

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.

14 June 2021 Edition | Issue #721



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During 2020, pressure on community palliative and end-of-life care surged, reaching levels of need not expected until 2040. Combined with existing gaps in the workforce, this suggests an urgent need to grow and train community clinicians skilled in palliative care.

'Dying at home during the pandemic: Increase in home deaths could be because of preference or pressure' (p.5), in *British Medical Journal*.

U.S.A.

National Hospice & Palliative Care Organization releases statement on resource allocation

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 11 June 2021 – Reflecting on the experience of the hospice and palliative care (PC) provider community throughout the course of the past year's global pandemic, the organization's board has issued a statement for providers, 'Allocation of Scarce Resources During a Pandemic.' This document is designed as a resource for hospice and PC leaders and their organizations when facing future resource allocation decisions. One of the most difficult ethical questions in healthcare is the fair allocation of scarce resources. The purpose of this document is to: 1) Assist hospice and PC leaders and organizations to (re)familiarize themselves with a small set of ethical concepts as they face resource allocation decisions; 2) Introduce four principles of healthcare ethics and place them in the context of resource allocation; and, 3) Guide leaders and

their organization through a compact decision-making and discernment model, mainly as a means to raise attention to a handful of foundational questions central to the topic. **Download statement at:** <https://bit.ly/3wfbWlt>

Specialist Publications

'**LIGHT: A church-based curriculum for training African American lay health workers to support advance care planning and end-of-life decision-making**' (p.4), in *Healthy Equity*.

'**Increasing advance care planning conversations among Korean Americans through a faith community nurse intervention**' (p.7), in *Journal of Christian Nursing*.



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.

International

New South Wales government boosts palliative care budget

AUSTRALIA (New South Wales) | Australian Associated Press (Sydney) – 10 June 2021 – Almost \$83 million more will be tipped into palliative care (PC) services in New South Wales (NSW) in this month's state budget, Treasurer Dominic Perrottet says. The funding would boost hospital-based palliative services in western Sydney including inpatient beds. It would also include up to 120 additional PC workers, increased care to boost patient independence at home and additional carer support. Some \$220 million is already spent each year in NSW on PC. The funding also includes \$2 million for the under-construction Manly Adolescent and Young Adult Hospice. <https://bit.ly/3xc4SpH>

Benefits claimants suffering under end-of-life Department for Work & Pensions rule

U.K. | *The Guardian* (London) – 9 June 2021 – More than 100 terminally ill people are each month being rejected for benefits despite having less than six months to live, and many are spending their final weeks fighting in vain for social security support, say campaigners. The Marie Curie and the Motor Neurone Disease Association charities have called for an urgent review of Department for Work & Pensions (DWP) rules after official data revealed that in an 18-month period 1,860 people in the U.K. died within six months of their claim for disability benefits being turned down. The charities said the government had to scrap the restrictive "six-month rule" under which people must prove they have six months or less to live to access fast-track benefits support. The charities said data, collected between April 2018 and October 2019, raised "serious concerns" about the DWP's ability to recognise when a claimant was approaching the end of life. They said they wanted to see rapid access to benefits kicking in as soon as terminal illness medical diagnoses were made. <https://bit.ly/351sjWT>

Noted in Media Watch 15 March 2021 (#708, p.3):

- U.K. | *The Daily Mail* (London) – 9 March 2021 – **'Grieving families still being denied help a year after landmark High Court ruling.'** Bereaved unmarried parents are still being denied thousands of pounds of vital support, a year after a landmark High Court ruling. Married couples and those in civil partnership can claim £9,800 through Bereavement Support Payment if their partner dies – a £3,500 initial lump sum plus 18 monthly payments of £350. A judge ruled the Department for Work & Pensions (DWP) was breaching human rights by not giving help to children of unmarried parents – but the Government is yet to act. Some 1,600 families with more than 2,800 children have been denied the cash since the ruling, the Childhood Bereavement Network says. <http://bit.ly/2OGJgke>

End of life fast track care is a postcode lottery which leaves many unable to fulfil their dying wishes

U.K. (England) | Marie Curie – 8 June 2021 – 'No time to wait: The state of Fast Track Continuing Healthcare in England' has revealed that on the eve of the COVID-19 pandemic, almost half of Clinical Commissioning Groups (CCGs) in England were not meeting the 48-hour standard for delivering Fast Track Continuing Healthcare (CHC) packages set out in the National Framework. Data Marie Curie sourced from CCGs

Specialist Publications

'Community end-of-life care during COVID-19: Findings of a U.K. primary care survey' (p.10), in *BJGP Open*.

'Cultural competency and sensitivity in the curriculum for palliative care professionals: A survey in Switzerland' (p.4), in *BMC Medical Education*.

'Development and implementation of a transmural palliative care consultation service: A multiple case study in The Netherlands' (p.5), in *BMC Palliative Care*.

'Projecting palliative and end-of-life care needs in Central Lancashire up to 2040: An integrated palliative care and public health approach' (p.12), in *Public Health*.

