

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.

27 September 2021 Edition | Issue #736



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“The system is well intentioned, but complicated and fallible”: Interviews with caregivers and decision-makers about palliative care in Canada’ (p.6), in *BMC Palliative Care*.

U.S.A.

COVID exposed gaps palliative care can fill

HOSPICE NEWS | Online – 22 September 2021 – The COVID-19 pandemic has exposed gaps in the fragmented U.S. healthcare system, along with opportunities for hospice and palliative care (PC) awareness and access to grow. Spreading awareness of PC among the public and clinicians in other disciplines can help providers work toward greater access to those services... An estimated 40 million people are in need of PC every year worldwide...¹ As many as 71% of people across the U.S. have little to no understanding of what PC is, including clinicians in a position to refer patients to PC or hospice...² While no standardized definition exists for “palliative care,” the U.S. Centers for Medicare & Medicaid Services defines the term as “patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. PC throughout the continuum of illness involves addressing

physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.” Using less clinical language when discussing PC with patients and families can help promote better understanding... <https://bit.ly/3i12Bsb>

Specialist Publications

‘The influence of POLST on treatment intensity at the end of life: A systematic review’ (p.12), in *Journal of the American Geriatric Society*.

‘Never waste a pandemic: Strategies to increase advance care planning now’ (p.11), in *Mayo Clinic Proceedings: Innovation, Quality & Outcomes*.

1. ‘Palliative Care, World Health Organization, August 2020. <https://bit.ly/3IXNjWl>
2. ‘Awareness of palliative care among a nationally representative sample of U.S. adults,’ *Journal of Palliative Medicine*, published online 30 April 2019. [Noted in 6 May 2019 issue of Media Watch (#613, p.9)]
Abstract: <http://bit.ly/2UT2Ozi>

Minority residents' palliative care training quality trails other medical education

RELIAS MEDIA | Online – Dated 1 October 2021 – Internal medicine and family medicine residents at two medical schools at a historically Black college and a historically Black university (Morehouse College and Howard University) see palliative care (PC) as important. However, most residents believe the quality of their PC education was not as good as their other medical training.¹ “Black medical schools are the leaders in training underrepresented minorities to become physicians,” says Robert Arnold MD, one of the study’s authors and section chief of PC and medical ethics at the University of Pittsburgh. “If we are going to integrate PC broadly, and if we want to make sure that Black physicians have the skill set to take care of their patients, then we have opportunities.” The 91 residents surveyed reported receiving less training on PC than they did on sepsis management. Half the residents reported receiving negative messages about PC. Two-thirds said they considered care for dying patients to be depressing. <https://bit.ly/3zBAxSx>

1. ‘Palliative care attitudes and experiences among resident physicians at historically Black colleges and universities,’ *Journal of Pain & Symptom Management*, published online 13 July 2021. [Noted in Media Watch 19 July 2021 (#726, p.8)] **Abstract (w. references):** <https://bit.ly/3ei88sx>

Note in Media Watch 16 November 2020 (#692, p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 November 2020 – ‘**Lack of exposure to palliative care training for Black residents: A study of schools with highest and lowest percentages of Black enrollment.**’ Little is known about Black trainees’ exposure to palliative care (PC) during their medical education. The authors evaluated 24 medical schools in pre-determined categories... None of the four historically Black colleges and universities with a medical school offered a PC course or clerkship, rotation during residency, or a specialty fellowship program. Institutions with the highest Black enrollment were less likely to offer PC rotations during internal medicine or family medicine residency training than those with the lowest Black enrollment. **Abstract (w. references):** <https://bit.ly/32LUqZh>

International

Lockdown Scotland: 40% spike in number of deaths at home during pandemic, according to Marie Curie

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 23 September 2021 – Marie Curie said its health teams looked after more than 9,000 dying Scots throughout 2020-2021 – the highest number since it was established in 1948. The charity ... has two hospices, one in Edinburgh and the other in Glasgow, but there was a jump in demand for services in people’s homes this year... With hospital admissions for non-COVID patients reduced, there were around 6,000 more deaths at home in Scotland, a 40% rise on the previous year... Overall, more than 63,000 people died in Scotland throughout 2020-2021, the vast majority of whom required some palliative care (PC)... Marie Curie Scotland policy chief Richard Meade said staff have “worked tirelessly to ensure as many people as possible had an end of life experience which reflected what was most important to them.” But he said it was “extremely worrying” that some people may have missed out on care and support.” By 2040 more than two-thirds of over-85s

are likely to die in the community, and the number of dying people who will need PC will rise to more than 62,000 per year. <https://bit.ly/3CAwZSi>

Specialist Publications

‘Trends and patterns in the public awareness of palliative care, euthanasia, and end-of-life decisions in 3 Central European countries using big data analysis’ (p.10), in *Journal of Medical Internet Research*.

‘Service change and innovation in community end-of-life care during the COVID-19 pandemic: Qualitative analysis of a nationwide primary care survey’ (p.13), in *Palliative Medicine*.

‘Palliative care resources in France: Territorial disparities in 2017’ (p.14), in *Santé Publique*.

As our population ages, palliative care will become increasingly important

IRELAND | *The Independent* (Dublin) – 18 September 2021 – Palliative care (PC) is vital for achieving positive experiences for both people nearing the end of their life and their families. It is also very important for improving the quality of life for many others who have distressing and hard to manage symptoms. Access to PC has been shown to benefit the wider family and informal caregivers and allows them to provide other support and care. The early developments of PC were mainly providing support for people with cancer. While this group remain a very important focus, it is now recognised that PC can support the management of symptoms from other serious chronic illness such as respiratory disease, heart disease, stroke and many others. PC in Ireland is well developed in comparison to many European countries, but significant gaps remain. Filling these will require expansion of services where they are already in place, and developing new services in areas that have been less well served. However, the bigger challenge will be to meet the growing needs for PC that will result from population ageing. Over the next 25 years, the number of people living with serious chronic diseases, and the numbers dying annually, will increase rapidly. It is now very important to plan for a major expansion and strengthening of PC in Ireland. A recent study estimated the current and future numbers of people living in Ireland who have diseases associated with a need for PC.¹ Excluding those who are near the end of life, it shows that the numbers with these conditions will rise by around 90% by 2046, partly due to increases in the population and partly due to ageing. <https://bit.ly/3hNurll>

1. 'Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046?' *HRB Open Research*, published online 13 February 2020. [Noted in Media Watch 10 February 2020 (#652, p.7)] Full text: <http://bit.ly/2OzrhJJ>

Noted in Media Watch 20 September 2021 (#735, p.3):

- IRELAND | *The Independent* (Dublin) – 13 September 2021 – '**One in four think they only have days to live if their doctor talked to them about palliative care: Survey.**' Four in five people living with a serious illness would like their doctor to talk to them about palliative care (PC) if it could help them. The finding was from a new survey of the public's perceptions of PC commissioned by the All-Ireland Institute of Hospice & Palliative Care. The survey of 1,000 people also highlighted some of the misconceptions that exist about PC. One in four people would think they only have days to live if their doctor or healthcare professional talked to them about PC, whereas PC may be appropriate for several years, not just for weeks and days at a person's end of life. <https://bit.ly/3nuagTA>



