

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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Physicians observed that while addressing the end-of-life care needs and expectations can help improve the experience for residents and families, doing so could impact overextended long-term care staff within an overextended healthcare system.

'Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: A qualitative descriptive study of community-based and specialist palliative care physicians' experiences, perceptions and perspectives' (p.9), in *BMJ Open*.

Canada

Four terminally ill Canadians get special exemption to use psychedelic therapy

CTV NEWS | Online – 4 August 2020 – In a landmark decision, four Canadians suffering from terminal illnesses have been approved to receive psilocybin therapy to treat their anxiety -- marking the first time that a legal exemption has been given in Canada for patients to access psychedelic substances for treatment. The drug, found in so-called "magic mushrooms," is a naturally occurring psychedelic compound. Research tracking the effects of the psychedelic drug has found that it has the potential to provide long-term relief for mental health struggles such as anxiety and depression, especially in those receiving palliative care due to a terminal diagnosis. The U.S. Center for Psychedelic & Consciousness at Johns Hopkins University in Baltimore is currently running clinical trials to assess whether the drug should be released on the market as a prescription medication. In Canada, the drug is illegal; possession, production, or sale of magic mushrooms or anything containing psilocybin is prohibited unless authorized for clinical trial or research purposes. <https://bit.ly/30wmOhf>

Noted in Media Watch 18 November 2019 (#640, p.8):

- *CURRENT ONCOLOGY*, 2019;26(4):225-226. '**Psychedelics for psychological and existential distress in palliative and cancer care.**' A so-called psychedelic renaissance is underway, with research programmes at major academic institutions worldwide conducting basic and clinical research into the potential therapeutic effects of psychedelic medicines for a variety of psychiatric conditions. These compounds were first studied in the 1950s, but by the mid-to-late 1960s, clinical research began to be curtailed and was almost fully terminated by the mid-1970s. Those early experiments and their contemporary counterparts invite the questions: Is there a role for psychedelics for treating patients in palliative medicine and cancer care today? And, if so, where? **Full text:** <http://bit.ly/2qK9gj2>

Cont.

Noted in Media Watch 4 March 2019 (#604, p.13):

- *JOURNAL OF PSYCHOACTIVE DRUGS* | Online – 1 March 2019 – ‘**Psychedelics and dying care: A historical look at the relationship between psychedelics and palliative care.**’ As researchers in the 1950s began exploring different applications for psychoactive substances ... dying care came into clearer focus as a potential avenue for psychedelics. Before that application gained momentum in clinical or philosophical discussions, psychedelics were criminalized and those early discussions were lost. This article looks back at historical discussions about LSD’s potential for easing the anxiety associated with dying, and considers how those early conversations might offer insights into today’s more articulated discussions about psychedelics in palliative care. **Abstract (w. link to references):** <http://bit.ly/2Ta1k7V>

Noted in Media Watch 29 January 2018 (#548, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 January 2018 – ‘**Taking psychedelics seriously.**’ Even with an expanding evidence base confirming safety and benefits, political, regulatory, and industry issues impose challenges to the legitimate use of psychedelics. Given the prevalence of persistent suffering and growing acceptance of physician-hastened death as a medical response, it is time to revisit the legitimate therapeutic use of psychedelics. This paper overviews the history of this class of drugs and their therapeutic potential. Clinical cautions, adverse reactions, and important steps related to safe administration of psychedelics are presented, emphasizing careful patient screening, preparation, setting and supervision. **Full text:** <http://bit.ly/2tQtJBa>

U.S.A.

Hospices struggle with respite care during pandemic

HOSPICE NEWS | Online – 5 August 2020 – The **COVID-19** pandemic has complicated hospices’ ability to provide respite care. Limited access to nursing homes, fears of spreading the virus and rising demand are throwing wrenches into providers’ respite programs. Congress is currently considering legislation that during any federally declared national emergency would increase the maximum length of stay for hospice respite care to 15 days, up from five days. If enacted, the bill would also allow hospices to offer respite care in the patient’s home. Medicare typically allows respite care to be provided on an inpatient basis for as long as five days when their caregivers become sick themselves or otherwise need a rest or address other priorities. Providers typically offer this care hospice facility, hospital or nursing home. Respite is one of four levels of hospice care that Medicare covers, along with routine home care, continuous home care and general inpatient care. For the time being however, many hospices are between a rock and a hard place when it comes to respite care, in part because of

the tremendous need spurred by the COVID-19 outbreak. <https://bit.ly/2XBaqL0>

Specialist Publications

‘**Reinventing palliative care delivery in the era of COVID-19: How telemedicine can support end-of-life care**’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

‘**Geographic variation in knowledge of palliative care among U.S. adults: Findings from 2018 Health Information National Trends Survey**’ (p.7), in *American Journal of Hospice & Palliative Medicine*.

‘**The “good” home death in pulmonary disease: Avoiding the “bad” and the “ugly”**’ (p.10), in *Chest*.

‘**“I don’t have time to sit and talk with them”: Hospitalists’ perspectives on palliative care consultation for patients with dementia**’ (p.13), in *Journal of the American Geriatrics Society*.

International

Do we need a national day of mourning after the Coronavirus pandemic?

U.K. (England) | *The Conversation* – 3 August 2020 – At the end of July, the charity Marie Curie UK launched a campaign for a national day to “reflect, grieve and remember” the thousands of people who have died during the **COVID-19** pandemic. The charity pointed out the incongruity between the scale of bereavement since March 23 and the absence of familiar mourning rituals. Indeed, the absence of public mourning during the pandemic is striking – particularly in Britain, where the closest equivalent to a patriotic national day is Remembrance Day. While Remembrance Day lacks the celebratory parades and fireworks of national days in other countries, it carries the same effect: mourning the dead binds people together through shared memories, rituals and values. Mourning, in short, creates a sense of solidarity, and even shared identity, amid a shared loss. That solidarity is neither arbitrary nor apolitical. Remembrance Day, for example, gives prominent roles to royals and politicians and invokes courage, heroism and sacrifice. Since mourning serves so many important purposes for individuals and nations alike, this raises the question of what happens in its absence. The alternative to mourning is melancholia: the denial that a loss is real, the inability to make sense of it or learn from it and, ultimately, the inability to move

on. The way we remember Britain’s experience of the pandemic will shape the way we understand Britain at large. Grappling with difficult memories enables us to critique leaders, policies and even identities. But whether a national day of mourning would achieve this very much depends on how it is framed. <https://bit.ly/2PxCcUr>

Specialist Publications

‘Disclosure and plan of care at end of life: Perspectives of people with intellectual disabilities and families in Ireland’ (p.10), in *British Journal of Learning Disabilities*.

