

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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Health disparities experts echoed themes of mistrust, spirituality, religiosity, desire to limit prognostication, and fatalism as barriers to effective advance care planning. These varying points of view call our attention to the pitfall of leaning too heavily on cultural competency as opposed to leading with cultural humility.

'Will you hear me? Have you heard me? Do you see me? Adding cultural humility to resource allocation and priority setting discussions in the care of African American patients with COVID-19' (p.7), in *Journal of Pain & Symptom Management*.

U.S.A.

U.S. NEWS & WORLD REPORT | Online – 31 August 2020 – Some people with advanced heart failure (HF) live for a long time, while others don't. That uncertain timeline poses challenges for doctors, their patients and families dealing with end-of-life (EoL) care. "We've had quality indicators for cancer for many years, which have been used to make sure that EoL patients get high-quality care," said Dr. Rebecca Hutchinson, a hospice and palliative medicine specialist at Maine Medical Center in Portland. "With HF, we don't have those indicators." That discrepancy motivated Hutchinson *et al* to conduct in-depth interviews with 23 cardiologists and primary care physicians across Maine about treating people with advanced HF. The study ... found "prognostic uncertainty" of advanced HF complicates how doctors care for patients for several reasons.¹ "HF is marked by frequent exacerbations where patients can get pretty sick and then recover back to baseline or pretty close back to baseline," said Hutchinson... "At some point, one of those

exacerbations usually marks the beginning of EoL, but it's not always easy to tell. Are you in one that's close to EoL or are you in one where there's going to be a recovery?" That, she said, forces doctors to balance the desire to prolong life against the possibility that more treatment will do no good and cause unnecessary suffering. The uncertainty often makes it harder for patients to recognize the reality of their disease, and harder for doctors to discuss the situation with them... <https://bit.ly/2EzVBSZ>

Specialist Publications

'Palliative care during public health emergencies: Examples from the COVID-19 pandemic' (p.3), in *American Family Physician*.

'Perceptions of palliative care: Voices from rural South Dakota' (p.4), in *American Journal of Hospice & Palliative Medicine*.

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1. 'What is quality end-of-life care for patients with heart failure? A qualitative study with physicians,' *Journal of the American Heart Association*, published online 31 August 2020. **Full text:** <https://bit.ly/31JpdpK>

N.B. Selected articles on the palliative care needs of patients living with HF noted in Media Watch 10 August 2020 (#678, p.12). Search back issues of Media Watch for additional articles on this issue/topic at: <http://bit.ly/2ThijkC>

Another Catholic hospital takeover raises death with dignity concerns in Washington

STATE OF WASHINGTON | *Nonprofit Quarterly* – 30 August 2020 – The expected merger of two nonprofit health systems in the Seattle region, Virginia Mason Health System and CHO Franciscan, is part of this trend. Yet, as we know, in a merger process, important patient rights can be compromised. In the State of Washington, patients who know that they have less than six months to live can, after consultation, request lethal doses of medication from medical and osteopathic physicians. The process is rigorous, requiring two separate doctors and full documentation to the state, but it does legally allow an individual to decide to avoid a painful, lingering death. When the merger is concluded, the combined system will become part of one of the nation's largest healthcare systems, CommonSpirit Health. Virginia Mason allows its staff to prescribe end-of-life (EoL) medications if requested, but CHI Franciscan and CommonSpirit are Catholic organizations and prohibit both the discussion and implementation of such means. When the merger is complete, CHI Franciscan policy will prevail. As a Catholic-affiliated organization, CommonSpirit follows directives issued by Church leadership. Expectations were set by the U.S. Conference of Bishops in 2018, which was disturbed by the way many hospitals were ignoring or working around Church law on contraception, abortion, LGBTQ-services, and EoL care. <https://bit.ly/31Zvgqf>

Noted in Media Watch 30 December 2019 (#646, p.2):