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Specialist Publications

Exploring costs, cost components, and associated factors among people with dementia approaching the end of life: A systematic review

ALZHEIMER'S & DEMENTIA: TRANSLATIONAL RESEARCH & CLINICAL INTERVENTIONS | Online – 14 September 2021 – This is the first systematic review to examine costs of care for people with dementia approaching the end of life (EoL). Costs of care in people with dementia are high and tend to increase toward death. There was a large variation in costs of care across studies. Long-term care facility and informal care costs were among the highest cost components. Only two studies included informal costs of care, and most studies were from the U.S. Non-White ethnicity, female sex, married status, higher education level, more severe dementia, and higher number of comorbidities were associated with higher costs. This review exposes the urgent need for studies describing and analyzing the cost of care at the EoL for people with dementia... This is not exempt of challenge. The lack of evidence in informal care costs may reflect important barriers in quantifying and analyzing informal care... **Full text:** <https://bit.ly/3lwLYWs>

Related:

- *HEALTH ECONOMICS REVIEW* | Online – 20 September 2021 – **'Using predicted length of stay to define treatment and model costs in hospitalized adults with serious illness: An evaluation of palliative care.'** In palliative care (PC), a strong body of evidence exists that quality of life (QoL) outcomes are at least as good for those who receive the intervention than those who do not. Cost-savings associated with the intervention are therefore interpreted as efficiency gains through changed treatment decisions, on an implicit assumption subject experience in observational cost analyses is equivalent to participant experience in QoL trials. If we can improve understanding of when and for whom PC impacts treatment decisions this evidence will have important policy implications. **Full text:** <https://bit.ly/2XAdFVQ>

Conversations about children when an important adult is at end of life: An audit

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 19 September 2021 – There remains a critical gap in the provision of psychological care to families at end of life (EoL) regarding the important relationships a patient has with children. Strikingly, the majority of professionals make a decision about whether to ask patients at EoL about relationships with children based on their age. This potentially overlooks children (e.g., grandchildren, nieces, nephews) who have a significant relationship with patients and may need support to understand their loved-one's illness and death. Most participants in a two-day virtual conference felt confident about initiating conversations with patients at EoL about children, and described their involvement as signposting patients and families to websites and services that provide family support. A similar finding had been reported in the literature. However, the majority of professionals reported they want training to equip them with the skills and confidence to provide families with psychosocial support at EoL about children. Although evidence-based guidelines to scaffold raising these topics with patients are

Research Matters

'Navigating the complex ecosystem of race, ethnicity, structural racism, socioeconomic factors, medical care delivery, and end-of-life care – casting away the compass to make a map' (p.15), in *JAMA Network Open*.

'Comparing the effect of a consult model versus an integrated palliative care and medical oncology co-rounding model on healthcare utilization in an acute hospital: An open-label stepped-wedge cluster-randomized trial' (p.16), in *Palliative Medicine*.

Publishing Matters

'Establishing patient perceptions and preferences for a journal authenticator tool to support health literacy: A mixed-methods survey and focus group study' (p.17), in *Research Square*.

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available, participants rated videos demonstrating how to deliver this aspect of care as their most preferred option for training followed by classroom-based courses. There is a need to develop these specific resources, which would also be relevant to professionals working in many different medical specialties, with evidence indicating the benefits of raising these issues with patients earlier in their illness trajectory. **Full text:** <https://bit.ly/3IKK9W9>

Noted in Media Watch 23 August 2021 (#731, p.4):

- *BMJ OPEN* | Online – 16 August 2021 – ‘**Experiences of preparing children for a death of an important adult during the COVID-19 pandemic: A mixed methods study.**’ Three themes were identified: 1) Obstacles to telling children a significant adult is going to die; 2) Professionals’ role in helping families to prepare children for the death of a significant adult during the pandemic; and, 3) How families prepare children for the death of a significant adult. Professionals need to: provide clear and honest communication about a poor prognosis; start a conversation with families about the dying patient’s significant relationships with children; and, reassure families that telling children someone close to them is dying is beneficial for their longer term psychological adjustment. **Full text:** <https://bit.ly/3iYGELA>

N.B. See literature review at ‘The Crossroads of Grief: Understanding Grief & Diversity,’ published by the Children & Youth Grief Network, Ontario, Canada, in particular, ‘Children’s Understanding of Death & Dying’ (p.5) and ‘Death of a Parent’ (p.30) at: <http://bit.ly/2OB4Y6C>

Related:

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 17 September 2021 – ‘**Parents’ perspectives on conflict in paediatric healthcare: A scoping review.**’ Current research explores perspectives of healthcare professionals (HCPs), but the parental views on conflict are lacking. Ten articles reviewed included parental views on conflict. Data were categorised into seven themes: 1) Communication breakdown; 2) Trust; 3) Suffering; 4) Different understanding of “best interest”; 5) Disagreements over treatment; 6) Spirituality; and, 7) Types of decision-making. Parental expertise, perspectives on suffering and ways of making decisions were significant themes. A subset of themes mirror those of HCPs. Parents identified views of conflict unique to their perspective. **Abstract:** <https://bit.ly/3JPLIjs>

“Saying goodbye all alone with no close support was difficult”: Dying during the COVID-19 pandemic: An online survey among bereaved relatives about end-of-life care for patients with or without SARS-CoV2 infection

BMC HEALTH SERVICES RESEARCH | Online – 22 September 2021 – This survey revealed mixed experiences of bereaved relatives in Germany regarding communication with the healthcare teams. About half indicated that the healthcare team had enough time to listen and discuss the patient’s condition and had been provided with enough information. Bereaved relatives’ judgment in this study did differ between doctors and nurses, but data from the U.K. shows that relatives had a greater level of confidence in the nursing staff and that they provided care with more respect and dignity than doctors. This might be due to differences in the healthcare system in the two countries... Three-quarters felt treated empathically by the healthcare team. However ... relatives expressed regret about a lack of open, proactive communication accompanied by a deficit of reliable contact persons and information. Studies underpinned the importance for relatives, especially when they are not allowed to physically visit the dying patient, to be provided with clear and precise information about his/her condition. This comprises information regarding symptom management, health decline, and personal aspects of care. In this aspect, the relatives’ needs were not met, not only concerning the amount of information but also the way it was provided. This demonstrates the relevance for healthcare teams to install ways to provide reliable information about the patient and to focus on empathic communication. U.K. patients’ relatives highly valued compassionate care from the healthcare team, allowing early visits before the death of the patient to say goodbye. **Full text:** <https://bit.ly/3CEUcT9>



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.18.