‘End-of-life doulas: A qualitative analysis of interviews with Australian and international death doulas on their role’ (p.11), in *Health & Social Care in the Community*.

‘Advance care planning in Asian culture’ (p.13), in *Japanese Journal of Clinical Oncology*.

‘Sustainment of innovations in palliative care: A survey on lessons learned from a nationwide quality improvement programme’ (p.14), in *Journal of Pain & Symptom Management*.

N.B. National Day of Reflection, Marie Curie UK website: <https://bit.ly/2Pxc2RR>

Noted in Media Watch 20 July 2020 (#675, p.2):

- CANADA | *Maclean’s Magazine* – 15 July 2020 – ‘**The pandemic has disrupted death and mourning in ways we don’t yet understand.**’ “This is not a good time to die,” says Dr. Harvey Chochinov, a psychiatrist and director of the Manitoba Palliative Care Research Unit in Winnipeg. Chochinov estimates that, since the pandemic was declared in March, 60,000 to 70,000 Canadians have died from causes other than **COVID-19**. Each of those deaths has, in some way, been tainted by the pandemic, which has limited visits in hospitals and long-term care homes, and led to restrictions on public memorial services, as well as high levels of stress across the population. Even the most elemental offering of comfort to another human being – touch – is off limits to all but the innermost circle. <https://bit.ly/2OyuAAB>

Noted in Media Watch 15 June 2020 (#670, p.5):

- *PSYCHOLOGICAL TRAUMA: THEORY, RESEARCH, PRACTICE & POLICY* | Online – 11 June 2020 – ‘**Prolonged grief related to COVID-19 deaths: Do we have to fear a steep rise in traumatic and disenfranchised griefs?**’ The circumstances of COVID-19-related deaths embed multiple traumatic characteristics, alongside several external factors that can disenfranchise individual grief. The authors of this article propose avenues for meaning-making practices to facilitate individual and collective mourning process, and invites clinicians to pay attention to the traumatic characteristics of COVID-19-related deaths adopting a holistic approach of prolonged grief disorder clinical manifestations, as well as in evaluation and treatment of cases. **Full text:** <https://bit.ly/2Yrtkns>

Cont.

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

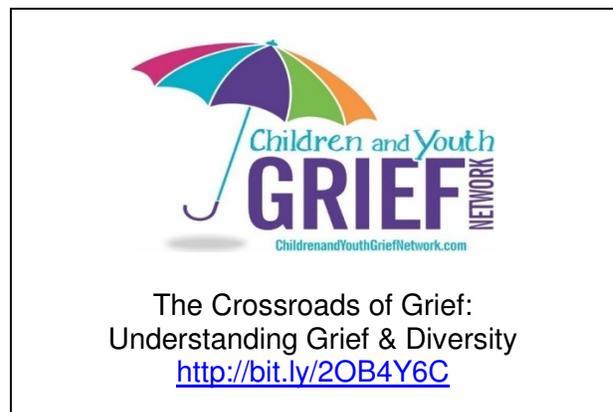
- *CANADIAN VIRTUAL HOSPICE* | Online – 12 May 2020 – ‘Action needed to address COVID-19’s hidden tragedy: National grief advocates urge support for grieving Canadians and health workers.’ Never has Canada experienced the volume and complexity of grief as has resulted from the COVID-19 pandemic. Canadians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

Specialist Publications

Preschool children’s emotional understanding of death: A forgotten dimension

ACTA MÉDICA PORTUGUESA, 2020;33(13):1-8. Scientific evidence regarding children’s understanding of the concept of death is scarce. This has recently been pointed out by the International Children’s Palliative Care Network as a priority area of research. In particular, the avoidance of emotion in this area of research is an important shortcoming. This study aimed to develop an in-depth view of the emotional dimension of the child’s understanding of death, also seeking to relate it to the cognitive dimension. The authors interviewed children (three to six years old) using a book illustrating a hypothetical scenario in which a child faced the death of a relative. They asked questions to assess the cognitive sub-concepts of death and the emotional dimension (what the child would feel and what parents should say). Of the 54 participants, the majority said that the child would feel sad ... and their responses did not vary significantly with age. The cognitive understanding of the concept of death in children who reported sadness was significantly higher. Even the youngest children feel death, and it is not possible

to disconnect cognitive and emotional understanding. Additionally, children should be informed in order to foster a proper and multidimensional elaboration of death. This study provides valuable information to health professionals and other interested adults about the way preschoolers position themselves in relation to death. **Full text (click on pdf icon):** <https://bit.ly/3i8uTi6>



N.B. Portuguese language article.

Bringing palliative care downstairs: A case-based approach to applying palliative care principles to emergency department practice

ADVANCED EMERGENCY NURSING JOURNAL, 2020;42(3):215-224. Although the emergency department (ED) may not be traditionally thought of as the ideal setting for the initiation of palliative care (PC), it is the place where patients most frequently seek urgent care for recurrent issues such as pain crisis. Even if the patients’ goals of care are nonaggressive, their caregivers may bring them to the ED because of their own distress at witnessing the patients’ suffering. ED providers, who are trained to focus on the stabilization of acute medical crises, may find themselves frustrated with repeat visits by patients with chronic problems. Therefore, it is important for ED providers to be comfortable discussing goals-of-care, to be adept at symptom management for chronic conditions, and to involve PC consultants in the ED course when appropriate. Nurse practitioners, with training rooted in the holistic tradition of nursing, may be uniquely suited to lead this shift in the practice paradigm. **Abstract:** <https://bit.ly/33rxerR>

Cont.

Noted in Media Watch 8 June 2020 (#669, p.11):

- *JAMA INTERNAL MEDICINE* | Online – 5 June 2020 – ‘**Early intervention of palliative care in the emergency department during the COVID-19 pandemic.**’ During the novel Coronavirus disease 2019 (COVID-19) pandemic, it is particularly critical to ensure that life-sustaining treatment (LST) such as intubation and resource-intensive cardiopulmonary resuscitation (CPR) are aligned with a patient’s goals and values, and to avoid LSTs in patients with a poor prognosis that are unlikely to be beneficial, but have a high risk of causing additional suffering. The authors implemented an ED-based COVID-19 palliative care response team focused on providing high-quality goals-of-care conversations in time-critical situations. **Full text:** <https://bit.ly/2Y7eFgS>

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

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

Noted in Media Watch 7 October 2019 (#634, p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 3 October 2019 – ‘**End-of-life care, palliative care consultation, and palliative care referral in the emergency department: A systematic review.**’ Palliative care (PC) interventions improved quality of life, though this improvement was not observed when comparing PC in the emergency department (ED) to inpatient PC. Most studies reported a concomitant reduction in hospital length-of-stay and increase in hospice utilization... Short-term mortality rates were high across all studies, but PC interventions did not decrease survival time compared to usual care. Existing data support that PC in the ED is feasible, may improve quality of life, and does not appear to affect survival. **Abstract (w. link to references):** <http://bit.ly/31NnxJ4>

