinking problem), and changed little for the other 8 (poor eyesight, anxiety, depression, musculo-skeletal pain, fatigue, dizziness or unsteadiness, frequent or painful urination and swelling in feet or ankles). “Based on our results, the occurrence

of most restricting symptoms at the EoL has been decreasing or stable over the past two decades,” said lead author Thomas M. Gill, MD, of the Yale School of Medicine. “These results suggest that EoL care has been improving, although additional efforts will be needed to further reduce symptom burden at the EoL.” <https://bit.ly/32cbZS2>

Specialist Publications

‘Teaching end-of-life preparation to African Americans’ (p.10), in *Palliative & Supportive Care*.

‘U.S. medical and surgical society position statements on physician-assisted suicide and euthanasia: A review’ (p.11), in *BMC Medical Ethics*.

1. ‘Trends in restricting symptoms at the end of life from 1998 to 2019...,’ *Journal of the American Geriatric Society*, published online 3 November 2020. **Abstract:** <https://bit.ly/388wZwH>

Concurrent hospice care demo yields \$26 million in cost savings

HOSPICE NEWS | Online – 3 November 2020 – The U.S. Centers for Medicare & Medicaid Services’ Medicare Care Choices Model (MCCM) demonstration has reduced the agency’s costs by \$26 million to date. The demonstration, established in 2016 and scheduled to end in June 2021, is designed to test the efficacy and efficiency of providing hospice concurrent with curative care. The agency attributed most of the savings to associated reductions in acute care utilization. The report also found that more MCCM patients elected the Medicare Hospice Benefit than their counterparts outside of the program. The MCCM participants tended to enter hospice earlier by about a week on average. <https://bit.ly/3jXzqVp>

N.B. Link to U.S. Centers for Medicare & Medicaid Services’ report embedded in *Hospice News* article.



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>

International

Prisoners “dying from poor care”

U.K. (England & Wales) | *Inside Time* – 2 November 2020 – A report by nurses’ leaders and an official watchdog found the average age of someone dying from natural causes was 56 in prison, compared with 81 in the general population.¹ It warned residents’ chronic long-term conditions were being poorly managed in jails, and concluded: “Evidence suggests many of these deaths are preventable.” The report called for: 1) A better system for escorting prisoners to hospital appointments, so that fewer are cancelled; 2) Better use of “medical holds” to ensure continuity of care for sick prisoners; 3) An overhaul of the compassionate release process to make it “transparent, timely and fair”; and, 4) Better transfer of information when patients enter and leave custody. Deaths of prisoners in England & Wales from natural causes rose from 114 in the year to June 2010 to 179 in the year to June 2020 (including 23 with COVID-19). Ann Norman, professional lead for criminal justice at the Royal College of Nursing said: “We are seeing a growing number of natural deaths in custody and this has now reached an unacceptably high level. These deaths may be prevented if there is adequate care, particularly for those prisoners with long-term chronic conditions.” <https://bit.ly/34RCfmk>

1. ‘Avoidable natural deaths in prison custody: Putting things right,’ Independent Advisory Panel (IAP) on Deaths in Custody and the Royal College of Nursing (RCN), September 2020. **Download/view at:** <https://bit.ly/387xneZ>

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

Extract from AP & RCN report

The prison estate has limited provision for specialist long-term care and end-of-life (EoL) healthcare, although the Prisons & Probation Ombudsman noted that an increasing number of prisons are building palliative care cells or units for prisoners who require specialist EoL care and a number of prisoners have died in these specialist units.

N.B. See section on PC beginning on p.16.

Specialist Publications

‘Home-based palliative care management: What are the useful resources for general practitioners? A qualitative study among GPs in France’ (p.5), in *BMC Family Practice*.

‘Caregiving adult children’s perceptions of challenges relating to the end of life of their centenarian parents’ (p.11), in *Scandinavian Journal of Caring Sciences*.