“The system is well intentioned, but complicated and fallible”: Interviews with caregivers and decision-makers about palliative care in Canada

BMC PALLIATIVE CARE | Online – 21 September 2021 – Canadian palliative care (PC) philosophy seeks to support individuals in a person-centered and sensitive manner. Unfortunately, philosophy does not necessarily translate into practice and this divide may leave patients without appropriate care at the end of life, causing distress for some families. The primary goal of this study was to identify key factors affecting perceptions of quality PC from the perspective of informal caregivers and decision-makers (e.g., program managers) and to understand how their experiences within the healthcare system may have influenced their perceptions. Nine caregivers and eleven decision-makers from Yukon Territory, British Columbia, Alberta, Ontario, & Nova Scotia shared their experiences in PC via interview or focus group. Three themes emerged: 1) The caregiver as anchor; 2) Bewildering system; and, 3) Patient, caregiver, and family-centered care. While these results resembled other studies on caregivers and individuals receiving PC, this study also uncovered systemic concerns. There was agreement between the two participant groups across most sub-themes, however only caregivers reported feelings of being trapped by the healthcare system and a general lack of

respect from healthcare professionals. Additionally, caregivers stressed the importance of preserving some sort of normalcy in daily life despite the individual’s illness. Caregivers are critical. The healthcare system expects them to help a great deal, but they often do not feel supported or respected and the system is lacking the capacity and resources to meet their needs while they are grieving loss and struggling to meet demands. **Full text:** <https://bit.ly/2XS8rFB>

Extract from *BMC Palliative Care* article

Based on their experiences, it is clear that a number of factors need to be included in the quality assessment of PC provided: anticipatory guidance about caregiver’s role, delineation of responsibilities between system and caregiver, extent of collaboration with caregiver, patient-centeredness of care, treatment of patient as a whole person, continuity of providers, and quality and frequency of provider communication. These factors should be addressed at the systemic level given how pervasive the critique of the system was by caregivers.

Primary care staff’s willingness to participate in compassionate community network and palliative care and the barriers they face: A mixed methods study

BMJ OPEN | Online – 21 September 2021 – Compassionate community models, successfully applied in several Western countries, have not been extensively promoted in Asian countries. This study explored primary care staff’s willingness to participate and factors associated with their participations in compassionate community education and network, palliative care (PC) education, providing PC and the barriers they faced. Primary care staffs in Beitou and Shilin districts in Taiwan, including physicians, nurses, pharmacists and administrative staff aged ≥ 20 years who had worked in a clinic for more than 2 months, were recruited. About half of survey respondents were willing to participate in compassionate community education and network and PC education, but only 19.5% were willing to provide PC. Compared with other staff, primary care nurses showed significantly more willingness to participate in compassionate community education and network and PC education and to provide PC. However, physicians were significantly not willing to participate in any of the three services apart from providing care. Capability, administrative and manpower concerns, time, age and motivation were the main barriers. To encourage primary care staff to participate more in compassionate community education and network and PC education and to provide PC, policy-makers should pay more attention towards removing the barriers to their engagement. **Full text:** <https://bit.ly/3u2CwxQ>

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Related:

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 22 September 2021 – ‘**Centering sexual and gender diversity within Compassionate Communities: Insights from a community network of LGBTQ2S+ older adults.**’ The compassionate communities movement emphasizes the importance of illness, disability, dying, caregiving, and grief across the lifespan and highlights the communal responsibility of caring for one another. There is a need to recognize and incorporate the needs of diverse communities within this movement and research on dying, caregiving and grief. The authors’ findings emphasize the importance of incorporating the voices of diverse sexual and gender identities and promoting health equity within compassionate community initiatives. **Full text:** <https://bit.ly/39y7mFi>

Implementing automated prognostic models to inform palliative care: More than just the algorithm

BMJ QUALITY & SAFETY | Online – 17 September 2021 – Palliative care (PC) is associated with improved patient-centred and caregiver-centred outcomes, higher-quality end-of-life care, and decreased healthcare use among patients with serious illness. The Centre to Advance Palliative Care has established a set of recommended clinical criteria (or “triggers”), including a projected survival of less than 1 year, to help clinicians identify patients likely to benefit from PC.¹ Nevertheless, referrals often occur within the last 3 months of life due in part to clinician overestimation of prognosis. A growing number of automated predictive models leverage vast data in the electronic medical record to accurately predict short-term mortality risk in real time and can be paired with systems to prompt clinicians to refer to PC. These models hold great promise to overcome the many clinician-level and system-level barriers to improving access to timely PC. First, mortality risk prediction algorithms have been shown to outperform clinician prognostic assessment, and clinician-machine collaboration may even outperform both. Second, algorithm-based “nudges” that systematically provide prognostic information could address many cognitive biases, including *status quo* bias and optimism bias, that make clinicians less apt to identify patients who may benefit from PC. Indeed, such models have been shown to improve the frequency of PC delivery and patient outcomes in the hospital and clinic settings. With that said, successful implementation of automated prognostic models into routine clinical care, at scale, requires clinician and patient engagement and support. **Full text:** <https://bit.ly/3hLIYV7>

1. ‘Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care,’ *Journal of Palliative Medicine*, 2011;14(1):17-23. **Full text (click on enotes.tripod.com icon):** <https://bit.ly/2Z6s50N>

“Dying and time”: Realist review of palliative and end of life care in primary care and the community, with a focus on timely patient identification and timely initiation of services

BMJ SUPPORTIVE & PALLIATIVE CARE | Inprint – Accessed 25 September 2021 – Community- and home-based palliative and end-of-life care (PEoLC) services, often underpinned by primary care provision, are becoming increasingly popular. One of the key challenges associated with them is their timely initiation. The latter requires an accurate enough prediction of how close to death a patient is. Using “realist synthesis” tools, this review sought to develop explanations of how primary care and community PEoLC programmes generate their outcomes... Numerous PEoLC policies and programmes are embedded in a framework of ‘Preparation and Planning for Death and Dying,’ with identification of the dying stage setting in motion key systems and services. This is challenged by: 1) Accumulated evidence demonstrating low accuracy of prognostic judgements; 2) Many individuals’ orientation towards living and hope; 3) Expanding grey zones between palliative and curative care; 4) The complexity of referral decisions; 5) The loss of pertinent information in hierarchical relationships; and, 6) The ambiguous value of having “more time.” Prioritising temporal criteria in initiating PEoLC services is not sufficiently supported by current evidence and can have significant unintended consequences. **Abstract:** <https://bit.ly/3kHvL1o>

Palliative medicine education: ‘Bed Race,’ the end-of-life board game in undergraduates

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 September 2021 – Educational board games facilitate active learning to conceptualise knowledge, and, promote collaborative learning and team work. Despite increasing interest in them, use in palliative and end-of-life care has been very limited to date. In ‘Bed Race, The End-of-Life Game,’ participants are divided into four teams who move a model hospital bed around a board to collect items (e.g., syringe driver; do not attempt resuscitation form; oral hydration gel; a “heart”; Just In Case medicines). To obtain items at themed “checkpoints,” each team needs to answer quiz questions, which require application of clinical knowledge and/or communication skills. Pregame and postgame quiz scores and feedback were collected from 12 game sessions involving 251 year 5 medical students. 169 (67%) of students completed pregame and postgame anonymous quiz questions and free-text feedback. Postgame quiz scores were higher for each topic, and the difference in the paired pregame and postgame questionnaires was statistically significant... Themes from the free-text feedback included “engaging and fun”; “relevant learning”; and, “peer learning and team work.” Educational board games are not a new panacea for education, but the concept can be successfully applied in palliative care. **Abstract:** <https://bit.ly/3AjRlhQ>

