

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.

5 April 2021 Edition | Issue #711



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Compiled & Annotated by Barry R. Ashpole

If healthcare systems are to respond to population needs for palliative care by promoting a primary level palliative approach, this care must be both conceptually clear and operationally defined and measurable.

'Frequency of providing a palliative approach to care in family practice: A chart review and perceptions of healthcare practitioners in Canada' (p.4), in *BMC Family Medicine*.

Canada

Death-friendly communities ease fear of aging and dying

THE CONVERSATION | Online – 29 March 2021 – Death looms larger than usual during a global pandemic. An age-friendly community works to make sure people are connected, healthy and active throughout their lives, but it doesn't pay as much attention to the end of life (EoL). What might a death-friendly community ensure? In today's context, the suggestion to become friendly with death may sound strange. But as scholars doing research on age-friendly communities, the authors wonder what it would mean for a community to be friendly towards death, dying, grief and bereavement. There's a lot to learn from the palliative care movement: it considers death as meaningful and dying as a stage of life to be valued, supported and lived. Welcoming mortality might actually help us live better lives and support communities – rather than relying on medical systems – to care for people at the end of their lives. Until the 1950s, most Canadians died in their homes. More recently, death has moved to hospitals, hospices, long-term care homes and other healthcare institutions. The societal implications of this shift are profound: fewer people witness death. The dying process has become less

familiar and more frightening because we don't get a chance to be part of it, until we face our own. <https://bit.ly/3m2GNxn>

Extract from *The Conversation* article

The compassionate communities approach came from the fields of palliative care and critical public health. It focuses on community development related to EoL planning, bereavement support and improved understandings about aging, dying, death, loss and care. The age-friendly and compassionate communities initiatives share several goals, but they don't yet share practices.

Specialist Publications

'Association between high cost user status and end-of-life care in hospitalized patients: A national cohort study of patients who die in hospital' (p.9), in *Palliative Medicine*.

N.B. Search back issues of Media Watch for additional articles on compassionate communities at: <http://bit.ly/2ThijkC>

U.S.A.

Starting Monday, patients can read your notes

MEDSCAPE | Online – 1 April 2021 – Monday, 5 April is the official start of a U.S. law requiring healthcare organizations to provide patients with free, full, and immediate electronic access to their doctor's clinical notes as well as test results and reports from pathology and imaging. The mandate, called "open notes" by many, is part of the 21st Century Cures Act, a wide-ranging piece of federal healthcare legislation. Organizations must provide access via patient portals to the following types of notes: consultations, discharge summaries, histories, physical examination findings, imaging narratives, laboratory and pathology report narratives, and procedure and progress notes. Noncompliant organizations will eventually be subject to fines from the U.S. Department of

Health & Human Services for "information blocking." The U.S. and Scandinavian countries are world leaders in implementing open notes in clinical practice. <https://wb.md/3rHwSyl>

Specialist Publications

'Four kinds of hard: An understanding of cancer and death among Latino community leaders' (p.4), in *Global Qualitative Nursing Research*.

'Economics of using telemedicine to supplement hospice care in rural areas' (p.7), in *Journal of Palliative Medicine*.

N.B. See 'Patient access to notes is coming? Is palliative care ready?' PalliMed blog, 19 October 2020. <https://bit.ly/3dzf0AC>

Behind closed doors, "the difficulty and the beauty" of pandemic hospice work

THE NEW YORK TIMES | Online – 29 March 2021 – Hanane Saoui is used to death. Sudden deaths and slow deaths. Painful deaths and peaceful deaths. This year was different. The coronavirus pandemic dramatically changed Ms. Saoui's work as a home hospice nurse in New York. Safety precautions created a physical distance between her and her patients and even cut some of her hospice colleagues off from their clients' homes altogether last year. It deprived families and caretakers of ways to grieve together, and confronted hospice workers, however familiar with death, with a staggering scale of loss. Through all the pressures, Ms. Saoui and other workers continued to provide solace and even moments of happiness to dying patients and their families. More than half a million Americans have died from the coronavirus, and many have died in pain, isolated from their families. Ms. Saoui contrasted those conditions with what she called a good death: "peaceful, pain-free, at home and surrounded by their loved ones." When hospice patients die, their caretakers often work through their own grief and loss in weekly staff meetings and gatherings with colleagues who shared the same client. These staff meetings are now online, but the loss of being able to hold each other and shed tears together has deeply affected hospice workers... <https://nyti.ms/3u3GHrZ>

Related:

- *THE WASHINGTON POST* | Online – 28 March 2021 – "'Pandemic grief' proves especially devastating and complex for many in mourning, health experts say." The months ahead will require us to carry an intense and a pervasive grief that is more acute and complicated than grief after death from other natural causes. Recent research suggests that the full effect of this onslaught will not be known for some time. We will feel it with each empty chair at the table, a holiday with one less present to wrap or a birthday without the guest of honor. "What we go through during the time of the dying and death of a loved one is fundamental," said Ted Rynearson, medical director at Virginia Mason Medical Center's Grief Services in Seattle. <https://wapo.st/3uhQs6f>