Specialist Publications

Palliative care in nephrology: The work and the workforce

ADVANCES IN CHRONIC KIDNEY DISEASE, 2020;27(4):350-355. Kidney palliative care (PC) is a growing subspecialty of clinical practice, education, and research in nephrology. It is an essential aspect of care for patients across the continuum of advanced kidney disease (AKD) who have high symptom burden, multidimensional communication needs, and limited life-expectancy. Training in kidney PC can occur in a variety of ways, from didactic curricula and clinical experiences embedded in nephrology fellowship training to the pursuit of additional dedicated fellowship training in PC. At this time, a minority of nephrologists pursue formal fellowship training in specialty PC. This article discusses opportunities and challenges in building a skilled workforce that will address the palliative needs of patients living with AKD. **Full text:** <https://bit.ly/3kPTv0N>

N.B. Additional articles on PC for people living with kidney disease noted in Media Watch 23 March 2020 (#658, p.5).

A multicenter qualitative analysis of medical student narratives after a palliative care elective

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 4 November 2020 – The medical student experience of a clinical elective in palliative care (PC) remains understudied. Reflective narrative interventions can help students hone narrative competency skills, make sense of their clinical experiences, and shed light on their perception of the rotation. Students were asked to write a short reflective essay after PC clinical electives using open-ended writing prompts. Thirty-four essays were analyzed and four major themes emerged: 1) Reflection on the mission of medicine or motivation for being in medicine; 2) Reflection on professional skills or lessons learned; 3) Reflection on patient's experience; and, 4) Personal responses to PC rotation. Sub-themes were also identified. Themes underscore the utility of the PC clinical elective as a meaningful experience that imparts useful skills, builds empathy, reminds students of their own motivations for being in medicine and serves as a catalyst for reflection on their own lives and relationships with their patients. Awareness of medical students' personal and emotional responses to a PC elective can help inform educators... **Abstract (w. list of references):** <https://bit.ly/3kYExWr>

Palliative care in Sweden

End-of-life experiences of spiritual nature are reported directly by patients receiving palliative care in a highly secular country: A qualitative study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 October 2020 – Patients with life-threatening diseases have reportedly end-of-life (EoL) experiences that are perceived positively. Loved ones and healthcare personnel may mistakenly interpret the phenomena as confusion and patients can be reluctant to talk about it due to fear of ridicule. Studies addressing patients directly are scarce and there is a lack of studies from highly secular countries. The aim of this study was to establish whether EoL experiences are present among patients, oriented in time, place and person and receiving palliative EoL care in one of the world's most secular countries. If present, to examine the content and patients' subjective experiences. Four themes were identified: 1) Vivid dreams while asleep; 2) Experiences while awake; 3) References to medical circumstances; and, 4) communication about EoL experiences. Education for healthcare personnel about EoL experiences is needed in order to support patients and loved ones and not mistakenly medicalize. Further directions for research could be to study the experiences of the phenomenon among healthcare personnel in the same context, which could strengthen the present findings. **Abstract (w. list of references):** <https://bit.ly/3mDBnrJ>

Pediatric palliative care in The Netherlands

Breaking bad news: What parents would like you to know

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 30 October 2020 – This study shows how parents perceive the communication of bad news. Their experiences highlight two main points. First, the experiences of parents mainly concern very "practical" aspects of communication: where conversations happen, who is present, how they are scheduled. Second, from the parents' perspective, communication of bad news often took place far too late. Indeed, in some cases, no such conversations ever took place. This study shows that parents experience a significant number of barriers in the communication of bad news. Their experiences, however, provide an opportunity to improve communication about life-threatening conditions, for example, by being aware that adequate information is disclosed to parents, especially in circumstances of uncertain knowledge. Parents express a need to be informed, even if their child's situation is uncertain. This may be anticipated by having conversations shortly after a condition is classified as life-threatening or by asking parents how much they want to know. Second, parents may be better prepared for the conversation by creating circumstances that empower, rather than overwhelm them – for example, by having regular one-to-one conversations. Good communication matters. It influences good care, and when parents voice dissatisfaction about their children's care, this tends to be about communication, rather than the purely medical aspects of care. By studying the ways in which parents perceive communication of bad news, we can learn how to improve the way in which we communicate when caring for children with life-threatening conditions. Above all, we need to remind ourselves to talk to parents about the future of their child, especially when the prognosis is uncertain. **Full text:** <https://bit.ly/3kMYFej>

