

**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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**As patients face the end of life, medical providers have one final chance to honor their values and identities – this is the essence of palliative care. But good intentions alone are not sufficient. Clinicians must also seek to understand African Americans' perceptions of death and dying.**

'Black lives in a pandemic: Implications of systemic injustice for end-of-life care' (p.7), in *The Hastings Report*.

## Canada

### **Palliative care training “woefully inadequate” in meeting need**

*HEALTHY DEBATE* | Online – 2 July 2020 – If we assume that every patient who dies in a given year would benefit from high-quality palliative care (PC), this would mean that 370,000 Canadians ... would benefit from PC every year. Current studies show that the majority of PC is only provided in the last month of a patient's life despite mounting evidence that providing earlier PC improves patient outcomes and even prolongs survival. A Canadian Society of Palliative Care Physicians (CSPCP) staffing model suggests we need one palliative physician for every 100 PC patients. A national survey by the Canadian Medical Association in 2014 identified 1,114 respondents as “palliative medicine physicians.” Of these, 132 were focused practice family physicians, 51 were specialists and 931 were identified as “other.” Based on a population of 37 million, this would represent one PC physician for every 33,000 people. The CSPCP estimates we need twice as many PC specialists. This bold statement is still an understatement. Clearly, our PC physician population is woefully inadequate from a provincial and national standpoint. <https://bit.ly/2BD95vo>

### **COVID-19 shows support for home care long overdue**

BRITISH COLUMBIA | *The Province* (Vancouver) – 1 July 2020 – The global COVID-19 pandemic has brought long-standing gaps in the Canadian care system sharply into focus, particularly for older adults who cannot live independently. As we collectively grasp the enormity of the troubling living conditions for Canada's residents of long-term care, and the resultant deaths due to the pandemic, we must also consider how such tragedy could have been prevented – or at least minimized – in the first place. It has been almost 20 years since Roy Romanow led the Royal Commission on the Future of Health Care in Canada, highlighting an urgent need to build Canada's home care programs. In 2009, the Canadian Healthcare Association published a road map for how to get there. And Canadians have repeatedly affirmed their wish to receive care “closer to home” and forego the ever-expanding costs of institutional care. Too bad these calls for robust home care services across the country have been largely ignored in favour of an inadequate piecemeal and patchwork system where few Canadians get the care they want or need. <https://bit.ly/2Ap6Knr>

## U.S.A.

### **An experiment in end-of-life care: Tapping AI's cold calculus to nudge the most human of conversations**

STAT | Online – 1 July 2020 – The daily email that arrived in physician Samantha Wang's inbox ... just before morning rounds, contained a list of names and a warning: These patients are at high risk of dying within the next year. This list of names was generated ... an algorithm that had reached its conclusions by scanning the patients' medical records. The email was meant as something of a nudge, to encourage Wang to broach a delicate conversation with her patient about his goals, values, and wishes for his care should his condition worsen. Those kinds of questions are increasingly cropping up among clinicians at the handful of hospitals and clinics around the country deploying cutting-edge artificial intelligence models in palliative care. The tools spit out cold actuarial calculations to spur clinicians to ask seriously ill patients some of the most intimate and deeply human questions: What are your most important goals if you get sicker? What abilities are so central to your life that you can't imagine living without them? And if your health declines, how much are you willing to go through in exchange for the possibility of more time? <https://bit.ly/38g2Auu>

Noted in Media Watch 2 March 2020 (#655, p.11):

- *THE LANCET*, 2020;395(10225):680-681. **'Power and perils of prediction in palliative care.'** Machine learning technologies can be useful in palliative care (PC), especially as clinicians and health systems seek to allocate and improve access to scarce PC resources. The potential of machine learning models in PC is their capacity to rapidly analyse data from various sources to predict who is likely to progress to unacceptable functional dependence or even die. Such predictions can signal who might need additional support, such as targeted communication or a PC consult. Appropriately timed introduction of PC services improves outcomes ... and healthcare spending efficiency. Figuring out who should get specialty PC and when is one of the field's most pressing questions. **Full text:** <http://bit.ly/2lqcUGV>

### **First culturally based end-of-life care protocol created by community members published**

ALABAMA | *UAB News* (University of Alabama) – 30 June 2020 – Culture shapes how people make meaning out of illness, suffering and dying, and it influences their responses to diagnosis, prognosis and treatment preferences. Researchers at the University of Alabama have created the first culturally based protocol for patients living with a serious illness or facing end-of-life care (EoLC). The protocol<sup>1</sup> ... was developed by Ronit Elk, a researcher in the Division of Gerontology, Geriatrics & Palliative Care at the university, in partnership with a Community Advisory Board made up of African Americans and white community members living in Beaufort, South Carolina. "EoLC values in the U.S. are historically rooted in values that represent the cultural and religious values of the white middle class, values that often do not apply, or even contradict, the values of people of different cultures or ethnicities," Elk said. "Lack of respect for cultural differences may compromise care for seriously ill minority patients. Until recently, cultur-

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

**'Six feet apart or six feet under: The impact of COVID-19 on the Black community'** (p.7), in *Death Studies*.

**'Black lives in a pandemic: Implications of systemic injustice for end-of-life care'** (p.7), in *The Hastings Report*.

**'Avoiding ineffective end-of-life care: A lesson from triage'** (p.7), in *The Hastings Report*.

#### **Specialist Publications**

**'State of integration of palliative care at National Cancer Institute-designated and non-designated cancer centers'** (p.8), in *JAMA Oncology*.