Related:

- *INTELLECTUAL AND DEVELOPMENTAL DISABILITIES*, 2021;59(5):392-404. ‘**Effect of online palliative care training on knowledge and self-efficacy of direct care workers.**’ The authors evaluated the effectiveness of an online training on palliative care (PC) knowledge and self-efficacy among staff working with people with intellectual and developmental disabilities... Staff from four non-profit residential and day services organizations ... participated. Among 132 staff who completed a baseline assessment, a 2-hour online training, and a post-test, 98 staff completed a 1-month follow-up survey. Overall PC knowledge and self-efficacy significantly improved while higher education and longer work tenure enhanced training effectiveness. **Abstract:** <https://bit.ly/3IV1eMO>

Palliative care referral criteria and outcomes in cancer and heart failure: A systematic review of literature

CARDIO-ONCOLOGY | Online – 23 September 2021 – The complexities of the multiple issues confronting patients diagnosed with cancer and concurrent heart failure (HF) present challenges in decision-making regarding palliative care (PC) initiation. The multiple comorbidities of this population and the unpredictable illness trajectory of HF add to the complexity of prognostication, particularly with the potential for sudden cardiac death. This systematic literature review provides evidenced-based data to inform the development of criteria for PC referral for patients with cancer and concurrent HF, being mindful that referrals should not rely only on end-of-life (EoL) or terminal stages. Integrating PC in cardio-oncology, particularly in the management of HF in patients with cancer, as early as at diagnosis, will enable patients, family members, and healthcare professionals to make informed decisions about various treatments and EoL care and provide an opportunity for patients to participate in the decisions about when and where they will spend their final days. Additional research is needed to develop and validate clinically useful criteria for PC referral to prospectively identify cancer patients with a concurrent diagnosis of HF patients who may most benefit from PC referral. **Full text:** <https://bit.ly/2XJrEZQ>

Parental experiences of the liminal period of a child’s fatal illness

HEALTH: AN INTERDISCIPLINARY JOURNAL FOR THE SOCIAL STUDY OF HEALTH, ILLNESS & MEDICINE | Online – 20 September 2021 – This article offers a description of parents’ experiences of their child’s ultimately fatal illness as it unfolds over the successive stages of medical treatment, in the context of the liminality theory. The parents were interviewed 1-4 years after their child’s death. The research method involved conducting narrative interviews with parents in order to obtain a spontaneous narration of the child’s illness as it unfolded. The grounded theory approach, including the narrative and performative aspects of such parental utterances, was applied as the main research strategy. The results provide insight

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into the main areas and processes of common parental experiences, such as the pervasive sense of becoming trapped in timelessness and ambiguity. Further states reported by parents included oscillating between a distancing stance and involvement, and a dualistic relationship with medical staff and the medical system: between alignment and disharmony. The study indicates the importance of treating delivery of such a diagnosis as a process rather than as a one-time event. The sense of ambiguity is treated as a kind of necessary parental coping mechanism, whilst the sense of timelessness gives parents a unique sense of time in which they do not have to think about the child's potentially imminent death. **Abstract (w. references):** <https://bit.ly/3Ap3xxQ>

Our best judgment

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 16 September 2021 – Strong recommendations from physicians do not preclude partnerships with patients and families. A purely paternalistic approach would forego discussion and simply allow the clinician to decide. Physicians who make strong recommendations in partnership with patients and families are not acting with paternalism. Instead, they are acting as doctors should, by putting patients' values first and then putting those values into the appropriate medical context for families. But this partnership is always unequal. It was even for me, a physician with years of experience caring for seriously ill patients, trying to help my brother's family without the specific skill, knowledge, and experience held by that capable intensivist. For some clinical dilemmas, truly balanced medical alternatives exist. These decisions need to be based on patient preferences we have not yet divined. Incumbent on us is the responsibility to elicit the patient's wishes, priorities, and principles. We then must translate those into the medical reality, make clear recommendations based on that reality, and operationalize them as best we can. We must try to do so with at least a sense of humility and of the patient as an individual who is loved and appreciated. When even tragic realities are faced with honesty, clarity, kindness, and compassion, present and future pain can be at least in part alleviated. I am at peace with our decisions and Les' death because of these compassionate and capable professionals who spoke and acted decisively. We have far to go as a healthcare system in providing the kind of support received by my brother and his family as we confronted his ultimately fatal illness. But it begins with clinicians acting as professionals exercising their best judgment, helping us to see down the road to decide how to proceed. **Full text:** <https://bit.ly/3kkB1YH>

Healthcare professionals' perspectives of patient and family preferences of patient place of death: A qualitative study

BMC PALLIATIVE CARE | Online – 20 September 2021 – Some studies have explored the views and responsibilities of healthcare professionals (HPs) toward the patient and their family with regards to the general end-of-life issues, but this study is focused on the topic of place of death (PoD) from the perspectives of a team of integrated inpatient and community palliative care service staff. This study uniquely describes the nature of HPs engagement with the family unit in the choice of PoD of patients – by mediating conversations between the patient and their carer, adjusting expectations and facilitating informed decision-making, whilst acting to maintain a positive relationship between patient and carer. According to HPs in this study, home is not invariably the most preferred PoD and the assumption that it is has negative consequences for patients, the carers, and the HPs themselves. This study adds a nuanced understanding of the carer experience from HPs' perspective within the context of decision-making regarding the PoD. Carers' struggle to cope with the demands of caregiving in order to keep "the promise" made to the dying patient was consistently observed by the HPs, further alluding to the moral distress and guilt experienced by carers caught between the romanticised and real versions of dying. This finding is consistent with reports that carers are less likely to prefer a home death than patients, and in some cases, where home death is achieved, carers' retrospective judgement that hospital would have been a better PoD. **Full text:** <https://bit.ly/3zqSmUd>



Would the *Journal of the American Medical Association* article be of interest to a colleague?

