

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

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A relational approach to knowledge mobilisation fostered a vibrant dialogue between researcher producers and users, enabling appraisal of the latest research evidence and generation of implications for palliative care policy and practice in Scotland.

'Palliative care research promotion in policy and practice: A knowledge exchange process' (p.12), in *BMJ Supportive & Palliative Care*.

Canada

Healing through community: Reflecting on collective grief from COVID-19

HEALTHY DEBATE | Online – 16 August 2021 – Pandemic restrictions have disrupted customary death rituals and traditions, forcing us to find new and alternative ways to individually and collectively cope, mourn and memorialize people who have been lost. While death is the form of loss most commonly associated with feelings of grief, we are also experiencing grief in other forms (e.g., anticipatory, disenfranchised, chronic, complicated, masked, etc.). This is because of new types of pandemic-related losses that have unexpectedly impacted our daily lives and experiences within our home, work, school, social, care and faith-based communities, including the loss of common routines, traditions, jobs and financial security, in-person social interactions and celebrations. We have had to leverage technology and online platforms to facilitate elements of human connection we rely on for these different communities to thrive. Long-term care (LTC) homes are an example of care communities that rely on interactions between residents, care providers, family and friend caregivers, staff and volunteer members. The COVID-19 pandemic has significantly impacted these LTC home communities on all facets of grief and loss. A disproportionate number of deaths, social isolation,

cancelled recreational and social programming, removal of communal dining and restricted visitor access for family and friends has culminated in concerns for the mental, physical, emotional and spiritual well-being of LTC community members. <https://bit.ly/3mgusl7>

Specialist Publications

'**Opioid safety recommendations in adult palliative medicine: A North American Delphi expert consensus**' (p.5), in *BMJ Supportive & Palliative Care*.

'**Call to action: The need to expand spiritual care supports during the COVID-19 pandemic**' (p.6), in *Canadian Oncology Nursing Journal*.

'**Effect of early palliative care on end-of-life healthcare costs: A population-based, propensity score-matched cohort study**' (p.9), in *JCO Oncology Practice*.

'**Navigating design options for large-scale interprofessional continuing palliative care education: Pallium Canada's experience**' (p.10), in *Palliative Medicine Reports*.

U.S.A.

Life without parole has turned Pennsylvania's prisons into hospices for the hopeless

PENNSYLVANIA | *Pennsylvania Capital-Star* – 19 August 2021 – Over 10 years ago I was in prison, tasked with the strange job of changing diapers, bathing paralyzed men, and preventing bedsores. I watched incarcerated people enter hospice and die, with me as a volunteer and stranger serving the role of their only family. While I'd come to think prisons were intended to rehabilitate people, my time spent incarcerated opened my eyes. People were aging and dying in prison, withering away to nothing with no chance of ever returning to the free world. The reality of prison hospice was unknown to me when my incarceration began in 1999, after a murder charge when I killed my abuser as a teen and found myself facing a long sentence. It wasn't until a hospice program began at my prison when I stepped

into the world of incarcerated elder care, as one of about 30 volunteers. After a two-day training on basic skills – including repositioning people so old they couldn't move themselves, brush their teeth and adjust their glasses – 20 of those people dropped off. By the time that we actually began working with those men who were dying, there were only three of us left. <https://bit.ly/3ATWhN>

Specialist Publications

'Cancer care in the incarcerated population: Barriers to quality care and opportunities for improvement' (p.8), in *JAMA Surgery*.

Workforce shortage shutting down hospice programs

HOSPICE NEWS | Online – 16 August 2021 – Worsening workforce shortages have been keeping hospice leaders awake at night for several years running. Rising turnover due to the COVID-19 pandemic has exacerbated the crisis, and some hospice providers and health systems are starting to shut down their programs or sell off their operations because they cannot recruit or retain a sufficient number of employees. Healthcare providers have seen staff turnover rise during the pandemic, and hospice is no exception. Slightly more than 20% of healthcare workers have considered leaving the field due to stress brought on by the pandemic, and 30% have considered reducing their hours, according to a recent study...¹ But the shortage did not begin with the outbreak, it has been building for years as hospice employees age with the rest of the population and seek retirement. Hospices face unique recruitment challenges, particularly because medical, nursing, and social work students receive very little exposure to hospice or palliative care during their training. <https://bit.ly/3iTnrec>

1. 'Experiences of a health system's faculty, staff, and trainees' career development, work culture, and childcare needs during the COVID-19 pandemic,' *JAMA Network Open*, 2021;4(4):e213997. **Full text:** <https://bit.ly/3yYc8aD>

Noted in Media Watch 7 June 2021 (#720, p.3):

- *HOSPICE NEWS* | Online – 1 June 2021 – '**Grand Ronde ends hospice program due to workforce shortage.**' Grande Ronde Hospital & Clinics ... indicated that the COVID-19 pandemic exacerbated industry-wide workforce issues, leading to the decision to close. Many hospice providers have seen staff turnover rise during the pandemic... Slightly more than 20% of healthcare workers have considered leaving the field due to stress brought on by the pandemic...¹ More than 35% of hospice leaders surveyed cited staffing shortages as a top concern for their organizations...² Staffing shortages have plagued the hospice industry for years. The U.S. has 13.35 hospice and palliative care specialists for every 100,000 adults 65 and older...³ <https://bit.ly/3q7sBkd>

1. 'Experiences of a health system's faculty, staff, and trainees' career development, work culture, and childcare needs during the COVID-19 pandemic,' *JAMA Network Open*, published online 2 April 2021. **Full text:** <https://bit.ly/3yYc8aD>
2. 'Top hospice worries 2021: Accessing facility-bound patients, staffing,' *Hospice News*, published online 8 February 2021. [Noted in Media Watch 15 February 2021 (#704, p.1)] <http://bit.ly/3p78SDs>

Cont.