**'Family caregiving at the end of life and hospice use: A national study of Medicare beneficiaries'** (p.8), in *Journal of the American Geriatric Society*.

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ally appropriate models of palliative and EoLC have not been available in the U.S.” The Advisory Board members included those who had cared for a loved one living with a serious illness or had been a caregiver to a loved one who had recently died, community leaders, and hospital staff, with equal numbers of African American and white members. Developing the protocol took three and a half years of monthly meetings. <https://bit.ly/2ZnTx6D>

1. ‘Developing and testing the feasibility of a culturally based tele-palliative care consult based on the cultural values and preferences of Southern, rural African American and White community members: A program by and for the community,’ *Health Equity*, 2020;4(1):52-83. [Noted in 6 April 2020 issue of Media Watch (#660, p.11)] **Full text:** <https://bit.ly/2wHWXaI>

## International

### **Elisabeth Kübler-Ross: The rise and fall of the five stages of grief**

U.K. | BBC News – 3 July 2020 – When Swiss psychiatrist Elisabeth Kübler-Ross moved to the U.S. in 1958 she was shocked by the way the hospitals she worked in dealt with dying patients. So she started running a seminar for medical students at the University of Colorado where she’d interview people who were dying about how they felt about death. Although she met with stiff resistance from her colleagues, there was soon standing room only. These interviews led in 1969 to a book titled *On Death and Dying*. In it, Kübler-Ross began by describing how patients talk about dying, and went on to discuss how end-of-life care could be improved. The part of it that stuck in the public imagination was the idea that when a person is diagnosed with a terminal illness they go through a series of emotional stages. She described them as “defence mechanisms... coping mechanisms to deal with extremely difficult situations.” There were never just five stages, though. While each of these gets a chapter heading, a graphic in the book describes as many 10 or 13 stages, including shock, preparatory grief – and hope. And her

son, Ken Ross, says she wasn’t wedded to the idea that you have to go through them in order. The five stages are meant to be a loose framework – they’re not some sort of recipe or a ladder for conquering grief. If people wanted to use different theories or different models, she didn’t care. <https://bbc.in/2AoRkiS>

#### Specialist Publications

“‘The way I am treated is as if I am under my mother’s care’”: **Qualitative study of patients’ experiences of receiving hospice care services in South Africa**’ (p.4), in *BMC Palliative Care*.

‘**Barriers in care for children with life-threatening conditions: A qualitative interview study in The Netherlands**’ (p.5), in *BMJ Open*.

‘**Care homes as hospices for the prevalent form of dying: An analysis of long-term care provision towards the end of life in England**’ (p.13), in *Social Science & Medicine*.

**N.B.** The November 2019 issue of the *American Journal of Bioethics*, noted in the 25 November 2019 issue of Media Watch (#641, p.15), focuses on the work of Kübler-Ross. **Download/view at:** <http://bit.ly/2ToM4zl>. Additional articles on Kübler-Ross noted in the 5 August 2019 issue of Media Watch (#625, pp.14-15).

## Specialist Publications

### **Family behaviors as unchanging obstacles in end-of-life care: 16-year comparative data**

*AMERICAN JOURNAL OF CRITICAL CARE*, 2020;29(4):e81-e91. Research on obstacles in providing end-of-life (EoL) care has been conducted for more than 20 years, but change in such obstacles over time has not been examined. In this cross-sectional survey study, questionnaires were sent to selected members of the American Association of Critical-Care Nurses. 509 usable responses were received. Six obstacle magnitude scores increased significantly over time, of which 4 were related to family issues (not accepting the poor prognosis, intra-family fighting, overriding the patient's EoL wishes, and not understanding the meaning of the term lifesaving measures). Two were related to nurse issues. Seven obstacles decreased in magnitude, including poor design of units, overly restrictive visiting hours, and physicians avoiding conversations with families. Four helpful behavior magnitude scores increased significantly over time, including physician agreement on patient care and family access to the patient. Three helpful behavior items decreased in magnitude, including intensive care unit design. The same EoL care obstacles that were reported in 1999 are still present. Obstacles related to family behaviors increased significantly, whereas obstacles related to intensive care unit environment or physician behaviors decreased significantly. These results indicate a need for better EoL ed-

ucation for families and health care providers. **Abstract:** <https://bit.ly/38lmtAt>

#### Publishing Matters

**'An alert to COVID-19 literature in predatory publishing venues'** (p.14), in *Journal of Academic Librarianship*.

#### **Experiences of oldest-old caregivers whose partner is approaching end-of-life: A mixed-method systematic review and narrative synthesis**

*PLOS ONE* | Online – 9 June 2020 – This is the first literature review to systematically collate, narratively synthesise and quality appraise the extant literature on oldest-old spouses providing end-of-life (EoL) care. The authors identified an upsurge of research published in the last three years, attesting to the growing interest in the academic community of putting oldest-old spousal caregivers on the policy agenda. Indeed, the fact no study was published before 1993 may also indicate that EoL caring amongst the very old is a particular product of present-day conditions where people reach their EoL in advanced age and are expected to be cared for in the community. **Full text:** <https://bit.ly/3gqUORz>

### **“The way I am treated is as if I am under my mother’s care”:** Qualitative study of patients’ experiences of receiving hospice care services in South Africa