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International

Polish abortion ban spotlights overlooked hospices

POLAND | Agence France-Presse – 28 March 2021 – In the wake of Poland’s near-total ban on abortions, the need for support for pregnant women with severe foetal defects is greater than ever, but few know there are specialised clinics they can turn to for help. The founder of the biggest of about 20 perinatal hospices in Poland said that women were often failing to be informed about the palliative care offered by the centres after a diagnosis. For decades in the devout Catholic country, Polish women had the option to terminate a pregnancy after discovering a foetal anomaly. But the Constitutional Court ruled against abortions in such cases late last year. The Warsaw Perinatal Hospice offers counselling, medical tests and classes on parenting a sick child, helping more than 400 women every year. It relies on state funds and donations to provide the services free of charge, and in some cases, doctors volunteer their time. With legal abortion out of the equation, some women diagnosed with severe foetal defects may end up going abroad to terminate or undergoing the procedure illegally.

But for the rest, perinatal hospice care can “ensure the pregnancy continues under the best possible conditions for the woman and child.” <https://bit.ly/3w72P6J>

Specialist Publications

‘Global experiences of pediatric palliative care teams during the first 6 months of the SARS-CoV-2 pandemic’ (p.6), in *Journal of Pain & Symptom Management*.

‘Spiritual care: Motivations and experiences through the lenses and voices of a cohort of spiritual care workers at an established hospice in Cape Town, South Africa’ (p.7), in *Journal of Religion & Health*.

‘European Resuscitation Council Guidelines 2021: Ethics of resuscitation and end-of-life decisions’ (p.11), in *Resuscitation*.

Specialist Publications

The Mother Baby Comfort Care Pathway

The development of a rooming-in-based perinatal palliative care program

ADVANCES IN NEONATAL CARE | Online – 25 March 2021 – Traditionally, the provision of comfort care and support during the dying process for infants born with life-limiting diagnoses has occurred in the neonatal intensive care unit (NICU). A major goal for the families of these infants is often the opportunity to spend as much time as possible with their infant in order to make memories and parent their infant. The objective of the Mother Baby Comfort Care Pathway [developed at the Women & Infants Hospital, Brown University, Providence, Rhode Island] is to implement a program of family-centered care with logistically flexible care delivery, allowing mothers and their families to share as normal a postpartum care experience as possible with a focus on quality of life, memory making, and time spent together. The program was developed with the nucleus of care

coordination and provision on the Mother Baby Unit (postpartum unit), with involvement from the labor and delivery room, NICU, and other units as necessary to provide the postpartum mother, her dying infant, as well as possible additional siblings (in the case of multiple gestation), postpartum care while rooming-in. The program was rolled out with training workshops for postpartum nurses. **Abstract:** <https://bit.ly/2PpPWUC>

Research Matters

‘Facebook recruitment for children with advanced cancer and their parents: Lessons from a web-based pediatric palliative intervention study’ (p.12), in *Progress in Palliative Care*.

An instrument to assess self-perceived competencies in end-of-life care for healthcare professionals: The End-of-Life Care Questionnaire

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 31 March 2021 – The End-of-Life Care Questionnaire (EoL-Q) consists of 28 questions assessing knowledge, attitudes and behaviors with subscale items addressing seven domains of care: 1) Decision-making; 2) Communication; 3) Continuity of care; 4) Emotional support for patients/families; 5) Symptom management; 6) Spiritual support for patients/families; and, 7 support for clinicians. The EoL-Q was used to assess competencies of 1,197 healthcare professionals from multiple work units at a large medical center. Analysis of the psychometric properties of the EoL-Q care across settings supports its reliability and validity as a measure of self-perceived end-of-life care (EoLC) competencies in the domains of communication and continuity of care, decision-making, symptom management, and emotional and spiritual support. The EoL-Q displays promise as a tool for use in a variety of educational, research, and program development initiatives in EoLC. **Abstract (w. references):** <https://bit.ly/2PNE3Yo>

Frequency of providing a palliative approach to care in family practice: A chart review and perceptions of healthcare practitioners in Canada

BMC FAMILY PRACTICE | Online – 27 March 2021 – Historically, the evidence for palliative care (PC) has emerged from studies of patients with cancer, however there is increasing recognition of the palliative needs of people with non-cancer diagnoses. This study reveals the application of a palliative approach to care (PAC) for patients with other chronic, progressive life-limiting illnesses. Patients with cancer tend to have a defined and short terminal phase, characterized by step-wise drops in function and they are more likely to receive formal PC services and for longer periods before death, compared to non-cancer illnesses. The duration of non-cancer palliative needs can be longer and less certain than that for cancer and the needs of patients with non-cancer life-limiting illnesses can be less intense over this prolonged period, making early identification a challenge. This could be one reason only 25% the patient population studied received a PAC in their last year of life, as most deaths were non-cancer related. Family medicine, being a community-based discipline that prioritizes the patient-physician relationship, is in a unique position to build upon the care processes that the authors have operationalized for a PAC. **Full text:** <https://bit.ly/39ovsT3>

Four kinds of hard: An understanding of cancer and death among Latino community leaders