- REUTERS HEALTH | Online – 27 December 2019 – **'Patients don't care about provider religious ties, expect all needed care.'** Nearly three quarters of Americans don't care about the religious affiliation of their hospital or healthcare network, but an equal number say they expect their healthcare preferences to take priority over the facility's religious doctrine, a new study finds.¹ The survey comes at a time when the number of Catholic-owned healthcare systems are on the rise, researchers note. And, perhaps unknown to many patients, physicians at those facilities are expected to follow the U.S. Conference of Catholic Bishops' "Ethical and Religious Directives for Catholic Health Care Services," which places limits on reproductive and end-of-life care methods. <http://bit.ly/2Q8i6Br>

1. 'Patient views on religious institutional healthcare,' *JAMA Network Open*, 2019;2(12):e1917008. **Full text:** <http://bit.ly/2Qty5bT>

Noted in Media Watch 6 May 2019 (#613, p.2):

- CALIFORNIA | *Kaiser Health News* – 29 April 2019 – **'Will ties to a Catholic hospital system tie doctors' hands?'** As Catholic healthcare systems across the country expand, the University of California's flagship San Francisco (UCSF) hospital has become the latest arena for an emotional debate: Should the famously progressive medical center increase its treatment space by joining forces with a Catholic-run system that restricts care according to religious doctrine? At issue is a proposal that UCSF Medical Center affiliate with Dignity Health, a massive Catholic healthcare system that, like other Catholic chains, is bound by ethical and religious directives from the U.S. Conference of Catholic Bishops. <http://bit.ly/2vtsmJ6>

Noted in Media Watch 18 March 2019 (#606, p.7):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2019;321(11):1103-1104. **'Disclosure of religious identity and healthcare practices on Catholic hospital websites.'** Among U.S. Catholic hospitals, 21% did not explicitly disclose their Catholic identity on their websites, and only 28% specified how religious affiliation might influence patient care. A recent review demonstrated that patients are more likely to encounter reproductive restrictions at Catholic facilities compared with non-Catholic facilities; less is known about end-of-life care restrictions. If patients are unaware of the affiliation and encounter restrictions, refusal of or delay in care due to the need to go elsewhere can result in increased medical risk and contribute to wasted healthcare expenditures. **Full text:** <http://bit.ly/2TAZX2e>

N.B. Additional articles on Catholic perspectives on palliative and EoL care in the U.S. noted in Media Watch 13 August 2018 (#576, p.2) and in the 6 November 2017 issue of the weekly report (#537, pp.8-9).

International

The culture of dying: Does the culture we are raised in, or the religion we choose, help us navigate death?

U.K. | *Al Jazeera* – 2 September 2020 – A century ago death was part of life, Dr. Kathryn Mannix, a pioneering palliative care doctor in the U.K. explains. But with medical advancements, the experience of death has become diluted. The rich wisdom around death, the vocabulary and etiquette that served us so well in the past, has been lost. In a 2017 study, Dr. David B. Feldman tested a theory that those with a religious belief have fewer anxieties surrounding death and grief than those without.¹ He discovered that levels of “death anxiety” were the same in both groups, but that those who believed in God and an afterlife showed greater “acceptance of death, and a greater growth in response to loss.” In the midst of the Coronavirus pandemic gripping the world today, fulfilling cultural and religious rites around death – as well as being there for the dying – has not

always been possible. In many cases, restrictions have meant people were unable to be with dying relatives. At the start of the pandemic, with personal protective equipment in short supply, confusion over whether [according to the Muslim faith] the washing and wrapping of the deceased would be allowed and even reports that bodies were being cremated or buried in body bags because of the risk of contagion, bereaved families experienced a “disconnect from their spiritual traditions.” <https://bit.ly/2QOO2u4>

Specialist Publications

‘Addressing fear of death and dying: Traditional and innovative interventions’ (p.10), in *Mortality*.

