Media Watch… *is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in* ***hospice*** *and* ***palliative care****, and in the quality of* ***end-of-life care*** *in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.*

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Compiled & Annotated by Barry R. Ashpole

Integrating palliative care as an essential part of humanitarian healthcare is vital in order to ensure that humanitarians fulfill their mandates and commitment not only to attempt to save lives, but also to alleviate suffering and promote human dignity, even in those instances when lives cannot be saved.

'Addressing obstacles to the inclusion of palliative care in humanitarian health projects: A qualitative study of humanitarian health professionals' and policymakers' perceptions' (p.7), in *Conflict & Health*.

Hospice social workers improve healthcare equity, justice

HOSPICE NEWS | Online – 30 October 2020 – Hospice social workers can play a key role in addressing matters of social justice and healthcare equity when working with patients in underserved populations such as the mentally ill, the LGBTQ+ community and people of color. Lack of funding and interdisciplinary research are among the barriers of improving access to care for these groups. Demographic disparities have persisted in hospice utilization, deepening racial and cultural divides in end-of-life care and causing rising concern in the industry. Issues of equitable access to hospice care have also plagued the LGBTQ+ community, with many reluctant to pursue hospice care out fear of discrimination and general mistrust of the health system. Social workers are a large part of the bridge that connects these underserved communities to hospice care, but often face challenges when seeking avenues of further inclusion. The COVID-19 outbreak has additionally strained issues of equitable care access, hitting high-risk hospice and palliative care patients long-term facilities, nursing homes and hospitals hardest out of the need to social distance during the pandemic. "Part of the hospice social worker's role is to really be the glue and the communication," said Katherine Supiano, associate professor in the College of Nursing at the University of Utah. "It's an important part of our ethos to listen, respecting dignity and respecting patient autonomy, to get the larger, fuller story. We need social worker's deeper, richer and collaborative ethos." https://bit.ly/3kJ9zBy

Specialist Publications

'Understanding Asian Indian Americans' knowledge and attitudes toward hospice care' (p.4), in *American Journal of Hospice & Palliative Medicine*.

'Understanding experiences of moral distress in end-of-life care among U.S. and U.K. physician trainees: A comparative qualitative study' (p.12), in *Journal of General Internal Medicine*.

'Variation in pediatric palliative care allocation among critically ill children in the U.S.' (p.14), in *Pediatric Critical Care Medicine*.

'The impact of COVID-19 on the hospice and palliative care workforce' (p.15), in *Public Health Nursing*.

Hospices work to reach underserved LGBTQ+ communities

HOSPICE NEWS | Online – 28 October 2020 – The LGBTQ+ [i.e., lesbian, gay, bisexual, transgender and queer or questioning] community has been among the groups historically underserved by hospice, with mistrust of the healthcare system at large and provider bias as leading roadblocks to quality end-of-life care. Hospice providers are increasingly working to better understand the LGBTQ+ population and improve access to care. Issues of equity, inclusion and diversity have plagued the nation's healthcare system. Providers of all walks are reaching deeper into the roots of disparities to understand barriers and expand care among underserved African American, Hispanic, Jewish and LGBTQ+ communities. While widespread data is scarce, available research indicates that the LGBTQ+ population is among those groups under-utilizing hospice care. With barriers such as patients' fear of discrimination and general mistrust, hospice providers will need to build up awareness and break down biases around gender identity and sexual orientation to foster greater trust among underserved LGBTQ+ communities. A general lack of understanding and awareness among providers, along with stigmas, stereotypes and biases have been drivers of under utilization. https://bit.ly/2TMYOm9

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

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 7 August 2020 – **'Barriers to palliative care in sexual and gender minority patients with cancer: A scoping review of the literature.'** Lesbian, gay, bisexual and transgender (LGBT) patients and their caregivers experience homophobia, exclusion, social isolation, criminalisation, persecution, and fear of discrimination. Areas of future research and targeted interventions include: 1) Healthcare professional (HCP) perceptions of LGBT-specific palliative care needs; 2) Addressing social isolation; 3) Protection and assessment of community needs for the ageing population; 4) Managing caregiver distress: 5) Counselling about advanced directives; and, 6) Education for HCPs through the creation a safe environment. **Full text:** https://bit.ly/2CfcAsw

N.B. Additional articles on hospice and palliative care for LGBTQ+ people noted in Media Watch 25 May 2020 (#667, pp.3-4).

International

Oncological end-of-life care shows high care intensity, but less and late palliative care in Austria

AUSTRIA | Austrian Institute for Health Technology Assessment – 27 October 2020 – At the end of their lives, fewer cancer patients in Austria receive palliative care in hospitals than in other European country. They also receive it at a later stage – despite or because the intensity of the general care of those affected is high. This is one of the clearest results of an analysis by the Institute, which dealt with the care of terminally ill cancer patients at the end of their lives. The analysis was based on anonymous data of the 283,228 individuals who were diagnosed with cancer in Austria between 2012 and 2016. 29% of these affected persons (80,818) died within this period, with more than half of them dying during an inpatient hospital stay – most of them in Vienna in relation to the population. This is one of several differences between Austrian federal states that the analysis revealed. https://bit.ly/3jKbFQe

Specialist Publications

'Effect of the Carer Support Needs Assessment Tool intervention (CSNAT-I) in the Danish specialised palliative care setting: A stepped-wedge cluster randomised controlled trial' (p.6), in *BMJ Supportive & Palliative Care*.

'Assisted life termination and truth-telling to terminally ill patients: A cross-sectional study of public opinions in Israel' (p.11), in *Israeli Journal of Health Policy Research*.

'Perceptions and experiences of laws and regulations governing access to opioids in South, Southeast, East and Central Asia: A systematic review, critical interpretative synthesis and development of a conceptual framework' (p.13), in *Palliative Medicine*.

Cont.

