

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

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Compiled & Annotated by Barry R. Ashpole

Similar or favourable quality-of-life outcomes to face-to-face palliative care were reported across studies, especially when virtual care is used as a supplement, rather than a substitute, to regular face-to-face care.

'Virtual care in end-of-life and palliative care: A rapid evidence check' (p.11), in *Journal of Telemedicine & Telecare*.

Canada

“A crisis for home care”: Droves of workers leave for hospitals, nursing homes

ONTARIO | Canadian Press – 31 October 2021 – Nurses, personal support workers and therapists have left home care in droves during the COVID-19 pandemic. “We lost literally over 3,000 nurses and skilled therapists and personal support workers to other parts of the healthcare system,” said Sue VanderBent, the CEO of Home Care Ontario, which represents home care providers in the province. “And that is very bad news for Ontarians who are receiving home care because now our capacity is so depleted that people are just waiting at home for a home care nurse or therapist or PSW who isn’t coming.” The organization achieved a 95% referral acceptance rate before the pandemic, meaning it could fulfil the vast majority of requests for home care. The current rate is 60%. “This is a crisis for home care,” VanderBent said. Home care workers left their jobs for better pay in hospitals and long-term care homes, she said. About 900,000 Ontarians receive home care every year, she said, with 730,000 in the publicly-funded system. That means several hundred thousand people in Ontario are either

receiving reduced home care services or no care at all, VanderBent said. <https://bit.ly/3bAcPMR>

Access to palliative care in the community

Community-based palliative care (PC) is a priority for governments across the country, with an emphasis on services that can help people remain in the community even at the end of life. Community-based PC includes visits to doctors’ offices, services provided in patients’ homes and care provided in long-term care facilities, residential hospices or PC homes. Services that are specific to palliative patients can be a part of community-based care more broadly, but they generally entail more comprehensive assessment of each patient’s needs and a holistic approach – that is, integrating physical, psychological, social and spiritual care that involves providers from multiple disciplines.¹

1. ‘Access to Palliative Care in Canada,’ Canadian Institute for Health Information, September 2018. [Noted in Media Watch 24 September 2018 (#582, p.1)]
Download at: <http://bit.ly/2MqmCYO>

Cont.



Share this issue of Media Watch with a colleague.

Noted in Media Watch 15 February 2021 (#704, p.4):

- *BMJ OPEN* | Online – 12 February 2021 – ‘**End-of-life outcomes with or without early palliative care: A propensity score matched, population-based cancer cohort study.**’ Across an 11-year population-based, cancer cohort in Ontario, Canada, those who received early palliative care (PC) ... compared with a matched cohort of those who did not, were more likely to receive supportive home care and less likely to receive hospital care in the last month of life. The results of this study support policies to enable earlier access to end-of-life homecare services and outpatient physician services for PC. Policies that prohibit the access of PC services unless one forgoes curative treatments or is certified as expected to die within 6 months or less are disincentives to earlier and concurrent access to PC. **Full text:** <http://bit.ly/3d9mSu9>

Noted in Media Watch 14 December 2020 (#696, p.2):

- ONTARIO | *Healthy Debate* – 9 December – ‘**Bill 3 is a good start, but more must be done for palliative care.**’ In 2014-2015, just under half of all patients began receiving PC in their last month of life. Nearly two-thirds died in hospital. Less than half received palliative home care services in their last month of life. About one-third received a home visit from a doctor in their last month of life. COVID-19 has had an unprecedented impact on PC. As more families opt to avoid hospitals for fear of COVID-19 exposure, there is even more need for support for hospice or home-based PC. Bill 3, a Private Member’s bill ... [was] ... approved 2 December, calls for a provincial framework to support improved access to hospice PC provided through hospitals, home care, long-term care homes and hospices. <https://bit.ly/3402num>

U.S.A.

