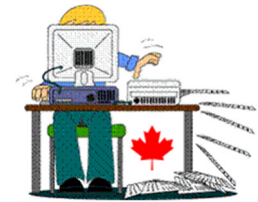


Media Watch... is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them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

1 February 2021 Edition | Issue #702



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Compiled & Annotated by Barry R. Ashpole

The current model of palliative care is not culturally competent. Once we really start to reflect upon the way our population is changing and meeting the needs of all different communities within palliative care, we will be in a much better place.

'Palliative care: Experts call for major reforms as pandemic accelerates demand by 20 years' (p.5), in *British Medical Journal*.

Canada

COVID-19 pandemic: Collateral damage

Palliative care residence for children in dire straits due to major staff shortage

QUEBEC | CTV News Channel (Montreal) – 23 January 2021 – A Montreal palliative care (PC) residence for children is in dire straits, as it is losing staff and risks having to cut services. The Lighthouse Children & Families Centre (i.e., Le Phare Enfants et Familles) is losing staff to the public sector and private agencies, who are offering bonuses to attract workers, the centre's executive director says. The Lighthouse, which has lost around a quarter of its staff since October, can't afford to compete with the bonuses. Executive director Lyne St-Martin says their mission goes beyond care to let kids be kids in very trying times. The residence on Mount-Royal Avenue East in Montreal is not large and cares for a handful of children at a time, but it cannot afford to lose more staff. "We hope to never have to go there because there is a need, our families need for le Phare to continue to offer its services whether it be for symptom management, end-of-life care or for respite stays, our families need us to be present," said St-Martin. The Lighthouse has offered ongoing and PC for children and support for their families for over 20 years. St-Martin said staff salaries are comparable to the public sector, and, unlike hospitals, there is no compulsory overtime. However, COVID-19 bonuses have enticed staff to the public sector, and competition with private agencies that can also offer more scheduling flexibility is fierce. St-Martin said current staff are filling gaps to ensure they maintain the level of care the children and their families deserve. The need for more personnel is dire. <http://bit.ly/3iDTlnK>

N.B. The Lighthouse Children & Families Centre/Le Phare Enfants et Familles website: <http://bit.ly/39dIPa5>



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U.S.A.

Hospices mobilize to meet demand for grief care during COVID-19

HOSPICE NEWS | Online – 29 January 2021 – Hospice providers have had to adapt their bereavement program to comply with social distancing recommendations during the COVID-19 outbreak. The public health emergency has complicated their ability to provide grief services even as demand continues to rise, largely due to the killer virus. The U.S. Centers for Medicare & Medicaid Services requires hospice providers to offer bereavement counseling for a minimum of 13 months following a patient's death, but hospices tend to go above and beyond by making grief care available to their entire communities, regardless of whether the deceased had been their patient. A pandemic of grief has emerged side-by-side with the virus. COVID-19 is now the leading cause of death in the U.S., claiming more than 400,000 lives to date, according to the U.S. Centers for Disease Control & Prevention. While a fraction of those patients were receiving hospice care in their final days, any family who has lost a loved one can benefit from bereavement services. Hospices have had to cancel in-person

counseling sessions, meetings with families as well as support groups and other services to avoid spreading the COVID-19 virus. These restrictions come at a time in which many families in addition to their grief are coping with increased anxiety, depression, loneliness and isolation as the outbreak continues. <http://bit.ly/3aigayT>

Specialist Publications

'COVID-19 pandemic impacts on U.S. hospice agencies: A national survey of hospice nurses and physicians' (p.3), in *American Journal of Hospice & Palliative Medicine*.

'Heart to Heart Cards: A novel, culturally tailored, community-based advance care planning tool for Chinese Americans' (p.4), in *American Journal of Hospice & Palliative Medicine*.

'Getting to the truth: Ethics, trust, and triage in the U.S. versus Europe during the COVID-19 pandemic' (p.10), in *The Hastings Centre Report*.

Palliative care, hospice help reduce suicide among cancer patients

HOSPICE NEWS | Online – 24 January 2021 – Rising utilization of hospice, psychosocial and palliative care (PC) contributes to falling suicide rates among cancer patients, a recent study has found.¹ Between 1999 and 2018 suicide rates dropped among cancer patients even as the nation's overall rate grew higher. Researchers aimed to identify cancer patients at the highest risk of suicide compared to the general population. The study concluded that patients were less likely to commit suicide if they had received hospice, PC or other psychosocial services. "Increased access to psychosocial, palliative, and hospice care plays an important role in contributing to the decline in suicide among cancer patients," the study indicated. "This is a sound hypothesis and highlights the need to understand more about factors that heighten risk for suicide among cancer patients as well as components of health services that are most critical in lowering suicide risk among cancer patients." Hospice and PC providers, who are focused on improving quality of life, work to address patients' psychosocial and emotional needs as well as their medical needs. The interdisciplinary team structure for both types of care includes social workers and chaplains, and hospices provide bereavement services to families following a loved one's death. Though the suicide rate among cancer patients is declining, it remains higher than the general population, according to the study. The emotional shock of a cancer diagnosis can be profound, and research shows that cancer patients are more likely to experience depression than the public-at-large. <http://bit.ly/3qOUqRN>

1. 'Optimizing patient-centered psychosocial care to reduce suicide risk and enhance survivorship outcomes among cancer patients,' *JNCI: Journal of the National Cancer Institute*, published online 19 January 2021. Full text: <https://bit.ly/39blweW>



Would the *JNCI: Journal of the National Cancer Institute* article be of interest to a colleague?

