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

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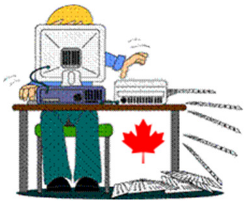

Compiled & Annotated by Barry R. Ashpole

> ***We need to improve screening efforts, reduce barriers to accessing support, improve our ability to assess the bereaved, improve the fit and efficacy of therapies, disseminate and implement empirically supported grief interventions, establish standards of care, increase the workforce of grief specialists, and minimize burnout of these providers.***
>
> 'Psychological risk factors of functional impairment following COVID-19 deaths' (p.10), in *Journal of Pain & Symptom Management.*

Canada

Ontario urged to suspend need for consent before withdrawing life support when COVID crushes hospitals

ONTARIO | *The National Post* (Toronto) – 21 January 2021 – Canada's Supreme Court ruled in 2013 that a major Toronto Hospital could not withdraw life-support from a minimally conscious and severely brain-damaged man without his family's consent. Now, in another sign of these extraordinary times, the Ontario government is being asked to temporarily suspend the law requiring doctors get consent of patients or families before withdrawing a ventilator or other life-sustaining treatment from people facing a grim prognosis, should COVID-19 crush hospitals. The recommendation for an Executive Order to suspend the province's Health Care Consent Act for withdrawal of treatment in the ICU, should the situation become so dire, comes as Ontario, Quebec and other provinces prepare protocols to determine who should get critical care – and who should be left behind – if hospitals are flooded with COVID patients. The request, deeply disturbing to disability advocacy groups, comes from Ontario's COVID-19 Bioethics Table, which is recommending that the province ensure "liability protection for all those who would be involved in implementing the Proposed Framework … including an Emergency Order related to any aspect requiring a deviation for the Health Care Consent Act." The act requires doctors obtain agreement from patients, or their substitute decision makers, with disputes resolved by the Consent and Capacity Board, an independent tribunal. This week, the Ontario Critical Care COVID Command Centre issued an "emergency standard of care" to prepare hospitals for the worst-case scenario, an Italy-like surge in demand for critical care. The over-arching objective, the document states, is to "save the most lives in the most ethical manner possible." http://bit.ly/2Mc1ucg

Specialist Publications

'Shortages of palliative care medications in Canada during the COVID-19 pandemic: Gambling with suffering' (p.7), in *Healthcare Quarterly.*

U.S.A.

LGBTQ seniors don't get the health and end-of-life care they need. Some Coloradans are working to change that

COLORADO | Colorado Public Radio – 22 January 2021 – On one of her many days in the hospital in 2017, Cathy asked her partner not to tell the nursing staff they were married. She'd been diagnosed with a rare form of leukemia. And Cathy feared the care she got would suffer if the staff knew she was a lesbian. "She says, 'Don't tell the nurses that we're married,'" said Cathy's wife, Esther Lucero. "And I said, 'Why?' And she says, 'Because they're treating you differently. They're treating me differently.'" According to a study recently published in *The Gerontologist*, older people who are lesbian, gay, bisexual, transgender or queer often face discrimination during end-of-life care.[1] They're also more likely to have their health care wishes ignored or disregarded. And many LGBTQ seniors go back into the closet because of a lack of family or social support in healthcare, assisted living and hospice facilities. http://bit.ly/394VL10

1. '"She's dying and I can't say we're married?": End-of-life care for LGBT older adults,' *The Gerontologist,* published online 11 December 2020. [Noted in Media Watch 21 December 2020 (#697, p.5)] **Abstract:** https://bit.ly/3al40XF

Specialist Publications

'Spirituality and the illness experience: Perspectives of African American older adults' (p.5), in *American Journal of Hospice & Palliative Medicine*.

'Can community health workers increase palliative care use for African American patients? A pilot study' (p.5), in *JCO Oncology Practice*.

'Place of death for persons with and without cognitive impairment in the U.S.' (p.4), in *Journal of the American Geriatrics Society*.

'Prioritization of pediatric palliative care field-advancement activities in the U.S.: Results of a national survey' (p.9), in *Journal of Pain & Symptom Management*.

Race, socioeconomics are largest barriers to hospice and palliative care

HOSPICE NEWS | Online – 19 July 2021 – Race, ethnicity and socioeconomic status are the leading differentiating factors fueling disparities in hospice utilization. Recent research reflects mounting concerns about inequitable access to hospice and palliative care (PC) across the U.S. Researchers from the John Hopkins University School of Nursing in Baltimore examined March 2020 data from three national healthcare databases that outlined disparities in hospice and PC. Of the studies the researchers assessed … 70% described differences in access outcomes to hospice and PC by ethnicity, race or socioeconomic status.[1] According to the researchers …. "there is growing evidence of disparities in access to hospice and PC services to varying degrees by sociodemographic groups." Studies have shown that demographic disparities can limit the scale of hospice. Roughly 82% of Medicare decedents in 2018 were Caucasian, according to the National Hospice & Palliative Care Organization. Comparatively, slightly more than 8% were African-American; 6.7% were Hispanic, and 1.8% were Asian. That year, only 0.4% of Medicare decedents were Native American. http://bit.ly/39HdTNi