*BMC PALLIATIVE CARE* | Online – 1 July 2020 – South African patients’ experiences of receiving hospice care do not appear dissimilar from those reported by hospice patients in resource-rich countries. This suggests underlying commonalities in patient experience and the fundamental psychosocial issues reported by them. Receiving hospice care that carefully considers patients’ psychosocial and physical needs assists people to live with their terminal illness with as good quality of life as possible until they die. Given the negative public perceptions of hospice and palliative care (PC) – which were also evident in this study – the need for raising awareness and educating the public about what hospice can offer to those in need is clearly evident at the policy level. For instance, public health campaigns could help reduce the stigma attached to PC, deflect negative perceptions, and communicate the advantages for patients, families and communities in culturally sensitive ways. This would help expand conceptions of hospice care and highlight the value of such care for people managing a terminal illness. Healthcare professionals who recommend hospice care to patients should also be aware of these perceptions and make every effort to tactfully communicate the benefits which patients and their families can derive from such care. **Full text:** <https://bit.ly/3gjdYZc>

## Expanding the 3 Wishes Project for compassionate end-of-life care: A qualitative evaluation of local adaptations

*BMC PALLIATIVE CARE* | Online – 29 June 2020 – The authors describe the adaptations and refinements to the 3 Wishes Project (3WP) that enabled successful implementation and fostered viability in variable intensive care unit settings despite different contexts, needs and resources. Commitment to quality end-of-life (EoL) care was an essential motivator, inspiring frontline clinicians to initiate the program, creatively resource it, and maintain enthusiasm. As the program became more established, it transitioned from an “add on” to existing EoL programs to become “embedded into” the unit’s approach to EoL care. **Full text:** <https://bit.ly/31t1M48>

Noted in Media Watch 15 June 2020 (#670, p.10):

- *PALLIATIVE MEDICINE* | Online – 10 June 2020 – ‘**Building organizational compassion among teams delivering end-of-life care in the intensive care unit: The 3 Wishes Project.**’ Interviews and focus groups were used to collect data from family members of dying patients, clinicians, and institutional leaders. Examining the 3 Wishes Project through the lens of organizational compassion reveals the potential of this program to cultivate the capacity for people to collectively notice, feel and respond to suffering. The authors’ data document multidirectional demonstrations of compassion between clinicians and family members, forging the type of human connections that may foster resilience. **Abstract (w. list of references):** <https://bit.ly/37zpz9E>

## Barriers in care for children with life-threatening conditions: A qualitative interview study in The Netherlands

*BMJ OPEN* | Online – 28 June 2020 – The barriers experienced by parents in care for children with life-threatening conditions and uncertain futures are related to six major themes. First, parents wished for more empathetic and open communication about the illness and prognosis. Second, organisational barriers create bureaucratic obstacles and a lack of continuity of care. Third, parents wished for more involvement in decision-making. Fourth, parents wished they had more support from the healthcare team on end-of-life decision-making. Fifth, parents experienced a lack of attention for the family during the illness and after the death of their child. Finally, parents experience an overemphasis on symptom-treatment and lack of attention for their child as a person. The parents’ wish to see the child as a person sheds new light on the relationship between medical professionalism and detachedness. The authors argue that in paediatric palliative care (PPC), the child behind the symptoms is sometimes forgotten. Paediatric PC might suit the needs of parents and children better when it re-evaluates its current professional detachedness, and progresses towards a medical professionalism where not only symptoms, but also people are treated. **Full text:** <https://bit.ly/3g9JI3c>

### Related:

- *CURRENT PROBLEMS IN PEDIATRIC & ADOLESCENT HEALTH CARE* | Online – 29 June 2020 – ‘**Primary palliative care: Skills for all clinicians.**’ All pediatric clinicians can positively influence the care of seriously ill children by incorporating palliative care (PC) principles into their daily care, resulting in better outcomes for their patients and families. PC involvement at the time of diagnosis rather than just at the end of life has moved coordinated care upstream. The American Academy of Pediatrics has called for pediatric PC to be available to all children who would benefit. Pediatric PC is essential for these children. Collaborative team-based methods focused on improving quality of life have shown to improve outcomes in physical, emotional, and cognitive domains. **Abstract:** <https://bit.ly/31BGBNo>

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### 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.15.

- *EUROPEAN JOURNAL OF PEDIATRICS* | Online – 30 June 2020 – ‘**Predictors for place of death among children: A systematic review and meta-analyses of recent literature.**’ Lower age was associated with higher odds of hospital death in eight studies... Children categorised as non-white were less likely to die at home compared to white ... as were children of low socio-economic position versus high... Compared to patients with cancer, children with non-cancer diagnoses had lower odds of home death... Country and region of residence, older age of the child, high socio-economic position, “white” ethnicity and cancer diagnoses appear to be independent predictors of home death among children. **Abstract (w. list of references):** <https://bit.ly/2NHYoKy>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 July 2020 – “**I could never prepare for something like the death of my own child”: Parental perspectives on preparedness at end of life for children with complex chronic conditions.**’ Parents of children who received care at Boston Children’s Hospital and died between 2006-2015 completed 21 open-response items querying communication, decision-making and end-of-life (EoL) experiences as part of the Survey of Caring for Children with complex chronic conditions (CCCs). Most ... described feeling unprepared for their child’s EoL, despite palliative care and advance care planning, suggesting preparedness is a nuanced concept beyond “readiness.” **Abstract (w. list of references):** <https://bit.ly/2NU3rI0>