Geriatrics and Palliative Care Final Report – Fall 2020 Cycle

NATIONAL QUALITY FORUM | Online – Accessed 6 November 2021 – The National Quality Forum (NQF) has endorsed more than 30 measures that address geriatric care, palliative care, and end-of-life (EoL) care issues such as physical, spiritual, and legal aspects of care, as well as the care of patients nearing the EoL. Factors such as the aging U.S. population; the projected increases in the number of Americans with functional limitations, chronic illnesses, and disabilities; and, increases of ethnic and cultural diversity have reinforced the need to improve the quality of both palliative, EoL, and geriatric care while emphasizing the need for individualized, person-centered care. **Download report at:** <https://bit.ly/304Zg5N>

Specialist Publications

‘**Health professionals palliative care education for older adults: Overcoming ageism, racism, and gender bias**’ (p.8), in *Current Geriatric Reports*.

N.B. Selected articles on the interface between geriatric and palliative medicine noted in Media Watch 9 August 2021 (#729, p.13).

In Alaska Native villages and across communities of color, the enduring silence of grief

THE WASHINGTON POST | Online – 4 November 2021 – In the last 20 months, COVID-19 has killed three-quarters-of-a-million people in the U.S., meaning an estimated 6.7 million Americans are grieving the death of a grandparent, parent, spouse or child because of the coronavirus, according to researchers.¹ But the nation’s bereavement burden has never been equal, and the coronavirus is no exception, targeting Black, Latino, and American Indian and Alaska Native people in their 30s, 40s and 50s with deadly efficiency. Through the first half of the year, among people 40-64 years old, COVID-19 has killed: one out of every 240 American Indian and Alaska Native people; one out of every 390 Latinos; one out of every 480 Black people; and, one out of every 1,300 Asian people and White people. In Alaska, with the most Native American people by percent of any state, Indigenous people represent 16% of the population, but 28% of COVID-19 deaths. Deaths from COVID-19 are causing gaps in grief – gaps that are tragically familiar: Black, American Indian and Alaska Native communities suffer a higher bereavement burden given persist-

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ent disparities in life expectancy and mortality. Native Americans, along with Black Americans, live shorter lives than all other Americans – 78.4 years for Native Americans vs. 80.6 years for White people. For Alaska Native people, life expectancy is 70.4 years... The shorter life spans reflect a broader disparity: Native Americans have much higher rates of obesity, diabetes, coronary heart disease, chronic liver disease and tuberculosis than White people do. Yet the gap in grief – with its own health consequences – is often overlooked. <https://wapo.st/3CQdSnP>

1. 'Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the U.S.,' *Proceedings of the National Academy of Sciences of the United States of America*, published online 10 July 2020. [Noted in Media Watch 13 July 2020 (#674, p.11)] Full text: <https://bit.ly/322myb8>

International

Public attitudes to death and dying in the U.K.

U.K. | Marie Curie Palliative Care Research Centre (Cardiff University School of Medicine) – 2 November 2021 – Most people believe it is important to plan care preferences in advance of dying, but very few have taken any action, according to new research... Researchers analysed survey data from 8,077 adults across the U.K. to understand attitudes to death and dying, including what people understand of palliative and end-of-life (EoL) care and willingness to discuss plans. Nearly 90% of respondents agreed that planning for EoL was essential, but just 14% of people had formally done so. Chief investigator Professor Annmarie Nelson ... said: "The responses suggest that as a society we have a long way to go to enable effective discussions and EoL planning, and although we are willing to have these conversations, we lack the language, and often don't follow through on our intentions to plan." Seven in 10 people believe their preferences around death and dying should take priority over the wishes of their next

of kin or their doctor's advice. Only 20% of people have made financial arrangements for their funeral and only 40% have talked to someone about whether they want their body to be buried, cremated, or donated. Around 60% of people did not agree, or did not know, whether adequate services are available. The majority of people (77%) think EoL care should be given equal priority in the National Health Service as care for people in any other stage of life. **Download at:** <https://bit.ly/3BL1tAb>

Specialist Publications

'Care needs of dying patients and their family caregivers in hospice and palliative care in mainland China: A meta-synthesis of qualitative and quantitative studies' (p.7), in *BMJ Open*.