End-of-life care during COVID-19: The central role of primary care must not be overlooked

BJGP LIFE | Online – 6 October 2020 – End-of-life care (EoLC) is a hugely important and emotive area of practice where GPs and district nurses have a key role. Prior to the COVID-19 pandemic multiple barriers to the effective provision of such care had already been identified, including insufficient time with patients and families, limited social care and practical support in the community, a lack of education and training for primary care staff, and inconsistent access to both community nursing and specialist palliative care services. Epidemics and pandemics are associated with increased numbers of deaths. Through the COVID-19 pandemic, GPs and district nurses have addressed a vast range of new challenges in community EoLC, including new symptom profiles, changes in the conduct of consultations with the need for personal protective equipment, and an increased number of consultations conducted by telephone or video-conference. There are growing concerns about complex bereavement among family members and the need for support for colleagues, including care home workers. There is a stark lack of pre-existing research into the role and response of primary healthcare services in

the provision of EoLC in the community through pandemics. There is little mention of EoLC in policy and planning documents for primary care services, and it has been mostly overlooked in the news. **Full text:** <https://bit.ly/2Gm5XGT>

Unintended consequences of rapid changes in community palliative care practice

BJGP LIFE | Inprint – Accessed 1 November 2020 – Community palliative care (PC) delivery is changing dramatically in response to the COVID-19 pandemic, especially in several of the worst affected countries. In the U.K. phone and video end-of-life (EoL) consultations have been widely adopted by GPs and PC teams alongside “virtual” care home ward rounds, nurse verification of death and remote death verification and after-death care. Prescribing of EoL care drugs is changing: family caregivers are being encouraged to assume greater involvement in administering medicines... This is a big ask, even when they are well supported and feel able to do so. Care has been radically overhauled in anticipation of a rapid rise in demand for community EoL care that may materialise during the coming months. **Abstract:** <https://bit.ly/35Rf1fr>

Home-based palliative care management: What are the useful resources for general practitioners? A qualitative study among GPs in France

BMC FAMILY PRACTICE | Online – 31 October 2020 – The problems related to the home-based practice of palliative care (PC) by GPs are well known, yet few studies highlight the resources actually used by GPs. This study outlines such resources, including structures (regional assistance networks, Hospitalization at Home), the use of resource personnel (medical, paramedical and family), and schedule organization. A GP's status implies a tacit moral contract that involves managing home-based PC when it is needed. This moral responsibility is more a resource than it is a burden for the GPs who rely on their care values in order to face difficulties. Some important divergences in opinion and resource use were found. These divergences could be due to the relationship between GPs and their patient, to the burnout syndrome and to differences in self-efficacy. In this context, the implementation of multidisciplinary teams such as regional assistance platforms and Hospitalization at Home structures is particularly important for the success of home-based PC practice for patients reaching the end of their life. Home-based PC is complex but fulfilling, and deserves to be recognized by policymakers in accordance with social responsibility, and to the benefit of caregivers, but above all of populations. **Full text:** <https://bit.ly/2HW6T5f>



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

Associations between informal care costs, care quality, carer rewards, burden and subsequent grief: The International, Access, Rights and Empowerment mortality follow-back study of the last 3 months of life (IARE I study)

BMC MEDICINE | Online – 3 November 2020 – The contribution of informal carers (ICrs) is considerable, accounting for around 50% of total care costs. These costs are similar across countries. Training and support interventions for ICrs should target the wide range of activities that they undertake. Increased informal care hours and costs, can lead to more rewards and lesser subsequent grief. Therefore ICrs, including family and friends and beyond one main informal carer, are central at the end of life and should be considered in all interventions. The authors' finding of an association between poor care quality and poorer ICrs outcomes, including greater burden and fewer rewards, suggests an urgent need to improve care quality, through the better integration and support for dedicated community palliative care (PC) services, and support people across the whole journey of care. Improving community PC may improve care value, the care experience for patients and ICrs; increase IC rewards; and, reduce IC burden and formal care costs and should be a focus for investment, including and importantly during the COVID-19 pandemic. **Full text:** <https://bit.ly/2TNcDAG>



N.B. Participants in this study included PC services in England (London), Ireland (Dublin) and the U.S. (New York, San Francisco).