GLOBAL QUALITATIVE NURSING RESEARCH | Online – 23 March 2021 – As the Latino population in the U.S. continues to age, it is even more imperative to address effective delivery of palliative care (PC) and understand the cultural perspectives on cancer and death that influence end-of-life decisions. This project elicited the cultural perspectives of Latino leaders who affirmed the need for, and feasibility of, trained community members to initiate conversations about advance care planning and symptom management among Latino families with cancer. In partnership with interprofessional healthcare teams, trained community leaders can bring best practices in PC to underserved families, and their new skill set can enhance their natural helping abilities in communities and churches. The authors' research further suggests that community leaders can provide valuable direction for the development of PC services for underserved groups and can assist in the delivery and ongoing refinement of such educational initiatives within the context of a continued commitment to participatory action research. **Full text:** <https://bit.ly/3csFvIQ>



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>

Practitioner bias as an explanation for low rates of palliative care among patients with advanced dementia

HEALTH CARE ANALYSIS | Online – 30 March 2021 – Due to the nature and course of dementia, there may be a failure to recognize the terminal stage of the disease. A possible and under-investigated explanation for this disparity is the healthcare practitioner who plays a primary role in end-of-life (EoL) decision-making. The authors demonstrate how the cognitive biases and moral considerations of practitioners related to clinical decision-making are inherent in clinical practice and may impact on providers' accuracy related to diagnostic and treatment related decision-making associated with patients with advanced dementia. Anchoring, default, availability, representativeness and framing biases are cognitive biases based on the "two system model" that relate to decision-making in EoL care. In patients with advanced dementia, those biases may result in a tendency to adhere to traditional mandatory care, involving an aggressive approach to care, which values saving lives at all costs, without taking into account the possible suffering and long-term consequences. Aspects such as moral sensitivity and moral courage play an important role in ethical decision-making related to advanced dementia. Investigations of clinical decision-making that include the cognitive biases and ethical considerations of practitioners might advance the comprehensive understanding of the clinical decision-making process related to care of patients with advanced dementia and promote the quality of care given to this population. **Abstract (w. references):** <https://bit.ly/3wcbUuS>

Related:

- *AMERICAN JOURNAL OF MEDICINE* | Online – 31 March 2021 – '**The limits of advance directives in maintaining autonomy in patients with advanced dementia.**' Advance directives can guide management, but usually are inadequate in caring for patients with advanced dementia. The "now" patient has very different sensibilities than the "then" patient who had expressed preferences for terminal care before dementia severely impaired cognition and executive function. Withholding life-sustaining oral feeding or fluids is ethically problematic. Controversies remain over precedent autonomy as the justification for advance dementia directives, and the consequent legal, ethical, and practical issues clinicians face, particularly involving feeding. **Abstract (w. references):** <https://bit.ly/2R1kEEf>

N.B. Search back issues of Media Watch for additional articles on palliative care for people living with Alzheimer's and other forms of dementia, including cognitive impairment at: <http://bit.ly/2ThijkC>

Healthcare staff's strategies to preserve dignity of migrant patients in the palliative phase and their families. A qualitative study

JOURNAL OF ADVANCE NURSING | Online – 23 March 2021 – Migrant patients often have particular needs and wishes that care staff find difficult to address, or meet, and hence the patient's dignity might be at stake. Care staff [i.e., participants in this study] creatively safeguarded the patient's dignity in daily care by attending to personal needs concerning intimate body care and providing non-verbal attention. Care staff, however, had difficulties in preserving dignity when the patient's family engaged themselves in the patient's choices or requests. The interference of family impeded the patient's quality of life or threatened the patient's dignity in the last days, or family member's choices (seemingly) prevailed over the patient's wishes. Care staff safeguarded dignity by catering to cultural or religious practices at the end of life and employing cultural knowledge during decision-making. Bypassing family was experienced as harmful, and repetitively informing family, about, for example, the patient's disease or procedures in the nursing home, was experienced as ineffective. **Abstract:** <https://bit.ly/31pgSGq>

Noted in Media Watch 8 February 2021 (#703, p.6):

- *BMC PALLIATIVE CARE* | Online – 4 February 2021 – '**Dignity of informal caregivers of migrant patients in the last phase of life...**' Prominent for informal caregivers is their desire to ensure good care for the patient and preserve the patient's dignity. To some that meant providing the care themselves; to others it meant advocating for good care and patient dignity in contacts with healthcare professionals (HCP) and with other relatives. Even though caregivers reported that the physical and emotional impact of caregiving was heavy, being a good caregiver and ensuring good care from HCP were vital to their own dignity. Many saw caregiving as part of maintaining a good relationship with their loved one. Providing care came with additional valuable aspects such as good conversations. **Full text:** <http://bit.ly/39N5NnK>

“Don’t talk to them about goals-of-care”: Understanding disparities in advance care planning

