If hospices had come under the remit of National Health Service services [in the U.K.] ... they might have received more attention from local and national government and not been an overlooked service.

‘What do we know about the impact of the COVID-19 pandemic on hospices? A collaborative multi-stakeholder knowledge synthesis’ (p.4) in AMRC Open Research.

U.S.A.

Short on staff, some hospices ask new patients to wait

THE NEW YORK TIMES | Online – 16 October 2021 – Hospice staff shortages have developed across the country, and while closing to new patients is not a common response, “it's getting worse,” said Edo Banach, the president and chief executive of the National Hospice & Palliative Care Organization. “If this goes on much longer, it's going to happen more.” More than half of the 2.3 million Medicare beneficiaries who die annually rely on hospice care... To qualify for hospice, patients are deemed to be within six months of death, which cannot be postponed. Because many put off enrolling – American patients spend only a median of 18 days in hospice – even short waits can mean the loss of valuable care, from pain relief to help with household tasks. The shortage, hospice administrators say, stems partly from an exhausted staff who visited patients’ homes through the worst of the pandemic, wearing full protective gear (once they could acquire it). Staff shortages also reflect economic pressures. Hospice nurses typically earn less than those employed by hospitals or traveling nurse agencies, which have raised their wages and bonuses as they also face a pandemic-related lack of nurses. https://nyti.ms/3lOKisR

Specialist Publications

‘Changing pediatric hospice and palliative care through Medicaid partnerships’ (p.6), in Pediatrics.

Cont. next page

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Hospices mobilize diversity education to reach underserved groups

**HOSPICE NEWS |** Online – 14 October 2021 – Despite rising demand and utilization for hospice care, gaps in access and awareness among communities of color continue to plague the industry. Grasping the systemic issues at the heart of these disparities will be key for hospice providers working to reach a larger and more diverse patient population. Hospices have room to grow in reaching a more diverse patient population. Demographic disparities in access to and quality of hospice and palliative care (PC) have been persistent problems in the field for decades. African American, Asian and Hispanic patients made up less than 20% of Medicare hospice patients in 2018, while the remaining 80% of beneficiaries were Caucasians... A boom in the senior population is fueling demand for hospice and PC nationwide. Every day, roughly 10,000 people in the U.S. become Medicare eligible, a trend that began in 2011 and is expected to continue through 2030, according to the Medicare Payment Advisory Commission. [https://bit.ly/3lKn07g](https://bit.ly/3lKn07g)

Noted in Media Watch 27 September 2021 (#736, p.15):

- **JAMA NETWORK OPEN |** Online – 22 September 2021 – ‘Navigating the complex ecosystem of race, ethnicity, structural racism, socioeconomic factors, medical care delivery, and end-of-life care...’ 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. **Full text:** [https://bit.ly/3KDqFIS](https://bit.ly/3KDqFIS)
End-of-life and Palliative Care for People with Dementia Framework

AUSTRALIA | Government of Western Australia (Department of Health) – 12 October 2021 – Dementia is the second leading cause of death in Australia and has a profound impact on end-of-life (EoL) and palliative care (PC) services. PC for people with dementia is different from other life-limiting illnesses and specific considerations. Dementia is unpredictable and the decline or loss of decision-making capacity are significant barriers to accessing responsive and respectful PC. The Framework offers health service providers and administrators a guide to planning, developing and implementing local processes and solutions to address the needs of people with dementia. The Framework also provides guidance and support to individuals and their families so people with dementia are as involved as possible in the advance care planning process to ensure person-centred EoL care. It outlines principles to ensure that people with dementia have timely access to appropriate EoL and PC services.

Download at: https://bit.ly/30iU2Dk

Specialist Publications

‘Palliative care integration: A critical review of nurse migration effect in Jamaica’ (p.4), in BMC Palliative Care.

‘Evaluation of a nurse practitioner role within a specialist palliative care service in Australia’ (p.6), in Progress in Palliative Care.