Burnout and resilience among Canadian palliative care physicians

BMC PALLIATIVE CARE | Online – 6 November 2020 – Physician members of the Canadian Society of Palliative Care Physicians and Société Québécoise des Médecins de Soins Palliatifs participated in an electronic survey. More than one third of Canadian palliative care (PC) physicians [i.e., survey respondents] reported high levels of burnout and many of these physicians feel emotionally exhausted and overextended. Higher scores on personal accomplishment, and lower scores on depersonalization highlight that PC physicians may experience a number of protective and resilience-building factors, but these factors need to be contextualized within broader care delivery stressors, related to control over workload, time, resources, and appreciation and respect for the profession of PC. Further research is required in understanding how PC physicians who have been practicing longer in the field have learned to not only build but sustain resilience over time, and importantly what learning can be shared with early and mid-career physicians to further support resilience-building factors at individual, interpersonal and organizational levels. Clearly highlighted is the importance of further study in learning about how PC physicians experience care delivery, the meaning and importance of this work in their lives overall, and how important it is that this learning is translated into policy and practice contexts. **Full text:** <https://bit.ly/2U5k9Hk>

Noted in Media Watch 19 October 2020 (#688, p.10):

- *PALLIATIVE MEDICINE* | Online – 15 October 2020 – ‘**Prevalence of burnout in healthcare professionals providing palliative care and the effect of interventions to reduce symptoms: A systematic literature review.**’ Burnout ranged from 3% to 66%. No major differences in prevalence were found between nurses and physicians. Healthcare professionals providing palliative care (PC) in general settings experience more symptoms of burnout than those in specialised PC settings. Ten studies reported on the effects of interventions aimed at preventing burnout. Interventions based on meditation, communication training, peer-coaching and art-therapy based supervision have positive effects but long-term outcomes are not known. **Abstract (w. list of references):** <https://bit.ly/353qKau>

N.B. Selected articles on burn-out, compassion fatigue, and the well-being and resilience practices in the hospice and PC workforce noted in Media Watch 31 August 2020 (#681, p.8).



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Sikh religion and palliative care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 2 November 2020 – Over time, end-of-life care has been heavily influenced by the systems of religion, ethics and spirituality. The Sikh religion was started by Guru Nanak Dev Ji in 1469. It has a unique philosophical understanding of life, death and God which can be relevant to commonly encountered clinical scenarios. Concepts such as 'Ik-Oankar,' Hukam (God's will), ego and karma all influence how practising Sikhs respond to situations in everyday life. Understanding the spiritual underpinnings of the Sikh religion is therefore important for clinicians caring for this group of patients. This article explores the fundamental concepts of the Sikh religion and how these apply to common scenarios encountered within palliative care. **Full text:** <https://bit.ly/34PR3C7>

The motion of the Italian National Bioethics Committee on Aggressive Treatment Towards Children with Limited Life Expectancy

HEALTHCARE | Online – 1 November 2020 – The motion ... comprises a premise that rejects therapeutic obstinacy and makes 12 recommendations. Recommendation #1 states the general rules: it ascribes a cardinal role to a shared care plan, it supports pain management therapy and pain relief, it opposes ineffective and disproportionate clinical treatment and defensive medicine. The other recommendations are correlated to the enacting of a national law establishing clinical ethics committees in paediatric hospitals; participation of parents and their fiduciaries in the decision-making processes; recourse to courts only as *extrema ratio* in the event of irremediable disagreement between the medical team and the family members; accompaniment at the end of life also through continuous deep sedation combined with pain therapy; access to palliative care; the need to reinforce research on pain and suffering in children; clinical trials and research studies conducted in children; the training of doctors, healthcare personnel and psychologists, to support parents in emotional and practical terms; the facilitation of the closeness of parents to children in extremely precarious clinical conditions; the relevant role of the associations of parents of sick children. Comments are made, in particular, about the innovative recommendations respectively relating to the adoption of care planning, the establishment, by law, of clinical ethics committees in paediatric hospitals and the limitation of recourse to courts – only as *extrema ratio* – in the event of irremediable disagreement between the medical team and the family members. **Full text:** <https://bit.ly/3853wDR>

Pediatric palliative care in the U.K.

