

**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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**Dealing explicitly with mortality and the many physical and emotional burdens that accompanies it shapes how staff form a genuine sense of closeness with patients, and establish a space for shared, quiet, recognition of the situation.**

'Ways of "being with" caring for dying patients at the height of the COVID-19 pandemic' (p.9), in *Anthropology in Action*.

## Canada

### **If not now, when? Applying a palliative approach in long-term care**

*HEALTHY DEBATE* | Online – 28 December 2020 – Earlier this month, the federal government committed to a \$1-billion investment into long-term care (LTC) homes across Canada over two years as part of its economic update. While the investment is welcome, and greatly needed, there is an omission in the list of deliverables, one we believe would greatly enhance the quality of LTC services across Canada – committing to, or deepening the commitment to, a palliative approach to care in long-term homes. The pandemic's impact on LTC has been unprecedented and has exposed the growing trend over the last several years towards increased numbers of residents dying in LTC. Many Canadians who enter LTC today have higher needs and acuity than in past years; their care is more complex and their stay often shorter. When it is apparent that end-of-life is near, decisions are often made on whether to transfer residents to hospital. Unless these patients have acute, treatable conditions and it would enhance their quality of life, transferring residents can be dangerous as acute care is not designed to support frail residents. Not to mention how traumatic moving locations can be for

residents and their families. Frequently, the best option is to have the resident remain in LTC – however, the challenge is that the LTC home is often not set up to provide a palliative approach. <http://bit.ly/2Mj8ggI>

#### **Ontario Long Term Care Homes Act**

A requirement to provide palliative care has been in the Ontario Long Term Care Homes Act for many years but the LTC licensees both for-profit and non-profit have ignored this legislated requirement.

**Source:** Judith Wahl, retired Executive Director of the Advocacy Centre for the Elderly. Posted comment on *Healthy Debate* article.

#### **Specialist Publications**

'Exploration of the acceptability and usability of advance care planning tools in long-term care homes' (p.6), in *BMC Palliative Care*.

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Noted in Media Watch 22 June 2020 (#671, p.1):

- *HEALTHY DEBATE* | Online – 16 June 2020 – ‘**Not scared of dying but of dying scared.**’ COVID-19 has shone a bright light on a flawed system in need of dramatic reform, and on a workforce that must be better supported and empowered to provide meaningful end-of-life (EoL) care. This is not to place blame at the feet of our underpaid and undervalued care workers. These workers are cycling in and out of and in-between long-term care settings without proper resources, training and educational supports. This workforce, much like the residents that they care for in an ageist society, has been largely ignored. While COVID-19 has brought this issue into focus, the lack of EoL support in LTC has been an ongoing injustice. <https://bit.ly/37F4bJS>

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

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 15 May 2020 – ‘**The relationship between caregivers’ perceptions of end-of-life care in long-term care and a good resident death.**’ 78 participants whose relative or friend died in one of five long-term care (LTC) homes in Canada completed questionnaires on their perceptions of end-of-life (EoL) care and perceptions of a good resident death. Findings confirm the critical role staff in LTC play in supporting caregivers’ perceptions of a good resident death. By keeping caregivers informed about expectations at the EoL, staff can enhance caregivers’ perceptions of a good death. By addressing spiritual issues staff may improve caregivers’ perceptions residents were at peace when they died. **Abstract (w. list of references):** <https://bit.ly/3cDyBOz>

Noted in Media Watch 2 March 2020 (#655, p.10):

- *CANADIAN NURSE* | Online – 24 February 2019 – ‘**Embedding palliative approaches to care in long-term care.**’ According to the 2016 Canadian Census, 6.8% of the population aged 65 years and older were living in long-term care (LTC); this figure jumps to 30.0% among Canadians aged 85 years and older, with over 90% of those admitted having a life-limiting diagnosis. LTC staff are ideally positioned to facilitate meaningful, timely conversations on advance directives and end-of-life care with residents and their families, but need the competence, support, and tools to do this. A cultural shift in how we talk about death and dying is required to facilitate acceptance and understanding of what palliative care is and how it can improve people’s lives. **Full text:** <http://bit.ly/2wNM2vh>

**N.B.** Additional articles on palliative care in LTC facilities noted in Media Watch 2 November 2020 (#690, p.10), 21 September 2020 (#684, p.8), 14 September 2020 (#683, p.4), and 10 August 2020 (#678, p.9).

## [U.S.A.](#)

### **Top hospice trends to watch in 2021**

*HOSPICE NEWS* | Online – 1 January 2021 – The year 2020 brought unprecedented disruption to the hospice space, mostly due to the COVID-19 pandemic. The outbreak strained providers ability to provide care, access patients in homes and facilities and to maintain a healthy bottom line in light of lost revenues and rising costs. Despite these challenges and economic headwinds, hospices adapted, improvised and overcame many of the obstacles 2020 imposed on them, though a good proportion have come through it bruised and battered. The pandemic of course is not over, but hospices are applying lessons learned from the early days of the crisis to bolster themselves for the next phases. While the industry had to shift many priorities in order to respond to the pandemic, hospices also made headway on efforts with the potential to reshape how they do business and care for patients, seeking to engage with patients long in advance of the end of life, experiment with new avenues of payment, adapt to new financial players in the space and consider new concepts about death and dying itself. <http://bit.ly/3pEXWO7>



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## Congress approves hospice care reforms to improve oversight, transparency

*THE LOS ANGELES TIMES* | Online – 23 December 2020 – Hefty fines, the suspension of Medicare payments and other new measures to increase oversight and transparency in the fast-growing hospice industry are set to become law as part of the omnibus spending bill approved by Congress this week. The reforms had been included in the bipartisan Helping Our Senior Populations in Comfort Environments (HOSPICE) Act... The new measures will address some of the serious flaws in hospice care highlighted by a recent *Los Angeles Times* that found widespread fraud and hundreds of instances in which California patients were harmed, neglected or put at risk, their mistreatment sometimes made worse by major gaps in government oversight.<sup>1</sup> Quality-of-care failures ranged from mismanaged medications to neglected wounds infested with maggots, to nurses and home health aides repeatedly missing appointments or sleeping on the job as patients lay writhing in pain. Even in the face of such failures, hospices – which are certified by

Medicare and overseen by the California Department of Public Health – have rarely been penalized, largely because they are regulated far less rigorously than other healthcare providers... <http://lat.ms/2KNrUR5>

### Specialist Publications

**'The impact of COVID-19 surge on clinical palliative care: A descriptive study from a New York hospital system'** (p.9), in *Journal of Pain & Symptom Management*.

**'Colorado palliative care and hospice crisis standards: Moving beyond critical care planning'** (p.10), in *Journal of Pain & Symptom Management*.

**'Hospice access and scope of services for undocumented immigrants: A clinician survey'** (p.15), in *Journal of Palliative Medicine*.