JOURNAL OF GERONTOLOGY (Series A) | Online – 29 March 2021 – Structurally marginalized groups experience disproportionately low rates of advance care planning (ACP). To improve equitable patient-centered end-of-life care, the authors examine barriers and facilitators to ACP among clinicians as they are central participants in these discussions. They conducted semi-structured interviews with purposively selected clinicians from six diverse health systems between August 2018 and June 2019. Thematic analysis yielded themes characterizing clinicians’ perceptions of barriers and facilitators to ACP among patients, and patient-centered ways of overcoming them. Among 74 participants, 49 (66.2%) were physicians, 16.2% were nurses, and 13.5% were social workers. Most worked in primary care (35.1%), geriatrics (21.1%), and palliative care (19.3%) settings. Clinicians most frequently expressed difficulty discussing ACP with certain racial and ethnic groups (African American, Hispanic, Asian, and Native American) (31.1%), non-native English speakers (24.3%), and those with certain religious beliefs (Catholic, Orthodox Jewish, and Muslim) (13.5%). Clinicians were more likely to attribute barriers to ACP completion to patients (62.2%), than to clinicians (35.1%) or health systems (37.8%). Three themes characterized clinicians’ difficulty approaching ACP (Pre-conceived views of patients’ preferences; narrow definitions of successful ACP; lacking institutional resources), while the final theme illustrated facilitators to ACP (Acknowledging bias and rejecting stereotypes; mission-driven focus on ACP; acceptance of all preferences). Most clinicians avoided ACP with certain racial and ethnic groups, those with limited English fluency, and persons with certain religious beliefs. The findings of this study provide evidence to support development of clinician-level and institutional-level interventions and to reduce disparities in ACP. **Abstract:** <https://bit.ly/3u7kYzk>



Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 April 2021 – ‘**Clinician identified barriers and strategies for advance care planning in seriously ill pediatric patients.**’ Thirty-five clinicians participated in identifying both clinician and perceived patient and family barriers to initiating and engaging in advance care planning (ACP) discussions, including mixed messaging, lack of knowledge of patient and family goals, prognostic uncertainty, poor prognostic awareness, unstandardized documentation, and family dynamics. Clinicians also identified strategies to overcome these barriers and to facilitate ACP discussions, including enhancing multidisciplinary communication, creation of a shared ACP communication framework, and formal training... **Abstract (w. references):** <https://bit.ly/3cM5f2T>

Global experiences of pediatric palliative care teams during the first 6 months of the SARS-CoV-2 pandemic

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 March 2021 – The coronavirus pandemic (COVID-19) has profoundly impacted the provision of pediatric palliative care (PPC) interventions including goals-of-care discussions, symptom management, and end-of-life care. This survey provides insights into the experiences of PPC clinicians during the COVID-19 pandemic from a wide range of resources, clinical settings, and experience, and how these experiences were both similar and unique. Identifying ways of maintaining a common mission and purpose, appropriate use of technological communication strategies, and access to self-care and resilience building resources are critical for PPC clinicians to navigate the ongoing pandemic. The financial effects of the pandemic on PPC clinicians are concerning and concerted efforts to ameliorate these economic challenges is important going forward both during the pandemic and even beyond. As PPC clinicians across the world face shared challenges, opportunities exist to apply these important experiences and lessons learned to together improve care for future patients, families, and PPC teams. **Full text:** <https://bit.ly/2PiLUNW>

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Related:

- *JOURNAL OF PSYCHOSOCIAL ONCOLOGY* | Online – 27 March 2021 – ‘**The invisible barrier: Providing end-of-life support to pediatric oncology families during COVID-19.**’ With the emergence of a global pandemic, the landscape for psychosocial service delivery to pediatric cancer patients and their families shifted. There was a transition to provide psychosocial support and interventions increasingly via ‘phone or through the utilization of both audio and visual technology (e.g., telehealth). While the ability to provide some in-person interventions and support remained, this looked drastically different, predominately due to the necessity of physical distancing to ensure safety. This article provides an overview of unique challenges psychosocial providers experienced... **First page view:** <https://bit.ly/3wl3d1m>

Economics of using telemedicine to supplement hospice care in rural areas

JOURNAL OF PALLIATIVE MEDICINE | Online – 1 April 2021 – Hospice care in rural areas is often characterized by provider shortages and vast geographical service areas to cover, making access to quality end-of-life care challenging. Telemedicine, broadly, is the utilization of interactive televideo (ITV) technology to provide health services over a distance. For over 25 years, telemedicine has been proposed as a solution to address access issues. In 2015, the University of Kansas Medical Center (Kansas City, Kansas) partnered with Hospice Services, Inc. (HSI) (Phillipsburg, Kansas), to augment traditional, face-to-face (FTF) hospice care with hospice care delivered through mobile tablets. The authors examine the costs of telehospice (TH) (telemedicine use in hospice care) when compared with the costs of FTF hospice services. The average time for a TH call was 18 and 17 minutes for nursing and medical director calls, respectively. Through various hospice functions, including administrative, patient, and nonpatient-related connections, HSI saved over \$115,000 in staff travel time and mileage reimbursement. Administratively, by hosting their weekly 15-member interdisciplinary meeting through ITV, HSI saved \$29,869 of staff travel time and mileage reimbursement. Further research is needed to assess the effects of TH utilization on the experiences and subsequent cost of hospice care. **Abstract:** <https://bit.ly/3cGTACz>