Noted in Media Watch 6 January 2020 (#647, p.4):

- *BMC PALLIATIVE CARE* | Online – 4 January 2020 – **'End-of-life decision making by Austrian physicians: A cross-sectional study.'** In 2014, the Austrian parliament set up a commission to study "dignity at the end of life (EoL)." The result was a position paper containing 51 recommendations, one of which was a call to expand hospice and palliative care (PC) programs in Austria. This study reinforces the recommendation of the Study Commission of the Austrian Federal Chancellery that the reach of PC in Austria should be extended and that medical, ethical and legal training relating to the treatment of dying patients should be improved. Almost 50% of the physicians that participated in this survey felt legally insecure when treating EoL patients. **Full text:** http://bit.ly/2rTC9tQ

Noted in Media Watch 18 November 2019 (#640, p.15):

- *SOCIAL SCIENCE & MEDICINE*, 2020;245. **'The good death and the institutionalisation of dying: An interpretive analysis of the Austrian discourse.'** The institutionalisation of dying is recurrently assessed as adverse to a good death. However, a majority of people die in institutions such as hospitals or nursing homes and end-of-life (EoL) care at home is more and more professionally supported. This article analyses how the discursive production of dying, the good death, and the issue of institutionalisation at the EoL are interrelated. The study investigates a parliamentary enquiry on dying with dignity that took place between 2014-2015. In order to enable a good death, the dying person needs comprehensive support that the informal social environment is incapable to provide. **Abstract:** http://bit.ly/2OjnMWT

COVID-19

Lack of regular testing for hospice staff compromising care of dying

U.K. | *Charity Today* – 27 October 2020 – End-of-life (EoL) charity Marie Curie warns that a lack of access to regular and comprehensive testing for frontline hospice staff is compromising the care of dying people. The charity is demanding that hospices be included in weekly testing (proactive surveillance) to mitigate the risks of asymptomatic staff unknowingly transmitting COVID-19 to other staff and to ensure the charity has enough staff to keep its hospices open fully. As the U.K.'s largest provider of hospice care outside the National Health Service, the charity is concerned that rising cases of transmission could impact the charity's ability to operate fully and safely while supporting the increasing number of people who need palliative and EoL care this winter. Alongside hospice staff, the charity is also calling for regular weekly testing of an identified close relative or carer, who will be able to continue to provide support and visit. Different approaches to testing across the U.K. are also leading to confusion and means that asymptomatic COVID-19 positive staff are not always identified early resulting in staff and patient safety issues. Some local Health Protection Teams recommend testing all staff in an outbreak situation while others will only test symptomatic staff. Marie Curie is also concerned that vulnerable people in crisis may decline admission to hospices for fear of contracting COVID-19. https://bit.ly/3kzRWUO

Pandemic Pressures: The struggles and resilience of families caring for a seriously ill child

RAINBOW TRUST
CHILDREN'S CHARITY

U.K. (England) | Rainbow Trust – 22 October 2020 – Caring for a child with a life-threatening or terminal illness at any time brings many challenges to a family, both emotional and practical. The COVID-19 pandemic has piled further pressure onto parents and children at the very time when many services and sources of support have been unable to assist them. This report presents the experiences of families caring for a seriously ill child over the last seven months. From parenting a critically ill baby at a distance, to maintaining strict shielding as a household for many months, the pandemic has been both challenging and exhausting. As the shape of the pandemic remains unclear, and as more areas go into tighter restrictions, Rainbow Trust calls on the Secretary of State for Health & Social Care to urgently address the long-standing gap in funding emotional and practical support for families, which can be a lifeline for families caring for a seriously ill child in a time of great uncertainty and anxiety. **Download/view at:** https://bit.ly/2GauEG9

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Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Queensland) | Australian Broadcasting Corporation (Brisbane) – 26 October 2020 – **'Public reasoning about voluntary assisted dying: What we found when we analysed submissions to the Queensland parliamentary inquiry.'** What are the reasons, forms of reasoning, and rhetoric that people use in their support for or opposition to physician-assisted suicide and euthanasia, and the introduction of "voluntary assisted dying" (VAD) legislation that would legalise these practices? While numerous polls estimate public attitudes to such practices and legislation, there is little interrogation of why people think the way they do. There are many reasons that may be valid, but not all reasons are strong reasons. Moreover, some reasons may conflict with other reasons. Understanding public reasoning about VAD can help to shape better policy grounded on coherent reasoning. In November 2018, the Queensland Parliamentary Inquiry in Aged Care, End-of-Life and Palliative Care, and Voluntary Assisted Dying invited submissions from the public on why they support or oppose VAD. Researchers at the Queensland Bioethics Centre analysed 1,119 of the submissions made by individuals of the over 4,500 submissions made to the inquiry.[1] They focused on individuals, not organisations, so that they could illuminate the rhetoric, reasons, and reasoning of the general public. https://ab.co/3jxSKbr

    1. 'Public reasoning about voluntary assisted dying: An analysis of submissions to the Queensland Parliament, Australia,' *Bioethics*, published online 19 August 2020. [Noted in Media Watch 24 August 2020 (#680, p.11)] **Full text:** https://bit.ly/3ld9SWb

Specialist Publications

Barriers to high quality end-of-life care in the surgical intensive care unit

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 29 October 2020 – End of life discussions frequently take place in surgical intensive care units, as a significant number of patients die while admitted to the hospital, and surgery is common during the last month of life. Multiple barriers exist to the initiation of these conversations, including: miscommunication between clinicians and surrogates, a paternalistic approach to surgical patients and, perhaps, conflicts of interest as an unwanted consequence of surgical quality reporting. Goal discordant care refers to the care that is provided to a patient that is incapacitated and that is not concordant to his/her wishes. This is a largely unrecognized medical error with devastating consequences, including inappropriate prolongation of life and non-beneficial therapy utilization. Importantly, hospice and palliative care needs to be recognized as quality care in order to deter the incentives that might persuade clinicians from offering these services. **Abstract (w. list of references)**: https://bit.ly/37RtrPn

Understanding Asian Indian Americans' knowledge and attitudes toward hospice care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 27 October 2020 – Previous research has found racial differences in hospice knowledge and misconceptions about hospice care, which may hinder access to hospice care. Asian Indians are a rapidly growing population in the U.S., yet limited research has focused on their beliefs toward end-of-life care. This project investigates Indian Americans' knowledge of and attitudes toward hospice care and advance care planning (ACP). A cross-sectional design was employed using surveys about participants' knowledge of and attitudes toward hospice care and ACP. Findings revealed that 42.5% of respondents had an advance directive and 57.1% had named a healthcare proxy. Only 10% of respondents had known someone on hospice care and 10.4% correctly answered 4-5 of knowledge questions. After being informed about hospice care, 69.6% of participants agreed that if a family member was extremely ill, they would consider enrolling him/her in hospice. This study's results present a need for greater education about hospice services among older Asian Indians. Health practitioners should remain cognizant of potential misconceptions of hospice and cultural barriers that Asian Indians may have toward hospice care, so they can tailor conversations accordingly. **Abstract (w. list of references):** https://bit.ly/2GamX2K