Trends and patterns in the public awareness of palliative care, euthanasia, and end-of-life decisions in three Central European countries using big data analysis

JOURNAL OF MEDICAL INTERNET RESEARCH | Online – 20 September 2021 – This study provides novel and essential information about the demands and interests of the residents of Austria, Germany, and Switzerland concerning palliative care (PC), euthanasia, assisted suicide, and end-of-life (EoL) decisions. In particular, policymakers may use these findings to target potential weaknesses within current regulations (e.g., the cost barrier for advance healthcare directives in Austria). Governmental promotion of the early implementation of PC into life-threatening disease trajectories may be another meaningful action. Experts in PC can sensitize patients to arranging advance healthcare directives, inform them about the different options at the EoL, and resolve misunderstandings. This study shows, for the first time, that governmental regulations, precise legal definitions, and broader access to advance healthcare directives might reduce interest in euthanasia, suggesting that loss of control is one of the predominant factors involved in the desire to hasten death. Early PC can guide patients through the necessary decision-making processes from the point of the diagnosis of a life-threatening disease to their death and provide advance care planning. After all, it is and has always been a core principle of PC to promote and value the autonomy of patients. **Full text:** <https://bit.ly/39rThsV>

Caregivers' death-preparedness states impact caregiving outcomes and patients' end-of-life care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 23 September 2021 – Preparing family caregivers, cognitively, emotionally, and behaviorally, for their relative's death is an actionable component of high-quality end-of-life care (EoLC). The authors examined the never-before-examined associations of joint cognitive prognostic awareness and emotional preparedness for death with caregiving outcomes and EoLC received by cancer patients. Caregivers [i.e., participants in this this longitudinal study] in the cognitive-death-preparedness-only state experienced a higher level of subjective caregiving burden than those in the sufficient-death-preparedness state. Caregivers in the no-death-preparedness and cognitive-death-preparedness-only states reported significantly more depressive symptoms and worse quality of life than those in the sufficient-death-preparedness state. Cancer patients with caregivers in the sufficient-death-preparedness state were less likely to receive chemotherapy/immunotherapy, intubation, mechanical ventilation, and nasogastric tube feeding than patients with caregivers in other death-preparedness states. However, patients' receipt of hospice care was not associated with their caregivers' death-preparedness states. Cultivating caregivers' accurate prognostic awareness and improving their emotional preparedness for their relative's death may facilitate more favorable end-of-life-caregiving outcomes and may limit potentially nonbeneficial EoLC. **Abstract (w. references):** <https://bit.ly/3kCPlpY>

N.B. Selected articles on the preparedness of family caregivers for death noted in Media Watch 5 October 2020 (#686, p.8).

Related:

- *JOURNAL OF PARKINSON'S DISEASE* | Online – 15 September 2021 – “**No one can tell me how Parkinson's disease will unfold**”: A mixed methods case study on palliative care for people with Parkinson's disease and their family caregivers.' Little is known about the experiences of patients with Parkinson's disease (PD) in the palliative phase and of their family caregivers (FCGs). FCGs gradually learned to cope with difficult situations... They had great expertise in caring for the person with PD, but did not automatically share this with healthcare professionals. Patients sensed a lack of time to discuss their complex needs with clinicians. Furthermore, PC was rarely discussed, and none of these patients had been referred to specialist PC services. **Abstract:** <https://bit.ly/3AxClqr>
- *BMC HEALTH SERVICES RESEARCH* | Online – 21 September 2021 – ‘**Challenges faced during the COVID-19 pandemic by family carers of people living with dementia towards the end of life.**’ The authors identified an overarching theme of uncertainty and reactivity during a crisis, and within this, five main themes were identified: 1) Concerns about care transitions; 2) Uncertainty in engaging support and help; 3) Pandemic-motivated care planning; 4) Maintaining the wellbeing of the person living with dementia; and 5) Trust, loss of agency and confusion. This is the first paper ... to explore the concerns and help seeking behaviours of carers of people living with dementia during the COVID-19 pandemic, from the perspective of leading U.K. charities in dementia and end-of-life care. **Full text:** <https://bit.ly/3u0Ezm9>

Retrospective pediatric telepalliative care experience

JOURNAL OF PALLIATIVE MEDICINE | Online – 21 September 2021 – Rady Children’s Hospital (RCH) [in Sand Diego, California] offers an out-patient pediatric palliative clinic that began offering telepalliative care in 2016. This study describes demographics of parents receiving pediatric telepalliative care, patient/family satisfaction with telepalliative care, and patient/family perspectives. Fifty-six patients were seen through 181 telepalliative visits. Forty-three percent were female and 32% were Hispanic/Latino. Ages ranged from 3 months to 25 years. Average Palliative Performance Scale was 47%. Seventy-nine percent used gastrostomy tubes for nutrition, but only 29% used home ventilation. Eighty-two percent completed a Physician Order for Life-Sustaining Treatment. Goals for 84% of patients were for life prolongation and attempt resuscitation. Visits averaged 86 minutes. Twenty-five surveys were returned: 92% felt very satisfied and 96% said the video visit was the same, better, or much better than an in-person visit. Sixty-four percent said the video visit was more convenient and 68% felt the video visit was safer. Identified themes from telepalliative consultations included advocacy for their child, challenges surrounding care for children with complex medical needs, medical team communication, caregiver support, facing uncertainty, and decision-making. Pediatric patients receiving telepalliative care varied in demographics, functional status, and goals-of-care. Telepalliative care can provide good quality

of care and patient satisfaction. In a telepalliative setting, parents were able to communicate challenging aspects of care including navigating uncertainty, finding support, and decision-making.

Abstract: <https://bit.ly/3CDBQqp>

From monochromatic to technicolor: Parent perspectives on challenges and approaches to seeing children with severe neurological impairment holistically

JOURNAL OF PALLIATIVE MEDICINE | Online – 22 September 2021 – Children with severe neurological impairment (SNI) commonly receive care in the hospital setting necessitating frequent interactions with clinicians. Yet, parents report that clinicians often have a limited understanding of their child’s unique needs and abilities which hinders their care. In this study, four themes emerged regarding both challenges and approaches to understanding children with SNI holistically. These included uniqueness, interdependency, complexity, and universality. Parents felt that by eliciting and incorporating their perspective on these sometimes contrasting but inherently necessary aspects of their child’s care, clinicians would understand their children more fully. By viewing the child through the prismed lens of parents, participants described how clinicians could transition from a monochromatic to a technicolor view of their child – including the inherent contrasting needs required for their comprehensive care. **Abstract:** <https://bit.ly/3u6ixyb>

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

Never waste a pandemic: Strategies to increase advance care planning now

MAYO CLINIC PROCEEDINGS: INNOVATION, QUALITY & OUTCOMES, 2021;5(5):946-950. The pervasiveness of COVID-19-related illness and deaths across age groups has required vast efforts in goals-of-care conversations in a time of crisis. The COVID-19 pandemic demonstrates the importance of everyone working collaboratively to promote advance care planning (ACP) efforts with no time to waste. It is important to build upon the important lessons of this pandemic to prepare for possible resurgence with new strains, future disasters, or pandemics. Critically, all primary care healthcare workers and sub-specialists must continue to engage patients in ACP discussions. Optimal discussions explicate patient values, identify surrogates for decision-making, and take place in advance of patient hospitalization for greater congruency of the healthcare plan. This is best done through systems that encourage discussions as an interprofessional healthcare team. Through the unfortunate shared experience of COVID-19, ACP discussions have become more urgent and relevant to all patients. During this time, individual healthcare workers can build upon their ACP skills while healthcare and public health systems can normalize and promote efficient ACP practices. The authors challenge readers to work within their sphere of influence to propagate a multilevel wave of