3. 'The growing demand for hospice and palliative medicine physicians: Will the supply keep up?' *Journal of Pain & Symptom Management*, published online 2 February 2018. [Noted in Media Watch 5 February 2018 (#549, p.12)] **Full text:** <http://bit.ly/2CRjxwO>

Isolation is debilitating for many near the end of life

NEXT AVENUE | Online – 16 August 2021 – Never have the debilitating effects of isolation been laid so bare as during the persistent COVID-19 pandemic. During the lockdowns of 2020, everybody got a taste of it. But for many older people and especially those nearing the end of their lives, social isolation and loneliness are often demons woven into everyday life. Newly published research begins to reveal the extent of that, as well as some of the dangers.¹ “The first thing that was really striking to me was just how common of an issue this is and how little we typically recognize this, as clinicians caring for people at the end of life,” says Dr. Ashwin Kotwal, assistant professor of geriatrics at the University of California in San Francisco, and lead author of the study. While healthcare providers – even palliative care specialists – tend to focus on the physical and medical needs of patients, Kotwal makes a startling claim: “Social well-being may be equally important to individuals and their families.” Kotwal’s team drew data from more than 3,000 individuals who participated in an ongoing national study of U.S. residents over 50. Known as the ‘Health & Retirement Study,’ it tracks people’s well-being through their final years through a regular series of surveys. They found that nearly one in five subjects said they were “frequently lonely” or felt socially isolated during the last four years of their lives. <https://bit.ly/3xTiKVR>

1. ‘The epidemiology of social isolation and loneliness among older adults during the last years of life,’ *Journal of the American Geriatrics Society*, published online 11 July 2021. **Abstract:** <https://bit.ly/3jVuQc8>

N.B. Selected articles on social isolation and loneliness noted in Media Watch 20 July 2020 (#675, p.4).

International

Palliative care is the opposite of giving up

SOUTH AFRICA | *Mail & Guardian* (Cape Town) – 18 August 2021 – Some people feel nervous when they hear the word “palliative,” but accepting this kind of care does not mean you are dying, and it does not mean you are giving up. In fact, anxiety, depression, fatigue and pain can set in at the beginning of treatment – palliative care (PC) trained practitioners understand the stresses that patients and their families face and can help them to cope. With better all-round care, good symptom management, and a comprehensive and holistic home-based care plan in place, patients are not only able to carry on their daily life, but also better able to undergo or complete their medical treatments. It’s important to remember that PC doesn’t stand in opposition to curative or disease-directed care; the two often co-exist side-by-side. You can receive it along with the care you get from your oncologist or general practitioner. Yet for too many patients, PC referral happens too late to improve quality of life. Many healthcare practitioners still struggle with messaging when it comes to PC. Patients, and sometimes practitioners, mistakenly view it as the same as end-of-life

care or hospice. Among the studied stumbling blocks to PC are doctor and patient resistance, the latter often as a result of unrealistic expectations of patients and their families. Of course, both doctors and patients want to reduce suffering and prolong life. The irony is that early PC referral has been shown to do just that. One of the big strengths of PC is recognition of the human side of illness. PC patients cite benefits such as: “being recognised as a person,” “having a choice and being in control,” “being connected to family and the world outside,” “being spiritually connected,” and “physical comfort and dignity.” <https://bit.ly/2XsACKE>

Specialist Publications

‘Multiple hospitalisations towards the end of life among patients with serious mental illness: A retrospective cohort study in England, U.K.’ (p.7), in *European Psychiatry*.

Cont.

Noted in Media Watch 1 March 2021 (#706, p.8):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 25 February 2021 – ‘**Public messaging for serious illness care in the age of coronavirus disease: Cutting through misconceptions, mixed feelings, and distrust.**’ A year ago, the authors began a project designed to align public messages from 10 organizations involved in advance care planning, palliative care, and hospice to increase public engagement. Their project plan was upended by the COVID-19 pandemic – but they used the opportunity to conduct focus groups during the pandemic that, compared with focus groups conducted before the pandemic, provide an important portrait of public perceptions of serious illness care that can be used to design for greater public engagement. **Abstract:** <https://bit.ly/3dRnbds>

Noted in Media Watch 29 June 2020 (#672, p.5):

- *BMC PALLIATIVE CARE* | Online – 22 June 2020 – ‘**Palliative care in its own discourse: A focused ethnography of professional messaging in palliative care.**’ Despite 50 years of modern palliative care (PC), a misunderstanding of its purpose persists. The original message that PC is focused on total care, helping to live until the person dies, is being replaced and linked to feelings of fear, anxiety and death, instead of compassion, support or appropriate care. Society is still afraid to speak its name, and specialized units are identified as “places of death” as opposed to “places of life” meant to treat suffering. It is imperative to identify what message PC professionals are relaying ... and how that message may condition understandings of the right to access PC. **Full text:** <https://bit.ly/2YnJ8sm>

Specialist Publications

Experiences of preparing children for a death of an important adult during the COVID-19 pandemic: A mixed methods study

BMJ OPEN | Online – 16 August 2021 – Obstacles to preparing children for a death of an important adult included families’ lack of understanding about their relative’s declining health; parental belief that not telling children was protecting them from becoming upset; and, parents’ uncertainty about how best to prepare their children for the death. Only 10.2% of relatives interviewed reported professionals asked them about their deceased relative’s relationships with children in contrast to the 68.5% of professionals who reported that the healthcare team asked about patient’s relationships with children. Professionals did not provide families with psychosocial support to facilitate preparation, and resources were less available or inappropriate for families during the pandemic. 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>

Research Matters

‘Views of healthcare professionals on recruiting to a psychosocial randomised controlled trial: A qualitative study’ (p.11), in *BMC Health Services Research*.