1. ‘Does religious belief matter for grief and death anxiety? Experimental philosophy meets psychology of religion,’ *Journal for the Scientific Study of Religion*, first published online 27 January 2017. **Abstract:** <https://bit.ly/31RgAcM>

Noted in Media Watch 13 April 2020 (#661, p.2):

- U.S. | National Public Radio (NPR) – 7 April 2020 – ‘**Coronavirus is changing the rituals of death for many religions.**’ For centuries, Hindus gathered to burn corpses on funeral pyres along the Ganges River. Jews received condolences at home during a 7-day mourning period. Muslims huddled together to wash the corpses of loved ones across the Arab world. But global burial rituals are being dramatically changed by the pandemic. The World Health Organization recommendations that relatives not touch or kiss the body and government rules on social distancing to prevent the spread of disease have upended important funeral and death rituals in virtually all of the world’s faiths.¹ NPR’s foreign correspondents share details of how **COVID-19** has changed traditions in the countries they cover. <https://n.pr/2Xrq2Zl>
1. ‘Infection prevention and control for the safe management of a dead body in the context of COVID-19: Interim guidance,’ World Health Organization, 24 March 2020. **Download/view English language version at:** <https://bit.ly/3aSqELm>

Specialist Publications

Palliative care during public health emergencies: Examples from the **COVID-19 pandemic**

AMERICAN FAMILY PHYSICIAN, 2020;102(5):312-315. In public health emergencies such as the COVID-19 pandemic, some patients – especially older patients or those who have chronic health conditions – are confronted with treatment choices as they face life-threatening illness. Drawing on longitudinal relationships, primary care physicians can help patients and their families reach decisions that best align with patient goals. These crucial conversations may take place under intense pressure. COVID-19, for example, can cause sudden decompensation, leading to abrupt respiratory failure and death. Other factors, including unpredictable clinical courses and resource limitations, may further complicate guiding patients through

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goal-aligned decision-making. Patients' expressed wishes (e.g., to stay at home no matter what) can conflict with their goals (e.g., to die with minimal discomfort). Dying with severe dyspnea from COVID-19 pneumonia is traumatic and may contribute to complicated grieving and lifelong regret and guilt for caregivers. In addition to relationship-based advance care planning, physicians can use palliative care and ethical principles to develop high-quality crisis care plans that best meet patient needs even in a pandemic. **Access article at:** <https://bit.ly/3hTYgg4>

Perceptions of palliative care: Voices from rural South Dakota

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 1 September 2020 – This study aimed to explore health professional, patient, family, and caregiver perceptions of palliative care (PC), availability of PC services to patients across South Dakota, and consistency and quality of PC delivery. Most participants were Caucasian (93.3%) and female (80%). Six primary themes emerged: 1) Need for guidance toward the development of a holistic statewide PC model; 2) Poor conceptual understanding and awareness; 3) Insufficient resources to implement complete care in all South Dakota communities; 4) Disparities in the availability and provision of care services in rural South Dakota communities; 5) Need for relationship and connection with PC team; and, 6) Secondary effects of PC on patients/family/caregivers and interprofessional healthcare team members. Disproportionate access is a principle problem identified for PC in rural South Dakota. PC is poorly understood by providers and recipients of care. Service reach is also tempered by lack of resources and payer reimbursement constraints. **Abstract (w. list of references):** <https://bit.ly/32IEW7v>

Noted in Media Watch 9 December 2019 (#643, p.2):

- *HEALTH AFFAIRS*, 2019;38(12):1971-1975. **'Bringing palliative care to underserved rural communities.'** Palliative care remains scarce among Alabama's smallest hospitals, offered at only five of twenty-seven (18.5%) of hospitals with fewer than 50 beds versus nearly all hospitals with 300-plus beds, according to the Center to Advance Palliative Care.¹ The national pattern is similar: About one-third of small hospitals incorporate palliative services, versus 93.7% of those with more than 300 beds. These patients might suffer needlessly at home without adequate symptom relief and other mental health support, or bounce in and out of their nearby rural hospital, using it more as a primary care clinic. Or, as their condition worsens, they might get transferred to a larger hospital far from home. **Full text:** <http://bit.ly/2DMjJ0x>