International

Royal College of General Practitioners and Marie Curie urge GPs to adopt end-of-life care standards for care homes

U.K. | *GP* – 27 January 2021 – The new standards are built on the ‘Daffodil Standards’ launched last year by the Royal College of General Practitioners (RCGP) and Marie Curie – a “set of standards that GP practices can sign up to as a commitment to continuously improve the quality of palliative and end-of-life care (EoLC) they deliver for patients.” One in six GP practices have now signed up to the original Daffodil Standards – and the RCGP and Marie Curie has now set out new standards for care homes. The new guidance ... has been developed with GPs and other health and care staff to offer support on two levels.¹ The guidance covers current processes in place, and whether these processes deliver “what patients and their families want and need.” The standards were in development before the pandemic and are not limited to care during the pandemic, but the RCGP says they are “designed to be as streamlined and supportive as possible”

in light of ongoing pressure on practice teams. RCGP and Marie Curie national clinical champion for EoLC Dr. Catherine Millington-Sanders said: “All patients who require palliative and EoLC are vulnerable, but those who live in care homes are some of our most vulnerable, which is why Marie Curie and the RCGP have created a focus of the Daffodil Standards, tailored to their needs, and the needs of their family members.” She said the standards aim to support practices and care homes to reduce variation in the EoLC patients receive. <http://bit.ly/3oqAYJw>

Specialist Publications

‘Palliative care: Experts call for major reforms as pandemic accelerates demand by 20 years’ (p.5), in *British Medical Journal*.

1. ‘Daffodil Standards for older patients living in care homes,’ Royal College of General Practitioners, January 2021. **Download/view at:** <http://bit.ly/2Ylt61j>

Specialist Publications

COVID-19 pandemic impacts on U.S. hospice agencies: A national survey of hospice nurses and physicians

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 27 January 2021 – This study assesses effects of the COVID-19 pandemic on U.S. hospice agencies, staff, and patients as reported by hospice agency staff. The target audience for this study was members of the American Academy of Hospice & Palliative Medicine and the Hospice & Palliative Nurses Association who self-identified as being active with hospice agencies in the U.S. Reported impacts include inadequate supplies of personal protective equipment, changes in hospice services, and decreased access by hospice personnel to patients in long-term care facilities. Flow of patients through hospice care settings was impeded. Agencies experienced changes in workforce availability and increased emotional support needs of staff. Patient and families experienced increased bereavement needs. Nearly one-third of respondents reported negative effects on patient outcomes, such as inadequate symptom management and negative psychosocial effects. Hospice agencies appear to face challenges unique among U.S. healthcare agencies due to their service delivery model and focus on interdisciplinary care. There is need for further exploration of the effects that the COVID-19 pandemic has on hospice agencies in order to improve care for their patient population during public health emergencies. **Abstract (w. list of references):** <http://bit.ly/3qWwBaV>

Heart to Heart Cards: A novel, culturally tailored, community-based advance care planning tool for Chinese Americans

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 27 January 2021 – A paucity of literature describes the growing Chinese American community's end-of-life (EoL) priorities and preferences. Informed by the Cultural Appropriateness Theory, the Chinese American Coalition for Compassionate Care (CACCC) developed Heart to Heart (HTH) Cards using a 3-step approach. First, CACCC created and refined a list of bilingual, culturally relevant EoL issues. Next, CACCC organized the EoL issues into a card deck. Finally, CACCC developed a unique playstyle of the cards – the HTH Café. From 2014-2019, CACCC recruited Chinese American volunteers and participants for HTH Cafés. Following each Café, participants completed an anonymous survey describing their socio-demographics, top 3 cards, and café evaluation. The 54 HTH Cards were organized into 4 suits (spiritual, physical, financial/legal, and social). Each card displayed a culturally-tailored EoL issue in English and Chinese. Playstyles included one-on-one and group formats (i.e., HTH Café). CACCC volunteers conducted 316 HTH Cafés for 2,267 Chinese American adults. Most participants were female (61.6%), between 18-50 years old (56.7%), lived in California (80.2%) and born in Asia (74.3%). The top priority (25.5%) was “If I'm going to die anyway, I don't want to be kept alive by machines.” Participants thought the session was pleasant (99.5%) and expressed intent to complete advance directives (86.5%). HTH Cards represents the first, theory-driven, culturally-tailored advance care planning (ACP) tool for Chinese Americans. More research is needed to establish its impact on ACP conversations and outcomes. **Abstract (w. list of references):** <http://bit.ly/3om2ibV>