‘Research participation in palliative medicine – benefits and barriers for patients and families: Rapid review and thematic synthesis’ (p.12), in *BMJ Supportive & Palliative Care*.

Publishing Matters

‘Willfully submitting to and publishing in predatory journals: A covert form of research misconduct?’ (p.13), in *Biochemia Medica*.

‘Structural racism and scientific journals – a teachable moment’ (p.13), in *Journal of the American Medical Association*

‘Publishing in predatory journals: Guidelines for nursing faculty in promotion and tenure policies’ (p.14), in *Journal of Nursing Scholarship*.

Cont.

Related:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 18 August 2021 – ‘**Breaking the silence about illness and death: Potential effects of a pilot study of the family talk intervention when a parent with dependent children receives specialized palliative home care.**’ Family communication improved after participation in family talk intervention (FTI) as family members learned communication strategies that facilitated open sharing of thoughts and feelings. Increased open communication helped family members gain a better understanding of each other’s perspectives. Parents reported that relationships with their partner and children had improved as they now shared several strategies for maintaining family relationships. Parents were also less worried following participation in FTI. **Full text:** <https://bit.ly/3swlQwL>

Noted in Media Watch 26 July 2021 (#727, p.8):

- *PATIENT EDUCATION & COUNSELING* | Online – 16 July 2021 – ‘**Parent’s with incurable cancer: “Nuts and bolts” of how professionals can support parents to communicate with their dependent children.**’ With adequate knowledge and skills, health and social care professionals (HSCPs) have a vital role in offering necessary care to parents to help them guide and support their children through the end of life (EoL) period. There is a need for HSCPs to encourage parents to start the difficult conversation soon after receiving the poor prognosis, to avoid crisis management when the ill-parent is actively dying or throughout the immediate bereavement. The ‘Talking, Telling & Sharing’ EoL framework is an evidence-based, theory-driven communication framework. **Abstract:** <https://bit.ly/3er1kJp>

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>

Opioid safety recommendations in adult palliative medicine: A North American Delphi expert consensus

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 August 2021 – Despite the escalating public health emergency related to opioid-related deaths in Canada and the U.S., opioids are essential for palliative care (PC) symptom management. Opioid safety is the prevention, identification and management of opioid-related harms. Through a Delphi process comprised of two rounds, U.S. and Canadian panelists in PC, addiction and pain medicine developed expert consensus recommendations. Elected Canadian Society of Palliative Care Physicians (CSPCP) board members then rated how important it is for PC physicians to be aware of each consensus recommendation. The panelists ... developed a total of 130 recommendations from the two rounds about the following six opioid-safety related domains: 1) General principles; 2) Measures for healthcare institution and PC training and clinical programmes; 3) Patient and caregiver assessments; 4) Prescribing practices; 5) Monitoring; and, 6) Patients and caregiver education. Fifty-nine topics did not achieve consensus and were deemed potential areas of research. From these results, the CSPCP identified 43 high-priority recommendations and 8 high-priority research areas. Urgent guidance about opioid safety is needed to address the opioid crisis. These consensus recommendations can promote safer opioid use, while recognising the importance of these medications for PC symptom management. **Full text:** <https://bit.ly/3CN4a5T>



Noted in Media Watch 1 March 2021 (#706, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 February 2021 – ‘**A national survey of challenges faced by hospices during the opioid crisis: Estimates of pain medication shortages, missing medications, and opioids left in the home post-death.**’ No national data exist on hospice medication shortages, the frequency that opioid medications go missing, and drug disposal practices. A national survey of 600 randomly selected hospices stratified by state and profit status was undertaken. Participants reported their knowledge and perceptions about medication shortages, frequency that opioid medications go missing, and the proportion of hospice deaths in which opioids are left in the home. **Abstract (w. references):** <https://bit.ly/3uEXOld>

Cont.

Noted in Media Watch 23 May 2020 (#658, p.7):

- *CURRENT ONCOLOGY REPORTS* | Online – 13 March 2020 – ‘**Stringent control of opioids: Sound public health measures, but a step too far in palliative care?**’ Opioids are the only class of drug with the proven ability to control severe pain. The introduction of stringent opioid prescribing restrictions has inevitably impacted upon the ability of those prescribing opioids for advanced life-limited disease to practice as previously and could limit the supply of adequate pain relief to patients with cancer. This review considers the evidence that symptom management of patients with advanced cancer contributes to the “opioid problem” and whether there is adequate recognition of the risks involved. **Abstract (w. references):** <http://bit.ly/2w7Ltwj>

Noted in Media Watch 30 December 2019 (#646, p.11):