### **Clinician responses to legal requests for hastened death: A systematic review and meta-synthesis of qualitative research**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 29 June 2020 – The legalisation of medical assistance in dying in numerous countries over the last 20 years represents a significant shift in practice and scope for many clinicians who have had little-to-no training to prepare them to sensitively respond to patient requests for hastened death. The authors performed a systematic review and meta-synthesis of primary qualitative research articles that described the experiences and perspectives of healthcare professionals who have responded to requests for hastened death in jurisdictions where Medical Assistance in Dying was legal or depenalised. Although the response to requests for hastened death varied case-by-case, clinicians formulated their responses by considering seven distinct domains. These include: policies, professional identity, commitment to patient autonomy, personal values and beliefs, the patient-clinician relationship, the request for hastened death and the clinician’s emotional and psychological response. Responding to a request for hastened death can be an overwhelming task for clinicians. An approach that takes into consideration the legal, personal, professional and patient perspectives is required to provide a response that encompasses all the complexities associated with such a monumental request. **Abstract:** <https://bit.ly/38igmN9>

Noted in Media Watch 4 May 2020 (#664, p.12):

- *MEDICAL HYPOTHESES*, 2020;142:109727. ‘**Hastened death due to disease burden and distress that has not received timely, quality palliative care is a medical error.**’ The authors’ hypothesis is that some requests for hastened death (known as Medical Assistance in Dying or MAiD in Canada) are driven by lack of access to palliative care (PC) or lack of quality in the PC attempting to address disease burden and distress such that the resulting provision of hastened death is a medical error. The root cause of the error is in the lack of quality PC in the previous weeks, months and years of the disease trajectory – a known therapy that the system fails to provide. The authors present three cases of request for assisted death that could be considered medical error. **Full text:** <https://bit.ly/2YdaiXr>



#### **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>

## Black lives in a pandemic: Implications of systemic injustice for end-of-life care

*THE HASTINGS REPORT*, 2020;50(3):58-60. Racial health and healthcare disparities, rooted as they are in systemic injustice, ought to carry far more weight in clinical ethics than they generally do. In particular, the authors examine palliative and end-of-life care for African Americans, highlighting the ways in which American medicine, like American society, has breached trust. In the experience of many African American patients struggling against terminal illness, healthcare providers have denied them a say in their own medical decision-making. In the midst of the COVID-19 pandemic, African Americans have once again been denied a say with regard to the rationing of scarce medical resources such as ventilators, in that dominant and ostensibly race-neutral algorithms sacrifice black lives. Is there such thing as a “good” or “dignified” death when African Americans are dying not merely of COVID-19 but of structural racism? **Full text:** <https://bit.ly/2Vxr9xN>



The focus of the current issue of *The Hastings Report* is the COVID-19 pandemic.  
**Journal contents page:**  
<https://bit.ly/3iiahor>

### Related:

- *DEATH STUDIES* | Online – 1 July 2020 – ‘**Six feet apart or six feet under: The impact of COVID-19 on the Black community.**’ The authors discuss COVID-19 relative to Black people and their over-representation among those who are infected and died from the disease. Their dying, death, and grief experiences are explored through a cultural and spiritual lens. The physical distancing, social isolation, misinformation, and restrictive burials and cremations now elicited by this unprecedented pandemic have had diminished familial, cultural, emotional, and economic impacts on the Black community. Implications for public health and Black peoples’ involvement in the political process are also addressed. **Full text:** <https://bit.ly/3dVpM2v>

Noted in Media Watch 15 June 2020 (#670, p.2):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2020;323(19):1891-1892. ‘**COVID-19 and African Americans,**’ The scourge of COVID-19 will end, but healthcare disparities will persist. Does the U.S. chronicle these poor outcomes due to COVID-19 complications with the higher burden of cardiovascular disease, poorer outcomes for breast cancer, higher amputation rates for peripheral vascular disease, lower kidney transplant rates, and worse rates for maternal mortality, then safely park everything in the health-care disparity domain and go back to “normal”? Or will the nation finally hear this familiar refrain, think differently, and as has been done in response to other major diseases, declare that a civil society will no longer accept disproportionate suffering? **Full text:** <https://bit.ly/30m4eZG>
- *THE HASTINGS REPORT*, 2020;50(3):71-72. ‘**Avoiding ineffective end-of-life care: A lesson from triage.**’ Many healthcare workers have noticed that, outside the pandemic shortage situation, we routinely supply patients in the ICU with invasive and painful care that will not help the patients survive even their hospitalization. This is the kind of pointless care that even the most basic protocol would triage against. Perhaps this widespread reflection on triage standards will draw our attention to our ongoing custom of supplying burdensome and inefficacious care to those near the end of life (EoL) – care that most healthcare providers would not want for themselves. This essay argues that reflecting on triage could help us improve EoL care. **Full text:** <https://bit.ly/3ii0xeb>
- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2020;26(5):3-7. ‘**Palliative care in coronavirus disease 2019 pandemic: Position statement of the Indian Association of Palliative Care.**’ This position statement represents the collective opinion of the experts chosen by the society and reports on the current situation based on recent scientific evidence. It purports to guide all healthcare professionals caring for COVID-19 patients and recommends palliative care (PC) principles into government decisions and policies. The statement provides recommendations for PC for both adults and children with severe COVID-19 illness, cancer, and chronic end-stage organ impairment in the hospital, hospice, and home setting. **Full text:** <https://bit.ly/2ZIMc7D>

**N.B.** The focus of the current issue of the *Indian Journal of Palliative Care* is the COVID-19 pandemic.  
**Journal contents page:** <https://bit.ly/2ZIMc7D>