Cont.

through Freedom of Information requests has revealed that in some parts of the country, people who are dying can be left waiting in hospital for more than a week before care is put in place to allow them to leave. Fast Track CHC is crucial to ensuring seriously ill and dying people receive the appropriate support they need to enable them to leave or prevent admission to hospital. This is often a key factor that allows people to die in the place they choose. Delays in putting Fast Track CHC in place can lead to people dying in hospital before a package of care is put in place, which can cause significant distress for those at the end of their lives and their loved ones. More than two-thirds of people wish to die at home, but around half of people ultimately die in hospital. Only 46% of respondent CCGs could meet the 48-hour deadline for getting fast track care in place to enable dying people to be cared for outside of hospital. **Download at Marie Curie report at:** <https://bit.ly/3gdDHnE>

Noted in Media Watch 31 May 2021 (#719, p.2):

- U.K. | Hospice UK – 26 May 2021 – ‘**Hospice UK report examines equality in the hospice and end-of-life sector.**’ Hospice UK has launched a new report looking at the inequalities in access to end-of-life (EoL) care some people experience. ‘Equality in Hospice & End-of-Life Care’ outlines what needs to be done ... to ensure that everyone – no matter who they are, where they are or why they are ill – receives the best possible care at the end of their life. Everyone has the right to high quality care and support at the EoL. But many people are still not enabled to access the help they need in their final days and months. Inequalities of access and standards of care are particularly felt by those who have already encountered unfairness and discrimination throughout their lives.. **Download report at:** <https://bit.ly/3bXkTb3>

Specialist Publications

An interprofessional approach to advance care planning

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 7 June 2021 – Role confusion in advance care planning (ACP) facilitation among team members from different disciplines exists, and health professional disciplines’ expectations for interprofessional collaboration in ACP are unclear. Guidelines and recommendations for ACP across disciplines including chaplaincy, medicine, nursing, psychology, and social work were identified and analyzed using content analysis. Main themes were then reviewed against national consensus statements on four ACP outcomes (process outcomes, action outcomes, quality of care outcomes, and healthcare outcomes), and mapped into existing domains for interprofessional education competency: values/ethics, roles/responsibilities, interprofessional communication, and teams and teamwork. Three major content themes were identified: professional commitment to advocating for patients’ values and self-determination, professional responsibility to facilitate ACP, and specific tasks in ACP. These themes addressed mostly process and action outcomes of ACP, but not quality of care outcomes or healthcare outcomes. Few disciplines included interprofessional collaboration as part of ACP competency. There is a need for

standardized competency guidelines for interprofessional collaboration in ACP as an important first step in reducing confusion among roles and other challenges in facilitating ACP. Further efforts in practice, research, and policy are needed to facilitate interprofessional ACP, achieve competencies, and improve patients’ outcomes. **Abstract (w. references):** <https://bit.ly/3fYnPqn>

Research Matters

‘Family caregiver partnerships in palliative care research design and implementation’ (p.13), in *Pediatrics*.

Publishing Matters

‘Predatory publishing solicitation: A review of a single surgeon’s inbox and implications for information technology resources at an organizational level’ (p.13), in *Canadian Journal of Surgery*.

‘Dealing with predatory journal articles captured in systematic reviews’ (p.14), in *Systematic Reviews*.

Cont.

Related:

- *HEALTHY EQUITY* | Online – Accessed 8 June 2021 – ‘**LIGHT: A church-based curriculum for training African American lay health workers to support advance care planning and end-of-life decision-making.**’ A partnership of academia with the African American Church can create a curriculum for training lay health workers (LHWs) for the principal role of enhancing and facilitating communications about end-of-life (EoL) decision-making. Health inequities of African Americans at the EoL require new interventions and approaches to care. Funders and health systems are increasingly deploying LHWs to meet this need. Communications of LHWs with African Americans about ... EoL decision-making should be buttressed by community-centered discussions and education. **Full text:** <https://bit.ly/3pvhJAK>
- *PATIENT & EDUCATION COUNSELING* | Online – 9 June 2021 – ‘**Promoting advance care planning via mediated health resources: A systematic mixed studies review.**’ Mediated advance care planning (ACP) resources and materials are useful tools to encourage ACP in adults. Various message design options have been used in intervention studies to inform target audiences about ACP and move them forward in the behavior change process. Even though the current body of research on mediated ACP interventions suggests positive associations between mediated ACP messages and ACP process and action outcomes, more research is needed to design and test different kinds of ACP messages to increase individuals’ engagement in the ACP process. **Full text:** <https://bit.ly/3w8F3H4>

Cultural competency and sensitivity in the curriculum for palliative care professionals: A survey in Switzerland

BMC MEDICAL EDUCATION | Online – 4 June 2021 – This survey produced original findings on Swiss palliative care (PC) professionals’ experiences with migrant patients and their training needs and interests related to cross-cultural care. They perceived interactions with migrant patients and their relatives to be difficult. The PC professionals identified language barriers, sensitive topics (e.g., end-of-life, death, and intimacy) and patients’ comprehension of illness and the healthcare system (e.g., role of PC) as major challenges in these interactions. In comparison, collaborating with other professionals (e.g., interpreters) and relatives was reported to be rather unproblematic, as was examining one’s own stereotypes. A vast majority of the respondents also reported a high level of interest in cross-cultural training. Their priorities were in line with their answers on difficulties in cross-cultural clinical interactions. Courses on techniques to provide access to migrant patients’ lifeworld and priorities (e.g., perceptions of illness and death, expectations, and meaning of symptoms) were reported to be among the most important needs. Learning how to collaborate with others and learning how to examine stereotypes were lower priorities. **Full text:** <https://bit.ly/3cnsO11>