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

The act of consoling helps those who console: A multi-center observational study in hospice services

JOURNAL OF PALLIATIVE MEDICINE | Online – 30 March 2021 – The contemporary scientific literature documents a lack of attention toward the act of consoling put into practice by healthcare professionals (HCPs) in hospice services. 218 HCPs responded (94%) to a survey. The results showed that most HCPs consider the practice of consoling to be essential to their profession, but they also underscored the extreme complexity of the process. The act of consoling is not simply a professional duty defined in contractual clauses. Rather, it is a set of specific communicative practices and skills required of HCPs. **Abstract:** <https://bit.ly/2QHU02S>

Spiritual care: Motivations and experiences through the lenses and voices of a cohort of spiritual care workers at an established hospice in Cape Town, South Africa

JOURNAL OF RELIGION & HEALTH | Online – 23 March 2021 – The importance of spiritual care services in palliative care (PC) is well documented both locally and internationally. While the literature in the Global North supports this assertion, it is imperative to bear in mind that the large body of such research is based on the premise that spiritual care workers have a prior recognised care background in, for example, medicine, psychology, or chaplaincy before entering the spiritual care services field, whereas the reality in the Global South, and in South Africa (SA) in particular, is that spiritual care work is taken up largely by volunteers with diverse backgrounds and educational qualifications. Amongst participants in this study, admittedly a small group, but insider experts, there emerged a felt need to grow spiritual care practitioners and to formalise spiritual care services in hospice PC settings in SA. **Full text:** <https://bit.ly/3rwoUlc>

An expanding pool of neuropalliative care specialists drive the founding of a new society for neuropalliative care

NEUROLOGY TODAY | Online – 1 April 2021 – The interest in neuropalliative medicine is growing ... particularly among medical students, neurology residents, and from people who are both early and later on in their practice. That interest has fueled the establishment of the International Neuropalliative Care Society, which will begin accepting members this spring. Only a tiny fraction of neurologists are trained in palliative care (PC); few PC physicians are trained in neurology; few occupational therapists and other allied health professionals have expertise in neurodegenerative illnesses. The new society is one of several signs that neuropalliative care is growing and maturing as a subspecialty. As neuropalliative care programs proliferate, so does the variety of practice models. **Full text:** <https://bit.ly/3cFsJqs>

N.B. International Neuropalliative Care Society website: <https://bit.ly/3ucx3n8>

Related:

- *BMC PALLIATIVE CARE* | Online – 1 April 2021 – ‘**An Australian neuro-palliative perspective on Huntington’s disease: A case report.**’ This case report provides insights into a dedicated neuro-palliative care service and highlights the crucial role palliative care (PC) can play in supporting both patients and their families with Huntington’s disease (HD). This model of care should be available more broadly. Many current PC health models are constrained by a healthcare system unable to provide the long-term, longitudinal and integrative PC HD patients require. To ensure the quality of life of patients with HD is optimised and maintained, in Australia and globally, measures need to be implemented to minimise health inequality and improve HD patients’ access to specialist PC services. **Full text:** <https://bit.ly/2R1lxg3>

Noted in Media Watch 1 February 2021 (#702, p.11):

- *MOVEMENT DISORDERS* | Online – 28 January 2021 – ‘**Palliative care in movement disorders: An evolving field.**’ 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. **Full text:** <https://bit.ly/2YmBOfR>

Noted in Media Watch 18 January 2021 (#700, p.4):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 January 2021 – ‘**Palliative care services in the Neuro-ICU: Opportunities and persisting barriers.**’ This study explored the extent of effective utilization of, and recorded barriers to, palliative and hospice services in a dedicated 30-bed Neuro-ICU at a large academic medical center. Across services, 146 expired patients were never referred to palliative care or hospice services. Of those referred, over one-third were referred more than 4 days past admission to the Neuro-ICU. On average, patients were referred with less than one day before expiration. Common barriers to referral for supportive services were documented (e.g., patient expected to expire, family declined service). **Abstract (w. list of references):** <http://bit.ly/3nykNJH>

Noted in Media Watch 20 July 2020 (#675, p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 10 July 2020 – ‘**Current collaboration between palliative care and neurology: A survey of clinicians in Europe.**’ Respondents to an online survey reported that there was good collaboration in the care for people with amyotrophic lateral sclerosis and cerebral tumours, but less for other progressive neurological diseases. The collaboration included joint meetings and clinics, and telephone contacts ... [and] ... was helpful, particularly for maintaining quality of life, physical symptom management, psychological support and complex decision-making, including ethical issues. The study shows evidence for collaboration between palliative care and neurology, but with the need to develop this for all neurological illness... **Abstract:** <https://bit.ly/3iS7fHT>

Family perceptions of quality of end of life in LGBTQ+ individuals: A comparative study

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 31 March 2021 – Members of the lesbian, gay, bisexual, transgender, and queer (LGBTQ+) community have encountered discrimination and stigmatization related to sexual orientation and/or gender identity both within healthcare establishments and in the larger community. Despite the literature describing inequities in healthcare, very little published research exists on the experiences of LGBTQ+ patients and family members in hospice care. One hundred and twenty-two family members of individuals who have died while under hospice care in the past 5 years participated in this study. The findings, in combination with previously published works on LGBTQ+ health, support the position that hospice providers must take concrete steps to ensure that professional caregivers and office staff are qualified to meet the needs of this marginalized population. **Full text:** <https://bit.ly/39uiCmy>