Factors influencing nurse retention within children's palliative care

JOURNAL OF CHILD HEALTH CARE | Online – 31 October 2020 – Whilst there are clearly difficulties associated with working with children who are receiving palliative care (PC), one of the key findings from the authors' research was the positivity and passion that staff articulated. Participants thought that those outside of the sector had a more negative view of PC – they felt that this meant that parents may be reluctant to consider a hospice option for their child as they may equate it with end of life. However, study participants highlighted that PC focuses on life and living rather than death and dying; they talked about the available resources and alternative therapies as well as holistic care and having more time to spend with children and their families. In addition, they really valued the relationships between nurses, children and their families as well as feelings of reward and benefit from being able to offer a substantive amount of respite provision. The authors' findings resonate with a range of other literature that acknowledges positive factors that may influence how staff view working in this sector which may, in turn, contribute to staff retention. This research revealed that staff are dedicated, motivated and passionate about their work; however, in order to retain staff in this demanding environment, they require the infrastructure to support their professional development and emotional well-being. Bespoke programmes, such as those offered in this study, offer a possible solution; whilst they are not without financial and resource implications, they have the potential to facilitate the retention of experienced nurses and impact positively on care for children and their families. **Full text:** <https://bit.ly/2GkyZXf>

Cont.

Noted in Media Watch 28 October 2019 (#637, p.4):

- U.K. (England) | Together for Short Lives – 20 October 2019 – ‘**Shortage of nurses and doctors in England hitting care for seriously ill children.**’ A growing shortage of skilled children’s palliative care (PC) doctors and nurses across England has reached crisis point, a new report reveals. It is leading to seriously ill children and their families missing out on crucial out-of-hours care and vital short respite breaks. ‘A workforce in crisis: Children’s palliative care in 2019’ shows a children’s PC workforce at breaking point. Staff shortages are having a direct impact on terminally ill children and their families. Despite being assessed as needing 24-hour support by the National Health Service, some children and young people are not getting around the clock care. **Download/view report at:** <http://bit.ly/33RWkG6>

Changing the culture of pediatric palliative care at the bedside

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 30 October 2020

– The benefits of palliative care (PC) services have been widely documented; however, many organizations are unable to financially support the number of professionals needed to meet the growing demand. Nurses receive minimal training in PC, and the resulting knowledge gap can lead to a lack of confidence when providing the essential aspects of PC. Recognizing the needs of patients and staff, one organization created a Palliative Care Champions Program to support and educate bedside staff. The Champions received initial and ongoing education, allowing them to function as liaisons to the Palliative Care Team while providing education and mentorship to staff. A program evaluation tool measuring Champion comfort and confidence in the provision of PC has shown positive results. Champions reported an increase in confidence in their ability to identify appropriate consults and mentor staff, as well as an increase in comfort in being considered an expert in PC. Consults to the PC service increased by 28% within the first 12 months of program implementation. The Palliative Care Champions Program framework can be easily adapted to fit the needs of other organizations. **Abstract:** <https://bit.ly/3ekTiAx>



Noted in Media Watch 15 July 2019 (#622, p.8):

- *BMC PALLIATIVE CARE* | Online – 11 July 2019 – ‘**The conceptual understanding of pediatric palliative care: A Swiss healthcare perspective.**’ Despite important changes in the formal definition of pediatric palliative care (PPC), it has still an overly negative connotation in the minds of many parents and healthcare providers. Calls have been made to initiate PPC at diagnosis and rebrand the term PPC as supportive or comfort care. Many participants in this study seemed critical about the “from diagnosis onward” directive and clearly associated PPC with non-curative treatment. The adequate timing of PPC remained a challenge. Although the philosophical definition of PPC leaves room for patient individuality, it complicates clinical practice as it does not provide clear protocols. **Full text:** <http://bit.ly/2XGKTSH>