1. 'America's Care of Serious Illness: 2019 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals,' Centre to Advance Palliative Care & National Palliative Care Research Centre, September 2019. [Noted in Media Watch 30 September 2019 (#633, p.3)] **Download/view at:** <http://bit.ly/2lrJOWl>

N.B. The focus of the December issue of *Health Affairs* is rural health. Contents page: <http://bit.ly/34PtarW>

Noted in Media Watch 4 November 2019 (#638, p.4):

- *FORBES* | Online – 28 October 2019 – **'The special challenges of nearly 11 million seniors who live in rural communities.'** According to a new report by the U.S. Census Bureau, about 10.6 million older adults live in rural communities – roughly one quarter of all seniors.¹ About 17.5% of rural residents are over 65, while only about 14% of urban residents are older adults. Three-quarters of rural older adults live in the South and Midwest, but in states such as Maine and Vermont almost two-thirds of seniors live in rural communities. The more rural the area, the older it likely is. In many rural areas, there are no Medicare- or Medicaid-certified home care agencies or hospice programs. Thus, providers must travel many miles to deliver care, if it is available at all. <http://bit.ly/36gn05f>

1. 'The Older Population in Rural America: 2012-2016 American Community Survey Reports,' U.S. Census Bureau, September 2019. **Download/view at:** <http://bit.ly/32YKbPn>

N.B. Selected articles on the provision and delivery of hospice and PC services in rural America noted in Media Watch 7 October 2019 (#634, p.2).



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Palliative care utilisation: Family carers' behaviours and determinants: A qualitative interview study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 31 August 2020 – Most research on starting palliative care (PC) focuses on the role of healthcare services and professional carers. However, patients and their family carers may also play a role. Especially opportunities for starting PC might exist among family carers. This study focused on family carers by identifying their behaviours and underlying determinants that might contribute to starting PC. Most reported behaviours regarding starting PC were related to communicating with the seriously ill person, other family members and professional carers; seeking information and helping the seriously ill person process information from professional carers; and, organising and coordinating care. Determinants facilitating and hindering these behaviours included awareness (e.g., of poor health), knowledge (e.g., concerning PC), attitudes (e.g., negative connotations of PC) and social influences (e.g., important others' opinions about PC). This study identified relevant family carers' behaviours and related determinants that can contribute to starting PC. As these determinants are changeable, the PC behavioural model that resulted from this study can serve as a basis for the development of behavioural interventions aiming at supporting family carers in performing behaviours that might contribute to starting PC. **Abstract:** <https://bit.ly/3gLquav>



Recommendations for advance care planning in adults with congenital heart disease: A position paper from the European Society of Cardiology Working Group of Adult Congenital Heart Disease, the Association of Cardiovascular Nursing & Allied Professions, the European Association for Palliative Care, and the International Society for Adult Congenital Heart Disease

EUROPEAN HEART JOURNAL | Online – 29 August 2020 – Survival prospects in adults with congenital heart disease (CHD), although improved in recent decades, still remain below expectations for the general population. Patients and their loved ones benefit from preparation for both unexpected and predictable deaths, sometimes preceded by a prolonged period of declining health. Hence, advance care planning (ACP) is an integral part of comprehensive care for adults with CHD. This position paper summarizes evidence regarding benefits of and patients' preferences for ACP and provides practical advice regarding the implementation of ACP processes within clinical adult CHD practice. The authors suggest that ACP be delivered as a structured process across different stages, with content dependent upon the anticipated disease progression. They acknowledge potential barriers to initiate ACP discussions and emphasize the importance of a sensitive and situation-specific communication style. Conclusions presented in this article reflect agreed expert opinions and include both patient and provider perspectives. **Access full text at:** <https://bit.ly/3hKxWNU>

Elisabeth Kübler-Ross and the five stages model in selected social work textbooks