1. 'Sociodemographic disparities in access to hospice and palliative care: An integrative review,' *American Journal of Hospice & Palliative Medicine*, published online 11 January 2021. [Noted in Media Watch 18 January 2021 (#700, p.9)] **Abstract (w. list of references):** http://bit.ly/3oBiKG3

N.B. Search back issues of Media Watch for articles on ethnic and racial disparities in the provision and delivery of PC and hospice in the U.S. at: http://bit.ly/2ThijkC

Share this issue of Media Watch with a colleague

How palliative care remade end-of-life care at New York hospitals

NEW YORK | *U.S. News & World Report* – 16 January 2021 – Providing palliative care (PC) in hospitals led to a 10% reduction in intensive care unit use by dying patients, a new study finds.[1] Researchers say that ICU use at the end of life (EoL) is considered an indicator of poor quality of care. The study's findings suggest that "implementing PC programs may be a way to improve the quality of EoL care for some patients who die in the hospital," said study lead author Dr. May Hua … assistant professor of anesthesiology at Columbia University Mailman School of Public Health in New York City. Hua and her colleagues noted that just a 4% decrease in EoL ICU use would translate to savings of about $265 million per year in the U.S. For the study, the researchers analyzed data from 51 hospitals in New York state that either did (24) or did not (27) implement a PC program between 2008 and 2014. Many of those that did were teaching and large hospitals. The analysis did not include hospitals in the state that consistently offered PC between 2008 and 2014, nor did it include rural hospitals and those with fewer than 100 beds. The study included more than 73,000 adult patients who died during hospitalization. Slightly more than half received care in hospitals that put PC into place during the study period. http://bit.ly/3oZXzxM

1. 'Association between the implementation of hospital-based palliative care and use of intensive care during terminal hospitalizations,' *JAMA OPEN NETWORK*, published online 8 January 2020. [Noted in Media Watch 13 January 2020 (#648, p.1)] **Full text:** http://bit.ly/2QBm0mz

International

Irish Hospice Foundation launches free toolkit for those delivering end-of-life care as COVID-19 surges

IRELAND | Irish Hospice Foundation (Dublin) – 20 January 2021 – The Foundation has launched a comprehensive Toolkit for Compassionate End-of-Life Care to enable healthcare workers deliver compassionate end-of-life care (EoLC) during this latest wave of the COVID-19 pandemic. Supporting people to die well in the circumstances now faced in health and residential care settings, is an enormous challenge. Infection control measures and strict visiting restrictions, although vital, mean the empathetic and high standards of EoLC that is the norm in theses settings is being impacted. Developed in consultation with healthcare staff in acute hospitals, residential care and nursing home sectors, and those working in bereavement support and education, the toolkit includes resources and guidance on subjects like communicating through personal protective equipment, care of the dying person, supporting the bereaved and self-care for staff. http://bit.ly/3iwaHYZ

Specialist Publications

'A national survey of ambulance paramedics on the identification of patients with end-of-life care needs' (p.6), in *British Paramedic Journal*.

'Current status of clinical practice guidelines on palliative sedation for adults in French-speaking countries' (p.11), in *Bulletin du Cancer*.

'Preparing for a good death? Palliative care representations in the Italian public television programming' (p.7), in *Death Studies*.

'Updates on palliative care: What, for whom, and how?' (p.8), in *Islamic University-Gaza Journal of Natural Studies*.

Media Watch: Access Online

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

Over 130,000 terminal patients choose to forgo life-prolonging treatment over 3 years: Data

SOUTH KOREA | *The Korea Times* (Seoul) – 18 January 2021 – Nearly 135,000 terminally ill South Koreans have chosen to forgo life-prolonging treatment since the legalization of the right to die with dignity three years ago... The number of patients who opted to die with dignity stood at 134,945 at the end of December last year, according to the data from the National Agency for Management of Life-Sustaining Treatment. Of the total patients, 80,594, or 59.7%, were male, with those aged 60 or older taking up 81%. The law took effect on 4 February 2018, allowing terminal patients to sign up to forgo a "meaningless extension of life" by stopping or postponing four life-sustaining treatments. The four treatments – cardiopulmonary resuscitation, artificial respiration, hemodialysis and anti-cancer drug administration – are only meant to prolong the lives of terminally ill patients without giving any treatment from the start. The data also showed slightly over 57,500 terminally ill patients have so far registered with authorities to die with dignity without receiving further treatment. A total of 790,193 people have so far registered a letter of intent with hospitals and public organizations to stop receiving life-sustaining treatment once they became terminally ill, according to the data. http://bit.ly/3sI1b9N

Noted in Media Watch 19 October 2020 (#688, p.4):

- *BMC MEDICAL ETHICS* | Online – 16 October 2020 – **'Forgoing life-sustaining treatment: A comparative analysis of regulations in Japan, Korea, Taiwan, and England.'** The analysis offers five important legal and philosophical points: 1) Defining the terminal stage and associated criteria for clinical judgment; 2) Discussion on withdrawing life-sustaining treatment in persistent vegetative state or motor neurone disease patients who are not terminal; 3) (Re)considering any moral and legal differences between withholding and withdrawing treatments (this is disputed particularly in Asian countries); 4) Ascertaining the family's role in end-of-life decision-making; and, 5) Devising ways to deal with incompetent patients who lack family or advance directives. **Full text:**

Specialist Publications

Place of death for persons with and without cognitive impairment in the U.S.