Reinventing palliative care delivery in the era of COVID-19: How telemedicine can support end-of-life care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 7 August 2020 – Telemedicine technology has become essential to healthcare delivery in the COVID-19 era, but concerns remain regarding whether the intimacy and communication that is central to high-quality palliative care (PC) will be compromised by the use of this technology. The authors employed a business model approach to identify the need for system innovation in PC, and a quality improvement approach to structure the project. Products from this project included a standard operating procedure for safe use of tablet computers for inpatient PC consultations and family visitations; tablet procurement with installation of video telehealth software; and, training and education for clinical staff and other stakeholders. The authors describe a case illustrating the successful use of PC telehealth in the care of a COVID-19-positive patient at the end of life. Successful use of video telehealth for PC involved overcoming inertia to the development of telehealth infrastructure and learning clinical video telehealth skills; and, engaging front-line care staff and family members who were open to a trial of telehealth for communication. Information gleaned from family about the patient as a person helped bedside staff to tailor care toward aspects meaningful to the patient and family and informed best practices to incorporate intimacy into future palliative video consultations and family visit. **Abstract (w. list of references):** <https://bit.ly/3abKcmt>

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Noted in Media Watch 29 June 2020 (#672, p.8):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 25 June 2020 – “**Are you wearing your white coat?: Telemedicine in the time of pandemic.**” The potential benefits of telemedicine are many and easy to appreciate during normal times; in times of the pandemic they are priceless. But, there is no doubt that the virtual visit is a fundamental alteration to the patient-physician encounter. Recent weeks have brought a massive and hurried adaptation that risks changing the ancient and sacrosanct practice of medicine. And as news, discoveries, ideas, and policies spin around in a flurry, now more than ever we must anchor ourselves in and cherish the wisdom of personal interactions. The place where it all starts. **Full text:** <https://bit.ly/2VjM4nY>

Noted in Media Watch 8 June 2020 (#669, p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 4 June 2020 – ‘**Feasibility and acceptability of inpatient palliative care e-family meetings during COVID-19 pandemic.**’ During the COVID-19 pandemic ... the authors demonstrated the efficient deployment of telemedicine for e-family meetings that was both feasible and effective for decision-making for patients who were near end of life and their families. Family meetings likely happened sooner and with far more participants than would have been possible without the use of the technology. While providers expressed limitations in the use of technology ... they reported key benefits including observation of prayer rituals and promoting understanding to the family of the patient’s condition. **Full text:** <https://bit.ly/2U8B78j>

Noted in Media Watch 25 May 2020 (#667, p.10):

- *NEUROLOGY TODAY* | Online – 18 May 2020 – ‘**Neuropalliative care during COVID-19: How clinicians help patients and families cope with isolation, fear, and life-limiting illness.**’ Neurologists who specialize in palliative care (PC) have been engaging in many gut-wrenching conversations with patients and families saddled with the complexities of chronic and terminal conditions. In the context of COVID-19, neurologists, neuro-oncologists, and palliative medicine physicians are improvising health-care delivery, acquiring new know-how and applying telemedicine to delicately broach the subject of advance care planning... Just as the pandemic has accelerated the demand for telemedicine, it has escalated the need for PC skills to manage COVID-19 patients... **Full text:** <https://bit.ly/2LGhu2Q>

Toward a practice-informed agenda for hospice intervention research: What are staff members’ biggest challenges?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 August 2020 – The translation of evidence-based interventions into routine hospice care is impeded by numerous barriers, including a disconnect between research priorities and clinical care. To inform the development of a more practice-informed agenda for hospice intervention research, the authors conducted a qualitative descriptive study, posing the following research questions: 1) How do hospice staff members describe their most significant work-related challenges? and 2) What regulatory changes do hospice staff members report would most improve hospice care? To answer these research questions, they interviewed 22 hospice staff members and then conducted a template analysis of the interview content. In doing so, the authors identified themes that described challenges in five key areas: 1) Time; 2) Documentation; 3) Professional roles; 4) Recruitment and retention; and, 5) Burn-out. In addition, they identified a perceived need among hospice staff members for more regulatory flexibility and clarity. Based on their findings, the authors conclude that a practice-informed agenda for hospice intervention research includes the development and testing of interventions that increase efficiency, explicitly speak to the humanity of hospice care, and elevate the roles of all members of the interdisciplinary team. **Abstract (w. list of references):** <https://bit.ly/2XCmQSR>



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

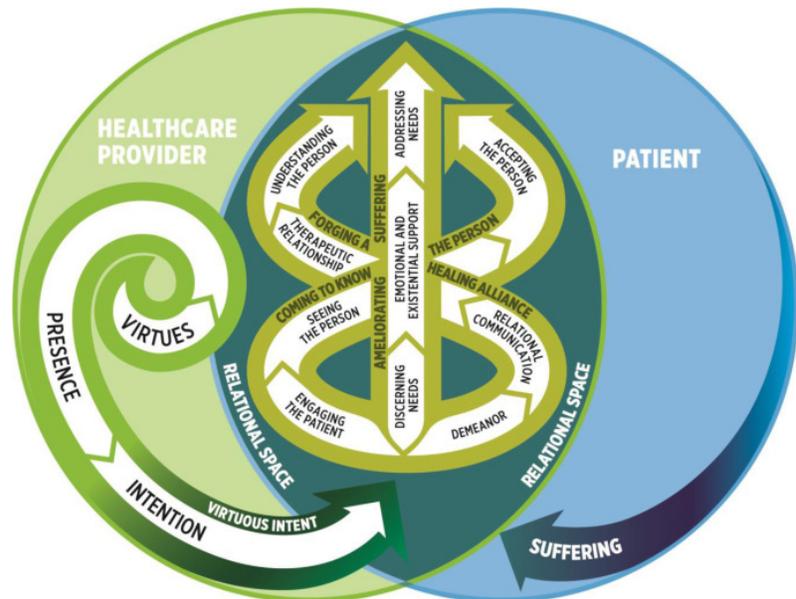
Geographic variation in knowledge of palliative care among U.S. adults: Findings from 2018 Health Information National Trends Survey