Specialist Publications

Ongoing value and practice improvement outcomes from pediatric palliative care education

ADVANCES IN MEDICAL EDUCATION & PRACTICE | Online – 10 October 2021 – Novice and experienced professionals who care for children with life-limiting conditions throughout Australia were provided with pediatric palliative care (PPC) education through the Quality of Care Collaborative Australia (QuoCCA). Impact evaluation has shown this education to be beneficial. More than 4 months after the QuoCCA education, 98% of respondents [to an online survey] rated it extremely valuable or valuable and 78% of respondents rated it extremely or very helpful in improving clinical practice. Improvements in knowledge, skills or confidence were reported by 90% or more respondents in the areas of PPC referral, responding to psychosocial needs, the benefits of the PPC approach, PPC resources and communication skills. Between 84% and 89% of respondents reported improvements in advance care planning, assessment and intervention, responding to physical needs, supporting spiritual needs and supporting health professionals and self-care. Providing bereavement care improved in 85% of responses. The most valuable aspects of the education, changes in practice and barriers to the implementation of learning were discussed. Respondents particularly mentioned improvements in awareness of the network of care, the practical management of patients and communication skills. Full text: https://bit.ly/3At0vI4

Research Matters

‘Patient and physician perspectives on engaging in palliative and healthcare trials: A qualitative descriptive study’ (p.7), in BMC Palliative Care.

‘Striving for diversity in research studies’ (p.7), in New England Journal of Medicine.

‘The promise of big data for palliative and end-of-life care research’ (p.7), in Palliative Medicine.

Publishing Matters


N.B. Quality of Care Collaborative Australia website: https://bit.ly/3mF9i4P
What do we know about the impact of the COVID-19 pandemic on hospices? A collaborative multi-stakeholder knowledge synthesis

AMRC OPEN RESEARCH | Online – 6 October 2021 – One of the major concerns during the pandemic is the strain it puts on healthcare services, especially when rates of COVID-19 infections within the population are at their peaks. Much of the media attention, and government decisions, focussed on overwhelmed hospitals and intensive care units. However, there was less attention afforded to other settings where a substantial amount of healthcare, including palliative and end-of-life care, took place – community health and social care services such as primary care, district nursing, or care homes. In particular, non-National Health Service (NHS) hospice services experienced rapid and sizeable changes affecting all aspects of care and support. Participants at a stakeholder event described how they felt that the role and importance of palliative care had been excluded by the government and the media. Providing hospice care during the pandemic has been incredibly challenging and this was further compromised by shortages of essential personal protective equipment, medicines, and staff. There was a view that this was made worse by hospices not being seen as “frontline NHS.” Some participants reported feeling that the extra work done above-and-beyond normal duties had not been adequately recognised. If hospices had come under the remit of NHS services, it was observed, they might have received more attention from local and national government and not been an overlooked service. Full text: https://bit.ly/3IMQHTn

N.B. Issues discussed in this article: impact on resources and funding; loss of volunteers; changes to visiting arrangements; demographics and geographies of care; places of care (towards integrated hospice care in the community); hospice at home; digital and remote palliative healthcare; changes to services that worked, changes that did not work; and, impact on bereavement support.

Palliative care integration: A critical review of nurse migration effect in Jamaica

BMC PALLIATIVE CARE | Online – 13 October 2021 – This critical review offers a comprehensive overview of the effects of nurse migration on palliative care (PC) integration in Jamaica. Emerged themes included: 1) Globalization creating opportunities for migration; 2) Recruitment of skilled professionals from Caribbean Community & Common Market; 3) Imbalance and inequities resulting from migration; and, 4) Mitigation reduction strategies. To fully contribute to PC integration, nurses require opportunities for education as well as policy support. Without significant policy change, such as expanding the role and capacity of Jamaican nurses, increasing salaries and offering leadership opportunities, nurses will continue to migrate. Continued loss of Jamaica’s skilled nursing workforce will negatively impact PC integration efforts and is a barrier to meeting the sixty-seventh World Health Assembly recommendations for strengthening PC. Formulated hypotheses from this review should guide future investigation of the effects of nurse migration on integration of PC in Jamaica. Novel mitigating strategies, and opportunities for enhanced nurse education such as investigating the role of advanced practice nurses with specialty PC training, should be considered within Jamaica’s healthcare system. Full text: https://bit.ly/3FG2MDJ

1. ‘Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course,’ World Health Assembly, 2014. Download at: https://bit.ly/3FKvizK

Please report any broken links.
Success of a community-based delivery at recruiting individuals from underserved communities for an observational cohort study of an advance care planning intervention