1. See Media Watch 14 December 2020 (#696, pp.2-3).

**N.B.** The omnibus spending bill approved by Congress included two key pieces of hospice legislation, the Rural Access to Hospice Act and the HOSPICE Act. Selected articles on the provision and delivery of hospice and palliative care services in rural America noted in Media Watch 7 September 2020 (#682, p.4).

## End-of-life experts call for expansion of patient-centered, goal-concordant care

*HOSPICE NEWS* | Online – 22 December 2020 – A deadly worldwide **COVID-19** pandemic has helped to expose pitfalls in a broken healthcare system, drawing increased awareness and attention around the delivery of serious illness and end-of-life (EoL) care, according to hospice and palliative care experts... The virus has claimed more than 1.6 million lives globally since its onset, according to a recent World Health Organization report which stated that the U.S. continues to bear the brunt of the pandemic's effects, accounting for 86% of new deaths worldwide in the last week alone. According to a number of healthcare stakeholders, the government and the healthcare system itself hasn't sufficiently adapted to meet patients' needs during the crisis. Some of the roadblocks to quality EoL and serious illness care often stem from social determinants of health, lack of awareness around hospice care, and racial divides in accessible care. While these issues are gradually coming to the forefront of discussions in the EoL space among clinical, business and policy leaders, stakeholders are renewing calls to accelerate a reorientation of the healthcare system towards patient-centered, goal-concordant care. <http://bit.ly/2M6jpRP>

## COVID-19 deaths to reverse U.S. life-expectancy gains

*THE WALL STREET JOURNAL* | Online – 22 December 2020 – U.S. life expectancy inched up last year, but in 2020 could decline by the largest amount since World War II, as COVID-19 becomes the nation's third-leading cause of death. Data released by the Centers for Disease Control & Prevention (CDC) showed that life expectancy rose to 78.8 years in 2019, an increase of one-tenth of a year, marking the second consecutive year of progress on the key measure of national well-being. The main drivers were lower death

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rates from heart disease and cancer, the country's #1 and #2 causes of death, respectively, said Robert Anderson, chief of the mortality-statistics branch of the CDC's National Center for Health Statistics. The death rate from drug overdoses rose after declining the prior year, while the suicide death rate fell for the first time since 2005. Last year's slim gain will be erased by a large drop in longevity when the government releases 2020 figures next year. Mr. Anderson said he performed a simple simulation based on mortality figures through August and found that life expectancy had declined by about 1½ years. For the full year, he expects that life expectancy could fall by two to three years. <http://on.wsj.com/38tYwr0>

## International

### **Hundreds more people dying at home than normal, latest Office for National Statistics coronavirus report shows**

U.K. (England & Wales) | *The Daily Mirror* (London) – 30 December 2020 – The number of deaths registered in England & Wales in the week ending 18 December 2020 was above the five-year average, Office for National Statistics data confirmed. The number of deaths in hospitals and private homes was above the five-year average in the week ending 18 December 2020, (678 and 835 deaths higher, respectively). Deaths in care homes and other places were below the five-year average (7 and 68 fewer deaths, respectively)... The total number of deaths ... in the week ending 18 December 2020 ... was 13,011; this was 719 more deaths than in the previous week. It was also 12.7% above the five-year average (1,463 deaths higher). <http://bit.ly/3rlOniU>

### Specialist Publications

**'Place of death of children and young adults with a life-limiting condition in England: A retrospective cohort study'** (p.5), in *Archives of Disease in Childhood*.

**'Qualitative study to explore what patients with heart failure find significant during integrated palliative care sessions in a Danish clinic'** (p.7), in *BMJ Open*.

**'Inappropriate end-of-life cancer care in a generalist and specialist palliative care model: A nationwide retrospective population-based observational study'** (p.8), in *BMJ Supportive & Palliative Care*.

**'The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: A multi-country qualitative study'** (p.16), in *Palliative Medicine*.

## Specialist Publications

### **Supported decision-making with people at the margins of autonomy**

*AMERICAN JOURNAL OF BIOETHICS* | Online – 29 December 2020 – The authors of this article argue that supported decision-making is ideal for people with dynamic cognitive and functional impairments that place them at the margins of autonomy. First, the authors argue that guardianship and similar surrogate decision-making frameworks may be inappropriate for people with dynamic impairments. Second, they provide a conceptual foundation for supported decision-making for individuals with dynamic impairments, which integrates the social model of disability with relational accounts of autonomy. Third, the authors propose a three-step model that specifies the necessary conditions of supported decision-making: identifying domains for support; identifying kinds of supports; and, reaching a mutually acceptable and formal agreement. Finally, they identify a series of challenges for supported decision-making, provide preliminary responses, and highlight avenues for future bioethics research. **Full text:** <https://bit.ly/3nZodq8>

#### **Related:**

- *JOURNAL OF CLINICAL MEDICINE* | Online – 29 December 2020 – **'End-of-life care preferences of older patients with multimorbidity: A mixed methods systematic review.'** This review assesses end-of-life care (EoLC) care preferences of older patients with multimorbidity. Such preferences need to be understood in the context of patients' knowledge and expectations of supportive – i.e., life-sustaining treatments (LSTs) – and palliative care. Patients should therefore receive information on treatment burden and expected outcomes, including the likelihood of an adverse treatment outcome, when discussing EoLC preferences. This will allow patients to make carefully considered and informed decisions about LSTs and alternative conservative care options. **Full text:** <http://bit.ly/3rl3Sb4>

## Speech-language pathologists in pediatric palliative care: An international study of perceptions and experiences

*AMERICA JOURNAL OF SPEECH-LANGUAGE* | Online – 22 December 2020 – Ten participants from Australia, Canada, and the U.S. were recruited from a previous survey study. In-depth interviews were conducted via videoconferencing. Emerging themes included clinical interventions, unique speech-language pathologists (SLP) skills in pediatric palliative care (PPC), multidisciplinary team relationships, workforce issues, education and training, governance, medicolegal considerations, bioethical issues, and holistic care. Additional sub-themes are also noted. In the absence of research evidence and practice recommendations, SLPs rely on client perspectives and clinical experience to guide their professional practice in PPC. Results expand on limited literature to date in the area of PPC. Future research using larger samples is needed to provide clinicians with best practice recommendations for working with patients, families, and the broader care team. **Abstract:** <https://bit.ly/2WFSqyh>

**N.B.** Additional articles on the role of speech-language pathologists in palliative care noted in Media Watch 15 January 2018 (#546, p.10).