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 August 2020 – It remains unclear whether the geographic variation in knowledge of palliative care (PC) exists in the U.S. Basic knowledge of PC, goal concordant treatment, misconceptions, and primary information source of PC were compared across four census regions. 3,194 respondents ... were included in this study. Overall, 29% of all respondents reported having knowledge of PC; 32.9% of those residing in Northeast had some knowledge of PC, followed by 30.8% in the South, 26.2% in Midwest, and 25.6% in West. By census divisions, respondents residing in three divisions were more likely to have PC knowledge ... compared to those in the Mountain division. The variation of PC knowledge on census division and state level in 2018 was consistent with the real-world geographic disparities in the availability of PC programs. These findings represent an opportunity for minimizing the gap of geographic disparity by initiating strategic programs and promoting PC programs nationwide. **Abstract (w. list of references):** <https://bit.ly/2XCavOu>

Healthcare providers perspectives on compassion training: A grounded theory study

BMC MEDICAL EDUCATION | Online – 5 August 2020 – Providing compassion has become a core expectation of healthcare and increasingly is being considered a core competency of healthcare education. Providing evidence-based, clinically informed training to help learners practice with compassion is crucial to their success, to organizational outcomes, and most importantly, to providing quality patient care. Based on the results of this study, the authors suggest that a combination of formal experiential learning modules and clinical mentorship that focuses on teaching learners techniques to engage with persons, self-awareness, and practices for sustaining the ability to provide compassion are necessary for training compassionate care providers. Further research is needed to determine learner needs, along with systematic reviews and environ-

mental scans of existing training to determine needs, content, teaching methods and the barriers and facilitators of existing training programs. Healthcare organizations are instrumental to provision of compassionate health care delivery, as the success and longevity of training clinical teams or individual healthcare professionals in compassion will be contingent on the degree that organizations cultivate sustain, and consider a culture of compassion as a core business of healthcare. **Full text:** <https://bit.ly/3gFbd5n>



Would the *BMC Medical Education* article be of interest to a colleague?

Differing needs of mothers and fathers during their child's end-of-life care: Secondary analysis of the "paediatric end-of-life care needs" (PELICAN) study

BMC PALLIATIVE CARE | Online – 4 August 2020 – To best meet parental needs in paediatric end-of-life (EoL) care, particular attention should be paid to both mothers and fathers and their specific caregiving roles, as differences in caregiving roles might influence their needs. Therefore, healthcare professionals should identify how parental dyads mutually navigate care for their sick child in order to appropriately meet their needs in support. Mothers and fathers should be supported in their individual coping strategies. Mothers, when primary caregivers, often have higher needs for a permanent exchange with members of the healthcare team, to talk about their child's medical condition as well as their own emotions. Fathers often favour more pragmatic options of coping, such as retaining hope. These gender-specific strategies should be acknowledged when providing care around a child's EoL and beyond. As this survey has been the first to quantitatively identify differences in caregiving needs between mothers and fathers regarding their child's EoL care, the authors' findings and their interpretations should be further explored in other samples and with mixed methodological approaches. Especially the perspectives and needs of parents living in non-traditional family structures should be emphasised. Only the appreciation and understanding of existing family structures and caregiving roles, as well as gender-specific differences will lead to improvements in the support of mothers and fathers during this vulnerable period. **Full text:** <https://bit.ly/2DEIZdb>

Noted in Media Watch 20 January 2020 (#649, p.8):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 17 January 2020 – **'Engaging fathers in pediatric palliative care research.'** Barriers to study participation included: recruiting healthcare providers' appraisal of fathers' lack of well-being, bereaved fathers' self-reported poor coping and the inability to locate and contact fathers, particularly after a child's death. Strategies for improving the engagement of fathers into research entailed: educating recruitment personnel, designing "father-focused" studies, communicating the value of the research to recruitment personnel and potential participants, and ensuring that child health records are accurate and include fathers' contact information. **Abstract:** <http://bit.ly/2TD9THo>

Noted in Media Watch 22 July 2019 (#623, p.11):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(4):333-343. **'Parents' wishes for what they had or had not done and their coping after their infant's or child's neonatal intensive care unit/pediatric intensive care unit/emergency department death.'** Mothers wished they spent more time with the child, chosen different treatments, advocated for care changes, and allowed the child his or her wishes. Fathers wished they had spent more time with the child and gotten care earlier. Mothers wished they had not agreed to child's surgery/treatment, taken her own actions (self-blame), and left the hospital before the death. Fathers wished they had not been so hard on the child, agreed with doctors/treatment, and taken own actions (self-blame). **Abstract:** <http://bit.ly/2GcuKK9>

Noted in Media Watch 21 January 2013 (#289, p.7):

- *INTERNATIONAL JOURNAL OF ADOLESCENT MEDICINE & HEALTH* | Online – Accessed 15 January 2013 – **'Detached, distraught or discerning? Fathers of adolescents with chronic illness.'** In this article, the authors address the challenges to the father's role as breadwinner, leader and strength-giver in the family. Three time-periods describe the obstacles fathers tackle when parenting children with chronic disease: 1) Diagnosis and short-term, characterized by distress, isolation and uncertainty; 2) The mastery period, characterized by the struggle to establish routine and by support and spirituality; and, 3) The long-term, characterized by relationship and personality change, worries and bereavement. **Abstract:** <http://bit.ly/38u4g2D>



Media Watch: Access Online

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

Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: A qualitative descriptive study of community-based and specialist palliative care physicians' experiences, perceptions and perspectives

BMJ OPEN | Online – 5 August 2020 – This Canadian study reports the supportive end-of-life care (EoLC) observations and experiences of 18 community-based and 5 specialist palliative care (PC) physicians who visit long-term care (LTC) facilities. The findings help explain perceived barriers to family involvement in care, optimal symptom assessment, and control and involvement of EoLC culture and practices within LTC. Other studies perceive communication problems with care providers as barriers to family involvement in decisions and EoLC. By explicating just how physicians respond to communication problems with families, this study revealed communication problems as opportunities to enable family involvement and conversations about advance care planning. What we do not know is how residents and families use communication problems with providers to accomplish their goals, how care providers respond or the effects on EoLC costs and outcomes. Policymakers and administrators should consider re-design of the physical and social environment within LTC facilities to better support the care needs of residents. Clinical researchers should develop and evaluate pain and symptom assessment tools for use in LTC for people with frailty, including among those with cognitive impairment. Health administrators and clinical leaders should also support LTC staff and physician involvement in PC education, mentorship and skills training programmes. **Full text:** <https://bit.ly/30yzeWb>

N.B. Additional articles on palliative and EoLC in LTC facilities in Canada noted in Media Watch 3 August 2020 (#677, pp.1-2).