ILLNESS, CRISIS & LOSS | Online – 2 September 2020 – Professional social work is a discipline in which practitioners often find themselves engaged in addressing issues related to illness, crises, and loss. Professional social work is also a discipline with links to many associated disciplines, especially those in the social sciences such as psychology, sociology, and gerontology, as well as provision of care in such fields as hospice/palliative care, bereavement support, and counseling. This article offers a critical analysis of one limited but important aspect of the education offered to social work students, namely how the work of Elisabeth Kübler-Ross and her five stages model are presented in five recent social work textbooks. In each case, there is a description and critical analysis of what authors of these five books write about these subjects. These analyses lead to suggestions concerning how these subjects should or should not be presented in educational programs for students and as guidelines for practice in social work, associated disciplines, and related areas of human services. **Abstract (w. list of references):** <https://bit.ly/3h2MXJE>

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Noted in Media Watch 15 April 2019 (#610, p.8):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 11 April 2019 – ‘**Elisabeth Kübler-Ross and the “five stages” model in a sampling of recent textbooks published in 10 countries outside the U.S.**’ Questions to be answered are: 1) Does the “five stages” model appear without significant change in the textbooks described here; 2) Is the “five stages” model applied in these textbooks to issues involving loss, grief, and bereavement as well as to those involving terminal illness and dying; 3) Is the “five stages” model criticized in some or all of these textbooks; 4) If so, is the criticism sufficient to argue, while the “five stages” model might be presented as an important historical framework, it should no longer be regarded as a sound theory to guide contemporary education and practice? **Abstract:** <http://bit.ly/2KwyaMo>

N.B. The November 2019 issue of the *American Journal of Bioethics*, noted in Media Watch 25 November 2019 (#641, p.15), focuses on the work of Kübler-Ross. **Download/view at:** <http://bit.ly/2ToM4zI>. Additional articles on Kübler-Ross noted in the 6 July 2020 (#673, p.3) issue of the weekly report.

Implementation models of compassionate communities and compassionate cities at the end of life: A systematic review

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online – 28 August 2020 – In the last decade, we have seen a growth of compassionate communities and cities (CCC) at the end of life (EoL). There has been an evolution of organizations that help construct community-based palliative care programs. The objective of this review was to analyze the implementation, methodology and effectiveness of the CCC models at the EoL. The authors retrieved 112 articles and included 31 articles in their final analysis: 17 descriptive studies, 4 interventions studies, 4 reviews and 6 qualitative studies. A total of 11 studies regarded the development models of CCC at the EoL, 15 studies were about evaluation of compassionate communities’ programs and 5 studies were about protocols for the development of CCC programs. There is poor evidence of the implementation and evaluation models of CCC at the EoL. There is little and low-/very low-quality evidence about CCC development and assessment models. The authors found no data published on care intervention in advance disease and EoL. A global model for the development and evaluation of CCC at the EoL seems to be necessary. Systemizing the processes will help emergent organizations or communities to develop CCC and it will facilitate the assessment or its impact and effectiveness. **Full text:** <https://bit.ly/34VsFzt>

N.B. Several articles on CCC noted in Media Watch 13 July 2020 (#674, pp.12-13).

Presence and the paradox of time for palliative care clinicians: A phenomenological study

INTERNATIONAL JOURNAL OF WHOLE PERSON CARE, 2020;7(2):13-25. A presence of quality is recognized as a central competence for palliative care (PC) clinicians in their mission to accompany patients and families in their end-of-life journey. However, PC clinicians’ capacity for presence may be affected by the increasing emotional, professional and organizational demands of their working environment. Those demands may, in turn, affect quality of care and clinicians’ health. To the authors’ knowledge, no previous study has aimed at a better understanding of how PC clinicians view and experience presence in their day-to-day work, although this holds the potential of generating insights to help clinicians develop and cultivate a high-quality presence towards dying patients. Results of this study account for three essential themes describing the experience of presence; connection to the self, to the other, and to the meaning of care. Results also suggest that presence was lived and experienced within a very particular relation to time, which appeared to study participants as a significant challenge in achieving high-quality presence. **Full text (click on pdf icon):** <https://bit.ly/3gCTSZL>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.11.