## Place of death of children and young adults with a life-limiting condition in England: A retrospective cohort study

*ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 21 December 2020 – The majority of children with a life-limiting condition in England continue to die in a hospital setting. There is some evidence of an increase in hospice deaths since the government report 'Better Care, Better Lives' in 2008 but there is still a relatively small number of deaths in hospices each year. The most recent national children's hospice data collection showed that only 21% of their caseload who died, died in the hospice. A higher proportion died in hospital in the present study than in studies from other countries which may not be surprising given the different models of provision of palliative care (PC) and funding of healthcare systems across the world. The proportion of deaths at home are similar to figures from the U.S. (10.1% in 1989 rising to 18.2% in 2003) and Portugal (19.4%). PC input has been associated with more children dying outside the hospital... The general consensus among studies to date is that home is the preferred place of death, although not all families prefer home deaths; preferences vary over time and the research base consists of small studies which were prone to selection bias. **Full text:** <http://bit.ly/3aGXpXU>

## Developing a model of bereavement care in an adult tertiary hospital

*AUSTRALIAN HEALTH REVIEW* | Online – 23 December 2020 – Hospitals are the most common place of death in Australia. Bereavement care is recognised by national standards as being central to providing high-quality care at the end of life, and has significant health implications on morbidity, mortality and health service usage. Despite this, bereavement care is not routinely or systematically provided in most Australian hospitals. This study aimed to develop a comprehensive, evidence-based model of bereavement care specific to the needs of an acute Australian adult tertiary hospital. Staff and bereaved family members strongly supported a systematic approach to bereavement, perceiving the need for greater support, training, coordination and follow-up. In all, 10 core elements were developed to support a structured model of bereavement care provision and follow-up for the acute hospital organisation.

The authors describe the development of a comprehensive, evidence-based model of bereavement care specific to the needs of an Australian acute hospital. **Abstract (w. list of references):** <http://bit.ly/34DrNP5>

### **Pandemic Grief Scale: A screening tool for dysfunctional grief due to a COVID-19 loss**

*DEATH STUDIES* | Online – 21 December 2020 – There have been no screening tools developed to identify individuals who may be suffering from dysfunctional grief during the pandemic. The objective of this study was to develop and evaluate the properties of the Pandemic Grief Scale. This 5-item scale demonstrated solid reliability, factorial validity and construct validity with strong correlations with suicidal ideation and substance use coping. **Full text:** <https://bit.ly/38H1DMD>

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Noted in Media Watch 9 November 2020 (#691, p.8):

- *JOURNAL OF HOSPITAL MEDICINE*, 2020;15(11):699-701. ‘**Grieving and hospital-based bereavement care during the COVID-19 pandemic.**’ It is likely bereaved individuals are at greater risk of poor bereavement outcomes during the pandemic ... because of social isolation. This is particularly true if loved ones died in the hospital and, due to visitor restrictions, faced limited or no visitation. For many, bereavement will be affected by stay-at-home orders and social distancing restrictions that reduce access to emotional support and rituals, such as funerals, that usually provide comfort. Urgent attention is needed to support bereaved individuals, to flatten the curve of mental health disorders associated with the death of loved ones during the pandemic. **Full text:** <https://bit.ly/3k0NjJ>

Noted in Media Watch 28 November 2020 (#685, p.12):

- *NURSING CHILDREN & YOUNG PEOPLE* | Online – 23 September 2020 – ‘**National Children’s Hospitals Bereavement Network standards for supporting families following the death of a child.**’ In England, a child death review process must be undertaken when a child dies, regardless of the cause of death. Scotland and Wales have their own version of the process, while it is the author’s understanding that Northern Ireland are still developing their process. An important aspect of this process is family engagement and bereavement support. This is an introduction to the bereavement support standards developed by the National Children’s Hospitals Bereavement Network, a group of specialist children’s nurses and allied health professionals interested in bereavement care. **Abstract:** <https://bit.ly/2RX9jSR>

Noted in Media Watch 10 August 2020 (#678, p.11):

- *HEALTH* | Online – 4 August 2020 – ‘**Beyond the hour of death: Family experiences of grief and bereavement following an end-of-life hospitalization in the ICU.**’ The process of advance care planning shapes family experiences of grief. Even prior informal conversations around end-of-life (EoL) are beneficial for family members both during the hospitalization and afterwards in bereavement. Clinicians’ compassionate caring for both patients and families through the “little things” or small gestures are important to families during the EoL hospitalization and afterwards in bereavement. The transition time in the hospital before the patient’s death facilitates family experiences of grief by providing a sense of support and meaning in bereavement. **Abstract (w. list of references):** <https://bit.ly/2PswxyM>

### **Exploration of the acceptability and usability of advance care planning tools in long-term care homes**

*BMC PALLIATIVE CARE* | Online – 22 December 2020 – The findings of this study provide some direction to improve advance care planning (ACP) engagement and uptake in long-term care (LTC). First, this review identified a series of tools that include psychosocial components. The authors encourage LTC home administrators and directors of care to use the list provided as a starting point to select material for possible distribution. They also encourage them to reconsider any tendencies to use materials with a strictly medical focus. Second, prior to implementation within a selected LTC home environment, the authors suggest preferred material be altered (if required) to include typical LTC home scenarios that may encourage ACP reflections and to ensure a relatively equal balance between prompting questions and exercises that encourage reflections and those that encourage communication and documentation. With the advent of the COVID-19 pandemic, additional adaptations or companion resources may be crucial to ensure the relevance of these tools. A number of the tools identified have already evidenced this... Third, while staff expertise in ACP tool selection represents a first step towards improving ACP uptake in LTC, implementation strategies that include discussions and planning around staff roles and expectations must follow. **Full text:** <http://bit.ly/3aMcmbh>

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Would the *BMC Palliative Care* article be of interest to a colleague?

## Related:

- *PATIENT EDUCATION & COUNSELING* | Online – 25 December 2020 – ‘**Individual, interpersonal, and healthcare factors associated with informal and formal advance care planning in a nationally-representative sample of midlife and older adults.**’ Informal advance care planning (ACP) was positively associated with greater confidence, history of life-threatening illness, designation as healthcare decision-maker for someone else, knowing at least one negative end-of-life story in one’s personal network, a desire to ease surrogates’ decision-making, and having a healthcare provider who had broached ACP. Formal ACP was positively associated with greater confidence, designation as a healthcare decision-maker, having a provider who had broached ACP... **Abstract:** <http://bit.ly/3mO8zwc>

## Qualitative study to explore what patients with heart failure find significant during integrated palliative care sessions in a Danish clinic

*BMJ OPEN* | Online – 31 December 2020 – In the field of palliative care (PC) as it is integrated into heart failure (HF) treatment, it is essential to explore the patient experience and build on this knowledge for the further development of PC practice and policy. The authors explored what patients with HF find significant in integrated sessions using a narrative S’ approach [see sidebar]. Analysis showed that the integrated S’ approach sessions were successful in joining an embodied patient perspective with a medical perspective. The thematic analysis resulted in three themes supporting the overall findings: 1) Sessions bring comfort; 2) Telling your story provides a sense of meaningfulness; and, 3) Integrating perspectives of HF into everyday life. The method using the S’ approach in integrated PC and HF sessions was significant in various ways. Patients experienced a calm and safe atmosphere and perceived that the nurse was truly interested in them. The integrated sessions based on the S’ approach were able to bring comfort to lived physical, psychosocial and existential issues. It allowed patients to

combine their embodied understanding of HF with a medical perspective, thereby finding meaning in the sense of how everything is connected.