Mortality prediction models, causal effects, and end-of-life decision-making in the intensive care unit

BMJ HEALTH & CARE INFORMATICS, 2020;27(3):e100220. End-of-life (EoL) decision-making in the intensive care unit (ICU) is challenging for both families and clinicians. This decision-making process is ideally framed around a shared understanding of a patient's values and goals, all taken in the context of their critical illness and prognosis. However, clinicians commonly face uncertainty regarding prognosis and may have difficulty offering families an accurate assessment of the likely outcomes of treatment decisions. Adding to the complexity of these scenarios, clinicians, patients and families are each susceptible to unconscious but influential cognitive biases when making decisions under stress. Given these challenges, and a rapidly growing interest in data science to inform care in the ICU, investigators have explored the use of prediction models (e.g., machine learning or ML algorithms) to assist with prognostication. Prediction models describe an outcome distribution among individuals with a particular set of characteristics, such as risk of acute kidney injury among individuals with particular laboratory values and clinical characteristics in a population. However, they do not compare how that outcome distribution would change were different treatment decisions made in that population – this requires causal effect estimation, rather than prediction modelling. The authors explain why prediction modelling alone is not sufficient to inform many ICU treatment decisions, including EoL decision-making, and describe why causal effect estimation is necessary. **Full text:** https://bit.ly/3mu3xFE

Noted in Media Watch 21 September 2020 (#684, p.7):

- *HEALTH AFFAIRS* | Online – 16 September 2020 – **'Ethical considerations in the use of artificial intelligence mortality predictions in the care of people with serious illness.'** For patients who desire it, prognostic information should ideally help them make decisions about treatments, prepare for the future, and focus on their priorities. The use of automated artificial intelligence (AI) algorithms by palliative care teams … to identify people approaching the end of life to prevent unwanted and non-beneficial care is an important goal. Because these people often incur high costs, reducing unwanted care can have the added benefit of lowering costs. Yet, despite AI's potential, there is a need to address at least three core ethical issues before implementation of AI in this unique context. **Full text:** https://bit.ly/3iBGGpP

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/2IgcUGV

N.B. The focus of the current issue of the *American Journal of Bioethics* is machine learning for human healthcare systems. **Journal contents page:** http://bit.ly/2ToM4zl

Strengthening palliative care in the hospital setting: A co-design study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 28 October 2020 – Changes to policy, practice, education and further research are required to optimise palliative care (PC) within hospital settings, in accordance with the domains inpatients with PC needs and their families consider to be important. Achieving these changes will require a whole of sector approach and significant national and jurisdictional leadership. The object of this study was to identify actions required to strengthen the delivery of person and family centred hospital-based PC... Nine actions were identified as required to strengthen inpatient PC provision: 1) Evidence-informed practice and national benchmarking; 2) Funding reforms; 3) Securing executive level support; 4) Mandatory clinical and ancillary education; 5) Fostering greater community awareness; 6) Policy reviews of care of the dying; 7) Better integration of advance care planning; 8) Strengthen nursing leadership; and, 9) Develop communities of practice for improving PC. **Abstract:** https://bit.ly/3mx0XOZ

Cont.

Related:

- *PALLIATIVE MEDICINE* | Online – 31 October 2020 – **'Do family meetings for hospitalised palliative care patients improve outcomes and reduce health care costs? A cluster randomised trial.'** There has been minimal research to determine the benefits and cost implications of family meetings. Family meetings may be helpful in reducing family caregiver distress and enhancing their preparedness for the caregiving role and it appears they may be conducted without increased hospital health utilisation impacts; although opportunity costs need to be considered in order to routinely offer these as a standardised intervention. Additional health economic examination is also advocated to comprehensively understand the cost-benefit implications. **Abstract (w. list of references):** https://bit.ly/2TEyvyr

- *PALLIATIVE MEDICINE REPORTS* | Online – 22 October 2020 – **'A social worker-led primary palliative care model for hospitalized patients admitted to the hospital medicine service.'** This primary palliative care (PC) social worker-led model allowed patients to explore life values and how these values affect treatment decisions and goals-of-care (GoC). Conversations earlier in their disease trajectory allowed the patient's voice to be heard and communicated to their family and care providers, while also allowing patients and family to process anticipatory grief and existential distress with necessary support. The model extended the reach of PC, increased GoC documentation, and maintained a hospice referral rate comparable with a specialty PC inpatient consultation service. **Full text:** https://bit.ly/37OXNBU

Effect of the Carer Support Needs Assessment Tool intervention (CSNAT-I) in the Danish specialised palliative care setting: A stepped-wedge cluster randomised controlled trial

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 28 October 2020 – The Carer Support Needs Assessment Tool intervention (CSNAT-I) has been shown to improve end-of-life care support for informal caregivers. This study investigated the impact of the CSNAT-I on caregivers of patients recently enrolled in specialised palliative care at home in Denmark. 437 caregivers were enrolled (control group, n=255; intervention group, n=182). Although no effect was found on caregiver strain, the CSNAT-I showed positive effects on caregiver distress, home care responsibility and key outcomes regarding caregivers' experience of the interaction with healthcare professionals. **Abstract:** https://bit.ly/37P3hwM

Noted in Media Watch 8 June 2020 (#669, p.6):

- *PALLIATIVE MEDICINE* | Online – 3 June 2020 – **'A drive for structure: A longitudinal qualitative study of the implementation of the Carer Support Needs Assessment Tool (CSNAT) intervention during hospital discharge at end of life.'** Overall, despite practitioner efforts, implementation proved challenging. This study revealed three main findings: 1) An emphasis on structured approaches to work, dominance of outcomes measurement, and performance metrics which framed practitioners' perceptions of the intervention and their implementation decisions; 2) Contradictions in the extent to which specialist practitioners felt that they were the "right" people to implement the intervention; and, 3) Practical implementation challenges of the hospital context. **Full text:** https://bit.ly/2XyP3KT