Improving end-of-life care for adults with cystic fibrosis: An improvement project

BMJ QUALITY OPEN | Online – 3 August 2020 – The aim of this project was to improve the quality of end-of-life (EoL) care through staff education and support, with the intention to empower staff to start early conversations around EoL thereby better meeting patient wishes. During the project, the authors successfully integrated bimonthly team debriefs which resulted in team learning and support. They also designed a cystic fibrosis (CF) specific advance care planning (ACP) that is now available on the U.K. Cystic Fibrosis Trust website and a free, internationally available, online training course for all healthcare professionals. The authors found that by offering staff support and training alongside empowering them with a structured ACP document they could positively change the culture of the CF multidisciplinary team resulting in early ACP and more patients dying in their preferred location. ACP is introduced in a timely manner by staff trained to support the process and each document can be reviewed regularly, either by the CF multidisciplinary team or at the request of the individual patient. Final wishes are known and supported by the team and patients are encouraged to share the ACP with loved ones. Recent literature suggests that CF teams, although identifying the issue, currently struggle to find solutions. It is important, however, that the ACP document does not become a “tick box exercise” and should not alone define ACP, instead the document should form a structure to empower staff to assist patients in documenting their thoughts and wishes. **Full text:** <https://bit.ly/31x13qT>

N.B. ‘Planning for end of life and cystic fibrosis,’ U.K. Cystic Fibrosis Trust website: <https://bit.ly/33mYkJn>

Noted in Media Watch 18 May 2020 (#666, p.14):

- *PEDIATRIC PULMONOLOGY* | Online – 8 May 2020 – ‘**Palliative care skills in cystic fibrosis (CF): Perspectives of adults with CF, caregivers, and CF care team members.**’ Clinicians consistently rated their palliative care (PC) skills higher than patients or caregivers rated them... While clinicians, patients, and caregivers rated clinicians as “very good” at basic pain assessment and “good” at discussing prognostic uncertainty, clinicians rated themselves more highly at providing most skills, including simultaneous PC and standard CF care, basic depression assessment, and discussing transplant, advance directives, end of life, code status, and hospice. Respondents affiliated with adult CF care teams rated clinicians more highly than respondents affiliated with pediatric CF care teams **Abstract:** <https://bit.ly/3bhU9Dt>

N.B. Additional articles on the PC needs of people living with cystic fibrosis noted in Media Watch 27 April 2020 (#663, p.10).

Disclosure and plan of care at end of life: Perspectives of people with intellectual disabilities and families in Ireland

BRITISH JOURNAL OF LEARNING DISABILITIES | Online – 30 July 2020 – This study has shown how people with intellectual disabilities (ID) and family members presume that receiving adequate information and engaging in an advanced care planning process gives people with ID some control over their future care. The practitioners could infer from these findings that end-of-life decision-making could take an inclusive approach, whereby the wishes and views of people with mild and moderate ID are respected and recorded in their clinical file, which will accompany them wherever they are transferred to. Finally, the findings also added evidence to previous research that people with mild and moderate ID can convey a clear choice. **Full text:** <https://bit.ly/3kfMcjs>

N.B. Selected articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in Media Watch 3 August 2020 (#677, p.10) and 8 June 2020 (pp.8-9).

The “good” home death in pulmonary disease: Avoiding the “bad” and the “ugly”

CHEST, 2020;158(2):449-450. Patients with pulmonary disease have a higher risk of dying in the hospital than adults with other serious illnesses. However, place of death in America is rapidly changing. Cross *et al* examined whether national trends toward more home deaths are similar in patients with pulmonary disease. Their results reveal a shifting tide. As home deaths become more common in pulmonary disease, clinicians must ensure that patients and their families have all the support they need to make those deaths at home good ones. Cross *et al* examined trends in place of death and factors associated with where people die using longitudinal death certificate data in over 2 million people with chronic obstructive pulmonary disease (COPD), interstitial lung disease (ILD), and cystic fibrosis (CF).¹ Between 2003 and 2017, the frequency of participants dying in the hospital decreased from 44% to 28%; hospice facility deaths skyrocketed from 0.1% to 9%; and home deaths increased from 23% to 35%. Several factors influenced place of death. First, older age was associated with a higher risk for dying in hospice and nursing facilities. Older adults are more likely to discuss wishes for the end of life (EoL) compared with younger adults; however, fewer than half complete an actual advance directive documenting those plans. Second, Black and Hispanic decedents with pulmonary disease were more likely to die in the hospital than white decedents. This is consistent with data showing that minority populations experience a high rate of high-intensity care at the EoL. Third, decedents with CF and ILD were more likely to die in the hospital than decedents with COPD..., and trends in home deaths remained relatively flat in patients with CF. **Full text:** <https://bit.ly/3is6YKZ>

1. ‘Place of death for individuals with chronic lung disease: Trends and associated factors from 2003 to 2017 in the U.S.,’ *Chest*, 2020;158(2):670-680. **Full text:** <https://bit.ly/3ik282b>

Noted in Media Watch 3 August 2020 (#677, p.10):

- *PALLIATIVE MEDICINE* | Online – 28 July 2020 – ‘**The preferences of patients with chronic obstructive pulmonary disease are to discuss palliative care plans with familiar respiratory clinicians, but to delay conversations until their condition deteriorates: A study guided by interpretative phenomenological analysis.**’ Patients deferred discussions to the future, usually once their condition had deteriorated significantly or planned to wait for clinicians to initiate conversations. This was not rooted in patient preferences, but related to clinicians’ lack of time, absence of an established relationship and belief that appointments were for managing current symptoms, exacerbations and disease factors rather than future care and preferences. **Abstract (w. list of references):** <https://bit.ly/39wXvyG>

Noted in Media Watch 4 May 2020 (#664, p.8):

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

Beyond the hour of death: Family experiences of grief and bereavement following an end-of-life hospitalization in the intensive care unit

HEALTH | Online – 4 August 2020 – First, this article explores how the process of advance care planning (ACP) shaped family experiences of grief, by demonstrating that even prior informal conversations around end-of-life (EoL) care outside of having an advance directive in the hospital was beneficial for family members both during the hospitalization and afterwards in bereavement. Second, clinicians' compassionate caring for both patients and families through the "little things" or small gestures were important to families during the EoL hospitalization and afterwards in bereavement. Third, the transition time in the hospital before the patient's death facilitated family experiences of grief by providing a sense of support and meaning in bereavement. The findings of this study have implications for clinicians who provide EoL care by highlighting salient aspects from the hospitalization that may shape family grief following the patient's death. Most importantly, the notion that ACP as a social process may be a "gift" to families during EoL decision-making and carry through into bereavement can serve as a motivator to engage patients in ACP. **Abstract (w. list of references):** <https://bit.ly/2PswxyM>

Barriers to palliative care in sexual and gender minority patients with cancer: A scoping review of the literature

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 7 August 2020 – Lesbian, gay, bisexual and transgender (LGBT) patients and their caregivers experience homophobia, exclusion, social isolation, criminalisation, persecution and fear of discrimination. Additionally, lack of provider knowledge has led to negative patient perceptions by healthcare professionals (HCPs) when providing palliative care (PC)... These barriers have reduced the quality of PC and further perpetuate marginalisation and healthcare inequities. The following areas of future research and targeted interventions are identified: 1) HCP perceptions of LGBT-specific PC needs; 2) Addressing social isolation; 3) Protection and assessment of community needs for the ageing population; 4) Managing caregiver distress; 5) Counselling about advanced directives; and, 6) Education for HCPs through the creation a safe environment. **Full text:** <https://bit.ly/2CfcAsw>

N.B. Additional articles on PC for LGBT people noted in Media Watch 25 May 2020 (#667, pp.3-4).