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- *INTENSIVE CARE MEDICINE* | Online – 2 June 2020 – ‘**Alone, the hardest part.**’ The added value of family caregivers in the context of critical illness should not be overlooked amidst the COVID-19 pandemic. The authors urge clinicians to think differently ... and consider a decision-making framework that minimizes infection risk, honors patient/family relationships, upholds culturally important rituals of dying, and mitigates potential psychological harm precipitated by the trauma of family separation. With careful screening, education, pragmatic psychosocially oriented facilitation and teamwork, we can accommodate the very real needs of patients to not be alone, for families to fulfill their sense of responsibility and duty, and for staff to uphold the tenets of family-centered care. **Full text:** <https://bit.ly/2ZtQj1J>
- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2020;22(4):260-269. ‘**Recommendations to leverage the palliative nursing role during COVID-19 and future public health crises.**’ The literature addressing the palliative care response to COVID-19 has surged, and yet, there is a critical gap regarding the unique contributions of palliative nurses and their essential role in mitigating the sequelae of this crisis. Thus, the primary aim herein is to provide recommendations for palliative nurses and other healthcare stakeholders to ensure their optimal value is realized and to promote their well-being and resilience during COVID-19 and, by extension, in anticipation of future public health crises. **Abstract:** <https://bit.ly/2BqyU1Z>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 July 2020 – ‘**The urgency of spiritual care: COVID-19 and the critical need for whole-person palliation.**’ Although spiritual care has long been recognized as one of the domains of quality palliative care (PC), it is often not fully integrated into practice. All disciplines are ultimately responsible for ensuring spiritual care is prioritized to improve quality of life and the experience of patients and families facing spiritual emergencies amid the complex life-and-death scenarios inherent to COVID-19. Although the pandemic has revealed serious fault lines in many healthcare domains, it has also underscored the need to recommit to spiritual care as an essential component of whole-person PC. **Abstract (w. list of references):** <https://bit.ly/2NVNxww>
- *SUPPORTIVE CARE IN CANCER* | Online – 2 July 2020 – ‘**Uncertainty upon uncertainty: supportive Care for Cancer and COVID-19.**’ A comprehensive and integrated strategy is essential to ensure that people with cancer are given the access, care and support they need, as do their care teams, a topic for a future paper. This editorial represents a call to action for healthcare professionals, policy-makers and patient groups to acknowledge and include social and psychological factors as risks resulting from the COVID-19 pandemic. This pandemic has highlighted stark inequalities at the societal, institutional and community levels. The need for research, understanding, interventions and action is critical. **Full text:** <https://bit.ly/3gcx3wm>

### **State of integration of palliative care at National Cancer Institute-designated and non-designated cancer centers**

*JAMA ONCOLOGY* | Online – 2 July 2020 – Timely integration of specialist palliative care (PC) to oncologic care is associated with improved patient outcomes. Although several studies have examined supportive and PC services at U.S. cancer centers, none to the authors’ knowledge have assessed the level of integration using a standardized set of indicators. In this study, they compared the level of integration between National Cancer Institute National Cancer Institute–designated and non–designated cancer centers. **Abstract:** <https://bit.ly/3gpkbml>

### **Family caregiving at the end of life and hospice use: A national study of Medicare beneficiaries**

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 30 June 2020 – Hospice care confers well-documented benefits to patients and their families, but it is underutilized. One potential reason is inadequate family support to make end-of-life (EoL) decisions and care for older adults on hospice at home. The authors assessed the association between amount of family support and hospice use among a population of decedents and among specific illness types. At the EoL, hours of family caregiving and numbers of helpers vary widely with individuals with dementia receiving the most hours of unpaid care ... and having 2.4 unpaid caregivers on average. In an adjusted analysis, older adults with cancer receiving 40 hours

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and more of unpaid care/week as compared with fewer than 6 hours per week were twice as likely to receive hospice care at the EoL. This association was not seen among those with dementia or among decedents in general. No significant association was found between number of caregivers and hospice use at the EoL. Better understanding of disparities in hospice use can facilitate timely access to care for older adults with a serious illness. **Abstract:** <https://bit.ly/3iluj1C>

**Related:**

- *BMJ OPEN* | Online – 2 July 2020 – ‘**Challenges and facilitators of hospice decision-making: A retrospective review of family caregivers of home hospice patients in a rural U.S.-Mexico border region – a qualitative study.**’ Hospice care (HC) enrolment is disproportionate for rural patients, who are less likely to use HC in comparison to their urban counterparts. HC patients’ family caregivers (FCGs) in this rural region reported a lack of knowledge or misunderstanding of HC. Healthcare providers need to actively engage family members in patient’s EOL care planning. Optimal transition to an HC programme can be facilitated when FCGs are informed and have a clear understanding about patients’ medical status along with information about HC. **Abstract:** <https://bit.ly/2ZxRFIC>

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

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 4 June 2020 – ‘**Hospice carve-in: Aligning benefits with patient and family needs.**’ Patient-centered care should be a defining feature of the healthcare system, and no time is more critical for having patients at the center of care than at the end of life (EoL). At this difficult and deeply personal time for patients and their families, it is paramount that the preferences of patients and their families be respected and their experiences prioritized. Compassionate EoL care should be available to the 2.8 million individuals who die every year in the U.S. and should be delivered in a way that is highly coordinated, seamless to patients and their families, and attuned to the patient’s goals and wishes. **Full text:** <https://bit.ly/30nm7aH>

Noted in Media Watch 8 July 2019 (#621, p.7):