N.B. Search back issues of Media Watch for additional articles on end-of-life care for the LGBTQ+ community at: <http://bit.ly/2ThijkC>

Mutual support between patients and family caregivers in palliative care: A systematic review and narrative synthesis

PALLIATIVE MEDICINE | Online – 2 April 2021 – The findings of this review highlight the complex nature of relations between patients and family caregivers (FCGs) in palliative care. Shared understanding and positivity can enable patients and FCGs adjust to progressive illness and engage effectively in the decision-making process. However, patients and FCGs also experience distress and do not routinely communicate their concerns to each other. In some cases, disclosure can be more challenging for FCGs. In practice, attention should focus not only on alleviating distress for patients and FCGs but also on how patients and FCGs can best communicate their distress to each other. Facilitating patients and FCGs in this context has potential not only to alleviate distress for both patients and FCGs but also to increase concordance between patients and FCGs in the decision-making process. **Full text:** <https://bit.ly/2PmvNiy>

The effectiveness of hope-fostering interventions in palliative care: A systematic review and meta-analysis

PALLIATIVE MEDICINE | Online – 30 March 2021 – The concept of hope is an important theme in chronic illness and palliative care (PC) and has been associated with increased psycho-spiritual well-being and quality of life (QoL). Psycho-spiritual interventions have been described in this population, but no systematic review of hope-enhancing interventions or hopelessness-reducing interventions has been conducted for persons with PC diseases. Thirty-five studies (24 randomized controlled trials, 5 quasi-experimental, 6 pre-post studies) involving a total of 3,296 PC patients were included. Compared with usual/standard cancer care alone, interventions significantly increased hope levels at a medium effect size, but did not significantly reduce hopelessness. It was found that interventions significantly increase spirituality and decrease depression, but had no significant effect over anxiety, QoL, and symptom burden. Overall, quality of evidence across the included studies was rated as low. **Abstract (w. references):** <https://bit.ly/3u8q52n>

Association between high cost user status and end-of-life care in hospitalized patients: A national cohort study of patients who die in hospital

PALLIATIVE MEDICINE | Online – 30 March 2021 – This study provides a window into the types of care that high cost users may be more likely to receive during the hospitalization in which they die, where clinicians may wish to focus discussions on clarifying preferences surrounding willingness to receive aggressive elements of end-of-life (EoL) care, especially during situations of uncertainty. One challenge with this approach is that physicians and patients are faced with care decisions at the time of hospital admission without knowing that it may be their last. However, most patients are hospitalized only once in their last year of life, and the continued advancement of artificial intelligence may improve our ability to identify when this is the case. Alternatively, having these discussions earlier, especially for older patients with complex

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medical illness who frequently interact with the healthcare system, may be one strategy to identify, clarify and document patient priorities for care which have been shown to reduce treatment burden and unwanted healthcare. Innovative strategies beyond high healthcare use may be required to identify the substantial numbers of non-high cost users in their last year of life who ultimately died in hospital. The findings of this study may therefore highlight an opportunity to focus efforts by clinicians and systems on maximizing value to patients at the EoL, where previous efforts to improve value more broadly have yielded disappointing results. **Full text:** <https://bit.ly/3m3uctE>

Missing the human connection: A rapid appraisal of healthcare workers' perceptions and experiences of providing palliative care during the COVID-19 pandemic

PALLIATIVE MEDICINE | Online – 29 March 2021 – During the COVID-19 outbreak, policies and infection prevention measures limited healthcare workers' ability to provide traditional end-of-life (EoL) care. A rapid appraisal was conducted incorporating a rapid review of policies from the U.K., semi-structured telephone interviews with healthcare workers, and a review of mass print media news stories and social media posts describing healthcare worker's experiences of delivering care during the pandemic. Reduced opportunity for interaction made it difficult to connect with patients, and staff felt pressure to prioritise clinical tasks. To address this loss of connection, healthcare workers focused on improving communication for patients and family. They also demonstrated personal acts of care by engaging in small talk, offering reassuring touch and improving patient appearance. Most importantly, staff comforted patients at EoL when family could not be present. Ensuring no one died alone was perceived as the duty of healthcare workers and an essential part of a good death. The changes in care appeared to affect healthcare workers' sense of identity as it contradicted their beliefs around quality care. Despite initial difficulties, staff adjusted their goals to focus on tasks considered most important to patients and their families, potentially developing staff resilience. While the loss of traditional elements of care were distressing for staff, actively engaging in new forms of human connection and care could be empowering. **Full text:** <https://bit.ly/3rvZpH5>

The benefits and challenges of embedding specialist palliative care teams within homeless hostels to enhance support and learning: Perspectives from palliative care teams and hostel staff