A systematic review exploring palliative care for families who are forced migrants

JOURNAL OF ADVANCE NURSING | Online – 31 August 2020 – This review offers valuable insights into the experience of children's palliative care (CPC) for forced migrant families and contributes to existing knowledge in this area with the creation of a framework guiding healthcare professionals (HCP) towards culturally sensitive care provision. CPC guidelines advise individualized care for all families, but for forced migrant families, this is particularly important as experiences of persecution and displacement can reduce agency which needs to be fostered to rebuild self-worth and a sense of belonging. The “normality” of parenting can be cultivated through a model of family centred care. There is a need for care which focuses on compassion, humility, and listening to individual experiences. This is imperative to building trusting relationships and increasing mutual respect and cultural understanding. Cultural humility may foster such an approach, so further research of its use in CPC would be

beneficial. The framework devised from this review is a useful tool for HCP to see how the antecedents and consequences of care relate to families' experiences. This unique insight into their world may help to improve knowledge, empathetic understanding, and the ability to facilitate future culturally sensitive CPC. **Full text:** <https://bit.ly/31KK7V9>

Care throughout the dying process

PEDIATRIC E-JOURNAL | Online – 1 September 2020 – The current issue of the e-journal is focused on various aspects of care throughout the dying process as related to pediatric palliative and end-of-life care. This e-journal is produced by the *Pediatric e-Journal* Workgroup and is a program of the U.S. National Hospice & Palliative Care Organization. **Download/view at:** <https://bit.ly/2DIALWA>

Related:

- *CHILDREN* | Online – 1 September 2020 – ‘**Quantifying the language barrier: A total survey of parents' spoken languages and local language skills as perceived by different professions in pediatric palliative care.**’ Pediatric palliative care (PPC) institutions must attune to many families who do not speak the local language. Language barriers are always an indication of cultural barriers, which must be identified and brought to the attention of the numerous multi-professional providers of pediatric PPC. If numbers on spoken languages in an institution are known, documents can, for example, be translated into certain languages, a pre-selection of interpreters can be made, or culturally-related training courses can be planned. **Full text:** <https://bit.ly/3bvvo3J>

Will you hear me? Have you heard me? Do you see me? Adding cultural humility to resource allocation and priority setting discussions in the care of African American patients with COVID-19

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 1 September 2020 – The COVID-19 pandemic has refocused our attention on healthcare disparities affecting patients of color, with a growing body of literature focused on the etiology of these disparities and strategies to eliminate their effects. In considering the unique impact COVID-19 is having on African American communities, added measure must be given to ensure for sensitivity, empathy, and supportive guidance in medical decision-making amongst African American patients faced with critical illness secondary to COVID-19. The authors explore the applications of cultural humility over cultural competency in optimizing the care provided to African American patients faced with critical healthcare decisions during this pandemic. In turn, they charge one another as healthcare providers to consider how ethical principles and guidance can be applied to honor African American patients' unique stories and experiences. **Full text:** <https://bit.ly/3hYfQIs>

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Palliative Care Network

Palliative Care for Everyone, Everywhere

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

Noted in Media Watch 6 July 2020 (#673, p.7):

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

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

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2020;323(19):1891-1892. ‘**COVID-19 and African Americans,**’ The scourge of COVID-19 will end, but healthcare disparities will persist. Does the U.S. chronicle these poor outcomes due to COVID-19 complications with the higher burden of cardiovascular disease, poorer outcomes for breast cancer, higher amputation rates for peripheral vascular disease, lower kidney transplant rates, and worse rates for maternal mortality, then safely park everything in the healthcare disparity domain and go back to “normal”? Or will the nation finally hear this familiar refrain, think differently, and as has been done in response to other major diseases, declare that a civil society will no longer accept disproportionate suffering? **Full text:** <https://bit.ly/30m4eZG>

The experience of Emergency Department providers with embedded palliative care during COVID-19