- *GERONTOLOGY & GERIATRIC MEDICINE* | Online – 27 June 2019 – ‘**Closing the gap in hospice utilization for the minority Medicare population.**’ The average *per capita* end-of-life medical spending in the last year of life is \$80,000, comprising a larger fraction of its gross domestic product than that for all eight other countries examined in a 2017 study.<sup>1</sup> With the potential to provide nearly \$270 million in annual cost savings while also improving health outcomes, research on specific programs that successfully reduce the racial/ethnic minority hospice enrollment gap is paramount. Collaboration between hospices, health systems and community organizations is needed to reduce the disparities between racial/ethnic minority and White Medicare beneficiary hospice utilization. **Abstract:** <http://bit.ly/307JLVf>

1. ‘End-of-life medical spending in last twelve months of life is lower than previously reported,’ *Health Affairs*, 2017;36(7):1211-1217. [Noted in 10 July 2017 issue of Media Watch (#520, p.10)] **Full text:** <http://bit.ly/2XhOpOy>

Noted in Media Watch 6 April 2020 (#660, p.12):

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



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## Creating a resilient research program: Lessons learned from a palliative care research lab

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 July 2020 – While limitations in funding and training opportunities are well-described, a less recognized barrier to successful palliative care (PC) research is creating a sustainable and resilient team. In this special report, the authors describe the experience and lessons-learned in a single PC research lab. In the first few years of the program, 75% of staff quit, citing burnout and the emotional tolls of their work. To address sustainability, the authors translated resilience theory to practice. First, they identified and operationalized shared mission and values. Next, they conducted a resilience resource needs assessment for both individual team-members and the larger team as a whole, and created a workshop based curriculum to address unmet personal and professional support needs. Finally, the authors changed the leadership approach to foster psychological safety and shared mission. Since then, no team-member has left and the program has thrived. **Abstract (w. list of references):** <https://bit.ly/2NOOczO>

Noted in Media Watch 10 February 2020 (#652, p.6):

- *BMC PALLIATIVE CARE* | Online – 3 February 2020 – ‘**International palliative care research priorities: A systematic review.**’ The authors call attention to the need for more end users in research priority setting exercises. Researchers and funding bodies should develop new strategies to ensure meaningful participation of palliative care (PC) patients and families, building in structures and processes to account for the vulnerability often present within this population. Findings provide an initial blueprint for PC research funders and policymakers to contribute to the future research agenda for PC from a patient and healthcare professional perspective. Given that funding resources are limited the importance of collaboration and international approaches to PC is growing... **Full text:** <http://bit.ly/37VsJxS>
- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 5 February 2020 – ‘**Economics of palliative care for cancer: Interpreting current evidence, mapping future priorities for research.**’ Early research studies on the economics of palliative care (PC) have reported a general pattern of cost savings during inpatient hospital admissions and the end-of-life phase. Recent research has demonstrated more complex dynamics, but expanding PC capacity to meet clinical guidelines and population health needs seems to save costs. Quantifying these cost savings requires additional research, because there is significant variance in estimates of the effects of treatment on costs, depending on the timing of intervention, the primary diagnosis, and the overall illness burden. **Abstract:** <http://bit.ly/3beeGW5>

Noted in Media Watch 27 January 2020 (#650, p.12):

- *PALLIATIVE MEDICINE* | Online – 23 January 2020 – ‘**Do journals contribute to the international publication of research in their field? A bibliometric analysis of palliative care journal data.**’ Research is important internationally, impacting on health service provision and patient benefit. Journals play an important dissemination role, but there may be geographical bias, potentially affecting access to evidence. North American authors are more present in North American journals and European authors in European journals. This polarised approach, if replicated across readerships, may lead to research waste, duplication, and be sub-optimal for healthcare development. **Abstract (w. list of references):** <http://bit.ly/3aCr8i5>

## Using grounded theory to inform the human-centered design of digital health in geriatric palliative care

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 June 2020 – Digital health offers innovative mechanisms to engage in palliative care (PC), yet digital systems are typically designed for individual users, rather than integrating the patient’s caregiving “social convoy” (i.e., family members, friends, neighbors, formal caregiving supports) to maximize benefit. As older adults with serious illness increasingly rely on the support of others, there is a need to foster effective integration of the social convoy in digitally supported PC. Digital health provides an opportunity to expand the reach of geriatric PC interventions. This article documents human centered preferences of geriatric PC digital health to ensure technologies are relevant and meaningful to healthcare providers, patients, and the caregiving social convoy. **Abstract (w. list of references):** <https://bit.ly/2YJdi9W>

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Noted in Media Watch 10 February 2020 (#652, p.8):

- *JOURNAL OF APPLIED GERONTOLOGY* | Online – 2 February 2020 – ‘**The overlap between geriatric medicine and palliative care: A scoping literature review.**’ This article provides a scoping literature review on the relationship between geriatric medicine (GM) and palliative care (PC) within the U.K.. The review encompassed literature written between 1997 and 2019. Three themes were identified: 1) Unclear boundaries between specialties; 2) Communication within and between specialisms; and, 3) Ambiguity of how older people fit in the current healthcare system. The authors suggest that more empirical research is conducted about the overlap between PC and GM to understand how interprofessional working and patient care can be improved. **Abstract:** <http://bit.ly/31pTQib>

**N.B.** Additional articles on the potential overlap of GM and PC noted in 6 January 2020 issue of Media Watch (#647, pp.6-7).