PALLIATIVE MEDICINE | Online – 29 March 2021 – This project is the first to evaluate a model providing in-reach support from palliative care (PC) professionals into homeless hostels. Overwhelmingly the champions and hostel staff felt this model was beneficial for the staff and residents. Despite embedding PC specialists (nurses or social workers) for only two half-days a month each, the champions developed trusting partnerships with hostel staff and created an ethos more open to a palliative approach, which was more person-centred care and explored residents' wishes and insights. Previous research has shown hostel staff are reluctant to discuss PC with residents, but using a parallel planning approach ("hoping for the best while planning for the worst") can be helpful in improving communication for those whose health may be deteriorating. The champions of this project were able to start destigmatizing death and dying. This was evidenced by the perceived success of vigils and death cafés, and a planned death within a hostel. **Full text:** <https://bit.ly/3u3vpEi>

Noted in Media Watch 8 October 2018 (#584, p.17):

- *NURSE EDUCATION TODAY*, 2018;71(12):135.144. 'Evaluation of training on palliative care for staff working within a homeless hostel.' Training around how to support hostel residents with deteriorating health is currently largely absent from the training received by hostel staff in the U.K. This study suggests that training can be beneficial for improving knowledge, confidence, openness and work related stress for hostel staff... Recommendations for implementing changes in how people experiencing homelessness are supported include embedding training into routine practice, promoting multidisciplinary working, incorporating flexibility within the recovery focused approach of services, and recognising the need for emotional support for staff. **Full text:** <https://bit.ly/3frVrwK>



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

The rollercoaster model of the bereaved caregiver

PROGRESS IN PALLIATIVE CARE | Online – 29 March 2021 – The grief associated with bereavement, while a natural response to loss, is usually a traumatic life event. The bereavement experience for a primary caregiver with the experience of caring for a loved one is complex, especially if this role has required them to relinquish aspects of their own life. The healing trajectory for the bereaved carer is often more complex than for many other bereavements, given the pre-death experience of caregiving. The authors describe the development of a bereavement model which arose from significant clinical experience of working with bereaved carers in a community palliative care environment. The model assists the bereaved carer in gaining insight into their experience and a focus for their psychological and emotional expression, thereby promoting adaptation to the transition and promoting a healthier grief trajectory. **Abstract:** <https://bit.ly/3wfnTlg>

Related:

- *PALLIATIVE MEDICINE* | Online – 30 March 2021 – ‘**A qualitative study of bereaved relatives’ end-of-life experiences during the COVID-19 pandemic.**’ In the absence of direct physical contact, it was important for families to have a clear understanding of their family member’s condition and declining health, stay connected with them in the final weeks/days of life and have the opportunity for a final contact before they died. Health and social care professionals were instrumental to providing these aspects of care, but faced practical challenges in achieving these. Results are presented within three themes: 1) Entering into the final weeks and days of life during a pandemic; 2) Navigating the final weeks of life during a pandemic; and, 3) The importance of “saying goodbye.” **Full text:** <https://bit.ly/3wpwoRc>

Widening the conversation: Paramedic involvement in interprofessional care

PROGRESS IN PALLIATIVE CARE, 2021;28(2):57-58. In this special issue of *Progress in Palliative Care* we explore the nexus between palliative care (PC) and paramedicine by presenting important initiatives being undertaken in Australia, New Zealand, the U.K., and Canada to improve access to care. In each of the settings described, paramedics are regulated or registered healthcare professionals working in health settings that include ambulance or emergency medical services. Paramedics within these regions can be rapidly deployed to provide urgent healthcare to the entire population of the areas they serve, including areas that are not served by out of hours specialist PC. The contributions to this special issue describe initiatives that involve paramedics and ambulance services planning for care that may include a broader range of management options than the default option of transport to a hospital. It is recognised that patients may experience illness or injury that is unrelated to their palliative condition, and that health emergencies associated with a life-limiting illness may require hospital admission. However, where the patient expresses a preference for care at home or has an advance care directive that describes this preference, every opportunity should be explored to pursue the universal maxim of person-centred care. **Journal contents page:** <https://bit.ly/3m0iPmn>

N.B. Search back issues of Media Watch for additional articles on the potential role of paramedics in palliative and end-of-life care at: <http://bit.ly/2ThijkC>

European Resuscitation Council Guidelines 2021: Ethics of resuscitation and end-of-life decisions

RESUSCITATION, 2021;161(4):408-432. These European Resuscitation Council Ethics guidelines provide evidence-based recommendations for the ethical, routine practice of resuscitation and end-of-life care (EoLC) of adults and children. The guidelines primarily focus on major ethical practice interventions, decision-making regarding resuscitation, education, and research. These areas are tightly related to the application of the principles of bioethics in the practice of resuscitation and EoLC. The Council’s ethics writing group provides sets of simple and clear recommendations supported by a wealth of systematic reviews, recent randomised controlled trials and non-randomised studies. Despite the generally low certainty about the precision of the effect estimates of several evaluated meta-analyses, the directions of the