Grieving and hospital-based bereavement care during the COVID-19 pandemic

JOURNAL OF HOSPITAL MEDICINE, 2020;15(11):699-701. COVID-19 related mortality has become a pressing public health issue, and as a result, support for bereaved family members, especially for minority populations, is also an important public health issue. It is likely that bereaved individuals are at greater risk of poor bereavement outcomes during the pandemic – irrespective of whether the death was a result of COVID-19 – because of social isolation. This is particularly true if loved ones died in the hospital and, due to visitor restrictions, faced limited or no visitation. For many, bereavement will be affected by stay-at-home orders and social distancing restrictions that reduce access to emotional support and rituals, such as funerals, that usually provide comfort. Urgent attention is needed to support bereaved individuals, to flatten the curve of mental health disorders associated with the death of loved ones during the pandemic. Within a preventive model of care, the authors offer guidelines for how hospitals, longitudinal providers, and mental health clinicians can provide bereavement outreach to all individuals whose loved ones died during the COVID-19 pandemic. **Full text:** <https://bit.ly/3k0NjJ>

Emerging palliative care innovations in the emergency department: A qualitative analysis of programmatic elements during the COVID-19 pandemic

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 5 November 2020 – Health systems have aspired to integrate palliative care (PC) into the emergency department (ED) in order to improve care quality for over a decade, yet there are few examples of implemented models in the literature. The COVID-19 pandemic led to an increase in the volume of seriously ill patients in EDs and a consequent rapid increase in PC integration in many EDs. The authors interviewed 31 participants, representing 52 hospitals. Several new innovations in care delivery were identified. These included elements of fully embedded PC, the use of PC extenders, technology both within the electronic medical record and outside of it, and innovations in training emergency clinicians in primary PC skills to support care delivery. Most PC efforts focused on increasing goals of care conversations. Institutions that implemented these programs reported that they increased PC utilization in the ED, were well received by clinicians, and changed patient's care trajectories. These innovations may serve as a framework for institutions as they plan for evolving needs in the ED during and after COVID. **Abstract (w. list of references):** <https://bit.ly/3euSZTT>

“Has anything changed since then?”: A framework to incorporate prior goals-of-care conversations into decision making for acutely ill patients

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 1 November 2020 – When in assuming care for a seriously ill hospitalized patient, we find documentation of previous decisions about goals-of-care (GoC), our conversation should take advantage of previous discussions and reduce decision-making burden on the patient, particularly when the patient is clinically declining and time is short. This article presents a framework to help clinicians incorporate prior GoC conversations into decision-making for an acutely ill patient. When there is strong evidence that a previous decision still applies, clinicians should, after a brief check-in about the previous decision with the patient, then present a plan consistent with their previous decision as a default option, to which they can opt out. If there is less evidence of the basis for a previous decision, clinicians should explore the thinking behind the decision and, if there is clarity about patient preferences, propose a treatment plan. If there is conflict or uncertainty about the patient's preferences, clinicians should engage in a more comprehensive GoC conversation, which involves exploring the patient's understanding of their illness patient values, and reasonable treatment options, before offering a plan. By giving the patient the ability to opt out of a previous decision they made about GoC, rather than another choice, we make it more likely that they will receive care consistent with their known wishes. **Abstract (w. list of references):** <https://bit.ly/3ellLpC>

Related:

- *BMC PALLIATIVE CARE* | Online – 2 November 2020 – ‘**Talking about death and dying in a hospital setting: A qualitative study of the wishes for end-of-life conversations from the perspective of patients and spouses.**’ This study revealed that the wish to talk about the end of life (EoL) differed widely between respondents. Impairment to the patients' everyday lives received the main focus, whereas talking about EoL was secondary. Conversations on EoL were an individual matter and ranged from not wanting to think about the EoL to being ready to plan the funeral and expecting the healthcare professionals to be very open about the EoL. The conversations thus varied between superficial communication and crossing boundaries. **Full text:** <https://bit.ly/3812Kb6>