Detoxifying do not attempt cardiopulmonary resuscitation decisions

BRITISH MEDICAL JOURNAL | Online – 28 October 2020 – Even before COVID-19, do not attempt cardiopulmonary resuscitation (DNACPR) orders featured in many a misunderstanding or formal complaint. The pandemic response has made these orders more contentious, and the [U.K.] Care Quality Commission recently announced that it would review how DNACPR decisions had been used during the pandemic. Stories had emerged earlier in the pandemic of National Health Commission commissioners pressuring local care homes to complete DNACPR orders for residents *en masse* or GP surgeries writing to registered patients with serious illnesses, asking them to complete forms. Doctors and advocacy groups expressed fears about using age or clinical frailty scores for crude rationing of intensive care or CPR, not least for younger people with physical or learning disabilities. Among medical and nursing staff who deal daily with end-of-life care, acutely deteriorating patients, or cardiac arrests, many of the issues involved seem far less contentious. But this topic continues to generate strong reactions, whether we like it or not. If we're to improve the public conversation we need to convey some key messages. **Full text:** https://bit.ly/3jDapyy

Addressing obstacles to the inclusion of palliative care in humanitarian health projects: A qualitative study of humanitarian health professionals' and policymakers' perceptions

CONFLICT & HEALTH | Online – 28 October 2020 – Humanitarian non-governmental organizations provide assistance to communities affected by war, disaster and epidemic. A primary focus of healthcare provision by these organizations is saving lives; however, curative care will not be sufficient, appropriate, or available for some patients. In these instances, palliative care (PC) approaches to ease suffering and promote dignity are needed. Though several recent initiatives have increased the probability of PC being included in humanitarian healthcare response, PC remains minimally integrated in humanitarian health projects. In this article, the authors report on the analysis of in-depth interviews with 24 participants related to their perceptions of obstacles to providing PC in humanitarian crises, and opportunities for overcoming these obstacles. Among the participants, 23 had experience as humanitarian health professionals, and 12 had experience with policy development and organizational decision-making. Participants discussed various obstacles to the provision of PC in humanitarian crises. More prominent obstacles were linked to the life-saving ethos of humanitarian organizations, priority setting of scarce resources, institutional and donor funding, availability of guidance and expertise in PC, access to medication, and cultural specificity around death and dying. Less prominent obstacles related to continuity of care after project closure, equity, security concerns, and terminology. Opportunities exist for overcoming the obstacles to providing PC in humanitarian crises. Doing so is necessary to ensure that humanitarian healthcare can fulfill its objectives not only of saving lives, but also of alleviating suffering and promoting dignity of individuals who are ill or injured during a humanitarian crises, including persons who are dying or likely to die. **Full text (click on pdf icon):** https://bit.ly/34AzVQB

Noted in Media Watch 31 August 2020 (#681, p.5):

- *AFRICAN JOURNAL OF EMERGENCY MEDICINE* | Online – Accessed 24 August 2020 – **'Providing end-of-life care in the emergency department: Early experience from Médecins Sans Frontières during the Covid-19 pandemic.'** Médecins Sans Frontières has combined research and field-based experience to develop a guidance document for clinicians with limited experience in the provision of palliative care (PC), including those working in emergency services. In this article, the authors describe how evidence-based PC protocols can be adapted to less-resourced contexts at the necessary scale for a rapidly spreading epidemic whilst still respecting the physical and emotional needs of critically unwell individuals and their families. **Full text:** https://bit.ly/2QoiQSg

  N.B. Scroll down to 'Appendix A' to download/view 'Covid-19 Resource Allocation & Palliative Care – Strategic Framework'

Noted in Media Watch 9 December 2019 (#643, pp.5-6)

- EUROPEAN ASSOCIATION OF PALLIATIVE CARE BLOG | Online – Accessed 2 December 2019 – **'A Field Manual for Palliative Care in Humanitarian Crises.'** Recently, there has been increasing recognition of the importance of integrating palliative care (PC) into humanitarian aid. This is reflected in a growing number of journal articles and position papers on this topic, most notably with the publication of the World Health Organization guide.[1] This increasing recognition is in part a reflection of the growth of PC as a medical subspecialty; it also reflects the increasing understanding that the goal of humanitarian aid is not simply to save lives, but also to alleviate suffering. **Download/view introduction to manual at:** http://bit.ly/2YcNjFJ

  1. 'Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises,' World Health Organization, October 2018. [Noted in Media Watch 1 October 2018 (#583, p.6)] **Download/view at:** http://bit.ly/2T4AScC

Noted in Media Watch 20 August 2018 (#577, p.12):

- *PALLIATIVE MEDICINE* | Online – 16 August 2018 – **'How do expatriate health workers cope with needs to provide palliative care in humanitarian emergency assistance? A qualitative study with in-depth interviews.'** Given the worldwide increase of chronic diseases, expatriate health workers on assignment with humanitarian emergency organisations can face more clinical situations that require advanced pain control or palliative care (PC). Multiple reasons can prevent the provision of this care. Fifteen expatriate health workers took part in individual in-depth interviews after their assignment with the organisation Médecins sans Frontières. Clinical situations requiring advanced pain control or PC do occur during assignments. **Abstract (w. list of references):** https://bit.ly/2YxoVjA

Palliative care in acute heart failure

CURRENT HEART FAILURE REPORTS | Online – 29 October 2020 – As with chronic heart failure (HF), providing palliative care (PC) to those with acute HF presents challenges and opportunities. Organizational barriers might come into play in that some systems of care may not sanction inclusion of PC within the HF care bundle, or the necessary workforce may be unavailable. More commonly, there is still a failure to appreciate that the concurrent provision of PC alongside guideline-directed medical therapy aimed at life prolongation is not incongruous. For many patients admitted with acute HF, some of whom will die in hospital, there is often a tension in reconciling the "treatment imperative" and the "ethical imperative" in the need to provide comfort care. This dilemma is evident in considering the clinical characteristics behind the I-NEED-HELP mnemonic, proposed as an *aide-mémoire* describing those potentially requiring advanced HF therapies, but which are no less applicable as markers of PC need. Embedding PC within a HF multidisciplinary team from the time of diagnosis avoids silo working, needs assessment undertaken as an iterative process along the capricious disease trajectory enabling incremental PC involvement during disease progression, with formulation of appropriate treatment escalation and withdrawal policies as patients decline towards the end of life. Close to death, it is important that HF professionals trusted by patients and families remain engaged, avoiding a perception of abandonment. **Full text:** https://bit.ly/2TDgXTd

Going against patients' will? A qualitative study of how palliative healthcare professionals handle competing considerations when children are excluded from parental illness and death