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 30 August 2020 – Although the importance of palliative care (PC) integration in the Emergency Department (ED) has long been recognized, few formalized programs have been reported and none have evaluated the experience of ED clinicians with embedded PC. 134 ED clinicians were surveyed. 101 replied (75% response rate). Of those that had interacted with PC, 100% indicated a benefit of having PC involved. These included freeing up ED clinicians for other tasks (89%), helping them feel more supported (84%), changing the patients care trajectory (67%), and contributing to clinician education (57%) and skills (49%). Among barriers related to engaging PC were difficulty locating them (8%) and lack of time to consult due to ED volume (5%). ED clinicians’ perception of embedded PC was overall positive, with an emphasis on the impact related to task management, enrichment of PC skills, providing support for the team, and improved care for ED patients. **Abstract (w. list of references):** <https://bit.ly/3bbdh2Z>

Noted in Media Watch 10 August 2020 (#678, p.4):

- *ADVANCED EMERGENCY NURSING JOURNAL*, 2020;42(3):215-224. ‘**Bringing palliative care downstairs: A case-based approach to applying palliative care principles to emergency department practice.**’ Although the emergency department (ED) may not be traditionally thought of as the ideal setting for the initiation of palliative care, it is the place where patients most frequently seek urgent care for recurrent issues such as pain crisis. Even if the patients’ goals of care are non-aggressive, their caregivers may bring them to the ED because of their own distress at witnessing the patients’ suffering. ED providers, who are trained to focus on the stabilization of acute medical crises, may find themselves frustrated with repeat visits by patients with chronic problems. **Abstract:** <https://bit.ly/33rxerR>

N.B. Additional articles on PC in the ED noted in this issue of Media Watch.

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>



Identifying as a good parent: Considering the Communication Theory of Identity for parents of children receiving palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 August 2020 – Parents of seriously ill children are at risk of psychosocial morbidity, which may be mitigated by competent family-centered communication and role-affirming conversations. Parent caregivers describe a guiding desire to do a good job in their parenting role but also depict struggling under the intense weight of parental duty. The Communication Theory of Identity (CTI) provides a framework for conceptualizing how palliative care (PC) teams can help parents cope with this reality. CTI views communication with care teams as formative in the development and enablement of parental perceptions of their “good parenting” role. PC teams may consider the four frames of identity (personal, enacted, relational, and communal) as meaningful dimensions of the parental pursuit to care well for an ill child. PC teams may consider compassionate communication about parental roles to support the directional virtues of multilayered dynamic parental identity. **Abstract:** <https://bit.ly/31Kwlwm>

To disclose or not to disclose: A case highlighting the challenge of conflicts in pediatric disclosure

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 2 September 2020 – Due to differences in opinion about patient autonomy and perceived maturity, discussing diagnosis and prognosis with children can be challenging. Shifting away from “never tell” and “always tell” approaches, recent articles have championed more nuanced case-by-case approaches to disclosure of information to children. The medical team’s experience highlights the complexity of navigating care for families who desire to withhold medical information from their child. They use this case as an opportunity to discuss the current literature on child and young adolescent preferences for disclosure of information and highlight existing guidelines around pediatric disclosure that can help clinicians when there are disagreements about pediatric disclosure. **Abstract (w. list of references):** <https://bit.ly/31F2TVX>

Related:

- *PEDIATRICS*, 2020;145(6):e20194018. “**Good-parent beliefs**: Research, concept, and clinical practice.’ Parents have willingly identified their personal beliefs about what they should do or focus on to fulfill their own definition of being a good parent for their ill child. This observation has led to the development of the good-parent beliefs concept... A growing qualitative, quantitative, and mixed-methods research base has explored the ways good-parent beliefs guide family decision-making and influence family relationships. The authors offer an overview of the good-parent beliefs concept over the past decade, addressing what is currently known and gaps in what we know, and explore how clinicians may incorporate discussions about the good-parent beliefs into clinical practice. **Abstract:** <https://bit.ly/2YTGGdd>