- *PALLIATIVE MEDICINE* | Online – 23 December 2019 – ‘**The perception of barriers concerning opioid medicines: A survey examining differences between policymakers, healthcare professionals and other stakeholders.**’ There are significant differences in the perception of barriers between policymakers and healthcare professionals working in the field of harm reduction, pain management and palliative care... The aspects that were most frequently perceived as a major barrier or as having major impact were lack of training, lack of financial resources, and physicians’ reluctance to prescribe opioids. The responses to the knowledge and attitude questions mirror familiarity with specific professional discourses in the diverse stakeholder groups. **Full text:** <http://bit.ly/34RxB4A>

Call to action: The need to expand spiritual care supports during the COVID-19 pandemic

CANADIAN ONCOLOGY NURSING JOURNAL, 2021;31(3):347-349. Providing a “good death” for patients dying in acute care is more challenging than ever with the COVID-19 pandemic. Spiritual care teams and palliative care providers strive to address the physical, psychosocial, and spiritual care needs at end of life – for both patients and their families, and often in concert with patients’ own faith groups. During the strict lockdown policy imposed in Ontario, Canada, during the pandemic, external faith groups, and religious rituals requiring direct contact were restricted. Delivering spiritual care in our “new normal” environment challenged us to think more broadly, beyond the walls of our own institutions, particularly when external resources exist outside of acute care centres, and are often of paramount importance to dying patients and their families in acute care. **Full text:** <https://bit.ly/3g7SJfw>



Lessons Learned from COVID-19

Articles in the August issue of the newsletter of the International Association for Hospice & Palliative Care, selected from recent issues of Media Watch, focus on COVID-19 from a hospice and palliative care perspective in North America, Europe, and Asia-Pacific. **Scroll down to ‘Media Watch’:** <https://bit.ly/3iAefLA>

Related:

- *ILLNESS, CRISIS & LOSS* | Online – 16 August 2021 – ‘**The many faces of grief: A systematic literature review of grief during the COVID-19 pandemic.**’ This study investigated how grief is understood and discussed in the extant literature during the pandemic. The synthesis of 33 articles indicates grief can be manifested at various levels such as grief for self, relational grief, collective grief, and ecological grief. Another theme emphasizes some of the factors that could intensify the grief process leading to prolonged grief disorder. A third theme relates to the focus of grief processes as experienced by individuals in different developmental periods from childhood to senescence. This study contributes theoretically by expanding perception and understanding of varied forms of grief. **Full text:** <https://bit.ly/3CUT6ne>



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Dignity at the end of life in traditional Chinese culture: Perspectives of advanced cancer patients and family members

EUROPEAN JOURNAL OF ONCOLOGY NURSING | Online – 14 August 2021 – Few researches have explored the meaning of patient dignity at the end of life (EoL) from perspectives of advanced cancer patients and family members with traditional Chinese cultural background. In this study dignity at the EoL in traditional Chinese culture were classified into four categories: 1) Cultural-specific dignity, including themes of stigma-free, moral traits and “face”; 2) Self-related dignity, including themes of staying healthy and alive, living a normal life as a normal person, spiritual peace, personal value and privacy; 3) Family-related dignity, including themes of concerns to the family, not being a burden to the family, and family support; and, 4) Care- and treatment-related dignity, including themes of being respected, high quality service and disclosure of information and consent-based decision-making. **Full text:** <https://bit.ly/3xRhQcx>

N.B. Selected articles on EoL care in China noted in Media Watch 3 August 2020 (#677, p.8).

Multiple hospitalisations towards the end of life among patients with serious mental illness: A retrospective cohort study in England, U.K.

EUROPEAN PSYCHIATRY | Online – 13 August 2021 – Multiple hospitalisations towards the end of life (EoL) is an indicator of poor-quality care. Understanding the characteristics of patients who experience hospitalisations at the EoL and how they vary is important for improved care planning. Data for all adult patients with a diagnosis of serious mental illness who died in 2018-2019 in England, U.K., were extracted from the National Mental Health Services Data Set linked with Hospital Episode Statistics and death registry data. Variables of interest included age, gender, marital status, underlying and contributory cause of death, ethnicity, place of death, deprivation status, urban-rural indicator, and patient’s region of residence. Of the 45,924 patients, 38.1% ... had at least one hospitalisation in the last 90 days of life. The median number of hospitalisations was 2... Most of those hospitalised ... died in a healthcare establishment (e.g., hospital or hospice). There were marked geographic differences in the proportions of hospitalisations. Further analysis is needed to understand factors independently associated with hospitalisations in people with serious mental illness. **Abstract:** <https://bit.ly/3m4BLCp>

Noted in Media Watch 26 April 2021 (#714, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 April 2021 – ‘**Help me understand: Providing palliative care to individuals with serious mental illness.**’ This review describes the benefits of providing palliative care (PC) to individuals with serious mental illness (SMI) with concrete suggestions for communication and use of recovery-oriented language in the treatment of individuals with SMI. Recommendations for working with individuals with SMI ... are provided, including strategies to effectively manage SMI exacerbations. Interdisciplinary PC teams are in a unique position to lend assistance to those with serious SMI given their expertise in serious illness communication, values-based care and psychosocial support. **Abstract (w. references):** <https://bit.ly/2QkASlz>

Noted in Media Watch 22 March 2021 (#709, p.13):