EUROPEAN JOURNAL OF ONCOLOGY NURSING | Online – 27 October 2020 – The Norwegian Health Personnel Act obliges health professionals to contribute to meeting minor children's need for information about their parents' illness and prognosis. This study supports the findings from previous research about the contextual conditions that limit palliative healthcare professionals' opportunities to involve children as relatives. This study contributes to this established knowledge by deeply investigating the health professionals' ways of handling the moral problem that occurs when parents withhold information about their illness and impending death from their minor children. The authors' findings point to how the primacy of the professional-patient relationship in the healthcare context and the importance given to patient autonomy in the present sociocultural context result in health professionals giving greater weight to patients' will than to children's right to – and need for – information about their parent's illness and prognosis. The authors propose that procedures for initiating collaboration with the professionals from the children's everyday-life context may help health professionals to involve the children without threatening the trust in various interpersonal relationships. **Full text:** https://bit.ly/2TzJlWg

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 October 2020 – **'Parents with advanced cancer: Worries about their children's unspoken concerns.'** Parents struggle initiating conversations with their children about the cancer. When parents do not have the tools to talk with their children, they silently watch their children attempt to navigate their illness, but can only wonder but not know what their children are thinking. The authors describe the worries and concerns parents wonder their child holds, but has not spoken, about the parent's cancer, adding to an understanding of the magnitude of the emotional burden parents with advanced cancer carry as they struggle to balance their diagnosis and treatment and their life as parents. **Abstract (w. list of references):** https://bit.ly/3ouXVfW

N.B. See 'The Crossroads of Grief: Understanding Grief & Diversity,' Children & Youth Grief Network, Ontario, Canada, 2018. Scroll down to 'Complete Literature Review' for 'Parental Illness, Dying & Death' (p.13) and ' Death of a Parent' (p.30). **Download/view at:** http://bit.ly/2OB4Y6C

Dignity and loss of dignity: Experiences of older women living with incurable cancer at home

HEALTH CARE FOR WOMEN INTERNATIONAL | Online – 21 October 2020 – Dignity-preserving care was experienced when physical as well as emotional and existential needs were met. The women emphasized the value of having a sense of control and making their own decisions to experience dignity in their everyday lives. When retaining hope and meaningfulness, feeling valued as an individual and being situated in a treasured and nurturing environment, dignity was preserved. Experiences that led to dignity loss included the loss of opportunity for self-determination and control, experiencing healthcare professionals (HCPs) invading and violating their personal lives, sensing hopelessness and worthlessness in a shroud of illness and when being situated in surroundings enhancing their senses of disconnections and alienations. The women experienced the quality of care as more important than the physical place in which they were to spend their final days. This seems to be caused by limitations in available HCP resources and competence, but also due to the women's fear of being a burden to their families. The findings of this study strongly suggest a need for HCP training and education in dignity-preserving care within the municipal palliative care service. **Full text:** https://bit.ly/3mpSFZj

A matter of life and death: Teaching undergraduates about the end of life

INTERNATIONAL JOURNAL ON AGING & HUMAN DEVELOPMENT, 2020;94(1):443-448. As the population ages, the number of careers that intersect with aging is expected to grow. However, many young people lack an interest in working with aging populations. As previous work has shown, though, students' interest in aging careers may be stimulated by coursework and experiential activities related to aging. Despite being a normative developmental process, anxiety about death and dying may be particular barriers to students developing interest in aging, and these topics may be particularly difficult subjects to teach in the college classroom. In this article, strategies and activities for teaching the end of life are offered. **Abstract (w. list of references):** https://bit.ly/37DXdHl

Noted in Media Watch 21 September 2020 (#684, p.5):

- *BMJ OPEN* | Online – 9 September 2020 – **'How effective is undergraduate palliative care teaching for medical students? A systematic literature review.** The effect of undergraduate palliative care (PC) teaching on clinical practice has not been studied and warrants investigation. For all teaching approaches, constructive alignment and the communication of constructive alignment in educational studies should be considered to ensure adequate teaching impact. Further research into PC teaching should explicitly detail this alignment to allow for evaluation as to whether constructive alignment, not the teaching method, may be responsible for any effect of PC teaching interventions. Medical students can learn about PC using a variety of methods; there is no definitive "best" way to learn about PC. **Full text:** https://bit.ly/2E1aVaH

Noted in Media Watch 20 April 2020 (#662, p.13):

- *JOURNAL OF PALLIATIVE CARE* | Online – 13 April 2020 – **'Building a medical undergraduate palliative care curriculum: Lessons learned.'** Previous literature demonstrates that current palliative care (PC) training is in need of improvement for medical students in global, European and Canadian contexts. The training of medical undergraduates is key to ensure that the ongoing and increasing need for enhanced access to PC across all settings and communities is met. The authors describe building a comprehensive palliative and end-of-life care curriculum for medical undergraduates at their university. Findings and lessons learned may help others who are working to develop a comprehensive undergraduate medical education curriculum. **Abstract (w. list of references):** https://bit.ly/3a1Yqpq

Noted in Media Watch 20 August 2018 (#577, p.13):

- *REVISTA BRASILEIRA DE GERIATRIA E GERONTOLOGIA*, 2018;21(3):261-271. '**Palliative care: A proposal for undergraduate education in medicine.**' In Brazil, the Universidade Federal de São Paulo was the first medical school to offer palliative care (PC) courses... In 2003, a compulsory PC discipline was created at the Universidade de Caxias do Sul. Despite these examples of approaches to PC in education, which were later followed by other universities, there is a lack of correlation between the provision of instruction in PC and the perception of its importance in most medical schools. Such schools have described insufficient time, a lack of faculty expertise and the time-consuming demands of multiple interests as the reasons for the lack of curricular under-representation of PC. **Full text:** https://goo.gl/5wTrSt

Expanding the concept of end-of-life care in long-term care: A scoping review exploring the role of healthcare assistants

INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING | Online – 29 October 2020 – The context of care provided in long-term care (LTC) homes is changing, as an increasing number of older adults are entering LTC with advance stages of illness and higher care needs. LTC homes are quickly becoming the place of death for an increasing number of older adults, despite recent literature identifying inadequate and suboptimal levels of end-of-life care (EoLC). Within LTC, healthcare assistants represent 60%-70% of the unregulated workforce and provide 70%-90% of the direct care to residents. Research indicates that a high level of uncertainty exists surrounding the role of healthcare assistants in EoLC, with numerous studies reporting the role of healthcare assistants to be unclear' with varying levels of responsibilities and autonomy. Findings from this scoping review highlight the numerous behaviours healthcare assistants perform outside their role description in order to provide EoLC to dying residents in LTC. They could inform policymakers and managers of LTC homes. **Abstract:** https://bit.ly/31X4E8C