**Full text:** <http://bit.ly/3b6IDto>

### The narrative S’ approach

Narratives in research or practice are not new. Interventions using personal narratives have shown promise with existential distress in PC. However, it is not easy to apply the resource-intensive reminiscence-based narrative in the fast-moving hospital setting. The S’ approach was developed ... to operationalise PC in a clinical setting by exploring needs and resources in the dimensions of symptom control, self-image, self-determination, social relationships, strategy for the future and sense of coherence. Based on the idea of narratives as a method to provide meaningful patterns, the S’ approach aims to integrate patient and professional perspectives in PC. However, the literature lacks research on the S’ approach in general hospital PC and in HF treatment.

**N.B.** Additional articles on meeting the PC needs of patients living with HF noted in Media Watch 2 November 2020 (#690, p.8), and 10 October 2020 (#688, p.9).

## What is spiritual care? Professional perspectives on the concept of spiritual care identified through group concept mapping

*BMJ OPEN* | Online – 28 December 2020 – This investigation identified six clusters of understandings of spiritual care (SC) that could be organised in three overall themes: 1) SC as an integral but underdeveloped part of healthcare; 2) Delivering SC; and, 3) The role of spirituality. Because spirituality in the common understanding is a fundamental aspect of each individual human being, SC should be an integral aspect of healthcare. Paradoxically, precisely because of this fundamentality, it is nevertheless also challenging to practise SC, as it involves the individual spirituality of the healthcare professional (HCP), tuning in on the individual spirituality of the patient (or relative), and engaging care for needs for which there are no quick fixes but that require personal attunement and investment. The benefits of engaging in SC nevertheless seem plentiful, both for HCPs, patients and relatives. **Full text:** <http://bit.ly/391CJaH>

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#### Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 December 2020 – ‘**Chaplain-physician interactions from the chaplain’s perspective: A mixed method analysis.**’ The value of healthcare chaplains to patient care is increasingly recognized. However, physicians’ understandings of the role of pastoral care have been reported to be poor, which have raised concerns about the quality of chaplain-physician interactions and their impact on patient care. This study provides contemporary data on the nature of chaplain-physician interactions as reported from the perspective of chaplains. Further, these findings highlight opportunities for interventions to enhance the chaplain-physician relationship. **Abstract (w. list of references):** <http://bit.ly/2Ju6uYl>

#### Palliative care in The Netherlands

#### **Inappropriate end-of-life cancer care in a generalist and specialist palliative care model: A nationwide retrospective population-based observational study**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 22 December 2020 – This study from The Netherlands shows that initiation of palliative care (PC) prior to the last month of life significantly decreases the likelihood of potentially inappropriate end-of-life care (EoLC) for patients with cancer. As generalist PC may play a substantial role, these results imply a strong need to focus local and national policy on improving access to generalist and specialist PC for every patient. Sustained investment in training of all healthcare professionals can improve timely identification of PC needs in the individual patient, distress caused by the disease and its impact on the person as a whole. This will lead to a larger number of patients receiving generalist PC earlier in their disease trajectory. Also, improving early access to specialist PC for patients with complex PC needs will lead to more prognostic awareness and better quality of EoLC for these patients. Recommendations on use of standardised referral criteria for specialist PC and funding of integrated PC models are needed to support these improvements. As such, these improvements to EoLC may have major implications for health policy. **Full text:** <http://bit.ly/34Ep6fQ>

#### Related:

- *SUPPORTIVE CARE IN CANCER* | Online – 22 December 2020 – ‘**Treatment goals and changes over time in older patients with non-curable cancer.**’ The findings of this study suggests that patients’ goals become less stable when they enter the late phase of their disease. In practice, it is a challenge for healthcare providers to determine when patients have entered this phase. The surprise question (“Would I be surprised if this patient died in the next year?”) has been shown to be a simple and effective tool for identifying patients with cancer who have a greatly increased 1-year mortality risk. Recently, it was suggested that a double surprise question, adding “Would it surprise me if this patient is still alive after 12 months?” had even better predictive values. **Full text:** <https://bit.ly/3aDUSgQ>

#### **Duration of palliative care involvement and cancer care aggressiveness near the end of life**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 21 December 2020 – This study aimed to evaluate the association between the duration of involvement of a palliative care (PC) team and aggressive cancer care and to identify factors associated with aggressive cancer care. The authors performed an observational retrospective study in a single academic teaching hospital. In total, 561 inpatients with solid tumours or haematological malignancies were included. Patients followed by a PC team for at least one month before death were classified in the PC group. Aggressive cancer care was defined as hospitalisations and/or a new line of chemotherapy within the last month of life, location of death, the use of chemotherapy in the last two weeks and hospice admissions within the last three days of life. Among the 561 patients, 241 (43%) were referred to the PC team; 89 (16%) were followed by the PC team for a month or more before death. In the last two weeks of life, 124 (22%) patients received chemotherapy, 110 (20%) died in an acute care unit. At least one criterion of aggressive cancer care was found in 395 patients overall (71%). **Abstract:** <http://bit.ly/3rjXh6h>

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Noted in Media Watch 30 November 2020 (#695, p.6):

- *BMC MEDICINE* | Online – 26 November – ‘**Duration of palliative care before death in international routine practice: A systematic review and meta-analysis.**’ This review suggests that duration of palliative care (PC) before death for patients with life-limiting illness is much shorter than is supported by research evidence and widely advocated in healthcare policy. This study highlights wide variation at the level of country, across disease types and settings to which patients are referred. To better understand the timing of PC provision internationally, there is need for more consistent terminology and methodology, and routine assessment of duration of PC from all countries, to allow benchmarking, service evaluation and quality improvement. **Full text:** <https://bit.ly/3mfMdo8>

### After **COVID-19**: The way we die from now on

*CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS* | Online – 29 December 2020 – This article proposes that the rising COVID-19 fatalities and the WHO’s failure to include palliative care (PC) as part of its guidance on how to maintain essential health services during the pandemic have exposed PC as an underlying global crisis. It therefore calls for a different ethical framework that includes a care ethics perspective and thereby addresses the ways in which the pandemic has triggered new difficulties in ensuring the delivery of appropriate end-of-life care for the dying. The author analyses the structural weaknesses of PC accentuated by the pandemic and proposes solutions that could set in motion lasting changes in the way it is delivered beyond COVID-19. **Abstract (w. list of references):** <http://bit.ly/2Jy2M0o>