- *PROGRESS IN PALLIATIVE CARE* | Online – 19 March 2021 – ‘**Lean in, don’t step back: The views and experiences of patients and carers with severe mental illness and incurable physical conditions on palliative and end-of-life care.**’ People with severe mental illness (SMI) have a life expectancy of up to twenty years less than the general population and many live with incurable physical health conditions. Yet, they continue to experience barriers when trying to access palliative and end-of-life care. Little research has been carried out which includes the views and experiences of people with SMI, and this study presents first findings which include people with both SMI and an incurable condition and their carers. **Abstract:** <https://bit.ly/30XohwA>

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Noted in Media Watch 24 August 2020 (#680, p.8):

- *JOURNAL OF PALLIATIVE CARE* | Online – 18 August 2020 – ‘**Working at the intersection of palliative end-of-life and mental healthcare: Provider perspectives.**’ The most prominent issues pertained to assessment of patients and differential diagnosis of chronic and persistent mental illness, and preparedness of caregivers to deliver mental health interventions, given the isolation of palliative care from other agencies. Among the assets mentioned, informal relationships with frontline caregivers were seen as the main support structure, rather than the formal policies and procedures of the practice settings. Strategies to improve mental healthcare in palliative and end-of-life care centered on holistic roles and interventions benefiting the entire palliative population... **Abstract (w. references):** <https://bit.ly/31fr7hr>

Palliative care: Critical concepts for the geropsychiatrist

FOCUS | Online – 18 August 2021 – Psychiatrists can make a significant contribution to improving quality end-of-life care (EoLC) for psychiatric patients, beyond managing their psychiatric and psychological conditions. Geriatric psychiatrists can build expertise in enhancing EoLC when caring for older adults with serious illnesses and their families, given the biopsychosociospiritual approach that significantly overlaps with palliative and hospice care approaches. To effectively add quality to EoLC, it is essential for psychiatrists to understand the core principles and practices of palliative and hospice care, learn basic symptom management skills, and hone the ability to have crucial conversations regarding prognosis and advance care planning. Also important is recognizing when to refer to hospice and palliative medicine subspecialists. This article provides an overview of palliative and hospice care, uses a case study to illustrate components of palliative and hospice care relevant to geriatric psychiatry practice, and comments on considerations pertinent to COVID-19 pandemic. **Abstract:** <https://bit.ly/3D7r7AQ>

Cancer care in the incarcerated population: Barriers to quality care and opportunities for improvement

JAMA SURGERY | Online – 18 August 2021 – Among deaths occurring in state and federal prison [in the U.S.] systems, cancer is the overall leading cause of mortality with lung cancer being the leading cause of cancer-related mortality followed by liver, colon, and pancreatic cancers, respectively. Access to high-quality oncological services remains variable; however, cost of care represents about a fifth of overall annual prison expenditures. Given the enormous patient burden, coupled with the rushed discretionary screenings performed by jail and prison nursing staff, early cancer symptoms are often missed altogether or misdiagnosed as a chronic illness or as acute infections. As such, many incarcerated individuals present with more advanced cancer stage. Incarcerated individuals have limited, if any, access to the internet, social media, and other sources of information, which severely limits their ability to research treatment options. There are no uniform quality-of-care monitoring standards for correc-

tional systems and facilities, nor are there mechanisms for reporting comparable performance data to enforce quality control within correctional health care systems. There is a growing trend in cancer incidence among incarcerated patients, which is multifactorial including barriers in access to care, increased burden of chronic medical conditions, and decreased screening tests. Efforts are needed to ensure quality healthcare outcomes for incarcerated patients with cancer. **Abstract:** <https://bit.ly/3k70mny>

Extract from *JAMA Surgery* article

Within the prison setting, access to professionals with special skills in assisting with social and spiritual concerns is also generally limited, and less than 4% of prisons have hospice programs.

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

Effect of early palliative care on end-of-life healthcare costs: A population-based, propensity score-matched cohort study

JCO ONCOLOGY PRACTICE | Online – 13 August 2021 – In this large population-based cohort study of cancer decedents, those who received early palliative care (PC) had lower overall healthcare costs than those who did not, in the last month of life. The main differences in costs were the early-PC group used more home care services and less inpatient acute care services. This suggests that cost savings is driven by increased home care services use, which serves to prevent late-life hospitalizations. Although the main findings were consistent with other studies examining PC and costs, this study's methods uniquely contribute to the evidence base. The authors addressed limitations noted in previous meta-analyses by using consistent exposure, intervention, and outcome definitions over an 11-year period of time. Their PC definition included a broad array of PC services from multiple settings, not just within inpatient hospital admissions. As well, although there are other observational cohort studies comparing early versus late PC, the authors used propensity score matching to reduce selection bias. Moreover, their home care sub-analysis allowed them to control uniquely for additional prognostic covariates (e.g., high pain or poor health instability) that are known to be associated with referrals to PC, but are typically unmeasured confounders in other studies. A major strength of this study is the use of a population-based cohort of all cancers, which creates a sample size considerably greater than previous randomized trials examining this topic and contributes to the external validity and real-world evidence that outside controlled settings, PC can reduce health system costs. In other words, the large population-based sample strengthens the credibility that the results were not because of any particular cancer center, any specific PC program, or cancer type. This study, combined with the growing evidence base, underscores the need to invest in hospital and home-community PC programs as a strategy to not only save the health system money but also address hospital bed overcrowding. **Full text:** <https://bit.ly/3yPJfY>

Pediatric palliative care parents' distress, financial difficulty, and child symptoms