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

Death education for children and young people in public schools

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 28 October 2020 – Conversations about death are often associated with fear, anxiety, avoidance and misunderstandings. Many adults feel that these discussions are inappropriate and confusing for young people. In this project, two fourth-year nursing students partnered with a local palliative care (PC) team to examine death education for children. The nursing students focused on children's understandings of death and their coping abilities, the lack of appropriate discussions about death with children, and the implementation of death education in public schools. Three online death education resources were identified and evaluated for use in public schools. This project fueled preliminary local discussions and advocacy efforts in the provision of death education for children. In the future, death education will need to be incorporated into education plans at local schools, and could be done in collaboration with the local PC team. **Abstracts:** https://bit.ly/37KQaN7

> **N.B.** Additional articles on including death education in the public school curriculum noted in Media Watch 14 September 2020 (#683, p.7).

Methodological and ethical challenges while conducting qualitative research on spirituality and end of life in a Muslim context: A guide to novice researchers

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 28 October 2020 – Spirituality could be understood as a personal belief, a relation with sacred, divine experience, a sense of purpose and meaning towards life, authenticity and connectedness. It is a continually evolving, highly complex, contextual, subjective, and sensitive construct. A continuous development is seen around understanding about spirituality and spiritual concepts, such as spiritual experiences, spiritual pain and spiritual distress, especially among patients and families at the end of life (EoL). The concepts, values, attitudes, and beliefs around spirituality, spiritual needs and expressions vary among different individuals, cultures, and religions. There is a dearth of literature around spirituality, especially among Muslim patients and families at the EoL. The complexities around the concept of spirituality in the literature raise several ethical and methodological concerns for a novice researcher while planning and conducting a study on spirituality during EoL care in a hospice setting, especially among a Muslim population. This article aims to share some of the methodological and ethical challenges that can be faced by qualitative researchers while conducting research around spirituality and EoL care in an Islamic/Muslim context. Major challenges include defining the term spirituality, spirituality and culture, communication, power relations, language and translation, recruitment and selection of the participants, emotional distress, and reflexivity and reciprocity. Having an in-depth understanding of these challenges can guide researchers to address these issues adequately in their spirituality research in a Muslim context. **Abstract:** https://bit.ly/3e2Bxpi

> **N.B.** Additional articles on the Islamic perspective on EoL and EoL care noted in Media Watch 6 April 2020 (#660, p.11).

Assisted life termination and truth-telling to terminally ill patients: A cross-sectional study of public opinions in Israel

ISRAELI JOURNAL OF HEALTH POLICY RESEARCH | Online – 26 October 2020 – Israelis are overwhelmingly supportive of truth-telling to patients about their medical status... This is in striking contrast to the proportion of Israeli physicians who support truth-telling, which is less than half. This finding calls for further scrutiny of the gaps in attitude between the public and caregivers. In addition, almost a half of the public is also supportive of an autonomist approach that would allow patients who wish for this to be assisted by the doctors in ending their lives. Based on this study and previous ones that assessed Israeli physicians opinions on the subject matter, policymakers may be prompted to consider differential policies for sub-groups of the populations to accommodate their wish for greater autonomy in end-of-life (EoL) decisions. Despite the apparent drift in Israeli public opinion toward a more supportive approach to EoL decisions and processes, there remains much to be understood about the effect of cultural worldviews on relevant attitudes. **Full text:** https://bit.ly/34xqNw3

Extract from *Israeli Journal of Health Policy Research* article

The awareness of the Israeli public to the psychosocial aspects of dealing with incurable diseases and [the] EoL process through palliative care (PC) is increasing. A national plan for PC was established in 2015... According to this plan, PC should be perceived as part of an overarching care system designed to improve terminally ill patients' coping capacities and quality of life. Nevertheless, and despite these improvements, the extent of palliative services offered in Israel is "poor, far from meeting the needs of the population, and does not compare to the services provided in advanced countries in the world."

Communication tools to support advance care planning and hospital care amidst the COVID-19 pandemic: A design process

THE JOINT COMMISSION JOURNAL ON QUALITY & PATIENT SAFETY | Online – 24 October 2020 – While patients and clinicians have a burning platform to have advance care planning conversations on an unprecedented scale, having these discussions involves negotiating an evolving and complex care environment. Patients are alone in rooms without family or visitors; conversations occur via phone or digital technologies; clinicians work tirelessly to care for patients while also fearing for their own safety, unable to spend time as much time as they want at the bedside; systemic inequities and disparities, which have always existed, are being amplified. These realities lead to moral injury, collective trauma, and distress for patients, families, and clinicians. Access to well-designed communication tools and supportive implementation strategies during times of high stress can better equip clinicians to innovate, adapt, and improvise in ways that foster connection with patients under difficult circumstances and create space for patients' voices to be heard. Attentive and meaningful communi-cation is not an antidote to this crisis but it may be one of the most powerful tools to spread care, compassion, and healing during this unprecedented time. **Full text:** https://bit.ly/2HoodQv

Noted in Media Watch 26 October 2020 (#689, p.9):

- *JOURNAL OF AGING & SOCIAL POLICY* | Online – 20 October 2020 – **'Rethinking the role of advance care planning in the context of infectious disease.'** The authors re-examine advance care planning (ACP) in light of the increased probability of death from COVID-19, an exemplar of death that occurs relatively quickly after disease onset. They draw several conclusions about ACP in the context of infectious diseases: interpersonal and socio-structural barriers to ACP are high; ACP is not well-oriented toward decision-making for treatment of an acute illness; and, the U.S. healthcare system is not well positioned to fulfill patients' EoL preferences in a pandemic. Passing the peak of the crisis will reduce, but not eliminate, these problems. **Abstract:** https://bit.ly/3ocwuaz

Understanding experiences of moral distress in end-of-life care among U.S. and U.K. physician trainees: A comparative qualitative study