N.B. Chinese American Coalition for Compassionate Care website: <http://bit.ly/3iYJmPy>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 January 2021 – ‘**The role and activities of board-certified chaplains in advance care planning.**’ A cross-sectional, web-based self-report survey was conducted with 585 board-certified chaplains recruited from three major professional chaplains’ organizations in the U.S. More participants worked in community hospital settings (42%) and academic medical centers (19.6%) than in any other setting. Over 90% viewed advance care planning as an important part of their work, 70% helped patients complete advance directives, and 90% helped patients discuss their preferences about end-of-life treatments. Many were not consistently included in team discussions regarding decision-making... **Abstract (w. list of references):** <http://bit.ly/3pobloC>
- *THE JOURNAL OF NUTRITION, HEALTH & AGING* | Online – 26 January 2021 – ‘**Implementing advance care planning in ‘The Age of Deferred Death’ – The Hong Kong experience over 4 years.**’ A community care program was found to reduce anxiety, depression, physical symptoms, improve communication within the family as well as promoting a feeling of peace among recipients of the service. The program also reduced care giver strain and anxiety, as well as hospital visits and duration of stay. A sustainable model would require uptake by policymakers and chief executives of Social Welfare & Health Bureaus, supported by amendments of relevant legal ordinances, which is in progress after public consultation. **Full text:** <https://bit.ly/36opno4>

Extending the depth and breadth of psychiatry care: Five strategies for residents to develop a foundation in hospice and palliative medicine

AMERICAN JOURNAL OF PHYSICAL MEDICINE & REHABILITATION | Online – 25 January 2021 – Hospice and palliative medicine (HPM) is one of seven accredited fellowship subspecialties available to graduates of physical medicine and rehabilitation (PM&R) residency programs. HPM and PM&R share many of the same principles and practices, and PM&R residency training can be excellent preparation for HPM fellowship. However, unlike the other six PM&R subspecialties, there is currently no requirement for HPM training during PM&R residency. As a result, PM&R residents may encounter limited HPM exposure or education, and lack explicit opportunities to develop the basic set of palliative care symptom management and communication tools that can be applied across the spectrum of psychiatry care. The authors provide five strategies that residents can utilize within their own programs to develop knowledge and experience in HPM. **Abstract:** <https://bit.ly/2N0OIRU>

Using natural language processing to explore heterogeneity in moral terminology in palliative care consultations

BMC PALLIATIVE CARE | Online – 25 January 2021 – This study is among the first to use text data from a real-world situation to extract information regarding individual foundations of morality. It is the first to test empirically if individual moral expressions are associated with individual characteristics, attitudes and emotions. The results of this study are relevant to those who seek to improve the quality of communication in order to achieve better and more values-concordant treatment at end of life (EoL). Some of the authors' findings may be relevant for a broader context. They found that those who feel that their spiritual needs are being met tend to use more moral language than those who do not. This study gives rise to the further development of conversation science which can be used by physicians to align moral and other sensitive aspects of palliative care (PC) consultations. For example, it may be helpful to differentiate prognosis communication with respect to patients *a-priori* moral or spiritual values which may influence their EoL preferences. More research would be needed to establish the exact relationship between (any) religious affiliation and spirituality on the moral dimensions of conversations, in PC and in a broader societal context. **Full text:** <http://bit.ly/3pfki9b>

Palliative and end-of-life care for military veterans: The forgotten few?

BRITISH JOURNAL OF GENERAL PRACTICE, 2021;71(703):86-89. Military veterans are likely to have encountered death, pain, and suffering, and to have prepared for them like few other groups in society. This is also a group trained to follow highly ceremonial rituals around death, burials, and commemoration. Yet veterans are not seen as “different” in palliative and end-of-life care, including that provided by GP practices. Throughout military service, encounters with death and dying are frequently intense, highly personal, and potentially traumatic, in ways seldom seen or understood in civilian life. Furthermore, the nature of military occupation – resembling more a lifestyle than a job – entails cultural separation from civilian life, with perceptions, norms, and ideals around death and dying forming part of this culture. Embodied experiences in military life as well as psychological, social, and ethical constructs (for example, guiding beliefs, value systems, norms, rules, and expectations) are often markedly different from those of civilian society. Not enough is known about how this legacy impacts the dying process in veterans and what the health services implications are, including in the context of general practice. **Background:** <http://bit.ly/3adK0ED>

Related:

- *MILITARY MEDICINE* | Online – 29 January 2021 – ‘**Female veteran use of palliative and hospice care: A scoping review.**’ The female veteran population [in the U.S.] is increasing and becoming more ethnically diverse. Female veterans are not well represented in the literature. This review uncovered a significant gap in study methodologies. Retrospective chart reviews dominate the palliative and hospice care literature specific to veterans. More prospective study designs are needed that explore the veteran and family experience while receiving end-of-life care. With the rising number of older female veterans and their risk for serious illness, it is imperative research studies purposefully recruit, retain, analyze and report female veteran statistics along with their male counterparts. **Abstract:** <http://bit.ly/39zrUy1>

Palliative care: Experts call for major reforms as pandemic accelerates demand by 20 years

BRITISH MEDICAL JOURNAL | Online – 26 January 2021 – Experts at a leading charity have made an urgent call for reforms to the U.K.'s palliative care system, as demand during the COVID-19 pandemic reached levels that had not been expected until 2040. More than half a million people in England and Wales were predicted to need palliative or end-of-life (EoL) care by 2040,¹ but this level of demand will have been achieved in 2020, said researchers from Cicely Saunders International.² They said that too many people who had life-limiting illnesses or were approaching death were spending unnecessarily long periods in hospital without being offered alternatives, when most would prefer to die at home.³ Around 80% of people would prefer to die at home or in their place of residence, but in some parts of England and Wales less than 50% do so. To help meet people's needs the authors call for face-to-face care, including symptom manage-

Cont.