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 19 August 2021 – Parents of patients with a serious illness experience psychological distress, which impacts parents' wellbeing and, potentially, their ability to care for their children. Parent psychological distress may be influenced by children's symptom burden and by families' financial difficulty. In a cohort of 601 parents of children with serious illnesses receiving pediatric palliative care (PPC), 52% of parents were moderately distressed and 17% were severely distressed. Parents reported that their children experienced an average of 6.6 out of 20 symptoms, with total symptom scores ranging from 0 to 63.8 out of 100. Additionally, over 65% of parents reported experiencing "a little" to "a great deal" of financial difficulty. While parent-reported children's symptom scores and family financial difficulty were associated with, and together accounted for greater variance in, parental psychological distress, parental distress was associated more strongly, and to a larger degree, with financial difficulty than with symptom scores alone. Findings of this study are consistent with previous findings and provide further evidence for the impact of parent-reported children's symptoms and families' financial difficulty on parental mental health. Other studies observed the effects of children's perceived disease burden and financial difficulty on parental mental health. This study is the first, to the authors' knowledge, to compare the relative contributions of parent-reported children's symptom burden and family financial difficulty levels to parental psychological distress in a sample of parents of children receiving PPC services across the full range of patient ages and underlying conditions. **Full text:** <https://bit.ly/3glR5XF>

Related:

- *PALLIATIVE MEDICINE REPORTS* | Online – 13 August 2021 – '**Long-term follow-up of legacy services offered by children's hospitals in the U.S.**' This novel study provides an updated description of legacy services offered by children's hospitals across the U.S. to children and their families and compares results with the authors' prior study. Research related to legacy interventions for children has substantially advanced over the past decade, with more children receiving services. Future research should evaluate the impact of legacy interventions on family members' (e.g., parents and siblings) experiences at end of life and in bereavement. Studies should also determine the best time in the illness trajectory to offer legacy services and their impact to families over time. **Full text:** <https://bit.ly/3yVsoZC>

Front-line hospice staff perceptions of barriers and opportunities to discussing advance care planning with hospice patients and their families

JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE | Online – 12 August 2021 – Participants in this qualitative study included 51 hospice professionals (31 clinicians, 13 leaders, and 7 quality improvement administrators) from four geographically distinct non-profit U.S. hospices serving more than 2,700 people. Capability was facilitated by interdisciplinary teamwork and specified clinical staff roles and inhibited by lack of self-perceived skill in engaging in advance care planning (ACP) conversations. Opportunities for ACP occurred during admission to hospice, acute changes, or deterioration in patient condition. Opportunity-related environmental barriers included time constraints such as short patient stay in hospice and workload expectations that prevented clinicians from spending more time with patients and families. Motivation to discuss ACP was facilitated by the employee's goal of providing personalized, patient-centered care. Implicit assumptions about patients' and families' preferences reduced staff's motivation to engage in ACP. Hospice staff made recommendations to improve ACP discussions, including training and modeling practice sessions, earlier introduction of ACP concepts by clinicians in pre-hospice settings, and increasing workforce diversity to reflect the patient populations the organizations want to reach and cultural competency. Even hospice staff can be uncomfortable discussing death and dying. Yet staff were able to identify what worked well. **Abstract (w. references):** <https://bit.ly/3iQjQ0s>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 19 August 2021 – ‘**A national survey of social workers focusing on attitudes, knowledge, and practice behaviors for educating patients about advance directives: Implication during COVID-19.**’ Engaging patients in advance care planning (ACP) may be influenced by clinicians' attitudes. During the COVID19 pandemic, the need to examine barriers to serious illness care across healthcare settings and areas of specialty practice became abundantly clear. This study examined attitudes about ACP and factors that influence the completion of advance directives (ADs). The authors identified 2 provider practice attitudes factors, 3 perceived barriers factors, and 2 perceived importance of AD factors. **Abstract (w. references):** <https://bit.ly/3gzPPR5>
- *JOURNAL OF MULTIDISCIPLINARY HEALTHCARE*, 2021;14:2087-2100. ‘**Advance care plans and the potentially conflicting interests of bedside patient agents: A thematic analysis.**’ This study provides insights into the potentially conflicting interests experienced by bedside patient agents who seek to represent the best interests of people with neurodegenerative disorders (PWND). Although bedside patient agents endeavour to respect patient choices, doctors feel conflicted about relying on advance care plans (ACP) as sources of truth. Whilst not all ACP are legally persuasive, doctors engage families and make decisions on behalf of PWND regardless of ACP legal status, thus placing bedside agents and patient agency in potential conflict. **Full text:** <https://bit.ly/3rWqc0Y>

Navigating design options for large-scale interprofessional continuing palliative care education: Pallium Canada's experience

PALLIATIVE MEDICINE REPORTS | Online – 13 August 2021 – To be effective, palliative care (PC) education interventions need to be informed, among others, by evidence and best practices related to curriculum development and design. Designing PC continuing professional development (CPD) courses for large-scale, national deployment requires decisions about various design elements, including competencies and learning objectives to be addressed, overall learning approaches, content, and courseware material. Designing for interprofessional education (IPE) adds additional design complexity. Several design elements present themselves in the form of polarities, resulting in educators having to make choices or compromises between the various options. This article describes the learning design decisions that underpin Pallium Canada's interprofessional Learning Essential Approaches to Palliative Care (LEAP) courses. Social constructivism provides a foundational starting point for LEAP course design, as it lends itself well to both CPD and IPE. The authors explore design polarities that apply to the LEAP courseware development. **Full text:** <https://bit.ly/3xSO6f7>

Cont.