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 27 October 2020 – This research highlights how the differing experiences of moral distress (MD) among U.S. and U.K. physician trainees are influenced by their countries' healthcare cultures … [and] … how experiences of MD reflect the broader culture in which it occurs and suggests how trainees may be particularly vulnerable to it. Clinicians and healthcare leaders in both countries can learn from each other about policies and practices that might decrease the MD trainees experience. A focus on clinician MD is even more important now in the setting of the COVID-19 pandemic. Given a growing scarcity of resources, the pandemic creates a setting in which explicitly rationing care – whether personal protective equipment, hospital beds, or ventilators – becomes necessary, prompting ethical dilemmas and inevitable MD. Other aspects of pandemic response, including clinician burnout, infection of healthcare workers, and witnessing increased sickness and death, can all also contribute to MD. As we address the physical health consequences and public health ramifications of the pandemic, we must also pay keen attention to the MD clinicians experience in these times. Developing clear ethical guidelines for allocation of scarce resources and robust strategies to mitigate MD in the setting of this pandemic is a crucial first step. **Full text:** https://bit.ly/2HxUe8N

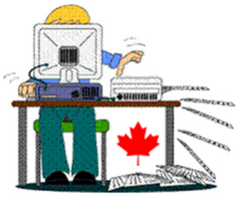
How healthcare providers' own death anxiety influences their communication with patients in end-of-life care: A thematic analysis

DEATH STUDIES | Online – 27 October 2020 – Healthcare providers' own death anxiety can influence end-of-life (EoL) communication. The authors interviewed nine palliative care health providers about their experiences of providing EoL care. Participants also completed the Revised Death Anxiety Scale. A thematic analysis of the interview transcripts identified one theme labeled "avoidant coping" and another labeled "death anxiety awareness"; each is presented in the context of the participants' own Revised Death Anxiety Scale scores. The findings show that avoidant death anxiety coping can compromise EoL communication, but that greater awareness of death anxiety can help overcome avoidant coping. The findings can inform potential improvements in healthcare practice and training. **Abstract:** https://bit.ly/2HIVBks

Improving advance care planning for seriously ill children: Engaging a diverse research population early and often

JOURNAL OF PEDIATRICS | Online – 26 October 2020 – DeCourcey *et al* describe the development of a new pediatric serious illness communication program (PediSICP) to support providers in advance care planning (ACP) conversations with their patients and families.[1] 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 stepwise, rigorous approach to adapt an adult communication guide for children. Study participants found the work to have the potential to "augment current practice and reduce variation" in ACP for children with serious illness. **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



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

Professional characteristics and the prevalence of advance directives among palliative care professionals: A cross-sectional study

PALLIATIVE CARE & SUPPORTIVE CARE | Online – 29 October 2020 – This study aimed to investigate the association between professional characteristics and the prevalence of advance directives (ADs) among palliative care (PC) professionals. A diverse sample of 327 healthcare professionals completed an online survey investigating demographic variables, length of time working in PC, post-graduate qualifications in PC, and development of their own ADs. The prevalence of ADs among professionals working in PC was associated with factors such as higher academic qualifications, holding a post-graduate qualification in PC, and working in PC for a longer time. Furthermore, psychologists were most likely to have registered their own ADs, compared with other healthcare professionals. This study suggests that just being involved in or familiar with the context of palliative and end-of-life care does not guarantee that health professionals register their ADs. **Abstract (w. list of references):** https://bit.ly/3jyQ0dW

Related:

- *JOURNAL OF MEDICAL ETHICS* | Online – 26 October 2020 – **'Practising what we preach: Clinical ethicists' professional perspectives and personal use of advance directives.'** Clinical bioethicists [i.e., study participants] are often sceptical about the value of advance directives (ADs), and their personal choices about ADs often deviate from what clinical ethicists acknowledge to be their profession's recommendations. Moreover, respondents identified a pluralistic set of justifications for completing treatment directives and designating surrogates, even while the consensus view focuses on patient autonomy. The results of this study suggest important revisions to academic discussion and public-facing advocacy about advance care planning. **Abstract:** https://bit.ly/31ItSaQ

Church leaders and parishioners speak out about the role of the church in advance care planning and end-of-life care

PALLIATIVE CARE & SUPPORTIVE CARE | Online – 29 October 2020 – Despite the increased focus on improving advance care planning (ACP) in African Americans through community partnerships, little published research focuses on the role of the African American church in this effort. This study examines parishioner perceptions and beliefs about the role of the church in ACP and end-of-life (EoL) care. Seven themes emerged: 1) Church role on EoL; 2) Advocacy for health and well-being; 3) Health literacy in EoL care; 4) Lay health training on ACP and EoL care; 5) Church recognized as a trusted source; 6) Use of church ministries to sustain programs related to ACP and EoL carte; and, 7) Community resources for EoL care needs. **Abstract (w. list of references):** https://bit.ly/2TBS2PO

Perceptions and experiences of laws and regulations governing access to opioids in South, Southeast, East and Central Asia: A systematic review, critical interpretative synthesis and development of a conceptual framework

PALLIATIVE MEDICINE | Online – 29 October 2020 – Access to opioids is inadequate across South, Southeast, East and Central Asia. Most existing literature on unmet need for opioids focusses upon estimates of need in a palliative care context and attitudes of clinicians towards opioids. The authors of this article show how barriers at international level raise further barriers at national and sub-national levels which limit accessibility of opioids, even when they are technically available. The international opioid regulatory framework is revealed as a self-perpetuating model, where restrictive forces at international and national level reinforce negative attitudes and fears of prescribing opioids at sub-national level. Data based upon inadequate levels of opioid consumption is then used to estimate opioid requirements for the following year, resulting in a cycle of inadequate opioid availability. Global policies must focus upon enabling access to opioids based upon evidence-based assessments of population-level need for opioids. Nations should implement legislation affirming governmental responsibility for ensuring access to opioids, to create a positive regulatory context and assuage concerns of clinicians relating to legal redress for prescribing opioids. Improved education and training opportunities regarding the benefits of opioids and safe prescribing are essential to challenge negative perceptions of opioids and increase human resources for prescribing and clinical care. **Full text:** https://bit.ly/2Jf958p

Caring precariously: An interpretive description of palliative care and welfare worker perspectives on end-of-life carers navigating social welfare