ment, seven days a week in hospitals, as well as 24/7 support and advice in the community. Prompt access to therapeutic, nursing, and pharmacy services to support people in their homes is also needed, they said. Choice at the EoL is being compromised by poor coordination between health and social care and a shortage of expertise, the report said. It advised that everyone in this situation should have a named senior clinician and care coordinator. The researchers also highlighted an independent, government commissioned review of choice in EoL care,⁴ which estimated that £150 million (€170 million; \$206 million) was needed to provide a “national choice offer” to patients and carers for EoL care. This would help to pay for timely intervention and a defined contact with a trained professional to support delivery of self-care. Other recommendations in the report’s seven point action plan include increased investment in social and community care services, a strategic approach to training, and a system of continuous learning and improvement. The authors called for an increase to the 0.2% of the medical research budget that is currently dedicated to developing better ways for caring for terminally ill patients. **Full text:** <http://bit.ly/2Ymsbhj>

1. ‘How many people will need palliative care in 2040? Past trends, future projections and implications for services,’ *BMC Medicine*, published online 18 May 2017. [Noted in Media Watch 22 May 2017 (#513, p.11)] **Full text:** <http://bit.ly/2IHcYCi>
2. ‘You Matter Because You Are You: Action Plan for Better Palliative Care,’ Cicely Saunders International, January 2021. **Download/view at:** <http://bit.ly/2YhksAT>
3. ‘Heterogeneity and changes in preferences for dying at home: A systematic review,’ *BMC Palliative Care*, published online 15 February 2013. [Noted in Media Watch 18 February 2013 (#293, p.5, p.11)] **Full text:** <http://bit.ly/3iQ8qrG>
4. ‘The Choice in End-of-Life Care Programme Board. What’s important to me: A review of choice in end-of-life care,’ Department of Health & Social Care, February 2015. [Noted in Media Watch 2 March 2015 (#399, p.4)] **Download/view at:** <http://bit.ly/39oxcw2>

Constructing a new role for family carers and volunteers providing care towards the end of life: An action research approach exploring a new model of hospice care

HEALTH & SOCIAL CARE IN THE COMMUNITY | In print – 18 January 2021 – The objective of this study was to understand the conceptualisation and development of a novel way of providing end-of-life care in a “cottage hospice” setting, with a focus on the role of family carers and volunteers within this care model. The study setting was a hospice in the South of England, and its network of wider associates in the local health economy. Participants were purposively sampled to provide relevant information. Data collection (2017-2018) included documents (e.g., meeting minutes) and interviews (individual and group) with external (e.g., GPs) and internal (e.g., staff, managers, volunteers, patients, family carers) stakeholders. These were followed by action cycles conducted by a core action group which explored issues related to family and young carers, the relationship between the main and cottage hospices, and workforce engagement with the change process. Twenty-six individual and eight “follow up” interviews, two group interviews, and five discrete action cycles were completed. At the core was a focus on “disruption” of the norm of professionally provided and mediated care, with three main themes: 1) Imagining the future of cottage hospice (growing demand, a home-like space, innovative roles for families and volunteers); 2) Developing the role of family caregivers (making agreements, meeting needs, social inclusion, and the “unknown” expectations); and, 3) Quality and safety issues (negative perceptions, personalised care, volunteer roles). Change was viewed as both a threat and an opportunity. Cottage hospice represents the possibility of a truly new way of meeting the needs of dying people and their families, and could act as a template for progressive service developments elsewhere. **Abstract:** <http://bit.ly/3qTuBjD>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.14.

Palliative care professionals' inner lives: Cross-cultural application of the awareness model of self-care

HEALTHCARE | Online – 15 January 2021 – Compassionate professional qualities traditionally have not received the most attention in either critical or end-of-life care. Constant exposure to death, time pressure and workload, inadequate coping with personal emotions, grieving, and depression urge the development of an inner curricula of competences to promote professional quality of life (QoL) and compassionate care. The COVID-19 pandemic highlights the universality of these problems and the need to equip ourselves with rigorously validated measurement and monitoring approaches that allow for unbiased comparisons. The main objective of this study was to offer evidence on the generalizability of the awareness model of self-care across three care systems under particular idiosyncrasy. 817 palliative care professionals from Spain, Argentina, and Brazil participated in this cross-sectional study using a multigroup structural equation modeling strategy. The measures showed good reliability in the three countries. When testing the multigroup model against the configural and constrained models, the assumptions were fulfilled, and only two relationships of the model revealed differences among contexts. The hypotheses posited by the awareness model of self-care were supported and a similar predictive power on the professional QoL dimensions was found. Self-care, awareness, and coping with death were competences that remained outstanding no

matter the country, resulting in optimism about the possibility of acting with more integrative approaches and campaigns by international policymakers with the consensus of world healthcare organizations. **Full text (click on pdf icon):** <http://bit.ly/3iVWeWl>

Self-compassion in hospice and palliative care: A systematic integrative review

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 21 January 2021 – Those involved with hospice and palliative care (PC), including nurses, will inevitably experience or be exposed to suffering. Self-compassion represents a personal resource and support for self-care, ensuring that needs are not neglected particularly during times of suffering. However, the empirical evidence for self-compassion in hospice and PC is yet to be reviewed systematically. For patients, self-compassion was associated with reduced stress, anxiety, shame, depressive symptoms, fear of cancer recurrence, and loneliness. It was also associated with increased social capital, self-soothing, mindfulness, compassion, causal reasoning ability, psychosocial and spiritual well-being, legacy, courage, and commitment. For healthcare professionals, self-compassion was associated with increased capacity for self-care, mindfulness, and professional quality of life and a decrease in perceived burnout risk and secondary traumatic stress. **Abstract:** <https://bit.ly/3t1eTox>