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ACP discussions across the country: 1) Individual level – Over the next week, choose one ACP discussion tool and use part or all of it with a patient or family member; seek feedback from local palliative or geriatric specialists when helpful; 2) Systems level – Develop approaches within healthcare teams to launch more ACP discussions with centralized documentation; and, 3) Population level – Implement public-facing campaigns to normalize ACP discussions for all patients. Never waste a pandemic – the time to act is now! **Full text:** <https://bit.ly/3m0NMHk>

Related:

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 22 September 2021 – ‘**The influence of POLST on treatment intensity at the end of life: A systematic review.**’ Despite its widespread implementation, it is unclear whether Physician Orders for Life-Sustaining Treatment (POLST) are safe and improve the delivery of care that patients desire. Among 104,554 patients across 20 observational studies, 27,090 had POLST. No randomized controlled trials were identified. The authors found moderate strength of evidence that treatment limitations on POLST may reduce treatment intensity among patients with serious illness. However, the evidence base is limited and demonstrates potential unintended consequences of POLST. **Abstract:** <https://bit.ly/3hYBwpH>

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

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 20 September 2021 – ‘**How does medical assistance in dying affect end-of-life care planning discussions? Experiences of Canadian multidisciplinary palliative care providers.**’ Medical assistance in dying challenges end-of-life care discussions and requires education and support for all concerned to enable compassionate health professional communication. It remains essential to address psychosocial and existential suffering ... but also to provide timely palliative care (PC) to ensure suffering is addressed before it is deemed irremediable. Clarification is required regarding assisted dying as an intervention of last resort. Professional and institutional guidance needs to better support PC providers... **Full text:** <https://bit.ly/3IYITQj>

End-of-life doulas: Documenting their backgrounds and services

OMEGA – JOURNAL OF DEATH & DYING | Online – 22 September 2021 – This is an exploratory study to document the demographic characteristics, backgrounds, and services provided by trained and certified International End-of-Life Doula Association doulas. Like birth doulas, end-of-life (EoL) doulas represent a divergent, yet complementary form of care for dying persons. The purpose of EoL care is to facilitate comfort of the dying person and their closest family members. Surveys were completed by 618 EoL doulas regarding their demographic characteristics, employment backgrounds, services, and their experiences providing EoL care to dying persons and their closest family members. Follow-up qualitative interviews were also conducted with a subset of 39 respondents who completed the original survey. Results show that trained doulas are largely white (91.4%), female (90.4%), hold a Bachelor’s (32.3%) or Masters (32.4%) degree, and are employed outside of their EoL doula work (70.1%). Qualitative data details services provided to dying persons and family members in addition to the benefits and challenges of working with traditional healthcare settings. **Abstract (w. references):** <https://bit.ly/3AEu9eg>

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



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>

Advanced analytics as an accelerator for palliative care and oncology integration

ONCOLOGY PRACTICE | Online – 20 September 2021 – Knowing when to integrate palliative care (PC) specialists requires a clear signal that patient needs are currently more complex or are changing, or that a negative outcome is imminent and just-in-time management recommended. Modern approaches to identify which patients will benefit from specialty services have transitioned beyond traditional blunt criteria such as disease stage (e.g., stage IV) or prognosis (e.g., 6 months or less to live). Although these criteria have high sensitivity for risk of low quality of life, their specificity is poor. In other words, patients with advanced disease frequently have needs that benefit from PC specialists, but earlier cancer stage or long estimated prognosis do not inoculate patients with cancer from suffering. Furthermore, recognized limitations in clinician prognostication accuracy and continued misunderstandings of specialty PC further undermine any approach that solely depends on clinician intuition for referral. Given that the referral to specialty PC is often a subjective decision, it is likely to be highly impacted by implicit biases as reflected in well-described disparities in receipt of PC services. **Full text:** <https://bit.ly/3AtskB5>

Service change and innovation in community end-of-life care during the COVID-19 pandemic: Qualitative analysis of a nationwide primary care survey

PALLIATIVE MEDICINE | Inprint – 17 September 2021 – Primary healthcare teams (general practice and community nursing services) within the U.K. provided the majority of community end-of-life care (EoLC) during COVID-19, alongside specialist palliative care (PC) services. As international healthcare systems move to a period of restoration following the first phases of the pandemic, the impact of rapidly-implemented service changes and innovations across primary and specialist PC services must be understood. The authors provide detailed insights and understanding into service changes and innovation that occurred in U.K. primary care to deliver EoLC during the first phase of the COVID-19 pandemic. A total of 559 valid responses were received from 387 community nurses, 156 general practitioners and 16 “other.” Over a third of respondents experienced changes in the organisation of their team in order to provide EoLC in response to the COVID-19 pandemic. Three qualitative themes were identified: 1) COVID-19 as a catalyst for change in primary PC; 2) New opportunities for more responsive and technological ways of working; and, 3) Pandemic factors that improved and strengthened interprofessional collaboration. Opportunity has arisen to incorporate cross-boundary service changes and innovations, implemented rapidly at the time of crisis, into future service delivery. Future research should focus on which service changes and innovations provide the most benefits, who for, and how, within the context of increased patient need and complexity. **Abstract:** <https://bit.ly/39mfE2J>

Related:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 20 September 2021 – ‘**A retrospective review of the impact of early palliative care consultation during the coronavirus disease 2019 pandemic.**’ Palliative care (PC) advanced practice registered nurses developed a workflow to provide early PC consultation to every COVID-19 patient under investigation admitted to a 368-bed acute care hospital... Early PC consultation resulted in a higher number of patients establishing a decision-maker (99%), changing code status (46%), changing goals-of-care (46%), and transitioning to comfort care (24%). In those not receiving PC, fewer established a decision-maker (10%), changed code status (7%), changed goals-of-care (4%), or transitioned to comfort care (3%). **Abstract:** <https://bit.ly/3EMbfEM>

“Permission to be kind to myself”: The experiences of informal carers of those with a life-limiting or terminal illness of a brief self-compassion-based self-care intervention

PROGRESS IN PALLIATIVE CARE | Online – 19 September 2021 – Previous studies suggest that prioritizing self-care needs is difficult for carers despite the positive value self-care is seen to have in supporting carers’ own functioning and well-being. Whilst self-care has been seen as playing a crucial part in maintaining Carers emotional and physical health, to date there have been no self-compassion-based self-care interventions designed to support carers. The authors’ findings suggest that a brief self-compassion-based intervention can help carers develop a kindly and friendly attitude to themselves. This in turn supports carers

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in recognizing and legitimizing their own needs leading to conscious practices of self-care. This new way of seeing and treating themselves lead to improvements in mood, as reported by participants. Recent research suggests that nurses need permission in order to practise self-compassion and self-care, with this permission needing to come from others or society at large, a position replicated in the wider public. If both the public and nursing professionals are unable to locate an internal self-permission and need an external “permission” before becoming more self-compassionate, then it is likely that carers require this too. Yet, the authors’ findings indicate that participants gained an inner permission and commitment to hear their own needs and then meet some of those needs through developing a kinder, more self-compassionate way of relating to themselves. This is in contrast to other research which suggests that carers are reluctant to engage in self-care practices. **Full text:** <https://bit.ly/39o2Ysa>