N.B. Search back issues of Media Watch for additional articles on PC for the “migrant”/“immigrant” population at: <http://bit.ly/2ThijkC>

Related:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 7 June 2021 – ‘**Equal palliative care for foreign-born patients: A national quality register study.**’ Foreign-born patients were less likely to be cared for in specialized palliative care (PC) units and had poorer access to PC teams than Swedish-born patients, despite having a higher proportion of cancer diagnoses. However, no general pattern was found indicating that foreign-born patients were disadvantaged in the quality indicators measured in the present study. Perhaps, this is an indication that the PC in Sweden is individualized; nonetheless, the quality of end-of-life care would be higher if dying patients, regardless of country of birth, have better access to specialized PC. **Abstract (w. references):** <https://bit.ly/3x4kETs>

Development and implementation of a transmural palliative care consultation service: A multiple case study in The Netherlands

BMC PALLIATIVE CARE | Online – 5 June 2021 – In The Netherlands, healthcare professionals attending patients in the last phase of life, can consult an expert palliative care (PC) team in case of complex problems. There are two types of PC teams: regional PC teams, which are mainly consulted by general practitioners, and hospital PC teams, which are mainly consulted by healthcare professionals in the hospital. Integration of these PC teams is expected to facilitate continuity of care for patients receiving care in different settings. The authors studied facilitators and barriers in the process of developing and implementing an integrated transmural PC consultation service. Healthcare professionals are motivated to collaborate in a transmural PC consultation service, but the development of such a service is a time consuming and complex process. Several facilitators and barriers play a role. The representation of multiple care organisations in the project teams made the development and implementation of a transmural PC consultation service complex. Healthcare professionals from different care organisations differed in perspectives on PC and working procedures. When developing the transmural consultation service, the authors mostly found ways to deal with these differences. Support of the management of several care organisations, which is needed to involve sufficient PC experts, was sometimes lacking. Those involved in the development of the transmural consultation service felt that they were insufficiently supported for their efforts and time investments.

Full text: <https://bit.ly/3ggZtqu>

Dying at home during the pandemic: Increase in home deaths could be because of preference or pressure

BRITISH MEDICAL JOURNAL | Online – 8 June 2021 – Any shift towards more deaths at home needs to consider the size of the community palliative care (PC) workforce. In 2018, researchers predicted that as the annual numbers of deaths increased over the coming two decades, community capacity would need to double unless hospital capacity increased substantially.¹ During 2020, pressure on community palliative and end-of-life (EoL) care surged, reaching levels of need not expected until 2040. Combined with existing gaps in the workforce, this suggests an urgent need to grow and train community clinicians skilled in PC. Help from family members and informal carers is a critical and often overlooked component of care at home. The furlough scheme and increase in working from home may have made it easier for some people to provide the flexible care needed to support those important to them at the EoL. In research done before the pandemic, for example, support from family members significantly increased the odds (range 1.78 to 7.85) of patients with cancer dying at home.² For others, however, pandemic restrictions such as shielding and travel bans may have prevented them from providing support. A detailed plan for better PC, *You matter because you are you*, recently published by Cicely Saunders International, gives a comprehensive approach to filling the gaps in palliative and EoL care. Providing expertise in places where people are cared for, joining up care, empowering patients to access PC, and increasing community support, training, and research are all essential to ensure that patients receive high quality EoL care in the place of their choosing – often at home.³ **Full text:** <https://bit.ly/3zaqvbr>

1. 'What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death,' *Palliative Medicine*, first published online 10 October 2017. [Noted in Media Watch 16 October 2017 (#534, p.16)] **Full text:** <https://bit.ly/3cr5a4a>
2. 'Factors influencing death at home in terminally ill patients with cancer: systematic review,' *British Medical Journal*, first published online 2 March 2006. **Full text:** <https://bit.ly/2TKzMXL>
3. 'You Matter Because You Are You: Action Plan for Better Palliative Care,' Cicely Saunders International, January 2021. [Noted in Media Watch 1 February 2021 (#702, p.6)] **Download at:** <http://bit.ly/2YhksAT>



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Perspectives on palliative care in chronic obstructive pulmonary disease

CHEST, 2021;159(6):2133-2134. Despite benefits to patients who are dying with non-cancer illnesses that include reduced hospitalizations, emergency visits, ICU admissions, and a greater likelihood of dying at home, palliative care (PC) is consistently underutilized for patients with advanced chronic obstructive pulmonary disease (COPD). Challenges with accurate prognostication and identification of the optimal time to initiate PC for patients with COPD are frequent barriers. The synonymous use of the terms “palliative care” and “end-of-life care” contribute to these barriers. Yet, the definition of PC has evolved in recent years to extend beyond the terminal phase. Patients with COPD would benefit from an approach that integrates PC and standard care early in the disease course and that offers the flexibility of intensifying care as the patients’ health status changes. **Full text:** <https://bit.ly/350WHke>