#### Related:

- *ANTHROPOLOGY IN ACTION*, 2021;28(1):16-20. ‘**Ways of “being with” caring for dying patients at the height of the COVID-19 pandemic.**’ Palliative care professionals often speak of the importance of forming meaningful relationships with patients and their families. Trust and rapport, usually established over extended periods of time through face-to-face interactions, and a “gentle honesty” regarding end-of-life and death are key aspects of developing a sense of intimacy with people who are approaching the end of their lives. A feature of this intimacy is conveying a sense of “being with” a patient. These ways of working were greatly challenged by the impact of COVID-19. This article explores how intimacy both was and was not established at the height of the pandemic... **Full text (click on pdf icon):** <http://bit.ly/3nDfucl>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 December 2020 – ‘**The impact of integrating palliative medicine into COVID-19 critical care.**’ The purpose of this proactive palliative care rounding model was to help critical care medicine (CCM) provide the best care possible to COVID-19 patients, with a focus on supporting serious illness communication and decision-making. Through fruitful daily interactions with CCM colleagues, palliative medicine (PM) providers grew in their own abilities to prognosticate and counsel patients and surrogates. With several months’ experience with the care of critically ill COVID-19 patients, PM and CCM colleagues can now work to formulate specific triggers for PM consultation in COVID-19 ICU care. **Full text:** <http://bit.ly/3mEiEvx>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 December 2020 – ‘**Palliative care consultation in hospitalized patients with COVID-19: A retrospective study of characteristics, outcomes, and unmet needs.**’ The peak of COVID-19 in New York State is an example of how a rapid increase in the number of patients with acute, critical illness impacts not only the need for hospital beds, ICU services and devices, but also for palliative care (PC) services. This study describes the surge, unsustainable demand for specialized PC resources created by hospitalized patients with COVID-19, social disparities among this population, and need for better allocation of resources and support services for PC teams at the frontline of this and future pandemics. **Full text:** <https://bit.ly/37FrwwQ>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 December 2020 – ‘**The impact of COVID-19 surge on clinical palliative care: A descriptive study from a New York hospital system.**’ This study provides a unique perspective on inpatient palliative care (PC) consultations from a large health system during the initial COVID-19 outbreak in New York. By comparing patients seen during the outbreak with patients seen before the outbreak, the authors describe some major differences between the two PC populations. The COVID-19 positive patients were more acutely ill than the baseline palliative patient population. COVID-19 positive patients had the highest rate of mortality and ICU stays, as well as longest length of stay. **Full text:** <http://bit.ly/3pjog0f>

Cont.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 December 2020 – ‘**Colorado palliative care and hospice crisis standards: Moving beyond critical care planning.**’ The authors review state and regional gaps already recognized in planning for scarcity in palliative care and hospice services during the pandemic and describe planning initiatives Colorado has developed to address potential scarcities for this vulnerable and diverse group of people. The authors hope to encourage other state and regional groups to anticipate needs in the coming surges of this pandemic or in public health crises to come. Such planning is key to avoid the degradation of care that may result if it is necessary to invoke crisis standards of care and ration essential services. **Abstract (w. list of references):** <http://bit.ly/3pdGJuP>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 December 2020 – ‘**Palliative care as essential to a hospital system’s pandemic preparedness planning: How to get ready for the next wave.**’ The sudden and unprecedented increase in seriously ill patients with **COVID-19**, coupled with both the lack of core palliative care (PC) training and expertise among frontline providers and the specialty-trained PC workforce shortage, produced immediate challenges to meet the needs of this novel seriously ill patient population. This overview demonstrates how PC services can be titrated up rapidly to meet the acute increase in hospitalized persons with serious illness due to COVID-19, and how these services tailored to the changing needs across a health system. **Abstract:** <https://bit.ly/2WVvmKol>
- *PALLIATIVE MEDICINE REPORTS* | Online – 28 December 2020 – ‘**Healthcare workers’ knowledge, attitudes, and beliefs related to COVID-19 in palliative medicine and hospice care.**’ Very limited attention has been directed to the needs and perceptions of the healthcare workers who provide the care at the end of life. As the COVID-19 crisis continues, one priority should be developing interventions to assure appropriate education to this critical element of the healthcare system. At the same time, emphasis should be given to monitoring for depression, anxiety, and burn out. Improving staff knowledge and information related to COVID-19 would enhance staff safety, improve patient care, and relieve anxiety. **Full text:** <https://bit.ly/2LioCFK>
- *PALLIATIVE MEDICINE REPORTS* | Online – 23 December 2020 – ‘**Patient and caregiver experience with outpatient palliative care telemedicine visits.**’ During the **COVID-19** pandemic, telemedicine has skyrocketed across the U.S. Telemedicine visits reduce the physical and financial burdens associated with in-person appointments... Little is known about patient and caregiver preferences regarding telemedicine visit timing and the discussion of sensitive topics by telemedicine. Telemedicine visits were highly rated by outpatient PC patients and caregivers [i.e., participants in a mixed-methods telephone survey]. They appreciated the convenience telemedicine visits offer and frequently cited telemedicine visits felt equivalent to other forms of communication, including in-person visits. **Full text:** <https://bit.ly/2LhVEWb>

### Summary of the key concepts on how to develop a perinatal palliative care program

*FRONTIERS IN PEDIATRICS* | Online – 3 December 2020 – Perinatal Palliative Care (PnPC) is a new concept in neonatal intensive care approach. Advancements in perinatal diagnostics and medical technology have changed the landscape of the perinatal world. The threshold of viability continues to decrease, and diagnostic information is available earlier in pregnancy and more rapidly at the bedside; overall outcomes continue to improve. This rapid technological improvement brings ethical debates on the quality of life of patients with life-limiting and life-threatening conditions and the need to involve the family in the decision-making process, according to their wishes and cultural beliefs. Although the perinatal hospice concept was developed in the 1980s in the U.S., the first recommendations on how to develop a PnPC pathway were published in the early 2000s. The authors considered the most relevant position statements or guidelines published in the last two decades. Some of them were more pertinent to pediatrics, but still useful for the fundamental concepts and PnPC project’s development. **Full text:** <http://bit.ly/3nGDf3R>

**N.B.** Additional articles on PnPC noted in Media Watch 23 November 2020 (#693, p.10).



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

## Key challenges and best practices in the coordination of volunteers in healthcare services: A qualitative systematic review

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 24 December 2020 – This systematic review sheds light on employee and volunteer experiences involving the coordination of volunteers from a healthcare service perspective. The findings reveal the challenges of volunteer coordination as faced by employees and, importantly, the strategies applied to resolve them. Furthermore, the findings indicated what volunteers need as contributors. These findings contribute to the existing literature by showing that when challenges and needs are not met, incorporating volunteers into healthcare services may present an additional burden, without providing any quality improvement. Thus, a clearer structure is needed to support volunteers in their interactions with healthcare services. Volunteer coordinators can play a key role in such scenarios, helping to improve the recruiting and managing processes of volunteers. The authors' findings contribute to an understanding of how these processes can be more effectively arranged in organisational settings. **Full text:** <https://bit.ly/3pp5uV2>