Social justice, organizational commitment and job satisfaction for palliative care social workers

HUMAN SERVICE ORGANIZATIONS: MANAGEMENT, LEADERSHIP & GOVERNANCE | Online – 25 January 2021 – Given the changing palliative care (PC) industry and the shift to privatization and managerialism, the primary purpose of this study was to explore how an organization's support of social justice as an organizational norm, enhances affective commitment to the organization and lowers intentions to leave. The findings of this study suggests that for PC social workers, more than an individual orientation of social justice, the environment of social justice that the PC organization both provides and encourages (i.e., social justice norms) contributes to organizational commitment and intention to leave when mediated by job satisfaction. Given that previous research has shown social workers who work in PC settings experience the lowest job satisfaction compared to all other members of the interdisciplinary team ..., the inclusion of job satisfaction is important to understanding how PC social workers experience their work in organizations. As the results suggest, PC social workers seem more committed to their organization, and less likely to leave, when they feel job satisfaction working for an organization that provides an environment in which they can actualize social work values of social justice. For PC social workers, extrinsic factors such as working in an environment that encourages social justice work and provides opportunities to do so, seems more relevant to organizational commitment, as mediated by job satisfaction, than intrinsic factors such as personal attitudes, intention, and behaviors. **Full text:** <https://bit.ly/2L1zEPG>

Cont.

Noted in Media Watch 2 November 2020 (#690, p.1):

- *HOSPICE NEWS* | Online – 30 October 2020 – ‘**Hospice social workers improve healthcare equity, justice.**’ Hospice social workers can play a key role in addressing matters of social justice and healthcare equity when working with patients in underserved populations... 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. <https://bit.ly/3kJ9zBy>

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

- *SOCIAL WORK HOSPICE & PALLIATIVE CARE NETWORK* | Online – Accessed 27 July 2020 – ‘**Social justice and palliative care policy.**’ The network’s ‘Statement on Racism and Structural Inequities in Hospice and Palliative Social Work’ is suggesting the bold and necessary step of asking us to critically question how hospice and palliative care social workers are contributing to maintaining systems of inequity in the work that we do. These are hard conversations to have, but needed to do the work necessary to correct racial and ethnic disparities inherent in end-of-life care. We need to examine personal biases and the systems of care that pay our salaries and contribute to poorer care provision for people who are not white. **Download/view network’s statement at:** <https://bit.ly/39z9ijS>

Evaluation of the usability, accessibility and acceptability for a family support intervention for end-of-life care discharge planning from hospital: A participatory learning and action research study

INTERNATIONAL JOURNAL OF NURSING STUDIES ADVANCES | Online – 23 January 2021 – Discharge at the end of life (EoL) is complex and consequently focuses on patient needs and securing appropriate resources and services to meet these needs. As a result, the emotional impact on family members and their concerns and contributions to discharge plans are seldom acknowledged. This study provided confidence about the usability, accessibility and acceptability of the Family-Focused Support Conversation, a brief intervention specially designed for use in acute hospitals in EoL care discharges, where time is of the essence. Importantly, it provides an evidence-based conversational guide that can be used by hospital palliative care teams, and potentially by ward and discharge teams with appropriate support, to meet family members’ support needs during the EoL care transitions from hospital to home/nursing home. To the authors’ knowledge this is first intervention developed with this purpose. **Full text:** <http://bit.ly/39dlrHH>

Noted in Media Watch 28 September 2020 (#685, p.6):

- *BMC PALLIATIVE CARE* | Online – 21 September 2020 – ‘**Co-construction of the family-focused support conversation: A participatory learning and action research study to implement support for family members whose relatives are being discharged for end-of-life care at home or in a nursing home.**’ Care transitions can be distressing for family members because they signify the deterioration and impending death of their ill relative... Whilst there is evidence about psychosocial support for family members providing end-of-life care at home, there is limited evidence about how this can be provided in acute hospitals during care transitions. The authors designed an evidence-based structured conversation, the Family-Focused Support Conversation. **Full text:** <https://bit.ly/2ZY1e5X>

Related:

- *EUROPEAN JOURNAL OF ONCOLOGY NURSING* | Online – 20 January 2021 – ‘**Transitions during end-of-life care from the perspective of informal caregivers: A concept analysis using Rodgers’ (2000) Evolutionary Approach.**’ Transition during end-of-life (EoL) care for informal caregivers can be a highly emotional time for this vulnerable cohort. Effective transitioning can ensure a stability and quality EoL outcomes, such as a peaceful death, as the awareness and learning that it brings prompts planning actions for terminal care. Through recognising the findings of this concept analysis, deeper insight may be gained to support the provision of care, by nurses, to informal caregivers, prompting them towards effective transitions that foster the best interest of the patient. **Full text:** <http://bit.ly/3pi3tdC>

PSST! I need help! Development of a peer support program for clinicians having serious illness conversations during COVID-19