### **Public perceptions of advance care planning, palliative care, and hospice: A scoping review**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 July 2020 – Although access to advance care planning (ACP), palliative care (PC) and hospice has increased, public attitudes may still be barriers to their optimal use. A limited number of studies met the authors’ inclusion criteria... The studies reflect public perceptions pre-COVID-19. Twelve studies met inclusion criteria and included >9,800 participants. For ACP, 80% to 90% of participants reported awareness, and a similar proportion considered it important, but only 10% to 41% reported having named a proxy or completed a written document. 66% to 71% of participants reported no awareness of PC, and those who reported awareness often conflated it with end-of-life care. However, after being prompted with a tested definition, 95% rated PC favorably. For hospice, 86% of participants reported awareness and 70% to 91% rated it favorably, although 37% held significant misconceptions. Consumer perceptions of ACP, PC, and hospice each have a distinct profile of awareness, perceptions of importance, and reports of action taking, and these profiles represent three different challenges for public messaging. **Abstract:** <https://bit.ly/3gl24yf>

#### **Related:**

- *EUROPEAN JOURNAL OF CANCER CARE* | Online – 1 July 2020 – ‘**The perception of people with cancer of starting a conversation about palliative care: A qualitative interview study.**’ Both positive and negative stances towards starting a conversation about palliative care (PC) with a professional carer were found. Influencing behavioural factors were identified, such as knowledge (e.g., about PC), attitude (e.g., association of PC with quality of life), and social influence (e.g., relationship with the professional carer). The behavioural model developed helps to explain why people with incurable cancer do or do not start a conversation about PC... Interventions can be developed to help patients taken the initiative in communication about PC with a professional carer. **Abstract:** <https://bit.ly/2AoPG0J>

### **Top ten tips palliative care clinicians should know about bereavement and grief**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 July 2020 – Palliative care (PC) focuses on caring for the whole person, from birth to death, while managing symptoms and helping to navigate medical complexities. Care does not stop at the time of death, however, as assisting patients, families, and fellow clinicians through grief and bereavement is within PC’s purview. Unfortunately, many clinicians feel unprepared to deal with these topics. In this article, PC and hospice clinicians define and explain bereavement, distinguish normative grief from pathological grief, offer psychometrically sound scales to screen and follow those suffering from grief, and discuss the interaction between grief and bereavement and the physical and mental health of those who are left behind after the death of a loved one. **Abstract:** <https://bit.ly/2ArNTTr>



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

## Why oral palliative care takes a backseat? A national focus group study on experiences of palliative doctors, nurses and dentists

*NURSING OPEN* | Online – 27 June 2020 – The findings in this study have shed some light on the oral care of palliative patients by healthcare professionals by obtaining information of their perspective through focus group discussions. This paves a way for governmental health organizations in providing support for oral care of palliative patients to ensure high quality of care. This study suggests that related organizations or authorities should establish appropriate oral care guidelines specific for palliative patients. To help improve the effectiveness, a wider scope of the healthcare setting should also be considered and improved. For example, oral care can be made as a part of training for all healthcare professionals to counter the issue of manpower. These, coupled with the improved health policies in healthcare settings, might bring about a better result towards the provision of high quality of care for these patients. **Full text:** <https://bit.ly/2BxFraT>

## A pilot study evaluating the effectiveness of a training module designed to improve hospice palliative care volunteers' ability to deal with unusual end-of-life phenomena

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 30 June 2020 – The need for training to help healthcare professionals and hospice palliative care (PC) volunteers deal with unusual experiences at or around the end of a person's life is an oft-repeated theme in the scientific literature. A pilot study was conducted to examine the effectiveness of a training module designed to improve volunteers' ability to recognize, understand, and respond to unusual end-of-life (EoL) phenomena in their work with dying patients and their families. Twenty-four volunteers from two community-based hospice PC programs completed the 25-item Coping with Unusual End-of-Life Experiences Scale prior to and immediately after attending a lecture and powerpoint training module. A series of paired sample tests revealed significant pre- and post-training differences on 14 items, suggesting that volunteers felt more knowledgeable about, better prepared to deal with, and more comfortable talking about EoL phenomena with others following the training. **Abstract (w. list of references):** <https://bit.ly/2Bvmx4D>

Noted in Media Watch 24 February 2020 (#654, p.13):

- *PALLIATIVE MEDICINE* | Online – 17 February 2020 – “**It's not what they were expecting**”: **A systematic review and narrative synthesis of the role and experience of the hospital palliative care volunteer.** The volume of research evidence in the studies that were included in this review, and that describe volunteers' actions of “being with” terminally ill patients, highlights not only the importance of this aspect of volunteer work but also exemplifies the aspects of volunteers' role they found most satisfying. Ideally, the patient-volunteer relationship would be determined as a result of a process of specifically matching volunteers to patients according to measures of personal compatibility and consideration of relational chemistry. **Full text:** <http://bit.ly/2vFhE5E>

Noted in Media Watch 10 December 2018 (#593, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 December 2018 – **The liminal space palliative care volunteers occupy and their roles within it: A qualitative study.** Volunteers have an important place in palliative care (PC), positively influencing quality of care for seriously ill people and those close to them and providing a link to the community. However, it is not well understood where volunteers fit into PC provision or how to support them adequately. The authors describe volunteer roles across care settings through the perspective of those closely involved in the care of terminally ill people. Two volunteer roles were identified. The first was “being there” for the dying person. The second was the “liaison” role. **Abstract:** <http://bit.ly/2XEMioy>



Would the articles above be of interest to a colleague?