End-of-life doulas: A qualitative analysis of interviews with Australian and international death doulas on their role

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 3 August 2020 – Death doulas (DD) are working with people at the end of life (EoL) in varied roles with more clarity needed around their role and place within the health and social care systems. Seven themes emerged from the authors' qualitative analysis: what a DD offers, what a DD does, challenges and barriers, occupational preferences, family support, contract of service/fee and regulation. There is a general perception that healthcare professionals (HCP) do not understand what it is that DDs do; thus, this study helps to demystify the DD role and potentially reduce suspicion. The lack of a DD business model sees inconsistencies in what services each DD offers and what patients and families can expect. EoL is complex and confusing for patients and families and there is a need to further explore the DD role and how it can work when there are many inconsistencies in working practice. **Abstract:** <https://bit.ly/30speh6>

Noted in Media Watch 3 August 2020 (#677, p.2):

- U.S. | *Vogue Magazine* – 30 July 2020 – '**How death doulas have adapted end-of-life care amid COVID-19.**' A 2017 study found that women who had continuous support during their labor – whether from a nurse, doula, or partner – reported a more positive birth experience. It seems likely that the same kind of constant emotional support from a death doula would have an equally positive effect on processing the grief around passing. EoL doulas have always strived to be a support system for those who are terminally ill, but in 2020 the people who take on that responsibility have been challenged to think outside the box when it comes to caregiving. They've had their presence questioned at a time when their skills could be most valuable. <https://bit.ly/39JDftw>

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Noted in Media Watch 2 September 2020 (#629, p.11):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 25 August 2019 – ‘**The voices of death doulas about their role in end-of-life care.**’ Death doulas have emerged not only as a response to the overwhelming demands on families and carers, but also demands placed on healthcare professionals ... at the end of life. They have identified gaps in health and social care provision, perhaps taking on tasks that health professionals don’t have responsibility for. However, the roles and scope of practice of death doulas is not clear-cut..., which can then make it hard for patients and families when choosing a death doula, especially as a lack of regulation and standardised training means that doulas are working without oversight, and often in isolation. **Full text:** <http://bit.ly/2ZuHcQb>

Noted in Media Watch 1 October 2018 (#583, p.13):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 26 September 2018 – ‘**What role do death doulas play in end-of-life care? A systematic review.**’ Current health and social care systems do not always meet the needs of the dying in our communities. This systematic review has highlighted the paucity of formal investigations into death doulas, and a need to undertake further inquiry. Death doulas are working in end-of-life care, but their role and place within the health and social care systems is not well understood. Death doulas may represent a new direction for personalised care directly controlled by the dying person, an adjunct to existing services, or an unregulated form of care provision without governing oversight. **Full text:** <http://bit.ly/2Ld0Oz8>

Palliative care needs-assessment and measurement tools used in patients with heart failure: A systematic mixed-studies review with narrative synthesis

HEART FAILURE REVIEWS | Online – 3 August 2020 – Six palliative care (PC) needs-assessment/measurement tools used in patients with heart failure (HF) were identified and compared according to their content and context of use, development, psychometrics and practicality, and applications in identifying PC patients and needs. The tools are not necessarily mutually exclusive as they may serve different purposes including patient identification, needs identification, needs-measurement, and needs-assessment (decision aids). Comparison results suggested that the Needs Assessment Tool: Progressive Disease – Heart Failure (NAT:PD-HF) is the most appropriate PC needs-assessment tool for use in HF populations. It covers most of the patient needs and has the best psychometric properties and evidence of identification ability and appropriateness. However, this conclusion is based on limited evidence. Four retrieved tools lack studies on their psychometric and practicality properties in HF populations, and one of these ... even lacks a research development paper. Nevertheless, NAT:PD-HF is preliminarily recommended for use in patients with HF, but it requires further testing and validation. The Integrated Palliative Care Outcome Scale has some similar advantages to NAT:PD-HF, but less evidence is available on its use in HF populations. **Full text:** <https://bit.ly/31kLLeO>

Noted in Media Watch 3 August 2020 (#677, p.10):

- *JAMA INTERNAL MEDICINE* | Online – 27 July 2020 – ‘**Improving the integration of palliative care in heart failure – it’s hard to hit a moving target.**’ Bakitas *et al* report the results of their nurse-led trial to improve outcomes in patients with advanced heart failure (HF).¹ They have adapted their original cancer-based ENABLE (Educate, Nurture, Advise, Before Life Ends) intervention to create ENABLE CHF-PC (Educate, Nurture, Advise Before Life Ends Comprehensive Heartcare for Patients and Caregivers) to help patients with advanced HF cope with serious illness. The intervention involves a combination of in-person PC consultations, nurse coaching sessions using a structured workbook as a guide, and ongoing monthly follow-up telephone calls to reinforce the content. **Introduction:** <https://bit.ly/30dppwt>

1. ‘Effect of an early palliative care telehealth intervention vs usual care on patients with heart failure: The ENABLE CHF-PC randomized clinical trial,’ *JAMA Internal Medicine*, published online 27 July 2020. **Abstract:** <https://bit.ly/3fzv4q>

Advance care planning in Asian culture

JAPANESE JOURNAL OF CLINICAL ONCOLOGY | Online – 6 August 2020 – Ageing has been recognized as one of the most critically important healthcare issues worldwide. It is relevant to Asia, where the increasing number of older populations has drawn attention to the paramount need for healthcare investment, particularly in end-of-life (EoL) care. The advocacy of advance care planning (ACP) is a means to honor patient autonomy. Since most East Asian countries are influenced by Confucianism and the concept of “filial piety,” patient autonomy is consequently subordinate to family values and physician authority. The dominance from family members and physicians during a patient's EoL decision-making is recognized as a cultural feature in Asia. Physicians often disclose the patient's poor prognosis and corresponding treatment options to the male, family member rather to the patient him/herself. In order to address this ethical and practical dilemma, the concept of “relational autonomy” and the collectivism paradigm might be ideally used to assist Asian people, especially older adults, to share their preferences on future care and decision-making on certain clinical situations with their families and important others. The authors of this article invited experts in EoL care from Hong Kong, Indonesia, Japan, South Korea, Singapore and Taiwan to briefly report the current status of advance care planning in each country from policy, legal and clinical perspectives. **Abstract:** <https://bit.ly/3fDI0aK>