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 20 January 2021 – Given the paucity of literature surrounding the relationship between place of death and associated quality of care … it is likely that awareness of this important aspect of end-of-life (EoL) care is lacking. Consequently, this topic may not be incorporated into advance care planning with patients, family, and caregivers. This is unfortunate, as the findings of this study indicate that place of death should be a central component of EoL care discussions for persons with and without cognitive impairment. As there is frequently incongruence between preferred and actual place of death, it is critical that providers in hospitals, long-term care, and palliative care settings are trained to provide person-centered care, particularly as provider knowledge of preferred place of death is associated with achieving that goal. It is also important that, in light of this incongruence, older adults allow for a degree of flexibility in EoL serving planning. At present, there remains a long way to go towards ensuring that persons at EoL, particularly those with cognitive impairment, receive adequate EoL care in accordance with their needs and preferences. **Full text:** https://bit.ly/3sKcGO9

Research Matters

'What should we report? Lessons learnt from the development and implementation of serious adverse event reporting procedures in non-pharmacological trials in palliative care' (p.12), in *BMC Palliative Care*.

'Designing and undertaking randomised implementation trials: A guide for researchers' (p.13), in *British Medical Journal*.

'Video-based online interviews for palliative care research: A new normal in COVID-19?' (p.13), in *Palliative Medicine*.

Cont.

Noted in Media Watch 28 September 2020 (#685, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 21 September 2020 – '**Top ten tips palliative care clinicians should know about cognitive impairment.**' Most long-term care (LTC) residents are of age >65 years and have multiple chronic health conditions affecting their cognitive and physical functioning. Although some individuals in nursing homes return home after receiving therapy services, most will remain in a LTC facility until their deaths. This article seeks to provide guidance on how to assess and effectively select treatment for delirium, behavioral and psychological symptoms for patients with dementia, and address other common challenges such as advanced care planning, decision-making capacity, and artificial hydration at the end of life. **Abstract:** https://bit.ly/2FHrtFO

Noted in Media Watch 29 June 2020 (#672, p.10):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 25 June 2020 – '**Associations between unmet palliative care needs and cognitive impairment in a sample of diverse, community-based older adults.**' The Montreal Cognitive Assessment and the Unmet Palliative Care Needs screening tools were used in this study to assess participants' cognitive status and palliative care (PC) needs. Findings revealed a quadratic relationship between unmet PC needs and mild cognitive impairment… This study is a first step toward elucidating the relationship between cognitive impairment and PC needs in a diverse community sample of older adults. More research is needed to better understand the unique PC needs of older adults with cognitive impairment living in the community. **Abstract (w. list of references):** https://bit.ly/2BfBqaZ

Spirituality and the illness experience: Perspectives of African American older adults

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 19 January 2021 – Disparities in hospice and palliative care for African Americans have been linked to mistrust toward the healthcare system, racial inequalities, and cultural preferences. Spirituality has been identified as important to African Americans in general. Less is known about the influence of spirituality on African American illness experiences. In partnership with 5 churches in the Denver metropolitan area, the authors conducted focus groups with African American older adults with chronic health conditions and their family caregivers. Themes referenced participants' spiritual orienting systems, spiritual coping strategies, and spiritual coping styles. Psycho-spiritual struggles, social struggles, and sources of social support were also identified. Findings suggest African Americans' spirituality influences chronic illness experiences. Participants relied on their spirituality and church community to help them cope with illness. In addition, social struggles impacted the illness experience. Social struggles included mistrust toward the healthcare system and not being connected to adequate resources. Participants expressed a need to advocate for themselves and family members to receive better healthcare. Churches were referred to as a trusted space for health resources, as well as spiritual and social support. **Abstract (w. list of references):** http://bit.ly/3itzs8o

Related:

- *JCO ONCOLOGY PRACTICE* | Online – 21 January 2021 – '**Can community health workers increase palliative care use for African American patients? A pilot study.**' African American patients with cancer underutilize advance care planning (ACP) and palliative care (PC). This study investigated whether community health workers (CHWs) could improve ACP and PC utilization for African American patients with advanced cancer. African American patients diagnosed with an advanced solid organ cancer (stage IV or stage III disease with a palliative performance score < 60%) were enrolled. The authors' findings demonstrated that the Utilization of CHWs to address PC domains and social determinants of health is feasible. **Abstract:** http://bit.ly/2KDNeIR

Noted in Media Watch 17 December 2018 (#594, p.9):

- *JOURNAL OF PALLIATIVE CARE* | Online – 12 December 2018 – '**Engaging the African American church to improve communication about palliative care and hospice: Lessons from a multi-level approach.**' The authors' primary goal was to encourage churches to embrace palliative care (PC) and hospice as acceptable alternatives for end-of-life care by creating venues to improve communications about PC and hospice. This article compares their experience in five churches in the Philadelphia region of Pennsylvania, revealing lessons learned and the challenges of engaging, implementing, and maintaining a multilevel approach in the churches, and the authors' strategies in response to those challenges. **Abstract (w. list of references):** https://goo.gl/Y1ebhk