## **Palliative care: The physician assistant role**

*PHYSICIAN ASSISTANT CLINICS*, 2020;5(3). Advances in modern medicine have not only prolonged living but also prolonged dying. Recent progress in medical technology has converted critical illnesses into chronic illnesses. Over 2 million Americans die each year; however, less than 10% of the population will experience a sudden or rapid death. Many will be diagnosed and live with a chronic illness for a prolonged period of time before dying. The field of hospice and palliative medicine has arisen out of a need to help these patients navigate the experience of living and dying with an advanced, chronic illness. This issue of *Physician Assistant Clinics* is groundbreaking and may be the first publication to cover palliative care (PC) skills written by physician assistants for physician assistants. There's an introduction to hospice and PC, with articles on the skills needed in communicating with patients and their families, on breaking serious news, advanced care planning and setting goals-of-care, and spirituality. Additional articles discuss pain management, the treatment of dyspnea, the treatment options for gastrointestinal symptoms, and the psychiatric aspects of hospice and PC. **Journal contents page:** <https://bit.ly/3dA8GXX>

Noted in Media Watch 5 September 2016 (#478, p.11):

- *JOURNAL OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS*, 2016;29(9):38-43. '**The benefits of expanded physician assistant practice in hospice and palliative medicine.**' The need for hospice and palliative care (PC) services is growing as the U.S. deals with evolving healthcare reform and continued disparities in healthcare access for racial and ethnic groups. Physician assistants (PAs) can help meet this need by widening their practice in palliative medicine, including hospice care. If PAs and others recognize the physician assistant role in the systemwide change necessary for PC improvements for populations, patients and families can have improved care experience in all settings, including hospice and PC. **Full text:** <https://bit.ly/2BhY8zn>

## **Care homes as hospices for the prevalent form of dying: An analysis of long-term care provision towards the end of life in England**

*SOCIAL SCIENCE & MEDICINE* | Online – 1 July 2020 – In the U.K. and the Westernised countries, most people die aged 80+ from disabling, chronic and degenerative diseases, having spent several years in poor health. There is thus continuity between long-term care (LTC) and end of life (EoL) care in old age, but this continuity is poorly understood within policy and almost nothing is known about what determines the modality and intensity of LTC provision in old age towards the EoL. Hospices provide EoL LTC for cancer diagnoses and adults aged 50-64, while care homes provide open-ended and EoL LTC for non-cancer diagnoses, dementia, severe disability, and adults aged 80+. Further, the informal, formal, mixed and care home LTC arrangements reflect increasing levels of disability and ill-health, and decreasing levels of family support, with differences concerning education and gender. Dementia and Parkinson's disease are the single strongest determinants of high formal LTC provision, and overall high care needs determine high formal LTC provision. Within the English context, the consequences of this are that: 1) Continued reliance on informal family care is not sustainable; 2) To provide free formal LTC to old adults with high care needs is appropriate; and, 3) Hospices do not cater for the prevalent form of dying in old age while care homes do, being the *de facto* hospices for severely disabled, very old (80+) adults with dementia. Yet this is not represented in English EoL care policy and research. **Abstract:** <https://bit.ly/3f8P5PK>

## **Live discharge from hospice care: Psychosocial challenges and opportunities**

*SOCIAL WORK IN HEALTH CARE* | Online – 2 July 2020 – Hospice social workers face many challenges in attempts to replicate or supplement the holistic support and unique services hospice provides for individuals discharged alive. This discontinuity in care can impact the types of supports needed by individuals and caregivers, which may or may not be accessible within their community. Patients and families who have access to community-based palliative care programs following a discharge generally tend to navigate the process with fewer challenges. This qualitative study explored both the challenges of the live discharge process and the opportunities within social work practice in the U.S. Results from this study

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emphasize the need for a framework to better approach a live discharge to ensure appropriate supports are accessible for all patients and caregivers. Specifically, results highlight both the concrete and psychosocial challenges in live discharges as a result of tension between current eligibility requirements and individual feelings and needs. Social workers also provided suggestions to improve the live discharge process, including attention to communication and preparation. The authors outline specific challenges of live discharge from hospice, a framework for understanding presented challenges, and implications for policy and practice. **Abstracts:** <https://bit.ly/3itJMMT>

## [Publishing Matters](#)

### **An alert to COVID-19 literature in predatory publishing venues**

*JOURNAL OF ACADEMIC LIBRARIANSHIP*, 2020;46(5):102187. The COVID-19 pandemic, which has led to a flood of papers and preprints, has placed multiple challenges on academic publishing, the most obvious one being sustained integrity under the pressure to publish quickly. There are risks of this high volume-to-speed ratio. Many letters, editorials, and supposedly “peer reviewed” papers in ranked and indexed journals were published in a matter of days, suggesting that peer review was either fleeting or non-existent, or that papers were rapidly approved by editors based on their perceived interest and topicality, rather than on their intrinsic academic value. In academic publishing circles, the claim of “peer review,” when in fact it has not been conducted, is a core characteristic of “predatory publishing,” and is also a “fake” element that may undermine efforts in recent years to build trust in science’s budding serials crisis. While the world is still centrally focused on COVID-19, the issue of “predatory publishing” is being ignored, or not being given sufficient attention. The risks to the scholarly community, academic publishing and ultimately public health are at stake when exploitative and predatory publishing are left unchallenged.

**Full text:** <https://bit.ly/38jWsBy>

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