Related:

- *PALLIATIVE MEDICINE* | Online – 23 September 2021 – ‘**Adaptation and continuous learning: Integrative review of coping strategies of palliative care professionals.**’ Coping mechanisms are evolutionary processes, in which there is interdependence between influencing factors (protective and risky) and coping strategies. It was observed that there was a systemic coalescence or fusion between all of them. There were coping strategies developed proactively, intentionally, and, at the same time, resulting from greater experience, training and professional maturity. Resilience takes a central value. Time is a variable that influences personal and professional development and, consequently, coping strategies. **Full text:** <https://bit.ly/3CGV7CE>

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

Palliative care resources in France: Territorial disparities in 2017

SANTÉ PUBLIQUE, 2021;33(2):169-175. The 2015-2018 French national palliative care (PC) program aimed to reduce territorial disparities of access to PC by increasing the number of beds in dedicated PC units and beds in hospital wards facing end-of-life situations, aiming to reach a minimum average density of 1 bed per 100,000 inhabitants in PC units. In 2017, France had on average 2.6 beds in PC units and 7.8 PC beds in hospital wards per 100,000 inhabitants. Strong territorial disparities remained: 27 counties still did not have any PC units and 4 had less than 1 bed per 100,000 inhabitants in PC units. The development of PC beds in hospital wards partly compensated for these inequalities: counties without PC units had an average density of 9.6 beds in hospital wards per 100,000 inhabitants but when pooling beds in PC units and beds in hospital wards, 17 of those counties had a density of PC beds lower than the national average (6.5 versus 10.5 PC beds per 100,000 inhabitants). If these results appear relatively satisfactory in quantitative terms, the quality of PC provided in those beds, especially in hospital wards, must be analyzed: does it meet patients’ needs? A better understanding of care provided in beds in PC units and in beds in hospital wards is necessary to verify whether the territorial inequalities of access to PC have been improved by the creation of PC beds in hospital wards. **Full text:** <https://bit.ly/3lXfpRE>

N.B. French language article.

Views and experiences of palliative care clinicians in addressing genetics with individuals and families: A qualitative study

SUPPORTIVE CARE IN CANCER | Online – 22 September 2021 – A proportion of people with palliative care (PC) needs unknowingly have a genetic predisposition to their disease, placing relatives at increased risk. As end-of-life (EoL) nears, the opportunity to address genetics for the benefit of their family narrows. Clinicians face numerous barriers addressing genetic issues, but there is limited evidence from the PC clinician perspective. Three themes were identified: 1) Harms and benefits of raising genetics: a delicate balancing act; 2) Navigating genetic responsibility within the scope of PC; and, 3) Overcoming practice barriers: a multipronged approach. Participants in this study described balancing the benefits of addressing genetics in PC against potential harms. Responsibility to address genetic issues depends on perceptions

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of relevance and the scope of PC. Suggestions to overcome practice barriers included building genetic-PC relationships and multi-layered genetics education, developing clinical resources and increasing organisational support. Integrating aspects of genetics is feasible, but must be balanced against potential harms and benefits. PC clinicians were uncertain about their responsibility to navigate these complex issues to address genetics. There are opportunities to overcome barriers and tailor support to ensure people nearing EoL have a chance to address genetic issues for the benefit of their families. **Abstract (w. references):** <https://bit.ly/3IS72XF>

Noted in Media Watch 23 September 2019 (#632, p.9):

- *EUROPEAN JOURNAL OF HUMAN GENETICS* | Online – 16 September 2019 – ‘**What do cancer patients’ relatives think about addressing cancer family history and performing genetic testing in palliative care?**’ Palliative care (PC) may be an opportunity to discuss cancer family history and familial cancer risks with patients’ relatives. It may also represent the last opportunity to collect, from dying patients, clinical data and bio-specimens that will inform cancer risk assessment and prevention in their surviving relatives. Participants in this study seemed aware that cancer family history is a potential risk factor for developing the disease. They considered the PC period an inappropriate moment to discuss cancer heritability. **Abstract (w. references):** <https://go.nature.com/2kljAFC>

Noted in Media Watch 2 April 2018 (#557, p.14):

- *MEDICAL LAW INTERNATIONAL* | Online – 23 March 2018 – ‘**Communication of genetic information in the palliative care context: Ethical and legal issues.**’ In the palliative care (PC) context, the question of when and how to disclose a patient’s genetic information raises a host of ethical, legal, and social issues, including the challenges of communicating during the end-of-life (EoL) stage and complex familial and cultural dynamics. The authors outline the legal components of these issues in three civil law jurisdictions with similarly comprehensive approaches to healthcare and PC – Quebec, Belgium, and France – and provide insights from bioethics literature and normative documents on the disclosure of genetic information at the EoL. **Abstract:** <http://bit.ly/2kSdRNn>

Noted in Media Watch 27 November 2017 (#540, p.13):

- *JOURNAL OF COMMUNITY GENETICS* | Online – 20 November 2017 – ‘**Mainstreaming genetics in palliative care: Barriers and suggestions for clinical genetic services.**’ Palliative healthcare professionals (PHCPs) frequently do not refer their eligible patients for genetic testing. After the death of the affected individual, clinically relevant information for family members is lost. In previous research, PHCPs stated that the end-of-life setting is not appropriate to discuss genetic issues. It is unclear if this has changed due to increasing awareness of genetics in the media and efforts to mainstream genetic testing. Participants in this study reported feeling unfamiliar with the role of clinical genetics services, and did not feel confident in addressing genetic issues with their patients. **Abstract:** <http://bit.ly/2kFOQFb>

Research Matters

Navigating the complex ecosystem of race, ethnicity, structural racism, socioeconomic factors, medical care delivery, and end-of-life care – casting away the compass to make a map

JAMA NETWORK OPEN | Online – 22 September 2021 – Nowhere is the intersection between culture, ethnicity, race, and medical care delivery more complex and nuanced than at the end of life (EoL). To provide culturally appropriate and high-quality EoL care and reduce potential structural racism in the healthcare system, we need a more detailed map that illuminates actual and culturally meaningful associations between beliefs and EoL care choices, one that starts to untangle the myriad existing confounders. We need research that not only uncovers existing disparities but also illuminates potentially actionable means to reduce them. At best, studies using secondary data sets are but a cloudy compass; they may suggest a potential direction for future research but offer little insight into the actual ecosystem to be explored. Quality measures used in such secondary data analyses are rarely chosen by the minority community and may be

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implicitly biased and culturally insensitive. Proactive research that actively engages with minority communities is needed to better explore the complex intersection of race, ethnicity, socioeconomic factors, structural racism, healthcare delivery, and EoL care priorities. Only when outcomes are culturally sensitive and meaningful, when minority communities are able to collaborate with research and researchers, and when studies point out not just the existence of but also the amelioration strategies for care inequities will we start to navigate our way through this most complex of ecosystems to achieve more optimal, beneficial, compassionate, culturally sensitive, and equitable EoL care for all. **Full text:** <https://bit.ly/3kDgFtS>