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

Incorporating palliative care into oncology practice: Why and how

CLINICAL ADVANCES IN HEMATOLOGY & ONCOLOGY, 2021;19(6):390-395. The provision of specialty palliative care (PC) alongside oncology care is now recommended by the American Society of Clinical Oncology on the basis of multiple randomized trials showing that it leads to better symptom control, less depression and anxiety, improved quality of life (QoL), improved caregiver QoL, and even longer survival. That said, simply not enough PC specialists are available to provide concurrent care, so oncologists are tasked with providing the greatest part of primary PC. It is useful to think of primary PC as comprising two skill sets, or “bundles”: the first symptom assessment and management, and the second communication. Symptom assessment begins with the use of a standardized scale that emphasizes the assessment of anxiety, depression, physical symptoms, and coping strategies. Communication requires knowing how much information the patient and family want, especially about prognosis, and involves shared decision-making. It also encompasses advance care planning, starting with the identification of a medical power of attorney and proceeding to a discussion about hospice and end-of-life (EoL) treatment choices. The communication skill set includes providing caregiver support and spiritual care referral, making culturally appropriate decisions, and providing a specific statement of non-abandonment near EoL. If specialty PC is involved, data show that the effect on QoL and EoL choices is most meaningful if consultation is started at least 3 months before death. In this article, The authors provide

a brief overview of the benefits of incorporating PC into routine oncologic practice and offer clinical pearls on how best to deliver the tenets of PC in the outpatient and inpatient settings. **Full text:** <https://bit.ly/2SoiMq3>

Actual and missed opportunities for end-of-life care discussions with oncology patients: A qualitative study

JAMA NETWORK OPEN | Online – 10 June 2021 – In this secondary analysis of outpatient oncology visits, end-of-life (EoL) discussions were rare and missed opportunities for these discussions were common. When oncologists did discuss EoL, they framed it around trade-offs, anticipatory guidance, and acknowledging patients as experts. In these instances, oncologists adeptly responded to patients’ emotions and expressed empathy. In contrast, missed opportunities for EoL discussions were characterized by failure to acknowledge patients’ concerns over disease progression, dying, or burdensome adverse effects; oncologists often responded to such concerns with optimism about prognosis or pessimism about treatment discontinuation. Although the authors recognize that not every patient or appointment may necessitate an EoL discussion, all patients in this study had stage IV malignant neoplasm and their oncologists had previously acknowledged that they “would not be surprised if they were admitted to an intensive care unit or died within one year.” Despite the urgent necessity of EoL discussions within this population, we found far more missed opportunities than actual discussions in this analysis. **Full text:** <https://bit.ly/3czwopy>

N.B. Search back issues of Media Watch for additional articles on PC in “hematology” and “oncology” at: <http://bit.ly/2ThijkC>

Cont.

Related:

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 7 June 2021 – ‘**Impact of palliative care involvement on end-of-life care patterns among adolescents and young adults with cancer: A population-based cohort study.**’ The authors aimed to evaluate the prevalence and predictors of high-intensity (HI) end-of-life care (EoLC) in AYAs with cancer across the entire province of Ontario, Canada. A secondary aim was to determine whether palliative care (PC) physician involvement is associated with lower-intensity EoLC. Almost half of AYAs experienced HI-EoLC... PC physician involvement substantially reduced the odds of AYAs receiving both HI and the most invasive EoLC (i.e., intensive care unit death and mechanical ventilation). **Abstract:** <https://bit.ly/3x5aP7R>

Intensity of outpatient physician care in the last year of life: A population-based retrospective descriptive study

CMAJ OPEN, 2021;9(2):E613-E622. The findings of this study have implications for operationalizing Canada’s national palliative care framework, which has called for models of care led by primary care providers in a shared-care approach. The average number of outpatient specialties involved in care in the last year of life was nearly 4, with an average of 6 different physicians involved. With multiple physicians involved in care, it is possible continuity of care, in the relational sense, could be disrupted. The authors did not examine the extent of shared care or communication among physicians, and the results do not suggest this is lacking. Their findings do suggest a need for understanding how best to organize care among multiple physicians to meet patients’ changing needs over the last year of life. Although home visits by physicians to patients who are at the end of life (EoL) are associated with reduced likelihood of emergency department visits and hospital death, the results of this study are consistent with other studies reporting home visits are infrequent. In the last year of life, patients have many encounters with various physicians in outpatient settings, and the volume and mix vary by EoL trajectory. Family physicians are the predominant specialty. Those who plan healthcare

models of the EoL should consider support for family physicians to coordinate care and ways to optimize the complementary roles of different physicians while maintaining adequate continuity for patients. **Full text:** <https://bit.ly/3cnBbtN>

Extracts from *CMAJ Open* article

Medical specialists may step back as patients move closer to death and are transitioned to palliative and EoL care. These patterns vary by the illness trajectory. Patients dying of organ failure or dementia are less likely to receive PC services, or they receive them closer to the EoL, compared with patients with cancer.