PALLIATIVE MEDICINE | Online – 28 October 2020 – Caring at end-of-life (EoL) is associated with financial burden, economic disadvantage, and psychosocial sequelae. Health and social welfare systems play a significant role in coordinating practical resources and support in this context. However, little is known about social policy and interactions with public institutions that shape experiences of informal carers with social welfare needs at EoL. Twenty-one workers employed within three public services in Western Sydney articulated understandings of welfare policy and its consequences for carers at EoL, including precariousness in relation to financial and housing circumstances. Identified resources and barriers to the navigation of social welfare needs by carers were categorised as personal, interpersonal and structural. Caring at EoL while navigating welfare needs was seen to be associated with precariousness by participants, particularly for carers positioned in vulnerable social locations. Further exploration of structural determinants of experience is needed, including aspects of palliative care and welfare practice and investment in inter-agency infrastructure for supporting carers at EoL. **Abstract (w. list of references):** https://bit.ly/2HG4Ceb

End-of-life care in Italy

End-of-life care after the legal introduction of advance directives: A qualitative study involving healthcare professionals and family caregivers of patients with amyotrophic lateral sclerosis

PALLIATIVE MEDICINE | Online – 28 October 2020 – Advance care planning (ACP) and advance directives (ADs) play a key role in the care of life-threatening illnesses such as amyotrophic lateral sclerosis. The results of this study indicated a lack of organization, collaboration and continuity on the part of healthcare services and professionals, a lack of information on palliative care, ACP, and ADs. End-of-life care (EoL) is often left to the goodwill of the individual professional. Difficulties can also derive from ethical dilemmas concerning EoL decision-making and from a lack of communication and relationships between health professionals, patients and their families. The introduction of ADs by law has not been sufficient to improve EoL care. **Abstract (w. list of references):** https://bit.ly/2GcMV5K

> **N.B.** Additional articles on Italy's law on the "provisions for informed consent and ADs treatment" noted in Media Watch 28 October 2019 (#637, p.14). Additional articles on EoL care for people living with amyotrophic lateral sclerosis noted in Media Watch 2 March 2020 (#655, p.8).

Variation in pediatric palliative care allocation among critically ill children in the U.S.

PEDIATRIC CRITICAL CARE MEDICINE | Online – 28 October 2020 – Palliative care (PC) consultation for critically ill children in the U.S. is low. PC utilization is increasing but considerable variation exists across institutions, suggesting inequity in PC allocation among this vulnerable population. In this study, the cohort included 740,890 subjects with 1,024,666 hospitalizations. About 1.36% of hospitalizations had a PC consultation. PC consult was independently associated with older age, female sex, government insurance, in-hospital mortality, and ICU-specific PC or complex chronic condition criteria. Among the hospitalizations, 30% met ICU-specific PC criteria, 40% complex chronic condition criteria, and 30% neither. ICU-specific PC patients received more mechanical ventilation and cardiopulmonary resuscitation, had longer hospital and ICU lengths of stay, and had higher in-hospital mortality. PC utilization increased over the study period with considerable variation between the institutions especially in the ICU-specific PC cohort and its subgroups. **Abstract:** https://bit.ly/34GZQWN

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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 beginning p.16.

Related:

- *JOURNAL OF LOSS & TRAUMA* | Online – 28 October 2020 – **'Interventions for siblings, extended family, and community members after pediatric death.'** The death of a child is felt by extended family, friends, and community members. Most bereavement care research focuses on programs for parents. Little is known about the efficacy of support programs for other grieving individuals. The authors conducted a scoping review of the literature describing the efficacy of bereavement support programs for siblings, extended family (other than parents), and community members after pediatric death. They found only four reports describing the efficacy of bereavement support programs for this population. All articles described benefits of the intervention studied. **Abstract:** https://bit.ly/3mAOdXB

  N.B. See 'The Crossroads of Grief: Understanding Grief & Diversity,' Children & Youth Grief Network, Ontario, Canada, 2018. Scroll down to 'Complete Literature Review' for 'Sibling Perspectives' p.11 and 'Death of a Sibling' p.24. **Download/view at:** http://bit.ly/2OB4Y6C

- *QUALITATIVE SOCIAL WORK* | Online – 29 October 2020 – **'Exploring opportunities for holistic family care of parental caregivers of children with life-threatening or life-limiting illnesses.'** The findings of this study add depth to the existing literature and identifies opportunities for addressing families' unmet needs, with specific attention to the role that social workers can play in facilitating family-centred care to promote effective support of parental caregivers. As such, the findings emphasize the important contributions that social workers can make within healthcare teams and in educational settings to optimize parents' ability to care for ill children while maintaining family functioning and well-being, and as advocates for social and policy change. **Abstract (w. list of references):** https://bit.ly/3eat0Rc

The impact of COVID-19 on the hospice and palliative care workforce [in the U.S.]

PUBLIC HEALTH NURSING | Online – 27 October 2020 – The findings of this cross-sectional survey suggest that the COVID-19 pandemic has strained the palliative and hospice care workforce as it provides increased services at an unprecedented rate to patients and families. The implications of these findings are important for public health nurses who are skilled in disaster management and quickly responding to emergencies. The expertise of public health nurses can be leveraged to support palliative care (PC) agencies as they strive to manage the pandemic in the communities they serve. Most survey respondents (70%) reported an increase in specific PC services as a result of the pandemic. Two thirds (78%) of respondents reported their agency has cared for confirmed COVID-19 patients. Only half reported the agency had access to laboratory facilities for surveillance and detection of outbreaks in both patients and staff (58%) and that the agency could test patients and providers for COVID-19 (55%). Qualitative comments described the impact of the pandemic and resulting social distancing measures on the emotional well-being of patients, families, and staff. **Abstract:** https://bit.ly/37KEvhj

Noted in Media Watch 3 August 2020 (#677, p.7):

- *PALLIATIVE MEDICINE* | Online – 31 July 2020 – **'Prioritising workforce wellbeing and resilience: What COVID-19 is reminding us about self-care and staff support.'** To maintain the provision of quality palliative care (PC) in the wake of such challenges [such as the COVID-19 pandemic], there is a clear need to prioritise wellbeing and resilience in the PC workforce. It has also been important to offer such opportunities to the broader healthcare workforce who also have been plunged into a steep learning curve to provide PC outside their usual scope of clinical practice. But whose responsibility is workforce wellbeing and resilience – the individual practitioner or the organisations in which they work? **Full text:** https://bit.ly/3k2SNNJ

Media Watch: Editorial Practice

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Cont.

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

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

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

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