Essential versus non-essential: The ethics of conducting non-COVID research in a population of persons living with serious illness during the COVID-19 Pandemic

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 20 September 2021 – The COVID-19 pandemic has created disruptions and ethical tensions in palliative care research; however, ethical principles must continue to be applied for evaluating the safety of conducting research with seriously ill patient participants and nurse participants in an acute care setting. This randomized controlled trial was conducted in an acute care hospital and tests the effects of a narrative intervention versus usual care on the primary outcome of patients' perception of quality of communication with their nurses and the secondary outcome of biopsychosocial well-being. In accordance with local and institutional COVID-19 guidance, research activities were temporarily suspended in March 2020, and when allowed to resume, some aspects of the protocol were adapted to maximize safety for all stakeholders: patients/families, nurses, and the research team. This article: 1) Considers case perspectives of all stakeholders involved in a randomized controlled trial conducted in the acute care hospital setting during the COVID-19 pandemic; 2) Describes the ethical dilemma and ethical principles in the context of the case; 3) Discusses lessons learned while resuming clinical research activities; and, 4) Provides an ethical framework for the decision-making processes around vulnerability and safety in conducting research during a pandemic with persons living with serious illness.

Abstract: <https://bit.ly/3CCdXuM>

Comparing the effect of a consult model versus an integrated palliative care and medical oncology co-rounding model on healthcare utilization in an acute hospital: An open-label stepped-wedge cluster-randomized trial

PALLIATIVE MEDICINE | Online – 17 September 2021 – The benefit of specialist palliative care (SPC) for cancer inpatients is established, but the best method to deliver SPC is unknown. The authors compare a consult model versus a co-rounding model; both provide the same content of SPC to individual patients, but differ in the level of integration between palliative care and oncology clinicians. Participants were cancer patients admitted to the oncology inpatient service of an acute hospital in Singapore. A total of 5,681 admissions from December 2017 to July 2019 were included, of which 5,295 involved stage 3-4 cancer and 1,221 received SPC review. Admissions in the co-rounding model had a shorter hospital length of stay than those in the consult model by 0.70 days for all admissions. In the sub-group of stage 3-4 cancer patients, the length of stay was 0.85 days shorter. In the sub-group of admissions that received SPC review, the length of stay was 2.62 days shorter. Hospital readmission within 30 days and access to SPC were similar between the consult and co-rounding models. The co-rounding model was associated with a shorter hospital length of stay. Readmissions within 30 days and access to SPC were similar. **Abstract (w. references; note sidebar):** <https://bit.ly/3nNTvTq>



Evidence for the benefits of specialist palliative care is already compelling. Its time to move on to research on comparing different ways of care delivery

Discussion by the authors of the *Palliative Medicine* article posted 17 September 2021 on the European Association for Palliative Care blog: <https://bit.ly/3uRqXJJ>

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Noted in Media Watch 10 February 2020 (#652, p.5):

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 5 February 2020 – ‘**Models of palliative care delivery for patients with cancer.**’ This review provides a state-of-the-science synopsis of the literature that supports each of five clinical models of specialist palliative care (PC) delivery, including outpatient clinics, inpatient consultation teams, acute PC units, community-based PC, and hospice care. The roles of embedded clinics, nurse-led models, telehealth interventions, and primary PC are discussed. Each of these five models of specialist PC serve a different patient population along the disease continuum and complement one another to provide comprehensive supportive care. Additional research is needed to define the standards for PC interventions and to refine the models... **Full text:** <https://bit.ly/3nMYZ0J>

Noted in Media Watch 10 April 2017 (#507, p.15):

- *PALLIATIVE MEDICINE* | Online – 5 April 2017 – ‘**What do we know about different models of providing palliative care? Findings from a systematic review of reviews.**’ A wide range of organisational models of palliative care (PC) exist. However, decision-makers need more information about which models are likely to be most effective in different settings and for different patient groups. Much of the evidence relates to home-based PC, although some models are delivered across care settings. Reviews report several potential advantages and few disadvantages of models of PC delivery. However, under-reporting of the components of intervention and comparator models are major barriers to the evaluation and implementation of models of PC. **Full text (click on enotes.tripod.com icon):** <https://bit.ly/3IEuR51>

Publishing Matters

Establishing patient perceptions and preferences for a journal authenticator tool to support health literacy: A mixed-methods survey and focus group study

RESEARCH SQUARE | Online – 15 September 2021 – Publishing results from research studies in academic journals is one of the most important ways that medical knowledge is shared. Fake academic journals called “predatory journals” are disrupting this method of sharing knowledge. Predatory journals can be found by patients and the public using a simple Google search. The goal of this study was to understand how patients use the Internet to find health information and to understand what patients need in a digital tool to identify predatory journals. This digital tool will help patients when searching for accurate health information from reliable sources. In the first part of this study, adult Canadian patients and caregivers completed a survey. Many (82%) said they use the Internet most often when looking for health information. Some (37%) said they sometimes read academic research articles when searching for health information. Over half (52%) of participants said they sometimes have difficulty knowing if online information is reliable. The second part of this study focused on what patients need in a digital tool to identify predatory journals. The key features of a digital tool include displaying journal features that show credibility, journal features that show lack of credibility, and the institutions associated with the work. A digital tool can help patients and the public in finding and understanding health information and predatory. The study results will be used to develop digital tools for patients and public. **Full text:** <https://bit.ly/3EIHIMc>

N.B. This is a preprint that has not been through peer review and not been published in a scientific journal.

Noted in Media Watch 17 May 2021 (#717, p.12):

- *CHEMICAL & ENGINEERING NEWS* | Online – 20 May 2021 – ‘**How the Centre for Journalology hopes to fix science.**’ The Centre is home to an array of experts with various backgrounds, including preclinical researchers, clinical epidemiologists, social psychologists, methodologists, behavioral scientists, and metrics literacy specialists. The organization has three pillars: 1) Performing research on the subfields of metascience; 2) Developing a course to teach the subject; and, 3) Conducting outreach about the topic to stakeholders such as universities, researchers, journals, and policymakers. The Centre aims to improve science and make scientific publishing more robust and rigorous. In late 2019, for instance, the center unveiled a definition of predatory publishing.¹ **Full text:** <https://bit.ly/3o7hE1Y>

1. ‘Defining predatory journals and responding to the threat they pose: A modified Delphi consensus process,’ *BMJ Open*, published online 9 February 2020. [Noted in Media Watch 17 February 2020 (#653, p.17)] **Full text:** <http://bit.ly/2SdQaNr>

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3tw1eqa>

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PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU>]

Asia



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[Scroll down to 'Media Watch']

Australia

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

Canada



BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION <https://bit.ly/3two4xX>

[Grief & Bereavement & Mental Health Summit 2021 'Resource Page.' Scroll down to 'International Palliative Care Resource Center']



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

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[Scroll down to 'General Resources' and 'Media Watch']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

ONTARIO | Mississauga Halton Palliative Care Network: <https://bit.ly/3tby3b3>

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTPS://BIT.LY/3WVL5RW>

HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

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

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