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 24 January 2021 – Clarifying patients' values and priorities is always important but especially so during a pandemic when many people will rapidly become seriously ill. The authors describe the design and implementation of a novel service, the PSST [Peer SIC Support Team], which utilized non-palliative care, volunteer peer supporters who offered rapid, confidential assistance to clinicians working to clarify the values and priorities of their patients across settings from ambulatory care to the ICUs. This service required moderate, upfront, administrative time but was otherwise a low-cost program. It gave an opportunity for clinicians with advanced communication skills to build a community through which they could offer important support to frontline clinicians which the peer supporters found rewarding. PSST took place in a hospital with an established program in serious illness conversation training and leveraged its staff with skills in this space, which may limit its replicability in other settings. However, serious illness conversation training materials are open access and many hospitals have access to social workers and others with interests and skills in communication who could participate in such a service. Thus, this service could be replicated in other institutions for this or future crises. **Full text:** <https://bit.ly/3pqyzjn>

N.B. The PSST was developed and implemented by the Continuum Project, the Serious Illness Care Program at the Massachusetts General Hospital. Continuum Project website: <http://bit.ly/36hFHXE>

Promoting racial equity in COVID-19 resource allocation

JOURNAL OF MEDICAL ETHICS | Online – 29 January 2021 – Due to COVID-19's strain on health systems across the globe, triage protocols determine how to allocate scarce medical resources with the worthy goal of maximising the number of lives saved. However, due to racial biases and long-standing health inequities, the common method of ranking patients based on impersonal numeric representations of their morbidity is associated with disproportionately pronounced racial disparities. In response, policymakers have issued statements of solidarity. However, translating support into responsive COVID-19 policy is rife with complexity. Triage does not easily lend itself to race-based exceptions. Reordering triage queues based on an individual patient's racial affiliation has been considered but may be divisive and difficult to implement. And while COVID-19 hospital policies may be presented as rigidly focused on saving the most lives, many make exceptions for those deemed worthy by policymakers such as frontline healthcare workers, older physicians, pregnant women and patients with disabilities. These exceptions demonstrate creativity and ingenuity – hallmarks of policymakers' abilities to flexibly respond to urgent societal concerns – which should

also be extended to patients of colour. This article dismantles common arguments against the confrontation of racial inequity within COVID-19 triage protocols, highlights concerns related to existing proposals and proposes a new paradigm to increase equity when allocating scarce COVID-19 resources. **Full text:** <http://bit.ly/3tdSMev>

Extract from *Journal of Medical Ethics* article

Hospitals create robust decision-making paradigms for unrepresented patients at end of life (EoL), since laws in many jurisdictions fail to provide these patients with adequate protections. Similarly, hospitals create policies to limit inappropriate life-sustaining treatment at EoL in the absence of legal clarity. These institutional policies are not comprehensive solutions, nor do they root out underlying causes, but they contribute to important societal goals and thoughtfully address a pressing ethical challenge. Similarly, hospital triage protocols can creatively confront racial inequity while knowing that it is only within their power to address the issue as it pertains to the policy at hand. No single measure will ever "solve" racial inequity but many such efforts can unite to produce meaningful change.

Cont.

Related:

- *THE HASTINGS CENTRE REPORT* | Online – 24 January 2021 – ‘**Getting to the truth: Ethics, trust, and triage in the U.S. versus Europe during the COVID-19 pandemic.**’ This essay compares both discussion and guidelines around triage and the reality of what happened in the U.S. and in Europe, both in anticipation of and during the first wave of the pandemic. Why did the issue generate so many vivid debates in the U.S. and so few in most European countries, although the latter were also affected by the rationing of healthcare resources? Are countries with socialized healthcare systems better equipped to face the hard choices of triaging? Important lessons in transparency, trust, and accountability for policy-makers can be drawn from this comparison... **Abstract:** <https://bit.ly/3cazQHK>

N.B. Additional articles on triaging the terminally ill noted in Media Watch 25 January 2021 (#701, pp.11-12).

Quality indicators in surgical palliative care: A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 January 2021 – Defining high quality palliative care (PC) in seriously ill surgical patients is essential to provide patient-centered surgical care. Quality indicators specifically for seriously ill surgical patients are necessary in order to integrate PC into existing surgical quality improvement programs. 263 unique measures were identified from 26 studies, of which 70% were process measures. Indicators addressing care of the patient near the end of life (31.5%) and physical aspects of care (20.6%) were the most common. Indicators addressing spiritual (2.6%) and cultural aspects of care (1.2%) were the least common. Methodological quality varied widely across studies. Although most studies defined a purpose for the indicators and used scientific evidence, many studies lacked input from target populations and few discussed the practical application of indicators. This review is a key step that informs efforts to develop quality indicators for seriously ill surgical patients. Future attention is needed toward the development and practical application of PC quality indicators in surgical patients. **Abstract (w. list of references):** <https://bit.ly/3t93SBF>

N.B. Additional articles on integrating primary and specialty PC into surgical practice noted in Media Watch 21 December 2020 (#697, p.2).