Noted in Media Watch 29 April 2019 (#612, p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 April 2019 – ‘**Changes over time in good-parent beliefs among parents of children with serious illness: A two-year cohort study.**’ The authors used latent transition models to classify parents into groups with similar good-parent beliefs ... and modeled the change in good-parent beliefs over time... Two parent belief profiles emerged: Loved (“Making sure my child feels loved”) and Informed (“Making informed decisions”). At 12 months, 21 parents (20.4% of study participants) had moved into the Loved group and no parents transitioned to the Informed group. By 24 months, 8 parents transitioned to the Loved group and 4 to the Informed group (13.04%). **Abstract (w. link to references):** <http://bit.ly/2ZvU5Xj>

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

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(4):333-343. ‘**Parents’ wishes for what they had or had not done and their coping after their infant’s or child’s neonatal intensive care unit/pediatric intensive care unit/emergency department death.**’ The authors asked 70 mothers and 26 fathers three open-ended questions. Mothers wished they had spent more time with their child, chosen different treatments, advocated for care changes, and allowed the child his or her wishes. Fathers wished they had spent more time with the child and gotten care earlier. Mothers wished they had not agreed to child’s surgery/treatment ... and left the hospital before the death. Fathers wished they had not been so hard on the child, agreed with doctors/treatment... **Abstract:** <http://bit.ly/2GcuKK9>

Addressing fear of death and dying: Traditional and innovative interventions

MORTALITY | Online – 30 August 2020 – The fear of death and dying is a multifaceted and prevalent source of human distress that can cause significant psychological and existential distress, especially at the end of life (EoL). Analysing current therapeutic approaches to this issue to identify promising modalities and knowledge gaps could improve EoL experiences and reduce human suffering. The authors analyse recent literature to explore treatments for thanatophobia. Effective intervention strategies for fear of death and dying do exist, but all have practical and therapeutic limitations. Psychotherapy appears to be an effective tool at reducing death anxiety. Mindfulness exercises are able to reduce anxiety as well but are not often associated with a change in afterlife belief. Psychedelics dissociate mind from body, causing a mystical experience that has been shown to reduce death anxiety, but restrictions on their use limit their availability for therapy. Virtual reality appears to have the potential to reduce death anxiety, possibly by simulating an out-of-body experience and strengthening belief in an afterlife. Although some interventions appear to have a positive impact on fear of death and dying, the literature does not support a clearly superior therapeutic approach. **Abstract:** <https://bit.ly/3gHR3qr>

How palliative care professionals deal with predicting life expectancy at the end of life: Predictors and accuracy

SUPPORTIVE CARE IN CANCER | Online – 31 August 2020 – In this study, physicians' and nurses' accuracy of survival of the patients was 46% and 40%, respectively. Survival was underestimated in 20% and 12% and overestimated in 34% and 48% of subjects. Both physicians and nurses considered metastases, comorbidities, dyspnea, disability, tumor site, neurological symptoms, and confusion very important in predicting patients' survival with nurses assigning more importance to intestinal symptoms and pain too. All these factors, with the addition of cough and/or bronchial secretions, were associated with physicians' greater accuracy. In the multivariable models, intestinal symptoms and confusion continued to be associated with greater predictive accuracy. No factors appreciably raised nurses' accuracy. Some clinical symptoms rated as relevant by the hospice staff could be important for predicting survival **Abstract (w. list of references):** <https://bit.ly/3gKxxd5>

Noted in Media Watch 30 March 2020 (#659, p.6):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 22 March 2020 – ‘**Specialist palliative medicine physicians and nurses accuracy at predicting imminent death (within 72 hours): A short report.**’ This study found that in the last 72 hours of life, clinicians' predictions were accurate on between 65% and 73% of occasions, indicating that they were incorrect in their predictions on up to one in three occasions. Nurses were slightly better than doctors at distinguishing between patients who were imminently dying and those who were not, a finding maintained after comparing only the cases that had a prediction from both professions... Previous reviews have identified limited evidence about the reliability of predictions of imminent death. **Full text:** <https://bit.ly/39j8ZEI>

Media Watch: Editorial Practice

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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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