Top ten tips palliative care clinicians should know about implementing a team wellness program

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 November 2020 – Although many wellness efforts have focused on building personal resilience skills for individuals, programmatic approaches to improve a culture wellness are equally important in supporting clinical teams. This article brings together the perspectives of palliative care (PC) leaders with expertise in wellness to collate practical pearls for interventions that impact the culture of well-being in their organizations. In this article, the authors use a 'Top 10' format to highlight the interventions that PC leaders can implement to support the well-being of clinical staff and promote program sustainability. **Abstract:** <https://bit.ly/3k0Fw7k>

Resolving disagreement: A multi-jurisdictional comparative analysis of disputes about children's medical care

MEDICAL LAW REVIEW | Online – 4 November 2020 – Recently, the English courts have dealt with a number high-profile, emotive disputes over the care of very ill children, including Charlie Gard, Alfie Evans... It is perhaps fair to say such cases have become a regular feature of the courts in England. But is the situation similar in other jurisdictions? If not, are there lessons to be learned from these jurisdictions that do not seem to need to call on judges to resolve these otherwise intractable disputes? The authors argue that many of the differences we see between jurisdictions derive from cultural and social differences manifesting in both the legal rules in place, and how the various parties interact with, and defer to, one another. The authors further argue that while recourse to the courts is undesirable in many ways, it is also indicative of a society that permits difference of views and provides for these differences to be considered in a public manner following clear procedural and precedential rules. These are the hallmarks of a liberal democracy that allows for pluralism of values, while still remaining committed to protecting the most vulnerable parties in these disputes – children facing life-limiting conditions. **Abstract:** <https://bit.ly/2HY0Blv>

N.B. Selected articles on the Charlie Gard and Alfie Evans cases and related issues noted in Media Watch 29 June 2020 (#672, p.4).

Teaching end-of-life preparation to African Americans

PALLIATIVE & SUPPORTIVE CARE | Online – 6 November 2020 – African American (AA) patients are more likely to choose life-sustaining measures at the end of their lives compared to other ethnic groups despite terminal illness. This decision is partly based on lack of knowledge of options of care at the end of life (EoL). Due to multiple life-sustaining measures, AA patients are not receiving the care to help them peacefully die. This study provides evidence that physicians need to increase their educational efforts with the AA population to help them better understand EoL options. An educational tool like the one developed in this study may be helpful and lessen the time of education so that the physician can answer any questions at the end of the session and also empower individuals and communities to take an active role in creating a culture of wellness at the EoL and decreasing morbidity. **Abstract:** <https://bit.ly/3jXQ4nK>

Determining the informational needs of family caregivers of people with intellectual disability who require palliative care: A qualitative study

PALLIATIVE & SUPPORTIVE CARE | Online – 3 November 2020 – People with intellectual disabilities (ID) are living longer, and many require palliative care (PC). There is a lack of evidence regarding information needs which may exist for their family caregivers (FCGs). FCGs [i.e., study participants] reported information needs chiefly concerning the disease, financial entitlements, and practical support which could change over the disease trajectory. Findings evidence the expertise of long-term FCGs, prior to the end of life. PC and ID teams acknowledged their role to work in partnership and facilitate access to information. Recommendations were mapped onto a co-designed logic model. The findings of this study offer new insights into the specific informational needs of this family caregiving population. The authors' co-designed logic model presents these needs and how they may be addressed. Central coordinators have been advocated for these caregivers. This model could have international applicability for similar family carers, supporting people with other disabilities or cognitive impairment, and should be further explored. **Abstract:** <https://bit.ly/32pWLJt>

N.B. Selected articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in Media Watch 21 September 2020 (#684, p.9).