A national survey of ambulance paramedics on the identification of patients with end-of-life care needs

BRITISH PARAMEDIC JOURNAL, 2020;5(3):8-14. Developing the proactive identification of patients with end of life care (EoLC) needs within ambulance paramedic clinical practice may improve access to care for patients not benefitting from EoLC services at present. To inform development of this role, this study aimed to assess whether ambulance paramedics currently identify EoLC patients, are aware of identification guidance and believe this role is appropriate for their practice. Between 4 November 2019 and 5 January 2020, registered paramedics from nine English NHS ambulance service trusts were invited to complete an online questionnaire. The questionnaire initially explored current practice and awareness, employing multiple-choice questions. The Gold Standards Framework Proactive Identification Guidance (GSF PIG) was then presented as an example of EoLC assessment guidance, and further questions, permitting free text responses, explored attitudes towards performing this role. Most participants (79.9%) perceived that they attended a patient who was unrecognised as within the last year of life on at least a monthly basis. Despite 72.0% of paramedics indicating that they had previously made an EoLC referral to a General Practitioner, only 30.5% were familiar with the GSF PIG and of those only 25.9% had received training in its use. Participants overwhelmingly believed that they could and should perform this role, yet current barriers were identified as the inaccessibility of a patient's medical records, inadequate EoLC education and communication difficulties. Consequently, facilitators to performing this role were identified as the provision of training in EoLC assessment guidance and establishing accessible, responsive EoLC referral pathways. **Full text (click on pdf icon):** http://bit.ly/35SjvTT

Related:

- *PROGRESS IN PALLIATIVE CARE* | Online – 18 January 2021 – **'Dealing with dying – progressing paramedics' role in grief support.'** There is a unique opportunity to better prepare paramedics to adequately participate in the death and dying process and address developing competency in grief support in a more strategic and integrated manner. The authors suggest employing a multi-faceted approach, focused on recruitment, initial and continuing education, and continued support in clinical practice. Importantly, paramedics will require support from interprofessional colleagues in palliative, grief and bereavement care to provide expertise in educational programs, clinical placements, and support at the patient's bedside. **Abstract:** https://bit.ly/392tMiB

Noted in Media Watch 18 January 2021 (#700, p.13):

- *PROGRESS IN PALLIATIVE CARE* | Online – 11 January 2021 – **'Developing a paramedic approach to palliative emergencies.'** Emergency health services have experienced a steady increase in demand from palliative patients accessing 9-1-1 during times of acute crisis, although the majority of these patients do not wish for conveyance to hospital following paramedic treatment. To address this demand, and to provide patients with the right care, the first time, the British Columbia Emergency Health Service (BCEHS) introduced the province's first Assess, See, Treat & Refer (ASTaR) Clinical Pathway. This commentary outlines the early integration of the ASTaR Palliative Clinical Pathway into the BCEHS paramedic approach to palliative patient care. **Abstract:** https://bit.ly/3qbaE7C

N.B. Additional articles on the role of paramedics in palliative and EoL care noted in Media Watch 23 November 2020 (#693, p.14).

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

Updated review of palliative care in dementia

CURRENT GERIATRICS REPORTS | Online – 18 January 2021 – There are disparities in hospice referrals and end-of-life care for patients with dementia compared to patients with other life-limiting conditions. Advance care planning interventions are being designed and tested as patients and their caregivers indicate a desire for more information from their healthcare providers, although significant challenges remain with regard to physician skills and time. Additional attention is being paid to non-cognitive symptoms of dementia, such as neuropsychiatric symptoms, with a new atypical antipsychotic medication recently submitted to the Federal Drug administration [in the U.S.] for approval. Pain management, accurate prognostication, timing of palliative care (PC) interventions, and the effects of caregiving on caregiver health remain understudied areas. There have been many recent advances in PC research as it pertains to patients with dementia. However, several gaps remain. Future research will be important to close these gaps in order to further optimize the care of patients with dementia. **Abstract (w. list of references):** https://bit.ly/3nYozMI

N.B. Search back issues of Media Watch for articles on palliative and end-of-life care for people living with dementia at: http://bit.ly/2ThijkC

Preparing for a good death? Palliative care representations in the Italian public television programming

DEATH STUDIES | Online – 21 January 2021 – The difficulty in accepting death is a constant that transcends differences of time and place. The literature shows that the dying is often subjected to invasive procedures with significant consequences on individual wellbeing and public health. If death is hard to accept even for the practitioners, what happens in the broader population? What narratives surround the end of life? This study focuses on the Italian context and its transformations, the public's understanding of palliative care (PC), and the television programs dealing with hospice and PC aired by the Italian public broadcasting company from the 1950s to the present day. **Abstract:** https://bit.ly/3iJMwqg

Shortages of palliative care medications in Canada during the COVID-19 pandemic: Gambling with suffering

HEALTHCARE QUARTERLY, 2021;23(4):17-22. Patients with serious illnesses such as cancer, advanced organ failure, dementia and COVID-19 rely on medications to alleviate suffering from uncontrolled symptoms. Numerous actual or threatened shortages of key medications used to provide palliation have been reported during the COVID-19 pandemic. This article explores the nature of these shortages, factors that have contributed to them and strategies to mitigate them. It calls on all levels of the healthcare system and the government to address this problem. Shortages in these medications are as serious as shortages in medications used to cure or control diseases. **Abstract (via PubMed):** http://bit.ly/3paxjAG

Palliative care in the Middle East

Updates on palliative care: What, for whom, and how?