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 19 August 2021 – ‘**Effectiveness of educational programs on palliative and end-of-life care in promoting perceived competence among health and social care professionals.**’ There is a growing need for palliative care for patients near the end of life (EoL) and their caregivers. Palliative and EoL care education are recommended for all healthcare ... and social care professionals ... to ensure the quality of services. However, less attention has been afforded to generic, in contrast to specialized, EoL care education. This study evaluated the effectiveness of a series of short-term generic EoL care educational programs for health and social care professionals. **Abstract (w. references):** <https://bit.ly/3sxJ6M0>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 August 2021 – ‘**An evaluation of the Communication at End-of-Life Education Program for personal support workers in long-term care.**’ Communication skills are crucial for personal support workers (PSWs) to foster therapeutic relationships with the residents and their families... The authors observed significant improvements ... with the greatest increase in the proportion of participants who responded “Often” or “Always” in the participation in end-of-life (EoL) care domain. They observed PSWs’ elevated confidence in speaking with families of the residents about EoL, discussing goals and plans with the residents, and realizing that a “good death” is possible. Time constraints and staff shortages were recurrent themes . **Abstract:** <https://bit.ly/3iVis0r>

From artmaking to changemaking: Conceptualizing the PATCH (Palliative care patient-led change) programme

PROGRESS IN PALLIATIVE CARE | Online – 17 August 2021 – This article charts the learning from an online, artmaking programme supporting individuals with a life-limiting illness. The programme sought to fill a gap caused by the temporary closure of face-to-face U.K. hospice-based day therapy programmes during the COVID-19 pandemic. Participants’ comments on this arts-based programme illustrated the sense of disrupted and diminished identity, linked to a deceased sense of agency, which terminal illness can bring. Responding to this need for increased agency led to the development of the PATCH programme. Individuals with a terminal illness will be invited to join an online collaborative group, to identify a specific issue they wish to address and to lead the change they wish to see. The PATCH group will be supported by a facilitator and a team of volunteers, whose roles will include supporting participants in planning and executing their change strategy. This article presents the conceptual underpinning for the PATCH programme, offering a tentative theory of the relationship between identity, moral purpose, agency, illness and the leadership of change for those living with a life-limiting illness. Challenging stereotypical views of palliative care patients, it explores a new community and asset-based approach to end-of-life (EoL) care which supports individuals at the EoL in developing a positive self-view. **Abstract:** <https://bit.ly/3meX5oL>

Research Matters

Views of healthcare professionals on recruiting to a psychosocial randomised controlled trial: A qualitative study

BMC HEALTH SERVICES RESEARCH | Online – 18 August 2021 – Given the problems recruiting into randomised controlled trials, particularly within palliative care and trials of psychological interventions, it is important to explore why trials may under-recruit. The present study conducted qualitative interviews with healthcare professionals who had been involved in recruitment for a trial of a psychosocial intervention in an advanced cancer population. Overall, the study identifies five main themes and eleven sub-themes. The authors’ findings suggest that whilst healthcare professionals felt that research was important, they did not have the time to engage in recruitment, and that trials of medicinal products were often prioritised over trials of psychosocial interventions. **Full text:** <https://bit.ly/3D8myGK>

Research participation in palliative medicine – benefits and barriers for patients and families: Rapid review and thematic synthesis

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 August 2021 – This review identifies the benefits or positive aspects of participation in palliative and end-of-life care (PEoLC) research and barriers, or negative aspects of participation, as described by patients, family members and carers. Despite participants often reporting altruistic benefits to participation, this review identifies a number of ways in which participants themselves can benefit, including gaining access to services, receiving additional support and validation of their caregiving role. This finding indicates that participants often have their own personal reasons for taking part in research and that they do not always necessarily share the ethical concerns of clinicians and healthcare professionals. These concerns can lead to gatekeeping, and may reflect a more paternalistic style of medicine, both of which have been reported elsewhere. Despite these reported benefits in the considered studies, the review also identifies barriers or negative aspects to participation in PEoLC research, which included feeling overwhelmed, practical barriers (such as feeling too unwell and travel distance) and the reminder of being a patient. This review considers these negative aspects and developed recommendations for researchers, clinicians and wider research teams, in an attempt to negate these barriers and support and encourage participation in research. **Full text:** <https://bit.ly/3AUAj9M>

Palliative care research promotion in policy and practice: A knowledge exchange process

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 16 August 2021 – In palliative care (PC), as in many areas of medicine, there is a considerable amount of research conducted that makes sound recommendations, but does not result consistently in improved care. For instance, though PC has been shown to benefit all people with a life-threatening illness, its main reach continues to be for those with cancer. Drawing on relational models of research use, the authors set out to engage policymakers, educators, clinicians, commissioners and service providers in a knowledge exchange process to identify implications of research for Scottish PC priorities. First, they mapped the existing PC research evidence in Scotland. The authors then organised evidence review meetings and a wider stakeholder event where research producers and users came together to co-produce implications of the evidence for policy, education and practice. They used questionnaires and key stakeholder feedback meetings to explore impacts of this process on research uptake and use immediately after the events and over time. In this article, the authors

reflect on this knowledge exchange process and the broader context in which it was set. They found that participation fostered relationships and led to a rich and enthusiastic exploration of research evidence from multiple perspectives. Potential impacts relating to earlier identification for PC, education and need-based commissioning ensued. The authors make suggestions to guide replication. **Full text:** <https://bit.ly/3meE4mu>

Scottish Research Forum for Palliative & End-of-Life Care

This open forum was established in May 2016 to bring together researchers, clinicians, service managers, policymakers and health and social care professionals. It was co-chaired by a professor of primary PC and a professor of nursing and PC and supported by an organising committee. A key objective was to share research findings across academic, policy and health and social care communities, including, where possible, patient and public involvement representation.