Noted in Media Watch 19 October 2020 (#688, p.5):

- *BMC PALLIATIVE CARE* | Online – 15 October 2020 – ‘**A mixed-method evaluation of a volunteer navigation intervention for older persons living with chronic illness (Nav-CARE): Findings from a knowledge translation study.**’ This study contributes to a growing body of evidence on how innovative volunteer models can improve care for older persons living at home with chronic illness. Building upon a palliative approach to care, this volunteer-led navigation intervention (Nav-CARE) has the potential to improve social support, access to low-cost resources, healthcare social negotiation and engagement of older persons living at home with advancing chronic illness. Volunteers provided physical and emotional respite for family. **Full text:** <https://bit.ly/3525lc9>

Noted in Media Watch 1 June 2020 (#668, p.17):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 May 2020 – ‘**National outreach of telepalliative medicine volunteers for a New York City safety net system COVID-19 pandemic response.**’ The authors successfully implemented a telepalliative medicine response within a large safety-net system without a pre-existing telehealth infrastructure. Within just 72 hours of the initial outreach, over 400 volunteers enlisted, reflecting a rapid and robust response. To the authors' knowledge, this is the first model to leverage external telepalliative medicine volunteers from across the country for an institutional COVID-19 pandemic response. Several concepts resonated through our process, which may aid other institutions in future efforts. **Full text:** <https://bit.ly/3qtEUXn>

Noted in Media Watch 9 March 2020 (#656, p.14):

- *SCANDANAVIAN JOURNAL OF CARING SCIENCES* | Online – 6 March 2020 – ‘**What it means to be a palliative care volunteer in eight European countries: A qualitative analysis of accounts of volunteering.**’ The authors explore the experiences of volunteers in hospice and palliative care (PC) from their insider perspective, to understand why volunteers choose to work in this field and to understand what it means to them to be involved in PC in this way. Stories were collected by the European Association for Palliative Care Task Force for Volunteering contacts in each of the eight countries. The majority of stories came from volunteers involved in different settings including adult patient's homes, hospices, hospitals and care homes. **Abstract:** <http://bit.ly/2PTbw0S>



### 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>

## **“I no longer feel alone”: Meeting the needs of bereaved grandparents through a children’s hospice support group**

*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | In press – Accessed 21 December 2020 – Children’s hospices provide a range of family-centred care services, including bereavement support. Not all hospices provide specific services for grandparents. Grandparents attending a support group were invited to complete an anonymous questionnaire. Three central themes were identified: 1) Environment and space; 2) Being with people who understand; and, 3) The opportunity to hear the stories of others. Grandparents valued hearing the stories of others, providing an opportunity to reflect on the experience of others. Grandparents felt supported and validated by the group. **Abstract:** <http://bit.ly/3pb6gVK>

Noted in Media Watch 1 July 2019 (#620, p.11):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 22 June 2019 – ‘**The arc of generational care: A case series considering grandparent roles and care needs in pediatric palliative care.**’ Children receiving palliative care (PC) services are held within the context of a family and often within multiple-generational arms. The purpose of this case series paper [from the Children’s Hospital & Medical Center, Omaha, Nebraska] is to recognize grandparents’ roles in their family system from a personal, cultural, and anthropological perspective; to explore emotions and experiences as applies to grandparents of children receiving PC; and, also to provide tangible insight into caring well for families across the generational arc. **Abstract (w. link to references):** <http://bit.ly/2lJ3d4s>

Noted in Media Watch 31 December 2018 (#595, p.15):

- *JOURNAL OF FAMILY NURSING* | Online – 17 December 2018 – ‘**How grandparents experience the death of a grandchild with a life-limiting condition.**’ Grandparents of grandchildren with life-limiting conditions experience multiple, progressive losses associated with the deterioration and death of the grandchild. These losses, when combined with the effects they have on the whole family and the resulting experiences of bearing witness, survivor guilt, and disenfranchisement create a footprint of grief that is unique to grandparents. These new perspectives into grandparental experience can help to improve the care and support available to better meet their needs as a parent, grandparent, and individual who has experienced the child death. **Full text:** <http://bit.ly/2NbLBCP>

## **New findings on palliative care issues near the end-of-life**

*JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 27 December 2020 – The public – and even clinicians – often confuse palliation with hospice care and believe that palliative care (PC) is restricted solely to the last hours, days, or weeks of life. Nothing could be further from the truth. According to the American Academy of Hospice & Palliative Medicine, “PC focuses on improving a patient’s quality of life by managing pain and other distressing symptoms of a serious illness. PC should be provided along with other medical treatments; hospice is PC for patients in their last year of life.” PC typically focuses on one of three core areas: 1) Advance care planning; 2) Pain and symptom management; and, 3) Psycho-social support. This editorial discusses PC with a focus on the important findings presented in the [upcoming] February 2021 issue of *JAMDA*. **Abstract (w. list of references):** <https://bit.ly/2M4HIVo>

## **Moral distress in end-of-life decisions: A qualitative study of intensive care physicians**

*JOURNAL OF CRITICAL CARE* | Online – 24 December 2020 – This study is the first to explore physicians’ moral distress in end-of-life decisions in intensive care via a narrative inquiry approach using case studies. Results have implications for the education, recruitment and retention of physicians, relevant in the **COVID-19** pandemic. The study was undertaken in a tertiary referral intensive care unit in Northern Ireland. Drawing upon patient case studies of decisions about non-escalation and/or withdrawal of life support, the authors undertook in-depth interviews with senior and junior physicians. Two predominant themes emerged: key moral distress triggers; and, strategies and consequences. Junior residents reported most instances of moral distress, triggered by perceived futility, lack of continuity, protracted decisions and failure to ensure “good death.” Senior physicians’ triggers included constraint of clinical autonomy. Moral distress was far reaching, affecting personal life, working relationships and career choice. **Abstract:** <http://bit.ly/3mTB8IP>

## Using palliative care nurses in a supportive care program to reduce hospital utilization for patients with multiple chronic conditions

*JOURNAL OF NURSING CARE QUALITY*, 2021 ;36(1):79-83. Healthcare organizations are designing comprehensive care programs to reduce hospital utilization by high-risk patients with multiple chronic illnesses. A community hospital recognized patients with multiple chronic conditions had higher rates of inpatient stays and emergency department (ED) visits. Patients with multiple chronic conditions enrolled in a supportive care program. Researchers analyzed hospital utilization, inpatient stays, and ED visits preintervention and postgraduation for the participants enrolled. Palliative care nurses were assigned to patients enrolled in the supportive care program. There was a statistically significant decrease in hospital utilization and inpatient stays following the implementation of the supportive care program. The study met its aim of reducing hospital utilization and inpatient stays by creating a comprehensive approach to support high-risk patients in self-management of their chronic illnesses. **Abstract:** <http://bit.ly/38DNDmD>