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 15 October 2021 – Underserved and minority populations are often reluctant to engage in advance care planning (ACP) and/or research often due to distrust in healthcare and/or research institutions. The authors present recruitment data from a prospective, mixed-methods observational cohort study that examined the feasibility and preliminary efficacy of a community-based delivery model involving an end-of-life conversation game to motivate participants to complete ACP behaviors. Game events were held in community venues in 27 states across the U.S. in 2018-2019. The model involved leveraging existing social networks to recruit attendees and research participants to community game day events. 1,122 individuals attended events at 53 sites. Use of the community-based delivery model successfully engaged undeserved communities in a research-based ACP related community outreach event. This model may be useful for overcoming underserved and minority populations’ skepticism and distrust of healthcare and research that is a common barrier to progress in health agendas, especially ACP. Abstract (w. references): [https://bit.ly/3FQ57vL](https://bit.ly/3FQ57vL)

Telemedicine utilization in the ambulatory palliative care setting: Are there disparities?

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 October 2021 – Given a shortage of specialty palliative care (PC) clinicians and geographic variation in availability, telemedicine has been proposed as one way to improve access to PC services for patients with cancer. However, the enduring digital divide raises questions about whether unequal access will exacerbate healthcare disparities. A total of 491 patients and 1,783 visits were identified, including 1,061 (60%) in-person visits and 722 (40%) telemedicine visits. This study reveals disparities in telemedicine utilization in the ambulatory PC setting for patients with cancer who are male, Spanish-speaking, uninsured, or do not have an activated patient portal. Abstract (w. references): [https://bit.ly/3oRoCy8](https://bit.ly/3oRoCy8)

Related:

- **BMC PALLIATIVE CARE** | Online – 14 October 2021 – ‘Building a telepalliative care strategy in nursing homes: A qualitative study with mobile palliative care teams.’ This qualitative study shows that depending on the motive for which the nursing home calls on the mobile palliative care (PC) teams, telemedicine may be more or less suitable as a solution for the delivery of PC. Findings show that requests regarding patient symptoms may be particularly amenable to telemedicine. Conversely, participants, psycho-social distress in a patient likely requires presence-based consultation. This study also identified “influencing factors” that impact on whether or not telemedicine could be used in specific PC situations. Full text: [https://bit.ly/2YRuBs5](https://bit.ly/2YRuBs5)

N.B. Search back issues of Media Watch for additional articles on “telemedicine” and “telepalliative” in PC at: [http://bit.ly/2ThijkC](http://bit.ly/2ThijkC)

Access to palliative care consultation for hospitalized adults with COVID-19 in an urban health system: Were there disparities at the peak of the pandemic?

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 8 October 2021 – In this retrospective cohort study of hospitalized COVID-19 patients, the authors found those who received palliative care (PC) consultation were older, had more comorbidities, required more oxygen support, and had higher predicted mortality. There was no association between race/ethnicity, household crowding, or insurance status and PC consultation. Despite robust PC services, there were disparities in access to PC consultation across hospital sites, suggesting the reallocation of resources could not meet rapidly changing clinical demand. Of note, no differences were found in receipt of PC consultation between the quaternary hospital and the small community hospital that received an inpatient physician extender. However, COVID-19 patients hospitalized at the mid-size hospitals, where additional staffing was not provided, were less likely to receive PC consultation even after adjusting for patient volume as measured by daily census. Given that resource allocation is a crucial part of pandemic responsiveness, the experience with COVID-19 highlights ongoing learning required to ensure equitable access to PC services among hospitalized patients. Full text: [https://bit.ly/3mRT9Jr](https://bit.ly/3mRT9Jr)
Changing pediatric hospice and palliative care through Medicaid partnerships

PEDIATRICS | Online – 13 October 2021 – Since its inception in 2010, the Concurrent Care for Children Provision of the Affordable Care Act [in the U.S.] has enabled seriously ill pediatric patients and their families to access comprehensive, supportive hospice services while simultaneously receiving ongoing treatment-directed therapies. Although this groundbreaking federal legislation has resulted in improvements in care for vulnerable pediatric patients, the implementation of the law has varied from state to state through Medicaid programming. The pediatric professional community is called to consider how Medicaid services can more effectively be delivered by leveraging legislative mandates and collaborative relationships between clinicians, Medicaid administrators, and policymakers. In this article, the authors examine ways concurrent care has been executed in three different states and how key stakeholders in care for children with serious illness advocated to ensure effective implementation of the legislation. The lessons learned in working with state Medicaid programs are applicable to any advocacy issue impacting children and families. Abstract: https://bit.ly/3mQIpuJ