What constitutes good quality end-of-life care? Perspectives of people with intellectual disabilities and their families

JOURNAL OF POLICY & PRACTICE IN INTELLECTUAL DISABILITIES | Online – 19 January 2021 – As with most individuals when considering the end of life (EoL), progressive physical and functional decline and the surrendering of independence were concerns for people with intellectual disabilities (ID). In addition, some people with ID have multiple disabilities with complex needs and, therefore, they also require comprehensive physical care. Populations which include people with ID expect to be socially connected with other people when approaching death, including via physical and psychological companionship, and to be able to engage in meaningful conversation. This study also confirmed that spiritual care at the EoL provides peace and comfort to people with ID. The findings of this study will help inform policymakers and professionals who are directly involved in providing EoL care to develop a plan to improve the care provided. In relation to further research, a large study that includes people with ID, their family members, and relevant professionals, should be carried out across multiple settings. Also, further research could be carried out with people with ID who are at the EoL phase examining the impact of the articulation of spiritual care expectations at the EoL; this would create interesting findings. **Full text:** <https://bit.ly/2MrfqjA>

N.B. Search back issues of Media Watch for additional articles on EoL care for people living with intellectual or developmental disabilities at: <http://bit.ly/2ThijkC>



Media Watch: Behind the Scenes
<http://bit.ly/2MwRRAU>

Palliative care in movement disorders: An evolving field

MOVEMENT DISORDERS | Online – 28 January 2021 – This review summarizes the current state of evidence for palliative care (PC) in movement disorders, describes the application of PC to clinical practice, and suggests future research directions. PC needs are common in persons living with movement disorders and their families from the time of diagnosis through end-of-life and contribute to quality of life. Early advance care planning is preferred by patients, impacts outcomes and is promoted by PC frameworks. Systematic assessment of non-motor symptoms, psychosocial needs and spiritual/existential distress may address gaps in current models of care. Complementary and emerging models of PC may be utilized to meet the needs of this population. A PC approach may identify and improve important patient and caregiver-centered outcomes. As a relatively new application of PC, there is a need for research to adapt, develop and implement approaches to meet the unique needs of this population. **Full text:** <https://bit.ly/2YmBOfR>

Noted in Media Watch 26 February 2018 (#552, p.9):

- *CURRENT TREATMENT OPTIONS IN NEUROLOGY* | Online – 20 February 2018 – ‘**Palliative care for movement disorders.**’ A palliative care (PC) approach can empower clinicians, patients, and families to reduce common sources of suffering and optimize quality of life. This field recognizes the importance of primary PC – palliative skills useful for any clinician caring for persons caring for serious illness – as a foundation of the PC approach and complementary to specialist PC. The authors focus on primary PC skills for movement disorder specialists including providing a diagnosis and prognosis with compassion, discussing goals-of-care, complex symptom management, caregiver support, spiritual and emotional well-being, and referral to hospice and specialist PC. **Abstract (w. list of references):** <https://goo.gl/6LwRXD>

Development and protocol for a nurse-led telephonic palliative care program

NURSING OUTLOOK | Online – 20 January 2021 – The authors describe the design and implementation of a novel nurse-led palliative care (PC) program. Additionally, initial analyses of their results demonstrated an overall patient engagement rate of 78%, and 42% engagement with advance care planning. Patient engagement is high, likely due to the ability to overcome those challenges encountered by PC delivered via the traditional outpatient model such as the logistics of scheduling, the scarcity of services, and difficulties associated with travel, particularly in more rural locations. Additionally, the COVID-19 pandemic brought forth new barriers, including infection control and concerns around the exposure to a vulnerable population. PC delivered telephonically may overcome these challenges through ease of delivery and the ability to bring PC directly to the patient. The authors’ data demonstrates that seriously ill patients are willing to engage in nurse-led telephonic PC programs and that engagement rates in their program do not differ from other telephonic interventions. The early analysis also demonstrated that nearly two-thirds of patients who died in the authors’ program were enrolled in hospice services, which suggests that nurses are able to facilitate goals-of-care discussions between patients and caregivers and to assist with referrals to hospice services telephonically. **Full text:** <https://bit.ly/369XNel>

Related:

- *CLINICAL JOURNAL OF ONCOLOGY NURSING*, 2021;25(1):17-22. ‘**Telehealth in palliative care: Communication strategies from the COVID-19 pandemic.**’ Palliative care (PC) was once believed to be too high-touch to be delivered via telehealth. Numerous studies have demonstrated the positive effects of PC delivered through telehealth. Because the COVID-19 pandemic has quickly shifted how healthcare is delivered to patients with cancer, particularly because of their immunocompromised status and the risks associated with unnecessary exposures in the clinic, previous lessons from PC research can be used to inform practice. This article presents a case study that illustrates evidence and best practices for continuing to deliver PC via telehealth after COVID-19 restrictions are lifted. **Abstract:** <http://bit.ly/2M3oM4g>

N.B. Search back issues of Media Watch for additional articles on telehealth/telemedicine in the provision and delivery of PC at: <http://bit.ly/2ThijkC>

Palliative care, a necessary approach for the successful treatment of the patient with tuberculosis

PALIAȚIA, 2021;14(1). Tuberculosis (TB) is one of the top ten causes of death globally, and more than 1,000 people die of TB every year in Romania. Thousands of new cases are diagnosed each year, most of them among the young population. Currently, Romania has the highest incidence of TB in the European Union. A major challenge in the control of TB at national level is the underfunding of the National Tuberculosis Control Programme, which has led to difficulties in: ensuring a rapid and complete diagnosis; correct and a high-quality treatment; and, adherence to specific treatment. Development of drug resistance TB is because of patients' poor adherence to specific medications and therefore requires longer treatment (1-3 years) and patients are more likely to fail or abandon their treatment. Palliative care of patients with TB is a relatively new form of specific care. **Abstract:** <http://bit.ly/2LRPPje>