## The impact of the coronavirus pandemic on pediatric palliative care team structures, services, and care delivery

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 21 December 2020 – As the first study to investigate the impact on pediatric palliative care (PPC) teams in the U.S. during the pandemic, this novel overview survey raises topics worthy of future in-depth exploration of topical areas. The rapid uptake in telehealth during the pandemic is juxtaposed with respondents' concern regarding the quality of care provided through telehealth. Telehealth modality evaluation and communication training remain research priorities for the field of PPC, particularly with inclusion of child and family caregiver perspectives. Seriously ill children often live at a distance from treatment centers, warranting consideration of whether telehealth may help bridge the care or communication gap for families. While telehealth uptake in PPC had historically been slow, this study shows that pediatric interdisciplinary teams now utilize telehealth and may have the potential to foster communication and connection through telehealth although teams are in need of additional telehealth training and quality outcome measures. The survey suggests a need to track financial vulnerabilities and sustainable care models for pediatric palliative programs. Already the **COVID-19** pandemic has impacted PPC providers through significant changes in daily practice paradigms and interactions with other healthcare providers, patients, and families. **Full text:** <https://bit.ly/3rjUTNb>

Noted in Media Watch 5 October 2020 (#686, p.7):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 September 2020 – ‘**Exploring the impact of the Coronavirus pandemic on pediatric palliative care clinician personal and professional well-being: A qualitative analysis of U.S. survey data.**’ There is no doubt that the **COVID-19** pandemic has changed the way we practice clinical palliative care (PC) – be it with telehealth, physical distancing, or new approaches to communication. What is less described, is the direct personal and professional impact on PC clinicians. Indeed, while the aim of the PANDEMIC study was to describe how the field of pediatric PC was responding to the pandemic, survey respondents made clear that they, as individuals, were struggling, learning, and changing, too. **Full text:** <https://bit.ly/2GjN7jl>

Noted in Media Watch 24 August 2020 (#680, p.9):

- *PALLIATIVE MEDICINE* | Online – 16 August 2020 – ‘**The pervasive relevance of COVID-19 within routine paediatric palliative care consultations during the pandemic: A conversation analytic study.**’ Guidelines released for inpatient and outpatient care during the COVID-19 pandemic provide recommendations for framing a specific conversation about COVID-19 with patients. While these guidelines are valuable, this study has shown that talk about the COVID-19 pandemic was pervasively raised by both parents (45%) and clinicians (55%) throughout actual consultations. Routine questions and recommendations from the doctor often inadvertently raised the relevance of the COVID-19 pandemic and the associated changes to care and lifestyle. **Full text:** <https://bit.ly/3KOLk5o>



## Factors associated with health professionals decision to initiate paediatric advance care planning: A systematic integrative review

*PALLIATIVE MEDICINE* | Online – 29 December 2020 – This review found a dearth of evidence specifically focusing on the initiation of paediatric advance care planning (ACP).<sup>1</sup> Overall evidence suggests that health professionals recognise early initiation to be the ideal, and they play a key role ensuring this. Yet ambiguity regarding prognosis, parents' reactions, who leads, and the skills needed to engage in such conversations act as deterrents in initiating paediatric ACP in clinical practice. Consequently, ACP conversation occur too late without time for the child and parent to reflect and enact their goals or wishes. Further research is needed on the experience of the initiation process from the professional, parent and child perspective to enable strategies to be developed to ensure conversations occur earlier and are of benefit to all. The identification of behavioural factors impacting on initiation of paediatric ACP may inform the development of interventions and to ensure the focus is on the appropriate changeable aspects. Evidence is required, perhaps through the use of a behaviour change theory such as capability, opportunity and motivation theory in further research to provide evidence on aspects of behaviour which could be adapted or changed to reduce the delay and avoidance behaviour evident in current practice and to ultimately make initiation work for everyone. **Full text:** <http://bit.ly/3mXA8mQ>

1. 'Paediatric advance care planning: Physician experience and education in initiating difficult discussions,' *Journal of Paediatrics & Child Health*, published online 21 December 2017. [Noted in Media Watch 1 January 2018 (#544, p.10)] **Abstract:** <https://bit.ly/2WWli4i>

Noted in Media Watch 2 November 2020 (#690, p.12):

- *JOURNAL OF PEDIATRICS* | Online – 26 October 2020 – '**Improving advance care planning for seriously ill children: Engaging a diverse research population early and often.**' DeCoursey *et al* describe the development of a new pediatric serious illness communication program to support providers in advance care planning (ACP) conversations with their patients and families.<sup>1</sup> Despite ACP long being considered the standard of care for patients with life-limiting or life-threatening conditions, there is increasing awareness that pediatric providers still have room to improve. To address this meaningful gap, the authors used a step-wise, rigorous approach to adapt an adult communication guide for children. **Abstract (w. list of references):** <https://bit.ly/37PwG9Z>

1. 'Development of a stakeholder driven serious illness communication program for advance care planning in children, adolescents, and young adults with serious illness,' *Journal of Pediatrics*, published online 16 September 2020. **Abstract (w. list of references):** <https://bit.ly/34yhCM4>

Noted in Media Watch 23 March 2020 (#658, p.8):

- *EUROPEAN JOURNAL OF PEDIATRICS* | Online – 19 March 2020 – '**Towards advance care planning in pediatrics: A qualitative study on envisioning the future as parents of a seriously ill child.**' Parents prefer open and honest information about their child's illness and prognosis and they value the concept of advance care planning (ACP), while they emphasize the need for an individualized approach. Healthcare professionals, however, see parental factors like unease and emotional burden as key barriers for ACP. When envisioning the future of their seriously ill child, parents tended to stay close to the near future initially, with a focus on disease-related, practical themes. In this study, ongoing conversations uncovered deeper, value-based elaborations towards the future. **Full text:** <https://bit.ly/3bjTbIN>

Noted in Media Watch 22 April 2019 (#611, p.5):

- *PAEDIATRIC RESPIRATORY REVIEWS*, 2019;29(2):1-2. '**Integrating ethics and palliative care concepts into pediatric end-of-life care and decision-making: A changing landscape?**' The ethical dimensions of clinical dilemmas challenge even the best and most experienced of us to negotiate conflicting values, cultures and religious beliefs and their interplay in decision-making; all while adhering to professional standards and setting appropriate medical limits. As medical technology and options continue to evolve, these dilemmas are bound to become even more complex; the evolving autonomy of the patient, the sometimes competing interests of more powerful parental voices and the struggle to promote the child's best-interests are additional challenges. **Full text:** <http://bit.ly/2vaklmU>

## **“Achieve the best while rushing against time”: A grounded theory study on caring for low-income immigrant cancer patients at end of life**