“I don't have time to sit and talk with them”: Hospitalists' perspectives on palliative care consultation for patients with dementia

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 3 August 2020 – Specialty palliative care (PC) for hospitalized patients with dementia is widely recommended and may improve outcomes, yet rates of consultation remain low. 171 hospitalists were eligible to participate in this descriptive qualitative study, and 28 (16%) were interviewed; 17 (61%) were male, 16 (57%) were white, and 18 (64%) were in practice less than 10 years. Overall, hospitalists' decisions to consult PC for patients with dementia were influenced by multiple factors across four themes: 1) Patient; 2) Family caregiver; 3) Hospitalist; and, 4) Organization. Consultation was typically only considered for patients with advanced disease, particularly those receiving aggressive care or with family communication needs (navigating conflicts around goals-of-care and improving disease and prognostic understanding). Hospitalists' limited time and, for some, a lack of confidence in PC skills were strong drivers of consultation. PC

needs notwithstanding, most hospitalists would not request consultation if they perceived families would be resistant to it or had limited availability or involvement in caregiving. Additional barriers to referral at the organization level included a hospital culture that conflated palliative and end-of-life care and busy PC teams at some hospitals.

Abstract: <https://bit.ly/31bshZW>



The current issue of the journal includes several articles on advance directives for patients living with dementia. **Contents page:** <http://bit.ly/2ToM4zI>

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[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>

Noted in Media Watch 20 April 2020 (#662, p.11):

- *CLINICS IN GERIATRIC MEDICINE*, 2020;36(2):329-339. '**Palliative care for dementia: 2020 update.**' With the increase of the elderly population and increasing burden of dementia care, one may consider the need for palliative and hospice services as an urgent public health priority... This need is underscored by the severe burden of emotional distress endured by family caregivers and the potential for relief afforded by appropriate end-of-life (EoL) services... In 1995, fewer than 1% of hospice patients were observed to have a primary diagnosis of dementia; almost 18% of all hospice enrolments in 2017 were in the context of dementia care. There remain challenges in ensuring patients with dementia are given the chance for the best possible care at EoL. **First page view (w. link to references):** <https://bit.ly/3edWZYc>

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

Netherlands Institute of Health Services Research

Sustainment of innovations in palliative care: A survey on lessons learned from a nationwide quality improvement programme

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 2 August 2020 – While much is known about factors influencing short-term implementation, little is known about what factors are relevant for the long-term sustainment of innovations. In the Dutch National Quality Improvement Programme for Palliative Care, innovations were implemented in 76 implementation projects. Information was gathered on 63 implementation projects (response 83%). The majority of the projects took place in home care, general practices and/or nursing homes. Sustainment was attained in 60% of the implementation projects. Six often applied strategies were statistically significantly related to sustainment: 1) Realizing coherence between the innovation and the strategic policy of the organization; 2) Arranging to have a specific professional responsible for the use of the innovation; 3) Integrating the innovation into the organization's broader palliative care (PC) policy; 4) Arranging accessibility of the innovation; 5) Involving management in the implementation project; and, 6) Giving regular feedback about the implementation. In three quarters of the projects, barriers and facilitators were encountered relating to characteristics of the care organizations, such as employee turnover and ratification of the project by the management. Applying the six strategies enhances sustainment. The organization plays a decisive role in the sustainment of innovations in PC. Engaging the management team in implementation projects from early onset is of utmost importance. **Abstract (w. list of references):** <https://bit.ly/2XoWB2m>



MVP (Medical situation, Values & Plan): A memorable and useful model for all serious illness conversations

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 July 2020 – Serious illness conversations (SIC) are integral to the optimal care of the vast and growing population of seriously ill patients, but they are under-taught in health professions training and widely feared, delayed or altogether avoided by clinicians. To redress this predicament, medical communication experts have published a variety of communication models designed to aid and promote SIC facilitation. The authors of this article, as three clinician-educators, are among their many beneficiaries. Yet despite their value, their experience in communication education and clinical encounters has revealed three recurring impediments to their instruction, retention and usefulness. Although to the authors' knowledge they have not been empirically evaluated, these pedagogic and practical weaknesses are potentially explained by both learning theory and mnemonics scholarship: 1) Different models for different types of SICs demand multiple rounds of information recoding and consolidation into long-term memory, which may overwhelm learners' cognitive load capacity; 2) Ostensibly sequential mnemonics (e.g., acronyms) that incorporate non-sequential components may burden working memory, compromise incorporation into long-term memory, and if recalled, muddle the very communication

Cont.

process they are designed to simplify; and, 3) Content that is selected to conform to a memorable mnemonic, rather than *vice versa*, often strains the language, increases the number and complexity of elements to be encoded and decoded, and hence may challenge retention and recall. The authors introduce MVP, a unified model for all SICs. It is designed to be readily teachable by medical educators, and memorable and useful for clinicians. **Full text:** <https://bit.ly/3gmQov9>

Noted in Media Watch 29 June 2020 (#672, p.3):

- *CMAJ OPEN* | Online – 19 June 2020 – ‘**Quality of clinicians’ conversations with patients and families before and after implementation of the Serious Illness Care Program in a hospital setting: A retrospective chart review study.**’ In this single-centre retrospective chart review study, the authors found that the quality of documented conversations regarding serious illness after implementation of the Serious Illness Care Program (SICP) was significantly higher than during usual care. In particular, after SICP implementation, the clinician and patient more often discussed patient values and goals, and understanding of prognosis and illness. The authors found conversations about serious illness were more clearly documented and more retrievable after SICP implementation. **Full text:** <https://bit.ly/3dmY6TG>

Palliative care transitions from acute care to community-based care: A qualitative systematic review of the experiences and perspectives of healthcare providers

PALLIATIVE MEDICINE | Online – 8 August 2020 – Transitioning from the hospital to community is a vulnerable point in patients’ care trajectory, yet little is known about this experience within the context of palliative care (PC). While some studies have examined the patient and caregiver experience, no study to date has synthesized the literature on the healthcare provider’s perspective on their role and experience facilitating these transitions. 1,791 studies were identified and 15 met inclusion criteria. Three core themes related to the role and experience of healthcare providers were identified: 1) Assessing and preparing for transition; 2) Organizing and facilitating the logistics of transition; and, 3) Coordinating and collaborating transitional care across sectors. The majority of studies focused on the discharge process from acute care; there was a lack of studies exploring the experiences of healthcare providers in the community who receive patients from acute care and provide them with PC at home. This review identified studies from a range of relatively high-income countries that included a diverse sample of healthcare providers. The results indicate that healthcare providers experience multiple complex roles during the transition facilitation process, and future research should examine how to better assist clinicians in supporting these transitions within the context of PC provision. **Abstract (w. list of references):** <https://bit.ly/2PCMEdb>