ISLAMIC UNIVERSITY-GAZA JOURNAL OF NATURAL STUDIES, 2021;29(1):1-11. Unfortunately in most of the Middle East and in third world countries, palliative care (PC) has not been fully integrated into all healthcare systems, despite evidence that it increases quality of life outcomes and reduces end-of-life suffering. In the Middle East, it is provided by various institutions, ranging from voluntary groups and non-governmental organizations to formal hospitals and hospital units .One of the biggest obstacles to establishing PC programs is the lack of training and awareness of PC among health professionals, an impediment to improving access to this service. There is another obstacle as PC professionals struggle to secure financing, and to establish basic education for PC, in order to raise awareness of this specialization. Despite this bleak picture, there are some achievements, as some individuals and institutions in this field have achieved notable successes since the early 1990s, after the opening of the first palliative treatment unit in the Kingdom of Saudi Arabia in 1992, and Jordan and Lebanon now have official and specialized programs for doctors, while Egypt, Jordan, Oman, Qatar, and Palestine have developed other advanced training... In Lebanon, it was announced that at least one PC unit was established to teach medical colleges as a separate topic, and Egypt and Kuwait decided to teach PC. However, some countries, including Yemen, Libya and Syria, have little or no PC activity due to political issues that can affect the availability of resource alongside with a lack of education and awareness. PC is one of the most interesting and growing areas of healthcare encompassing holistic care, a growing evidence base, broad range of diseases and ages, pharmacological and non-pharmacological interventions, teamwork, a focus on vulnerable populations and the opportunity for a deepening therapeutic relationship from the healthcare provider based on compassion and shared humanity. **Full text (click on pdf icon):** http://bit.ly/2Ncv3em

Palliative care in the Eastern Mediterranean Region

The June 2017 issue of *Palliative Medicine & Hospice Care* focuses on palliative and end-of-life care in the Eastern Mediterranean Region, specifically Iran, Iraq, Israel, Jordan, Lebanon, Morocco, Palestine, Turkey and the United Arab Emirates. [Noted in Media Watch 25 March 2019 (#607, p.5)] **Download/view at:** http://bit.ly/2HI3q86

N.B. See 'Atlas of Palliative Care in the Eastern Mediterranean Region,' a joint project of the Lebanese Center for Palliative Care and the Institute for Culture & Society, University of Navarra, Spain. [Noted in Media Watch 22 May 2017 (#513, p.14)] https://goo.gl/i5Lc4e …and, search back issues of Media Watch for articles on the Islamic perspective on palliative and end-of-life care at: http://bit.ly/2ThijkC

Continuing education outcomes for advance care planning: A systematic review of the literature

JOURNAL OF CONTINUING EDUCATION IN THE HEALTH PROFESSIONS | Online – 8 January 2021 – Health professional continuing education programs have been proposed for facilitating patient participation in advance care planning (ACP); however, their impacts on participants, patient and clinical outcomes, and organizational approaches to ACP are not well understood. This systematic literature review examined interventional studies of education programs conducted with health professionals and care staff across a

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broad range of settings. Of the 7993 articles identified, 45 articles met the authors' inclusion criteria. Program participants were predominantly medical, nursing, and social work staff, and students. Interventions were reported to improve participants' self-perceived confidence, knowledge, and skills; however, objectively measured improvements were limited. Multimodal programs that combined initial didactic teaching and role-play simulation tasks with additional activities were most effective in producing increased ACP activity in medical records. Evidence for improved clinical outcomes was limited. Further studies that use rigorous methodological approaches would provide further evidence about what produces improved patient and clinical outcomes. Needs analyses and quality indicators could be considered to determine the most appropriate and effective education resources and monitor their impacts. The potential contribution of a broader range of health professionals and interprofessional learning approaches could be considered to ultimately improve patient care. **Abstract:** http://bit.ly/3ifNLx6

Prioritization of pediatric palliative care field-advancement activities in the U.S.: Results of a national survey

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 21 January 2021 – The field of pediatric palliative care (PPC) continues to encounter challenges and opportunities to improving access to high-quality PPC services. In early 2019, a workshop identified eleven potential "next step" actions and, subsequently, a national survey-based poll of members of the PPC community was conducted to prioritize these potential actions in terms of their "actionable importance."[1] Invitations to the survey were distributed in to interdisciplinary PPC healthcare professionals via email to two major listservs, one hosted by the Section of Hospice & Palliative Medicine of the American Academy of Pediatrics, the other by the Center to Advance Palliative Care. Respondents rated the "actionable importance" of items relative to each other via a discrete choice experiment. Median importance scores are reported for each item. 177 individuals responded to the survey. The majority (62.2%) were physicians, with nurses (16.4%), advanced practice nurses (7.9%), and social workers (7.3%) being the other most common responders. The top 5 potential actions, in descending rank order, were: 1) Determine what parents value regarding PPC; 2) Define and disseminate core primary PPC curriculum; 3) Develop PPC national representation strategy and tactics; 4) Create PPC-specific program development toolkit; and, 5) Analyze payment and financing ratios. Those seeking to advance the field of PPC should take into account the findings from this study, which suggest that certain actions are more likely to have a beneficial impact on moving the field forward. **Abstract (w. list of references):** https://bit.ly/395ZqeL

Decision-making in the era of new medical technologies in pediatric hematology-oncology: The death of palliative care?