*PALLIATIVE MEDICINE* | Online – 25 December 2020 – Between 2000 and 2020, Europe experienced an annual net arrival of approximately 1.6 million immigrants per year. While having lower mortality rates, in the setting of severe diseases, immigrants bear a greater cancer-related burden due to linguistic and cultural barriers and socio-economic conditions. Professionals face a two-fold task: managing clinical conditions while considering the social, economic, cultural, and spiritual sphere of patients and their families. In this regard, little is known about the care provision to low-income immigrant cancer patients in real contexts. The study, conducted at a Hospital in Northern Italy, involved 27 participants among health professionals, family caregivers, and other stakeholders who had recently accompanied immigrant cancer patients in their terminal phase of illness. Findings evidenced that professionals feel they were not adequately trained to cope with immigrant cancer patients, nonetheless, they were highly committed in providing the best care they could, rushing against the (short) time the patients have left. Analyses evidenced four main categories: “providing and receiving hospitality,” “understanding each other,” “addressing diversity,” and “around the patient,” which the authors conceptualized under the core category “achieve the best while rushing against time.” The model reveals the activation of empathic and compassionate behavior by professionals. It evidences the need for empowering professionals with cultural competencies by employing interpreters and specific training programs. **Abstract (w. list of references):** <http://bit.ly/2WGSii2>

### **Related:**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 December 2020 – ‘**Hospice access and scope of services for undocumented immigrants: A clinician survey.**’ The 10.5 million undocumented immigrants in the U.S. are not covered by Medicare’s hospice benefit... Limited data are available regarding hospice services for this population. 294 interdisciplinary palliative care clinicians from across the U.S. completed a survey regarding hospice access and scope of services for undocumented immigrants in their location. A majority perceived access to hospice was limited or unavailable for undocumented immigrants in their location, and among respondents who provided data regarding hospice scope, 38% reported that services provided to undocumented immigrants were limited... **Abstract:** <https://bit.ly/3poip9X>

**N.B.** Additional articles on hospice access for undocumented immigrants in the U.S. noted in Media Watch 1 April 2019 (#608, pp.14-15).

## **The impact of public health palliative care interventions on health system outcomes: A systematic review**

*PALLIATIVE MEDICINE* | Online – 23 December 2020 – Public health palliative care (PC) interventions are increasingly implemented, with growing recognition of the importance of building evidence to support their utility in end-of-life (EoL) care. Previous efforts have focused on community outcomes. Searches yielded 2,622 unique titles screened for eligibility, resulting in 35 studies measuring outcomes from a public health PC approach. Five studies assessed health system outcomes, and three reported some mixed evidence of impact, including reduced hospital emergency admissions, hospital bed days, hospital costs and increased home deaths. Most studies instead reported on conceptual, knowledge, programme participation and/or individual health outcomes. The impact of public health PC is an evolving area of empirical inquiry with currently only limited evidence that it improves healthcare utilisation outcomes at the EoL, and limited focus on measurement of these outcomes. Further empirical studies are needed to support the reorientation of health services, which remains an important component in realising “whole of system change” to bring about quality EoL care for all. **Abstract (w. list of references):** <http://bit.ly/2M37kwB>



### **[Media Watch: Access Online](#)**

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

## Palliative care in sub-Saharan Africa

### **The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: A multi-country qualitative study**

*PALLIATIVE MEDICINE* | Online – 23 December 2020 – Informal caregivers are a major partner in providing advanced cancer patients with palliative care (PC) in sub-Saharan Africa. This comparative, in-depth analysis of the role, impact, and support of informal caregivers of advanced cancer patients across three countries [i.e., Nigeria, Uganda and Zimbabwe] highlights that they provide the majority of medical, physical, financial, and emotional needs of the patient, often incurring sacrifices relating to their employment, finances, health, and social life. The authors highlight novel caregiver experiences that are unique to the three participating countries, which includes an increased burden arising from a lack of access to transport, finances, and work. Further research is required to better explore how these findings can inform future adaptation of practice and intervention development targeting caregivers. This could be an important step toward improving PC pathways to better support caregivers in providing patients with the best possible PC at home. **Full text:** <http://bit.ly/3nLJrYp>

### **Archaeology and contemporary death: Using the past to provoke, challenge and engage**

*PLOS ONE* | Online – 29 December 2020 – In this interdisciplinary pilot study, archaeological case studies were used in 31 structured workshops with 187 participants from health and social care backgrounds in the UK, to explore their reactions to a diverse range of materials which documented wide and varied approaches to death and the dead. The study supports the hypothesis that the past is a powerful instigator of conversation around challenging aspects of death, and after death care and practices: 93% of participants agreed with this. That exposure to archaeological case studies and artefacts stimulates multifaceted discourse, some of it difficult, is a theme that also emerges in data from pre, post and follow-up questionnaires, and semi-structured interviews. The material prompted participants to reflect on their biases, expectations and norms around both treatment of the dead, and of bereavement, impacting on their values, attitudes and beliefs. Moreover, 87% of participants believed the workshop would have a personal effect through thinking differently about death and bereavement, and 57% thought it would impact on how they approached death and bereavement in their professional practice. This has huge implications today, where talk of death remains troublesome, and for some, has a near-taboo status – “taboo” being a theme evident in some participants’ own words. The findings have an important role to play in facilitating and normalising discussions around dying and bereavement and in equipping professionals in their work with people with advanced illness. **Full text:** <http://bit.ly/3rCJRCE>

### **Social relationships in nurses’ caring of adolescents and emerging adults with life-limiting illnesses or injuries**

*QUALITATIVE HEALTH RESEARCH* | Online – 16 December 2020 – Nurses’ experiences with and within people’s social worlds are comparatively underexamined. The purpose of this inquiry was to uncover dimensions of social relationships in nurses’ caring for adolescents and emerging adults with life-limiting illnesses and injuries. From the perspective of *Caring for You Around You* and within a context, *Assessing Right for You*, *Diagnosing the Circle*, and *Planning Right for Me* establish the conditions under which nurses shift between witnessing and participating in social relationships as they engage in the process *I Draw and Redraw the Circle*. The findings contribute an explanation of why and how nurses engage in relational care. Contextualizing the findings in nursing theory, family-centered care, and professional ethics elucidates directions for inquiry and practice. **Abstract (w. list of references):** <http://bit.ly/3hb5e9h>

### **Media Watch: Editorial Practice**

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

## Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

## Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

## Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

## Media Watch: Access on Online

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/36XAaXg>

[Scroll down to 'Media Watch']

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

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

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

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

### **Asia**



Asia Pacific  
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Care Network

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

[Scroll down to 'Media Watch']

### **Australia**

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

### **Canada**



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

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

Cont.

## Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): [HTTPS://BIT.LY/3EPKUAC](https://bit.ly/3EPKUAC)

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

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

## South America

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

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