By definition, PC should be initiated early and provided in the community; however, specialized PC teams in the community cannot meet all of the needs of the population. This necessitates viewing healthcare throughout the last year of life as an opportunity to address palliative needs. Therefore, it is important to understand overall patterns of care across the health care system when planning services for the EoL period, and inpatient hospital and PC services do not provide a full picture.

Related:

- *JOURNAL OF CHRISTIAN NURSING*, 2021;38(3):187-193. ‘**Increasing advance care planning conversations among Korean Americans through a faith community nurse intervention.**’ Minority populations have lower rates of advance care planning (ACP) than the general population. Faith community nurses (FCNs) can facilitate ACP training to improve end-of-life (EoL) care outcomes for patients and caregivers. A nurse-led ACP training delivered to a primarily Korean American faith community increased the number of families who discussed EoL care values and wishes. Considerations for ACP outreach to Korean Americans and implications for FCNs are discussed. **Abstract:** <https://bit.ly/3izECBP>



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Implantable cardiac defibrillator deactivation during end-of-life care in the COVID-19 pandemic

JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE, 2021;34(3):474-476. People with implantable cardiac defibrillators (ICDs) who are nearing the end of life (EoL) are at risk for arrhythmias, which activate the ICD and may cause unnecessary shocks and suffering. Because ICDs have enabled more patients to live longer, they often succumb to noncardiac diseases and may be cared for by primary care physicians. Despite published recommendations 10 years ago regarding the management of ICDs during the EoL, over half of patients with ICDs who are dying still have not been offered the choice of deactivation. The COVID-19 pandemic has complicated this issue and the need to discuss it because of practices that separate patients from loved ones and that modify the usual interactions of patients with doctors and nurses. The authors offer the following recommendations: 1) The management of ICDs at the EoL needs to be understood by all physicians who care for patients with ICDs; 2) Discussions about deactivating the ICD should occur while patients have decision-making capacity and are clinically stable, beginning at the time of ICD implantation, then periodically at follow-up appointments, and certainly when a change in the patient's clinical status warrants a reconsideration of the goals-of-care (GoC); and, 3) Clinicians should compensate for the impediments to communication with patients and families associated with the COVID-19 pandemic, which includes patient isolation and restrictive visitor policies, by using devices that permit visual communication to reexamine GoC, including defibrillator deactivation, in patients with ICDs who are expected to die. **Full text:** <https://bit.ly/3psrNKF>

Noted in Media Watch 17 May 2021 (#717, p.6):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 May 2021 – ‘**When, how and who should discuss deactivation with patients: A systematic literature review.**’ The authors identified five main themes: 1) Timing of implantable cardioverter defibrillators deactivation discussions; 2) Initiation of deactivation discussions; 3) Advance directives; 4) Barriers to discussions; and, 5) Facilitators of discussions. Despite available guidelines, conversations on device deactivation are not being undertaken consistently. Evidence suggests lack of professional awareness of guidelines and limited training in communication skills. There needs to be a proactive clinical and policy initiative in the education of both professionals and patients and their relatives about device deactivation. **Abstract:** <https://bit.ly/3vNCPfu>

Inmates care: Computer-based training for geriatric and end-of-life care in prisons

JOURNAL OF CORRECTIONAL HEALTH CARE | Online – 4 June 2021 – The growing aged and dying incarcerated population increases demands on corrections healthcare. People who are incarcerated can assist in care delivery; however, currently, their training is typically face-to-face, home grown, and variable in content and duration. Three prototype modules – standard precautions; loss and grief; and, the role of the inmate caregiver in the final Hours – were developed in consultation with an advisory board. Face-to-face usability testing with peer caregivers and staff confirmed contextual relevance and feasibility of the inmates care training. Inmates Care holds promise to complement nurse-led training with a standardized e-training package. **Abstract:** <https://bit.ly/3cB1CfX>

N.B. Palliative and end-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report, last updated 1 May 2021, can be downloaded at the Palliative Care Network website at: <http://bit.ly/2RdegnL>

[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>



“She’s not ready to give up yet!”: When a family member overrides the patient’s medical decisions

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 June 2021 – Autonomy, which gives individuals the right to make informed decisions about their medical treatment, is a central principle in Western bioethics. However, we often encounter patients for whom a family member seems to dominate medical decision-making, to the extent that clinicians become concerned that the patient is subject to excessive pressure or even coercion. In this article the authors describe one such case and how they assessed a decision-making process that involves family influence. This entailed acknowledging that many individuals weigh their family member’s preferences and/or well-being heavily in making medical decisions, and family norms for decision-making differ. A family member who tells their loved one “You can’t give up now” is typically not usurping the patient’s liberty to make a different decision. However, there are some family influences which may be autonomy-limiting, including those that include credible threats, or in situations of abuse. Aside from these scenarios, our role is not to alter a couple’s long-standing dynamics and decision-making processes. However, for the patient who

wants to assert herself, we can set the stage in a family meeting and amplify her voice. We must also attend to the emotional level of family members’ statements. “I won’t let you give up” might be more a statement of grief rather than a true reflection of their values or intent. Supporting the family member’s coping may help to bring together what initially seem to be divergent goals. Exploring these decision-making dynamics is key to providing good palliative care. **Abstract (w. references):** <https://bit.ly/351byLx>