Evaluation of a nurse practitioner role within a specialist palliative care service in Australia

PROGRESS IN PALLIATIVE CARE | Online – 10 October 2021 – In Australia, despite the growing need for palliative care (PC), there is a shortage of PC professionals. The literature suggests that nurse practitioners (NPs) are well positioned to innovate the current model of palliative medicine. This prospective study evaluates the implementation of a new NP role within an established multidisciplinary PC service. In this study, patients under the care of the NP had fewer admissions to an acute hospital compared to the rest of the service (17.0% vs. 27.2%), as well as no acute admissions for terminal care and a greater number of patients who achieved their preferred place of death (87.2% vs. 72.2%). A survey of the multidisciplinary team revealed that the majority of responders (93.3%) felt that the NP role had a positive impact on patient care and was holistic, safe, and met patients’ needs. Neutral or negative survey responses highlighted the need for further education or refinement of the role in areas such as prescribing and ability to refer patients directly to medical specialists. Overall, study results were positive and support the introduction of the NP role into a specialist PC service but more research is required to assess the effectiveness of the role. Abstract: https://bit.ly/3lt3X0Z

Related:
- PALLIATIVE & SUPPORTIVE CARE | Online – 13 October 2021 – ‘Rural community-based nurses’ self-reported knowledge and skills in the provision of psychosocial care to palliative and end-of-life clients and carers.’ Nurses from a rural area of Victoria, Australia, completed an electronic questionnaire rating their knowledge against six national palliative care (PC) standards and ten screening and assessment tools. Respondents were confident in their knowledge and skills in the majority of psychosocial care. As generalist nurses make up the majority of the rural nursing workforce, further research should be undertaken on what educational strategies are needed to support and upskill rural community-based nurses to undertake formal training in PC. Abstract (w. references): https://bit.ly/3v5R9RH

The online representation of palliative care by practice, policy, and advocacy organizations: Definitional variations and discursive tensions

QUALITATIVE HEALTH RESEARCH | Online – 11 October 2021 – Negative beliefs and a lack of clarity surrounding the meaning of palliative care (PC) have been widely reported as obstacles to its uptake. Information available to the public possibly contributes to this. A descriptive and discourse-theoretical analysis was conducted of information spread online by PC policy, advocacy, and practice organizations. Discrepancies were found in the way PC was defined in relation to curative, end-of-life, terminal, and supportive care. Beyond these definitional variations, meaning was generated through the representation of PC as a culture, connected to total care, compassion, and openness. Tensions arose around the concepts of autonomy, a natural death, and an emphasis on the quality of life away from death and dying. Overall, this study showed that the online information of PC is a potential source of confusion and might even contribute to its stigmatization. Insights are provided that may help improve clarity toward the public. Abstract (w. references): https://bit.ly/3atf63e
Research Matters

Patient and physician perspectives on engaging in palliative and healthcare trials: A qualitative descriptive study

*BMC PALLIATIVE CARE* | Online – 14 October 2021 – This study identified challenges related to conducting and participating in research as perceived by primary care physicians, patients, and caregivers/proxies. Themes from patient and caregiver interviews included time constraints, privacy concerns, lack of research familiarity, disconnect with research institution, self-perceived health status, and concerns with study randomization. Physician-identified barriers focused on time constraints and study randomization. Patient and caregiver recommendations for study recruitment included in-person recruitment, recruitment at healthcare providers’ offices, recruitment via mail, additional study information, and frequent calls. Physician recommendations were related to placement of flyers at clinics, financial incentives, and formal events. Through this understanding of the relationship between the patient, proxy, caregiver, and physician perspectives, this study provides a better understanding of how researchers could work with physicians to build participant trust in research by providing a “warm hand-off” during recruitment. Full text: [https://bit.ly/3lH8ldc](https://bit.ly/3lH8ldc)