Compassionate design: Utilizing design thinking to preserve sanctity, dignity, and personhood when children die

PEDIATRIC QUALITY & SAFETY, 2020;5(4):e3127. Health “care” normally means “cure.” When this is impossible, care means comfort. In pediatric healthcare, care of the whole family is normative. Care, as comfort for a dying child and their family, mitigates poor outcomes for the parents and prepares them to grieve well. Perimortem and postmortem space influence parental emotional functioning. The authors describe the design process undertaken to improve parental and staff perimortem experience in a pediatric hospital. This process led to the description of 5 actionable process improvement opportunities, and the development of a low-fidelity prototype for each. The process additionally resulted in defining the criteria for a dedicated end-of-life (EOL) space to inform future renovation or construction planning. This project presents the novel application of Craig and Vogel’s design thinking as a method of addressing the need for quality improvement in pediatric EoL care. Their method provided a structured framework with which to gather and understand data. One of the benefits of this process was the breadth of knowledge that was sought. Persons not generally accessed for participation in research studies (e.g., bereaved parents, protective services, and interpreters) vetted the intervention prototypes to improve EoL care at this institution. The specific end products may not be generalizable. However, the development process is generalizable and replicable in any setting. The results are strengthened by the diversity of participants, which included representation from the numerous roles that influence the EoL process. Future directions include the engagement by hospital development representatives to seek donors to fund individual aspects of this project. **Full text:** <https://bit.ly/31rfWkE>

Pediatric suffering and the burden of proof

PEDIATRICS, 2020;146(Suppl.1):S70-S74. The alleviation of suffering has always been central to the care of the sick. Yet as medical technology has advanced and life-sustaining treatments multiplied, medicine's capacity to both prevent and create suffering has grown exponentially. In pediatric medicine, the ability to stave off death with life-sustaining treatments allows children to survive but also to suffer in ways that are diverse and unprecedented. However, although parents and pediatric clinicians broadly agree that all children can suffer, there is little published literature in which researchers analyze or clarify the concept of pediatric suffering. This gap is worrisome, especially in light of growing concerns that the label of suffering is used to justify end-of-life decision-making and mask quality-of-life determinations for pediatric patients with profound neurologic impairment. Moreover, the awareness that some children can experience suffering but cannot communicate whether and how they are suffering creates a problem. Does the determination of suffering in a non-verbal child lie in the judgement of clinicians or parents? In this article, the author addresses several important questions related to the suffering of children through an analysis of two prevalent conceptualizations of pediatric suffering and suggest a possible avenue forward for future scholarship. **Full text:** <https://bit.ly/39SnMrs>

Noted in Media Watch 3 August 2020 (#677, p.11):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 25 July 2020 – ‘**Suffering.**’ Suffering ... has always been a fundamental concern in philosophy, theology and literature. More recently, it has become the subject matter of highly contextualized analyses in medical end-of-life (EoL) decision-making. Three articles scheduled for publication in an upcoming issue of this journal contribute to this strand of research. More specifically, they focus on the following questions: 1) What is suffering?; 2) What should medicine do about suffering?; 3) What is the role of suffering when justifying medical decisions at the EoL? The authors call attention to the complicated nature of suffering in medicine and EoL decision-making. More specifically, they call attention to three ambivalences. **Full text:** <https://bit.ly/2X7i1B3>

Jahi McMath: Lessons learned

PEDIATRICS, 2020;146(Suppl.1):S81-S85. Jahi McMath's story has been an important reference in medicine and ethics as the landscape of the understanding of death by neurologic criteria is shifting, with families actively questioning the once-firm criterion. Palliative care providers have a role in seeking understanding and collaborating with families and clinical teams to navigate the many challenges that arise when a medical team has determined that a child has died, and their parents disagree. In this case-based narrative discussion the author considers the complexity of the family experience of brain death. Severe brain injury and brain death is a tragedy. The families met in these cases will start and end each day with the pain of their loss. They will also recall those of us who did or did not see the humanity of their child as they navigated this journey. When we leave the person out of the medical story, or separate the person from their death, we are

forgetting the human story and forgetting that the words we use do not die with our patients. **Full text:** <https://bit.ly/3i09nvW>

Determination of brain death/death by neurologic criteria: The World Brain Death Project

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 3 August 2020 – This report provides recommendations for the minimum clinical standards for determination of brain death/death by neurologic criteria in adults and children with clear guidance for various clinical circumstances. They have widespread international society endorsement and can serve to guide professional societies and countries in the revision or development of protocols and procedures for determination of brain death/death by neurologic criteria, leading to greater consistency within and between countries. **Full text:** <https://bit.ly/3i48sL3>

N.B. See also 'Defining death: Lessons from the case of Jahi McMath,' *Pediatrics*, 2020;146(Suppl.1):S75-80. **Full text:** <https://bit.ly/2BUOUcK>. Additional articles on the Jahi McMath case and brain death diagnosis noted in Media Watch 14 May 2018 (#563, p.8).

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Related:

- *MEDICAL LAW REVIEW* | Online – 31 July 2020 – ‘**Getting the balance right: Medical futility, scientific advancement, and the role of law.**’ The concept of medical futility as an applied ethical framework has seen a rise and fall in its popularity over the last 30 years. It is a term used in relation to the assessment of a patient’s health condition that is deemed untreatable, irreversible, and unresolvable. In four recent cases, Gard, Evans, Haastrup, and Raqeeb, the concept has been brought to the fore once again. These cases highlight a mounting tension between clinicians and families. Parental desires to see their child’s treatment continued, while understandable, should not dominate treatment planning. **Abstract:** <https://bit.ly/2Pj5OEY>

Self-care planning supports clinical care: Putting total care into practice

PROGRESS IN PALLIATIVE CARE | Online – 7 August 2020 – In palliative care the concept of total care represents a continuum beginning with care and compassion for oneself, extending to care and compassion for others. Given that self-care is highly relational to those around us, as well have the same potential for human suffering and vulnerability, this notion of total care can be further understood in the context of Dame Cicely Saunders’ pioneering work on the concept of “total pain.” Just as Saunders’ elucidation of total pain clarifies the need for total care, self-care, then, might best be understood as an important conduit to the promotion of holistic wellbeing and quality of life (QoL) for everyone – clinicians, patients/clients, and their families. QoL is a shared concern, and care provider’s QoL has both personal and professional impacts on their capacity to promote QoL for patients and their families. **Full text:** <https://bit.ly/2PCSRWY>

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