The hands of time

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 June 2021 – When making decisions about goals-of-care for a patient who lacks decision-making capacity, surrogates sometimes have internal disagreements, particularly if there are complicated family dynamics. The author describes the evolution of end-of-life discussions for a patient who had a catastrophic stroke amongst a family who had pre-existing discord. **Abstract:** <https://bit.ly/35aO6eN>

Noted in Media Watch 7 June 2021 (#720, p.9):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2021;325(21):2147-2148. ‘**Reconceptualizing how to support surrogates making medical decisions for critically ill patients.**’ The authors propose a broader and more individualized view of how to support surrogate decision-makers that involves not only providing clear information but also attending to the intense emotional and psychological difficulty of making major decisions for critically ill patients who lack decisional capacity. These considerations may be particularly important for individuals from historically marginalized communities, for whom distrust of the medical system and prior psychological trauma may be prevalent, such that a patient’s critical illness could be experienced as a retraumatizing event. **Full text:** <https://bit.ly/3wQqBDp>

Innovation in a crisis: Lessons learned from the rapid development of an end-of-life palliative care unit during the COVID-19 pandemic

JOURNAL OF PALLIATIVE MEDICINE | Online – 4 June 2021 – The COVID-19 pandemic has presented new challenges and opportunities for palliative care (PC) delivery. As COVID-19 surged in Boston in March of 2020, the authors saw a rapid influx of patients admitted to inpatient surge teams at Massachusetts General Hospital, many of whom were suffering from immense physical and psychosocial symptoms at the end of life (EoL). There were also significant systems challenges that made usual EoL care challenging. Community shortages of personal protective equipment presented a barrier to discharge to home or to subacute facilities with hospice care. Family concerns for COVID-19 exposure also made discharge to home hospice difficult. Simultaneously, the hospital’s inpatient capacity to care for new COVID-19 patients was stretched thin. The charge of the hospital’s PC team then became: how can we ensure compassionate PC for those dying amid an escalating pandemic while simultaneously reducing the burden on inpatient teams? To address these challenges, the inpatient PC team rapidly developed the Palliative Care Compassion Unit for patients with and without COVID-19 at EoL. **Full text:** <https://bit.ly/2SjssCf>

Cont.

Related:

- *BJGP OPEN* | Online – 11 June 2021 – ‘**Community end-of-life care during COVID-19: Findings of a U.K. primary care survey.**’ This study, based on the findings of a web-based survey, has identified the contrasting and potentially conflicting roles that emerged between general practitioners and community nurses in their responses to the increased demand and complexity of palliative and end-of-life care in the community in the early months of the COVID-19 pandemic. The significant emotional impact, especially for community nurses, needs to be addressed alongside promoting effective, collaborative and mutually supportive team working that can recognise and quickly adapt to changing patient needs. **Full text (click on pdf icon):** <https://bit.ly/3cCxqte>
- *PALLIATIVE MEDICINE* | Online – 8 June 2021 – ‘**Communication in palliative care during the COVID-19 pandemic: Lessons from rapidly changing, uncertain, complex, and high-stake interventions.**’ The suffering caused by COVID-19 is devastating and patients, families, healthcare professionals and systems can benefit from the knowledge of palliative care (PC). Strategies to extend PC during and after COVID-19 include immediate responsiveness to adapt to pandemic parameters, as well as the long-term preparedness strategies that embed PC into the core of healthcare practices, services and systems. We need to understand how to achieve this effectively and what is the best way to evaluate new models of communication and PC provision in this dynamic context. **Full text:** <https://bit.ly/3pvVxGN>

How to deal with the past memories of patients in palliative care: A suggested new approach

KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE, 2021;24(2):69-73. Dealing with existential concerns experienced by patients is an important part of palliative care (PC). Interventions that use the life review method to encourage patients to reminisce about their lives can help them find new positive meanings, promote ego integrity, and reduce emotional suffering. Not everyone has positive memories when they look back on the past, however. This poses a limit on the effectiveness of the life review method for healthcare providers working in PC contexts. In this study, the author discusses the limits of life review and suggest imagery rescripting as a new modality constituting a psychotherapeutic approach to deal with negative memories safely and effectively. **Full text:** <https://bit.ly/3pBsxx8>

European Resuscitation Council Guidelines 2021

Ethics of resuscitation and end-of-life decisions

NOTFALL + RETTUNGSMEDIZIN | Online – 2 June 2021 – 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 guideline primarily focus on major ethical practice interventions – i.e., advance directives, advance care planning, and shared decision-making – 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. **Full text:** <https://bit.ly/3vYRjKg>

N.B. German language article.