Noted in Media Watch 14 August 2017 (#525, p.13):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 August 2017 – ‘**Palliative care for tuberculosis.**’ Tuberculosis (TB) remains a major cause of death and suffering globally in spite of the fact that it is supposed to be a curable disease. Drug resistant forms of TB have developed as a result of poor treatment compliance, including multi-drug and extreme drug resistant forms that take longer to treat and have higher likelihoods of treatment failure. In 2010, at the initiation of the TB community, a partnership was formed between the WHO ‘Stop TB Program, the Worldwide Hospice Palliative Care Alliance,’ and the Open Society Foundation’s ‘International Palliative Care Initiative’ to explore how to improve the ability of TB professionals to deliver palliative care to their patients. **Full text:** <https://bit.ly/3c5GQFw>

Noted in Media Watch 18 June 2012 (#258, p.15):

- *THE LANCET INFECTIOUS DISEASES* | Online – 11 June 2012 – ‘**Palliative and end-of-life care in the global response to multidrug-resistant tuberculosis.**’ Despite guidance to improve treatment outcomes, little attention has been paid to palliative care (PC) of patients and families, such as for physical, psychosocial, social, and spiritual difficulties. An international expert symposium was convened to articulate an appropriate PC response for people with multidrug-resistant tuberculosis. Several policies should be updated to ensure that palliative and end-of-life (EoL) care is in place alongside treatment should cure be achieved, and to the EoL if not. Many services have been developed that exemplify integrated PC (i.e., provided from within existing TB care). **Summary (w. list of references):** <https://bit.ly/3odBDOv>

Legacy perceptions and interventions for adults and children receiving palliative care: A systematic review

PALLIATIVE MEDICINE | Online – 25 January 2021 – Legacy has been invoked as a means for strengthening human attachments, continuing bonds, and ensuring that individuals will be remembered; however, little is known about the spectrum of approaches to, outcomes associated with, and best practices for legacy interventions. The 67 studies reviewed describe a variety of legacy perceptions and interventions with adult and pediatric patients receiving palliative care (PC). Statistically significant improvements in various dimensions of wellbeing are documented, with significant reduction in incidence and symptoms of depression in adults. Studies highlight the utility, feasibility, and perceived benefits of legacy interventions according to adult patients and their caregivers, and parents/caregivers of pediatric patients. Though future research with high-quality, experimental designs is needed, the positive outcomes associated with legacy interventions are documented in adult patient populations; additionally, the application of legacy interventions for children with serious illnesses receiving PC is reasonable based on the existing body of evidence. A consistent and operational concept of legacy is still needed for future research and practice. **Abstract (w. list of references):** <http://bit.ly/3ilUqQs>

Cont.

Related:

- *JOURNAL FOR SPECIALISTS IN PEDIATRIC NURSING* | Online – 25 January 2021 – ‘**Therapeutic letters: A qualitative study exploring their influence on the hope of parents of children receiving pediatric palliative care in Portugal.**’ Findings highlight the positive influence of therapeutic letters including supporting parental hope, facilitating personal inner-strengthening, recognition of parental skills, and promotion of self-efficacy during hospitalization. This study adds value to the existing literature and highlights the need for supportive palliative nursing care aimed at promoting parental hope. To optimize the value of supporting parental hope, therapeutic letters can be delivered at time of diagnosis, during times of celebration, when learning the difficult tasks of daily childcare. **Abstract:** <https://bit.ly/3cem1rE>

The importance of narrative medicine in palliative care

PALLIATIVE MEDICINE IN PRACTICE | Online – 13 January 2021 – Narrative medicine, i.e., gathering information from patients’ stories used in the process of diagnosis and treatment is an important tool in palliative care (PC). This kind of therapeutic presence is among the medical personnel’s most vital skills. The COVID-19 pandemic still causes numerous communication challenges... The limited physical contact makes the therapeutic presence, as well as taking the time to pay attention to the other person especially important. Dr. Danielle Chammas, who worked with many terminal patients, wrote: “we can touch with words, support with silence, speak with our breath and see using sounds.”¹ The current global challenges caused by the pandemic have resulted in teleconsultation via telephone calls and other means of communicators becoming particularly vital, with such services consisting in doctors determining the diagnosis and treatment primarily based on what the patients say.² Paradoxically, the restrictions imposed due to the SARS-CoV-2 pandemic – especially regarding direct contact – may help improve the quality of communication, especially in the long term. Today one can look to the future with hope, believing that active listening, mutual understanding and the time devoted to the other person will support the diagnosis and therapy processes in PC patients. **Full text (click on pdf icon):** <http://bit.ly/3cdF9pT>



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1. ‘Seeing with my ears,’ *Journal of Pain & Symptom Management*, published online 22 September 2020. **Full text:** <https://bit.ly/3pf5W8O>
2. ‘Behind the veil,’ *Academic Medicine*, 2016;91(1):1575. **Full text:** <https://bit.ly/3p9nO4V>

N.B. English language version precedes the Polish language version.



[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>

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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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