Noted in Media Watch 8 February 2021 (#703, p.7):

- *BMJ OPEN* | Online – 3 February 2021 – ‘**How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery.**’ The authors project that by 2040, the number of people requiring palliative care will increase by at least 14%; and, by 20% if they factor in multimorbidity. The number of people dying from multiple diseases associated with different disease groups is projected to increase from 27% of all deaths in 2017 to 43% by 2040. To address increased need and complexity, experts prioritised sustained investment in a national digital platform, roll-out of integrated electronic health and social care records; and, approaches that remain person-centred. **Full text:** <http://bit.ly/39HdPyy>

N.B. Selected articles on palliative and end-of-life care noted on p.3 in this issue of Media Watch.

Publishing Matters

Willfully submitting to and publishing in predatory journals: A covert form of research misconduct?

BIOCHEMIA MEDICA | Online – 5 August 2021 – A predatory journal could be provisionally defined as one masquerading as a genuine academic publication but offer little, if any, rigorous peer review. Predatory journals or publishers place a focus on maximising financial profit, as opposed to regulated dissemination of scientific advancements. As a result, authors can often get their work published in such journals with little scrutiny on quality. Although generally warned against and discouraged, universally practiced sanctions against researchers' submission to and publication in predatory journals are not common. Predatory publishing thus remains prevalent, particularly in places where academic success is measured by the quantity rather than quality of publication output, which feeds the journal's business model that thrives upon significant market demand. However, such an undesirable enterprise has the potential to flood the scientific literature with unsound research that could be misleadingly perceived as authoritative. This may result in or add to the confusion of policymakers and the layperson, consequentially bringing disrepute to science and all parties involved. The authors of this article argue that willfully submitting one's manuscript to a predatory journal may constitute an active act of avoidance of rigorous peer review of one's work. If such is the intention, it would be a questionable research practice and could be considered an, albeit covert, form of scientific misconduct. If labelled as such, and with institutional and funding rules erected to discourage the practice, predatory publishing could be effectively put out of business through diminishing the consumer demand. **Full text:** <https://bit.ly/3z3P3Te>

Structural racism and scientific journals – a teachable moment

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2021 ;326(7):607-608. 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, including *JAMA* and the *JAMA* Network 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. A teachable moment is an opportunity to deliver a message about a concept in such a way that a light goes on and promotes change. As problematic as this incident was, there is an opportunity to make it a teachable moment and an inflection point. This moment should lead to a meaningful change in culture that is not swept aside after an apology, follow-up podcast, strong statement, or leadership transitions, and it also may serve as an important opportunity for self-examination and meaningful change for all medical journals. **Full text:** <https://bit.ly/3APDMGK>

N.B. The focus of the current issue of *JAMA* is racial and ethnic disparities and inequities in medicine and healthcare. **Journal contents page:** <https://bit.ly/2WeRg01>



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>

Publishing in predatory journals: Guidelines for nursing faculty in promotion and tenure policies

JOURNAL OF NURSING SCHOLARSHIP | Online – 16 August 2021 – Clinicians rely on researchers, many of whom are faculty, to publish rigorous studies that produce evidence they can translate into practice. One measure of the quality of a study's findings is where the paper is published and reflects the level of peer review it has been through. Faculty who publish in predatory journals may not have had their work reviewed by experts; evidence produced may or may not be adequate for translation to guide nursing practice. This study examined how schools of nursing in research-intensive universities address the issue of predatory journals. Academic promotion and tenure (APT) criteria do not provide guidance to faculty and promotion and tenure committees about issues related to predatory publications as low-quality publication outlets. Recommendations for APT committees, mentors, and faculty are provided. **Abstract:** <https://bit.ly/3jZ19H8>

Preprint: Already the bride or still the bridesmaid?

POSTGRADUATE MEDICAL JOURNAL | Online – 19 August 2021 – Preprint, as the term is self-explanatory, is the final draft of a research paper that is digitally shared openly before being certified by peer-review. The long and tedious process of publishing a scientific paper coupled with researchers' desire to stake their claim as publishing first in the field to protect their intellectual property rights has led to the increasing popularity of preprints. A preprint allows them to quickly and publicly share their research online; get a digital object identifier (DOI) number; retain the copyright and get online feedback from peers to improve the manuscript before submitting it for peer-review. Its most significant advantage lies in the immediate digital dissemination of important scientific information, as seen in the exponential increase in and impact of preprint publications during the current COVID-19 pandemic. Idea of preprints appealed to many publishing houses, and ~86% of clinical journals with high-impact factors are now preprint friendly, but their guidelines vary. The recent spotlight on preprints has been because of their ascending prominence during the ongoing COVID-19 pandemic. **Abstract:** <https://bit.ly/3y62MI5>



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

[Scroll down to 'Media Watch: Lessons Learned from COVID-19']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

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Asia



Asia Pacific
Hospice Palliative
Care Network

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2SWdYWP>

[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



CSPCP Canadian Society of
Palliative Care Physicians
SCMSP Société canadienne des
médecins de soins palliatifs

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

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

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

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

Europe



EAPC
VZW

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>

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

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