Related:

- *RESUSCITATION*, 2021;161(4):408-432. ‘**European Resuscitation Council Guidelines 2021: Ethics of resuscitation and end-of-life decisions.**’ The guidelines provide evidence-based recommendations for the ethical, routine practice of resuscitation and end-of-life care (EoLC) of adults and children. They 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. **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/3dmqgau>

‘Walking the Walk’: Support for carers of a loved one at the end of life

NURSING TIMES, 2021;117(7):32-34. ‘Walking the Walk’ is an initiative first developed to learn how to better meet the needs of carers in the acute hospital setting; this article describes a pilot adapting it for use in care homes, GP practices and community hospitals. Developed by a small team of carers and health professionals, it was born out of the need to improve the experience of distressed and grieving carers as their loved ones were approaching the end of life. Funded by National Health Service England, the project studied six sites (two in each care setting) from a large clinical commissioning group that were recruited by invitation. There was a focus on using the language of improvement, rather than inspection, to encourage open, collaborative discussions between the ‘Walking the Walk’ team and the host sites. The project has received overwhelmingly positive evaluation responses, with participants reporting a renewed motivation to better support and cater to the needs of carers. **Full text:** <https://bit.ly/3zbXI6W>

Palliative care in Switzerland

Public perception of palliative care: A survey of the general population

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 8 June 2021 – The authors aimed to generate a better understanding of the public’s perspectives of palliative and end-of-life (EoL) care in a predominantly German-speaking region of Switzerland. Visitors at an exhibition about palliative care (PC) in six locations provided hand-written answers on provided cards to two statements: 1) If I hear the term “palliative care” I think of... and, 2) When thinking about my own EoL, the following is important to me... The term “palliative care” was mostly associated with positive terms such as relief of symptoms and EoL with dignity. This is similar to other findings which show that the public associates PC with positive aspects such as good communication by professionals, delivery of comfort and improvement of quality of life. Understanding public perceptions about PC provides important information to address any potential misconceptions of the meaning of PC in this population. Among others, maintaining one’s own dignity as well as dying without suffering was essential to the visitors at the exhibition. The insights from this study could be used to educate the public regarding the specifics of PC and to eliminate the stigma that PC is only intended for the last days of life. The results may also help healthcare professionals to better understand how the public view PC. New strategies to engage the general population in PC initiatives need to be established. Therefore, it is essential that educational initiatives be developed for the public about the importance of an interprofessional and holistic PC approach early in the disease trajectory. **Full text:** <https://bit.ly/3ipXJy1>

Defining end of life in dementia: A systematic review

PALLIATIVE MEDICINE | In print – Accessed 7 June 2021 – This systematic review presents evidence that a definition for end of life (EoL) in dementia remains poorly defined, and unrepresentative of the general population with dementia. Research investigating palliative care (PC) that only includes cognitive or functional decline, may fail to recognise other significant signs and unmet needs relevant to dementia and EoL. The authors suggest that researchers and healthcare professionals in dementia care accept the complex nature of EoL in dementia between and within individuals. They advocate for a transition beyond defining EoL by disease-stage, and to consider signs beyond cognitive and functional decline. Identifying the appropriate signs and needs of individuals at the EoL with dementia will require further research, but this will be imperative to an improved understanding of EoL in dementia. Finally, identifying EoL in dementia through a needs-based approach may provide a more holistic and multidimensional view of PC, with a focus on addressing unmet needs. This approach may provide an improved response to EoL care for people with dementia and their families. **Full text (click on pdf icon):** <https://bit.ly/3pr9rKe>

N.B. Search back issues of Media Watch for additional articles on PC in “dementia” care at: <http://bit.ly/2ThijkC>



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

Organizational determinants of information transfer in palliative care teams: A structural equation modeling approach

PLOS ONE | Online – 3 June 2021 – Several organizational factors facilitate or hinder information transfer in palliative care (PC) teams. According to past research, organizational factors that reduce information transfer include the inconsistent use of shared electronic patient files, frequent changes of healthcare staff, a lack of opportunities for personal exchange, and a lack of evaluation of collaborative processes. Insufficient information sharing between professionals can negatively impact patient safety, whereas studies have shown that some organizational factors improve collaboration between professionals and thus contribute to improved patient outcomes. The main purpose of this study is thus to investigate whether, and if so how, organizational factors contribute to successful information exchange in PC teams in Switzerland, while also accounting for the different care contexts of primary and specialized PC. A nationwide survey was aimed at medical professionals working in PC. Findings revealed that the strongest predictors for effective information transfer in PC teams were sufficient opportunities for face-to-face meetings and supervision alongside feedback tools to improve collaborative practices and the application of guidelines and standards for collaboration. Face-to-face meetings were an even greater contributor to information transfer in specialized settings, whereas sharing the same work-based values with colleagues was considered more important in primary settings. Results from this study contribute to the existing literature elucidating how information transfer is facilitated in the field of PC. If proposed measures are implemented, this could possibly improve patient outcomes in PC. Furthermore, the findings can be useful for healthcare organizations and associations to make more efficient resource allocation decisions with the aim to optimize information transfer within the workforce. **Full text:** <https://bit.ly/3gfQPJ0>

Projecting palliative and end-of-life care needs in Central Lancashire up to 2040: An integrated palliative care and public health approach