JOURNAL OF PEDIATRIC HEMATOLOGY/ONCOLOGY | Online – 20 January 2021 –Recent advances in immunology, genomics, and cellular therapy have opened numerous therapeutic possibilities in pediatric hematology-oncology, generating new hope in poor prognosis situations. How decisions are made when it comes to treatments and aims needs to be explored in this new technological context. In particular, their impact on the gold standard of early referral to palliative care (PC) must be assessed. The authors discuss the decision-making process when a patient faces poor prognosis. Although health care providers individually envisioned that PC may be the best course of action for patients receiving emergent therapy, they remained collectively in the curative mode. The intricate relationship between science, hope, caregiver, and care receiver sustains this perspective even when (near) death is the probable outcome. When proven treatment fails, emerging therapeutic possibilities offer new hope that can delay the referral to the PC team. **Abstract:** https://bit.ly/2Y25pLw

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1. 'Challenges and priorities for pediatric palliative care research in the U.S. and similar practice settings: Report from a Pediatric Palliative Care Research Network Workshop,' *Journal of Pain & Symptom Management*, published online 21 August 2019. [Noted in Media Watch 26 August 2019 (#628, p.12)] **Abstract (w. link to references):** http://bit.ly/2MxvM8r

Cont.

Related:

- *BMC PALLIATIVE CARE* | Online – 22 January 2021 – **'Development of a managed clinical network for children's palliative care: A qualitative evaluation.'** The study identified key features that aided development of a managed clinical network (MCN) for children's palliative care, including having a funded MCN coordinator, a committed leadership team, a governance structure that fosters collaboration, and a shared vision for the future. Some of these factors have been identified as influencing MCN implementation in other contexts. However, the study found that these features alone, which have been identified in previous research as enablers for MCN success, were not sufficient to overcome the cross-cutting barriers that were impeding the MCN's development. **Full text:** http://bit.ly/2Mc35yN

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | In print – Accessed 25 January 2021 – **'Ensuring safe, responsive and effective hospice care: Developing a nursing dependency scoring tool for children's palliative care.'** The authors sought to develop a dependency tool that enables the hospice to safely and effectively manage the use of beds for planned short breaks (respite), preserving capacity for children requiring symptom management and end-of-life care. A literature review and existing tools were used to inform the development of the Martin House Dependency Tool Framework. The tool has enabled consistent and transparent assessment of children, improving safety, effectiveness and responsiveness, and the management of the workforce and resources. **Abstract:** http://bit.ly/3oOWecY

Psychological risk factors of functional impairment following COVID-19 deaths

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 18 January 2021 – The predicted worldwide tsunami of grief from this pandemic is likely to be associated with much functional impairment experienced by grieving persons, particularly for bereaved individuals reporting symptoms of separation distress, dysfunctional grief, and posttraumatic stress. Efficacious and cost-effective strategies to identify, limit, and treat functional impairment experienced by people bereaved by COVID-19 are urgently needed. Palliative care, which is the most well-developed approach to managing end-of-life (EoL), grapples with questions concerning who to provide bereavement support, when and what to provide, and on what basis. Psychologists and other mental health professionals are ideally placed to provide evidence-based guidance. Yet, the role of psychologists within EoL care is under-developed. This gap underpinned a recent editorial calling for improvements in supporting the bereaved in greatest need.[1] This editorial affirmed: "We need to improve screening efforts, reduce barriers to accessing support, improve our ability to assess the bereaved, improve the fit and efficacy of therapies, disseminate and implement empirically supported grief interventions, establish standards of care, increase the workforce of grief specialists, and minimize burnout of these providers." Psychologists and other mental health professionals working in EoL settings could find that the inclusion of brief screeners for dysfunctional grief, traumatic stress, and functional impairment like those used in this study could help identify family members meriting preventive intervention or systematic follow up in the course of bereavement. Such measures could also pinpoint specific symptoms or struggles to help target intervention.[2] **Full text:** https://bit.ly/2XWQD8C

1. 'Supporting the bereaved in greatest need: We can do better,' *Palliative & Supportive Care*, published online 18 September 2018. [Noted in Media Watch 24 September 2018 (#582, p.15)] **First page view:** http://bit.ly/3nVUj51

2. 'Pandemic Grief Scale: A screening tool for dysfunctional grief due to a COVID-19 loss,' *Death Studies*, published online 21 December 2020. [Noted in Media Watch 4 January 2021 (#698, p.5)] **Full text:** https://bit.ly/38H1DMD