End-of-life care in Germany

Caregiving adult children's perceptions of challenges relating to the end of life of their centenarian parents

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online – 27 October 2020 – The number of centenarians in Europe is increasing; many face health impairments. Adult children often play a key role in their care, but there is a lack of research into what it means for these caregiving relatives to be confronted for many years with their parents' end of life (EoL), dying and death as well as their own advancing age. Three main themes were identified in this study: 1) Confronting EoL; 2) Communicating about death and dying; and, 3) Assisting in the terminal phase. The caregivers interviewed commented on burdensome demands and concerns about the future. Further, a strong underlying presence of intra- and interpersonal conflicts relating to EoL became apparent. Findings indicate several potential burdens for centenarians' caregiving offspring. They are confronted with a double challenge resulting from the combination of their own advanced age and experiencing the burdens of their parents' very old age. Further, some participants struggled with their own unclear perspective on the future because of the relative but unclear proximity of the parent's death. Multiple conflicts and overlapping conflict dimensions emphasise the potential of the EoL topic to influence the well-being of family caregivers and care recipients. The findings suggest that interventions designed for family-related care situations should include topics like "finiteness and grief," "communicating about dying and death," and "decisions and dispositions at EoL." **Abstract:** <https://bit.ly/2Js14gz>

Noted in Media Watch 30 March 2020 (#659, p.13):

- *SWISS MEDICAL WEEKLY* | Online – 22 March 2020 – ‘**The oldest old: The newest focus in end-of-life care?**’ Hug and colleagues examine the differences between the oldest old and younger patients in terms of the frequency of various end-of-life decisions, such as intensified alleviation of pain and other symptoms and, most notably, withholding and withdrawing life-sustaining treatments.¹ Already, more than half of all Swiss deaths concern people over the age of 80, with a further increase expected in the future. These growing numbers of people also have increasingly long trajectories of health decline – both physical and cognitive – and of chronic and degenerative illness progression, depending on their specific afflictions. **Download/view full text at:** <https://bit.ly/2WCjsHW>

1. ‘Medical end-of-life decisions in the oldest old in Switzerland,’ *Swiss Medical Weekly*, published online 15 January 2020. **Full text (click on pdf icon):** <https://bit.ly/2WEbcr0>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMC MEDICAL ETHICS* | Online – 3 November 2020 – ‘**U.S. medical and surgical society position statements on physician-assisted suicide and euthanasia: A review.**’ Only a dozen secular U.S. medical and surgical professional societies have position statements on physician-assisted suicide (PAS) and euthanasia, and only three of these statements have been published in peer-reviewed journals. The reasons for these small numbers are unclear but may be related to the controversial nature of the topics, the positions of large and influential societies, and the relevancy of the topics for specific specialty societies. Aside from the use of the words *suicide*, *medicine*, and *treatment* in opposing statements and the words *psychologists*, *law*, and *individuals* in studied neutrality statements, the most popular words used in opposing and studied neutrality position statements are similar. Use of the word *suicide* or *assisted death* does not appear to indicate a statement's comprehensive use of emotionally positive or negative language. Opposing statements generally claim PAS contradicts the healing role of the physician and that alternative approaches to symptom control exist for extreme cases (e.g., palliative sedation). Studied neutrality statements highlight patient autonomy in decision-making associated with the dying process. The opposing statements and the studied neutrality statements cite potential long-term societal risks associated with legalization of PAS and suggest that effective palliative care can diminish a patient's desire for PAS. **Full text:** <https://bit.ly/34QCBK8>



Would this article be of interest to a colleague?

Publishing Matters

The A-Z's of predatory publishing

CABELLS | Online – 4 November 2020 – Earlier this year Cabells published an A-Z list of issues regarding predatory publishing practices, with one Tweet a week going through the entire alphabet. In this week's blog, Simon Linacre, Director of International Marketing & Development at Cabells, republishes all 26 tweets in one place as a primer on how to successfully deal with the phenomenon. <https://bit.ly/2TSSeul>

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3ddX0v7>

[Scroll down to 'Media Watch: Nursing']

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

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

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

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

Asia



Asia Pacific
Hospice Palliative
Care Network

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2SWdYWP>

[Scroll down to 'Media Watch']

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



CSPCP SCMSP
Canadian Society of
Palliative Care Physicians Société canadienne des
médecins de soins palliatifs

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



EAPC
VZW

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <https://bit.ly/3iZKjXr>

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

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

South America

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

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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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.

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