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effects on patient outcomes clearly favour the use of interventions such as advance care planning, shared decision-making, and termination of resuscitation rules. The writing group also produced three narrative reviews to summarise the existing key evidence/knowledge/issues on education/system organisation, patient outcomes, and ethics of emergency research. Lastly, the writing group has provided a set of consensus definitions of key terms, which could potentially prove useful in both routine clinical practice and the design of future research protocols. **Full text:** <https://bit.ly/3IZ7oLM>

N.B. This issue of *Resuscitation* includes additional articles on the European Resuscitation Council Ethics guidelines. **Journal contents page:** <https://bit.ly/3dmggau>

Related:

- *BMC MEDICAL ETHICS* | Online – 29 March 2021 – ‘**Do-not-attempt-resuscitation orders: Attitudes, perceptions and practices of Swedish physicians and nurses.**’ Swedish healthcare professionals take patient autonomy into account when making do-not-attempt-resuscitation (DNAR) decisions. Nevertheless, as 50% of patients in this retrospective observational study were considered unable to participate in the discussion prior to the decision, questions remain about the timing of patient participation and whether more discussions should have been conducted earlier. Given the uncertainty about timing, the majority of patients deemed competent participated in DNAR discussions. This is a positive trend towards a clearer emphasis on patient autonomy. **Full text:** <https://bit.ly/3sAVytR>
- *RESUSCITATION* | Online – 30 March 2021 – ‘**Does ReSPECT¹ neutralise medical paternalism in end-of-life care?**’ From early this century, it was identified that patients were not informed when the end of life was predictable due to disease progression and lack of further treatment options, thereby denying them prospective choice as to the where and how of dying. In the U.K., government policy in 2008 intended to address this deficit by “promoting high quality care for all adults at the end of life.” The General Medical Council as the regulatory body in the U.K. followed with guidance in 2010, which majored on the principle of patient choice and mandated provision of information, determination of preferences regarding life-sustaining treatment including cardiopulmonary resuscitation... **Abstract:** <https://bit.ly/3m5EmtY>

N.B. ReSPECT = Recommended Summary Plan for Emergency Care and Treatment.

Noted in Media Watch 29 March 2021 (#710, p.6):

- *BRITISH MEDICAL JOURNAL* | Online – 24 March 2021 – ‘**Improving do not attempt cardiopulmonary resuscitation discussions, decisions and documentation.**’ The Care Quality Commission (CQC) published a report on the quality of decision-making, discussion with patients and families, and documentation on do not attempt cardiopulmonary resuscitation (DNACPR) decisions in the COVID-19 pandemic.¹ The report was commissioned by the government in response to news stories, complaints, and campaigns about perceived failings. The CQC acknowledged that the extreme demands of the pandemic response had increased pressure on clinical and care staff and services, which may have hampered decisions and communication. DNACPR decisions don’t exist in isolation... **Full text:** <https://bit.ly/3INyyk0>

1. ‘Protect, respect, connect – decisions about living and dying well during COVID-19,’ Care Quality Commission, March 2021. [Noted in Media Watch 22 March 2021 (#709, pp.3-4)] <http://bit.ly/3eMn6ly>

Research Matters

Facebook recruitment for children with advanced cancer and their parents: Lessons from a web-based pediatric palliative intervention study

PROGRESS IN PALLIATIVE CARE | Online – 29 March 2021 – Participant recruitment for pediatric palliative intervention studies is a chronic challenge for researchers. Digital recruitment strategies, or digital technology-assisted recruitment methods used to remotely reach and enroll research subjects, can help address these recruitment challenges for pediatric palliative care (PC) clinical trials. This study a) describes Facebook recruitment procedures targeting children with cancer and their parents for a pediatric palliative

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intervention randomized clinical trial, b) reports recruitment results, and c) discusses successful strategies to recruit pediatric populations via Facebook advertisements. Researchers used Facebook advertisements to recruit children with advanced cancer (aged 7–17 years) for a web-based legacy intervention. Between years 2015 and 2018, the research team enrolled 150 child-parent dyads to participate in the web-based legacy program. Results suggest that Facebook advertisements can be a successful tool to access and recruit pediatric populations with life-threatening conditions. Further research is needed to determine how innovative social-media recruitment strategies could be used in other populations of patients with serious illnesses and their caregivers to further advance the science in PC. **Full text:** <https://bit.ly/31wniUn>

Noted in Media Watch 8 March 2021 (#707, p.14):

- **PEDIATRICS** | Online – 1 March 2021 – ‘**End-of-life childhood cancer research: A systematic review.**’ The authors selected 24 articles published in English that examined perceptions or experiences of research participation for children with cancer at the end of life (EoL) from the perspectives of children, parents, and health professionals (HPs). Eight themes were identified: 1) Seeking control; 2) Faith, hope, and uncertainty; 3) Being a good parent; 4) Helping others; 5) Barriers and facilitators; 6) Information and understanding; 7) The role of HPs in consent and beyond; and, 8) Involvement of the child in decision-making. Some families participate in EoL research seeking to gain control and sustain hope, despite uncertainty. **Abstract:** <http://bit.ly/3b8uaNm>

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Canada



CSPCP
Canadian Society of
Palliative Care Physicians

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

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Barry R. Ashpole, Ontario CANADA

e-mail: BarryRAshpole@bell.net