Noted in Media Watch 20 January 2020 (#649, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 January 2020 – **'Mental healthcare and palliative care: Barriers.'** Psychological symptoms are common among palliative care (PC) patients with advanced illness, and their effect on quality of life can be as significant as physical illness. The demand to address these issues in PC is evident, yet barriers exist to adequately meet patients' psychological needs. This article provides an overview of mental health issues encountered in PC, highlights the ways psychologists and psychiatrists care for these issues, describes current approaches to mental health services in PC, and reviews barriers and facilitators to psychology and psychiatry services in PC, along with recommendations to overcome barriers. **Abstract:** http://bit.ly/35YlN1e

Informal caregiving for people with life-limiting illness: Exploring the knowledge gaps

JOURNAL OF PALLIATIVE CARE | Online – 20 January 2021 – The complex needs and demands of informal caregivers (ICs) have exposed numerous system level challenges in the current healthcare climate. ICs need integrative, supportive interventions such as access to health/caregiving education, helpful resources, mindful coping strategies, and others. While European countries are actively working on acknowledging the role of ICs and developing programs such as the Integrative Palliative Care Initiative to meet their complex needs, Canada is lagging behind in designing and implementing a rapid reform in this field. Current supports such as the Compassionate Care Benefit (CCB) are not always known and can be inadequate for the needs of ICs as described above. Robust policy change is required to empower ICs. Policymakers need to recognize the contribution of ICs, for this is the first step toward a system level change and development of active strategies to lighten their burden. **Full text:** http://bit.ly/2Y0agg2

Talking improves the subjective life of the dying person: Review of the literature

MÉDECINE PALLIATIVE | Online – 19 January 2021 – End-of-life (EoL) care tends towards good treatment, from the announcement of the diagnosis and throughout the entire medical course until death. The palliative approach gives reference points concerning this benevolent accompaniment coming from the French legislative framework, international scientific research, the authors' practice, presuppositions, sensitivity. In palliative care, the law of 2016 governs the last moments of life by introducing three new rights: the right not to suffer unreasonable obstinacy, the right for the person to be respected in his or her will – notably through the possibility of drafting anticipated directives (AD) – the right to be relieved of pain and suffering. Is this law satisfactory? Does it allow French people to choose their EoL? While the French welcome the right to draft ADs, few have actually drafted them. What exactly do the French want at the end of their lives? How do they need support? How to open up a space for speaking conducive to dialogue on the wishes and fears of the person at the EoL? Are these questions posed by the societal debate likely to favor the evolution of legislation towards the right to euthanasia or assisted suicide? The authors develop a reflection supported by the review of international and French literature. **Abstract:** http://bit.ly/38Whgkh

N.B. French language article.

Current status of clinical practice guidelines on palliative sedation for adults in French-speaking countries

BULLETIN DU CANCER | Online – 15 January 2021 – Many clinical practice guidelines on palliative sedation have been developed. To date, studies on French-language guidelines are lacking, despite the specific and potentially influential end-of-life positions taken by some French-speaking countries. Twenty-one guidelines from 18 countries were identified. Among them, at the time of the data collection, 14 guidelines were effectively compiled in four countries or provinces: Belgium, France, Canada (Quebec) and Switzerland. No guidelines were found for African countries. The recommendations analyzed were very heterogeneous in form (simple proposals or formal guidelines) and in substance (i.e., different types of sedation). The quantity and volume of the guidelines found and the heterogeneity of the terminology prevented a detailed analysis of the content of the texts. An analysis must be performed using a synchronic approach only and focusing on a specific element of one type of sedation. **Abstract:** http://bit.ly/2M8KgwA

N.B. French language article. Search back issues of Media Watch for additional articles on palliative sedation at: http://bit.ly/2ThijkC

Validation of the responding to urgency of need in palliative care (RUN-PC) triage tool

PALLIATIVE MEDICINE | Online – 21 January 2021 – The Responding to Urgency of Need in Palliative Care (RUN-PC) Triage Tool is a novel, evidence-based tool by which specialist palliative care (PC) services can manage waiting lists and workflow by prioritising access to care for those patients with the most pressing needs in an equitable, efficient and transparent manner. An online survey of PC intake officers applying

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the RUN-PC Triage Tool to a series of 49 real clinical vignettes was assessed against a reference standard: a postal survey of expert PC clinicians ranking the same vignettes in order of urgency. The RUN-PC Triage Tool has good intra- and inter-rater reliability in inpatient, hospital consultation and community PC settings, and moderate to good correlation to expert opinion used as a reference standard. **Abstract (w. list of references):** http://bit.ly/2Y7WesI

N.B. Additional articles on triaging the terminally ill noted in Media Watch 21 December 2020 (#697, p.3).