Striving for diversity in research studies

*NEW ENGLAND JOURNAL OF MEDICINE*, 2021;385(15):1429-1430. Physicians often find it challenging to apply the lessons of large research studies to their clinical practice, especially when the research participants do not reflect the racial identity, ethnicity, age, or sex and gender of the physicians’ patients. Strict eligibility criteria for enrollment in a study may exclude relevant participants. The study population may not include groups representing large fractions of those who might be candidates for the trial intervention. This can leave clinicians in a quandary about whether and how to apply the research findings to their own patients, for whom the risk-benefit profile may differ. There are several possible reasons for this lack of representation in research studies. Simple logistic obstacles, such as an inflexible work schedule or the lack of convenient and affordable transportation to a research center, can act as impediments. Another major contributor is the dearth of investigators and study staff who are themselves members of minority groups. Involvement of such persons in conducting the study may increase the confidence of potential minority research participants and community leaders, who can be key to engaging broader participation and accommodating the needs of their communities. Mentoring such investigators, who could then work with underserved communities, would both enhance the recruitment of representative participants and improve communication so that it contextualizes the research questions and the potential benefits of participation in the study appropriately. Full text: [https://bit.ly/3iMfUx8](https://bit.ly/3iMfUx8)

The promise of big data for palliative and end-of-life care research

*PALLIATIVE MEDICINE* | Online – 12 October 2021 – When looking specifically at the field of palliative and end-of-life care (EoLC) research, big data is particularly promising as it has the potential to overcome some of the usual difficulties that come with traditional research design, such as the difficulty to recruit and retain a sufficient number of study participants. However, big data research in this field also holds considerable challenges. An example is how to address the issue of prognostic uncertainty in retrospective cohorts of decedents: while, in practice, care providers, and patients make choices about treatments and care prospectively, with a considerable degree of uncertainty as to what will happen in the future, researchers selecting decedents and looking back at the trajectory leading to death already know the final outcome. This means that these studies typically miss individuals who had another outcome than death. Also, the different ways in which palliative care and EoLC are organized, and thus registered, across care settings and countries, pose a challenge. Full text: [https://bit.ly/3lylfdp](https://bit.ly/3lylfdp)

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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.9.
Publishing Matters

A framework for anti-racist publication in palliative care: Structures, processes, and outcomes

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 15 September 2021 – Systemic or structural racism describes an embedded pattern of explicit and implicit racial biases that, through policy and action, systematically confer advantage to white people and disadvantage Black, indigenous, and other people of color. Hospice and palliative care (PC) journals participate in this broader system of racial discrimination. Building on PC’s explicit focus on patients’ goals and values, which may in and of itself comprise a form of social justice in healthcare, PC journals and their publishers have an opportunity to lead others in cultivating anti-racist practices and explicitly promoting equity. The publication life cycle of submission and solicitation, manuscript peer-review, and publication provide a framework for examining the structures, processes, and outcomes by which PC and other journals might address systemic racism. The authors describe the current academic publishing landscape, which diminishes the voices and experiences of racial and ethnic minority patients and undermines the careers of under-represented scholars. They then propose reforms that they believe will improve publication equity and quality as well as healthcare outcomes. These include an ‘Equity in Publication’ checklist, solicitation of manuscripts on equity-relevant topics, promotion of scholars through editorial structures and peer review processes, and a standard ‘Equity Rating’ for publications. Greater efforts to include non-dominant voices in every aspect of publication, through appropriate recognition of their scholarship and remuneration for their efforts, will drive equity in health outcomes. By pursuing an anti-racist and equity-focused publishing agenda, hospice and palliative medicine journals and their publishers have an opportunity to transform healthcare.

Abstract (w. references): [Link]

Noted in Media Watch 23 August 2021 (#731, p.13):

- JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2021;326(7):607-608. ‘Structural racism and scientific journals...’ Racism is pervasive and deeply entrenched in every aspect of society, and academic medicine, and scientific publishing are not immune. Structural racism may influence multiple facets of the publishing arena, including the composition of journal leadership, editorial boards, the peer review process, published content, and more. There is work to be done among medical schools, academic centers, research funders, and major journals... Recent events at JAMA involving the posting of a podcast and tweet that were racist, discriminatory, painful, and harmful, as well as subsequent developments over the ensuing months, represent an important teachable moment. Full text: [Link]

N.B. The focus of this issue of JAMA is racial and ethnic disparities and inequities in medicine and healthcare. Journal contents page: [Link]

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: [Link]

Search Back Issues of Media Watch @ [Link]
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International

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Asia

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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’]

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ONTARIO | Acclaim Health: https://bit.ly/3g82uuS
[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


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

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

Closing the Gap Between Knowledge & Technology
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Something Missed or Overlooked?

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

Barry R. Ashpole, Ontario CANADA e-mail: BarryRAshpole@bell.net