PUBLIC HEALTH, 2021;195(6):145-151. A collaborative study was undertaken by palliative care (PC) and public health on behalf of Chorley & South Ribble and Greater Preston Clinical Commissioning Groups. Going beyond a traditional needs assessment by providing projections of local palliative and end-of-life care needs in all conditions over 20 years, the study will support locality commissioning and development of appropriate healthcare services. This study demonstrates practical application of public health data to support the development of locally responsive PC services. Dissemination of findings from this needs assessment on rising PC need, including numbers of deaths in different disease groups, provides direction to plan appropriate, equitable and sustainable services. Rapidly growing dementia deaths deserve particular attention in the planning of care. Collaborative work between public health and PC in other settings is encouraged, and will likely increase in significance as the full impact of COVID-19 is felt. **Abstract:** <https://bit.ly/3x9Uqz0>

A scoping research literature review to map the evidence on grief triggers

SOCIAL SCIENCE & MEDICINE | Online – 5 June 2021 – Grief is understandably severe in the first days, if not weeks or months, following the death of a beloved person. Unless the mourner develops complicated grief, which is prolonged severe and impactful grief, the initial acute grief lessens in severity over time, although waves of significant grief will still occur with grief triggers. A scoping research literature review was undertaken in early 2021 to determine how often grief triggers occur, what the most common grief triggers are, the impact of triggered grief, and what can be done (by those not diagnosed with complicated grief) to manage grief triggers and mitigate the effect of them. Six research papers relevant for review were published in the last two decades, with some evidence gained on how often grief triggers occur, what constitutes a grief trigger, and the impact of grief triggers. Major gaps in evidence were revealed, despite grief triggers being identified as a major consideration for grief in general and for grief recovery specifically. **Abstract:** <https://bit.ly/3in1zHZ>

Palliative care as a human right: A new challenge for the 21st century

UTOPIA Y PRAXIS LATINOAMERICANA | Online – 9 June 2021 – This monograph examines specific aspects of palliative care (PC) as a human right. The requirements of the Inter-American Convention on the Protection of the Human Rights of Older Persons and the United Nations international system for the promotion and protection of human rights are analyzed, identifying how PC has been considered. In the same way, the 2030 Agenda of the United Nations, doctrine and jurisprudence to establish the existing relationships with PC are analyzed. Finally, reflections are raised regarding the legal status of PC in the international human rights system. **Abstract:** <https://bit.ly/3v2IIF2>

N.B. Spanish language article.

Research Matters

Family caregiver partnerships in palliative care research design and implementation

PEDIATRICS | Online – 8 June 2021 – Patient- and family-centered care “is an innovative approach to the planning, delivery, and evaluation of healthcare that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient’s life.” Similarly, family partnerships in pediatric palliative care research represent an innovative approach to the planning, delivery, and evaluation of research that is grounded in mutually beneficial relationships that recognize the importance of the family caregiver perspective. The goal of partnered research or study teams is to synthesize the unique perspectives of family caregivers, clinicians, regulatory representatives, and researchers to strengthen research design and implementation. This is accomplished by each unique stakeholder speaking from their own perspective, contributing what they know, and working together to integrate perspectives. **Abstract:** <https://bit.ly/3plK07f>

Noted in Media Watch 3 May 2021 (#715, p.15):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 April 2021 – “**“It can be hard but it’s not bad”**: **Three questions to solicit caregiver perceptions of benefits and burdens to participating in pediatric palliative care research.**’ To allay uneasiness among clinicians and institutional review board members about pediatric palliative care research and to yield new knowledge relevant to study methods, documenting burdens and benefits of this research on children and their families is essential. The most frequently reported themes in this study were of positive personal impact: “Hoping to help others,” “Speaking about what is hard is important,” and “Being in the study was sometimes hard but not bad.” No caregiver described the study as burdensome.. **Abstract:** <https://bit.ly/3tYYMrs>

Publishing Matters

Predatory publishing solicitation: A review of a single surgeon’s inbox and implications for information technology resources at an organizational level

CANADIAN JOURNAL OF SURGERY, 2021;64(3):E351-E357. Over a 6-month period, roughly one-third of emails received in a single surgeon’s email inbox were predatory in nature (i.e., soliciting material for nonexistent journals or conferences). While existing databases (e.g., Beall’s list and The CalTech Library list of questionable conferences) catalogue many fraudulent senders, the list is ever-expanding. The overall cost to healthcare organizations in terms of wasted bandwidth and financial diversion is extensive, as is confusion for trainees and colleagues. For the sake of fiscal responsibility and the maintenance of scholarly standards, it is incumbent upon organizational information technology departments to continually refine strategies to reduce this adverse impact. **Full text (click on pdf icon):** <https://bit.ly/3pGNZkl>

Dealing with predatory journal articles captured in systematic reviews

SYSTEMATIC REVIEWS | Online – 11 June 21021 – There is currently no agreed-upon guidance that exists for how best to manage articles from predatory journals that meet the inclusion criteria for a systematic review. The authors describe a set of actions that authors of systematic reviews can consider when handling articles published in predatory journals: 1) Detail methods for addressing predatory journal articles a priori in a study protocol; 2) Determine whether included studies are published in open access journals and if they are listed in the directory of open access journals; and, 3) Conduct a sensitivity analysis with predatory papers excluded from the synthesis. Encountering eligible articles published in presumed predatory journals when conducting a review is an increasingly common threat. **Full text:** <https://bit.ly/3ghAmW3>

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International



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

South America

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