Spanish medical interpreters' management of challenges in end-of-life discussions

PATIENT EDUCATION & COUNSELING | Online – 21 January 2021 – The authors conducted semi-structured interviews with professional Spanish medical interpreters. They asked about their experiences interpreting end-of-life (EoL) discussions, including questions about values, professional and emotional challenges interpreting these conversations, and how those challenges might impact accuracy. Seventeen Spanish language interpreters participated. Participants described intensive attention to communication accuracy during EoL discussions, even when discussions caused emotional or professional distress. Professional strains such as rapid discussion tempo contributed to unintentional alterations in discussion content. Perceived non-empathic behaviors of providers contributed to rare, intentional alterations in discussion flow and content. The authors found that despite challenges, Spanish language interpreters focus intensively on accurate interpretation in discussions of EoL. **Abstract:** http://bit.ly/3iEwmhW

N.B. Selected articles on the role of medical interpreters in EoL discussions noted in Media Watch 14 December 2020 (#696, p.6).

Maintaining control: A qualitative study of being a patient in need of specialized palliative care during the COVID-19 pandemic

PROGRESS IN PALLIATIVE CARE | Online – 18 January 2021 – Being a patient in need of specialized palliative care (PC) during the COVID-19 pandemic is challenging. Governments around the world have reduced the available healthcare services as well as restricted in-person meetings between patients, healthcare professionals (HCPs), and relatives. The aim of this study was to explore the experiences of patients with specialized PC needs during the period of restrictions requiring social distancing due to the COVID-19 pandemic. The analysis of this qualitative study was guided by a grounded theory approach. The participants were patients living in their own homes who were being treated by the outpatient clinic PC unit at the Herlev & Gentofte University Hospital in Denmark. Participants' main concern was maintaining control during the pandemic. They achieved this by aiming to secure a meaningful life by remaining occupied during the day, balancing social contact, contemplating the reopening of society, and seeking help from HCPs. Participants were concerned about losing control and this concern increased with the reopening of society. HCPs must ensure that they provide support and care for patients with specialized PC needs when societal restrictions change. **Full text:** https://bit.ly/3sDLbpg

Research Matters

What should we report? Lessons learnt from the development and implementation of serious adverse event reporting procedures in non-pharmacological trials in palliative care

BMC PALLIATIVE CARE | Online – 20 January 2021 – The need to improve the quality of reporting of serious adverse events in trials has been recognised but there is a lack of practical guidance on how to manage this process, particularly in palliative care (PC) non-pharmacological trials. This may be because published trial protocols and results papers may have limited space to document these processes and/or they are challenging to implement because of the characteristics of a PC trial. The authors address this issue by presenting a number of recommendations based on the lessons learnt from managing serious adverse event reporting procedures in two non-pharmacological trials in PC. **Full text:** http://bit.ly/2Y073Nz

Designing and undertaking randomised implementation trials: A guide for researchers

BRITISH MEDICAL JOURNAL | Online – 18 January 2021 – Implementation science is the study of methods to promote the systematic uptake of evidence-based interventions into practice and policy to improve health. Despite the need for high quality evidence from implementation research, randomised trials of implementation strategies often have serious limitations. These limitations include high risks of bias, limited use of theory, a lack of standard terminology to describe implementation strategies, narrowly focused implementation outcomes, and poor reporting. This article aims to improve the evidence-base in implementation science by providing guidance on the development, conduct, and reporting of randomised trials of implementation strategies. Established randomised trial methods from seminal texts and recent developments in implementation science were consolidated by an international group of researchers, health policy makers, and practitioners. This article provides guidance on the key components of randomised trials of implementation strategies, including articulation of trial aims, trial recruitment and retention strategies, randomised design selection, use of implementation science theory and frameworks, measures, sample size calculations, ethical review, and trial reporting. It also focuses on topics requiring special consideration or adaptation for implementation trials. The authors propose this guide as a resource for researchers, healthcare and public health policymakers or practitioners, research funders, and journal editors with the goal of advancing rigorous conduct and reporting of randomised trials of implementation strategies. **Full text:** https://bit.ly/2XSng7q

Extract from *British Medical Journal* articles

This guide is also aimed at journal editors, reviewers, and funders of implementation research as a resource to improve the quality of the implementation science evidence base.

Video-based online interviews for palliative care research: A new normal in COVID-19?

PALLIATIVE MEDICINE | Online – 21 January 2021 – There is no doubt that COVID-19 has significantly disrupted the course of health and clinical research. In some cases, researchers may have had to arrest data collection or re-design studies to accommodate to COVID-19. However, despite the challenges of carrying out research during COVID-19, researchers in palliative care (PC) are conducting research including research on PC needs in the context of COVID-19. The pandemic has necessitated online participation in studies, particularly for studies involving patients and caregivers. Across research fields, we are now beginning to see online data collection moving beyond the confines of surveys, electronic forums, and chat and instant messaging services. Videoconferencing platforms such as Zoom, Webex, GoToMeeting, Skype and Microsoft Teams are being used by researchers in the context of social distancing measures imposed by the pandemic. In qualitative research, video-based online interviews are emerging as a substitute to traditional "in-person" interviews as researchers and research participants adapt to the conditions of COVID-19. Videoconferencing platforms allow for maintaining the face-to-face element of interviewing even when the researcher is not physically proximate to participants. **Full text:** http://bit.ly/3iC0vy2

Media Watch: Editorial Practice

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Something Missed or Overlooked?

IF YOU ARE AWARE OF A CURRENT REPORT, ARTICLE, ETC., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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