Related:

- U.K. (England) | Public Health England – 2 November 2021 – '**Palliative and end of life care profiles: November 2021 data update.**' These profiles have been developed by the National End-of-Life Care Intelligence Network to improve the availability and accessibility of information and intelligence around palliative and end-of-life care. They provide an overview across multiple geographies in England, to support commissioning and planning of local services. Data are grouped into domains: 1) Place of death; 2) Underlying cause of death; 3) Mortality; 4) Death in usual place of residence; 5) Care homes and community; 6) Hospital care; and, 7) Dementia. Classification of place of death is a guide that supports the methods used for all place of death indicators on these profiles. **Download at:** <https://bit.ly/3q6FwsZ>

N.B. National End of Life Care Intelligence Network website: <https://bit.ly/31xCTGD>

Neglecting grief risks personal and professional loss

U.K. (Scotland) | *The Herald* (Glasgow) – 1 November 2021 – A recent survey by end-of-life charity Marie Curie found that nearly half of bereaved employees were forced to return to work before they were ready because they couldn't afford to stay off.¹ Nearly one in five said they received no paid leave, and more than half were worried about their job security while taking bereavement time. All of this amid a fog of intense pain that it can take weeks or even months to emerge from. Anyone classed as an employee has the right to time off work after the death of a dependent such as a partner, child or parent. However, there is no legal right to be paid except in the case of the death of a child under the age of 18. The latter became the case with the introduction last year of Jack's Law, also known as the Parental Bereavement Leave & Pay Regulations. The Chartered Institute of Personnel & Development, Marie Curie and others are now calling for an extension of Jack's Law so employees experiencing the bereavement of other close family members are also supported by statutory provisions. In the wake of the pandemic, which has put a spotlight on grief and mental health, there are sound reasons for employers to consider overhauling their bereavement policies before being forced to do so. More than half of the 1,000 people polled by Marie Curie experienced performance issues in the months after losing a loved one, with many citing a lack of support from their workplace. <https://bit.ly/3BxVWgg>

1. 'Employees can't afford to take time off work following a bereavement,' Marie Curie, September 2021. <https://bit.ly/3nLb8BM>

Euthanasia and palliative care funding: "Horribly distorted"

NEW ZEALAND | *Scoop* (Wellington) – 31 October 2021 – Providing equity of access for assisted dying without equity of access to palliative care (PC) is to completely undermine the goals of New Zealand's End of Life Choice Act (2019). The Act's funding mechanism means that choice is distorted towards assisted dying and away from PC. First, why has this fully-funded priority to "end-of-life choice" been given when the Government does not fully fund many other services, particularly PC. Second, the level of funding becomes critical to the implementation of the Act. If the funding does not cover the cost of provision of these services then very few can be expected to provide these services. To fully fund euthanasia and not fully fund PC makes a mockery of the title of the Act. The "choice" between fully funded assisted dying and severely underfunded PC as "horribly distorted." Responding to calls to increase euthanasia funding would be even worse in the absence of addressing the underfunding of PC. Currently PC is recognised as an essential health service. Consequently the majority of hospice funding comes from government. But hospices remain seriously underfunded and there is no charge to patients. Instead hospices must depend on regular community fundraising. Currently they must raise over \$77 million nationally. In the advocacy for a "yes" vote in the referendum a common reason given was difficulties of access to PC. PC specialists, nurses and others working in hospices provide excellent care for the terminally ill in difficult under-resourcing circumstances. But many terminally ill patients struggle to get access when they need it. <https://bit.ly/3nJIKRM>

Noted in Media Watch 21 June 2021 (#722, p.1):

- CANADA | *The Conversation* – 14 June 2021 – '**Why is access to medically assisted death a legislated right, but access to palliative care isn't?**' In 2016, federal legislation gave all eligible Canadians the right to request medical assistance in dying (MAiD). Colleges of physicians and surgeons required physicians to refer people who request MAiD to services or arrange for a physician who would make the referral. Since then, every province and territory devoted resources to navigate requests and assessments for MAiD. Typically, provinces have a website for self-referral, easily found by Internet search and/or dedicated healthcare staff to help navigate the MAiD process or inform those who are MAiD-curious. By contrast, the referral process for palliative care is often convoluted. <https://bit.ly/3qziULA>



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.12.

Specialist Publications

More than means to an end: Assessing surgical provider familiarity with palliative care

THE AMERICAN SURGEON | Online – 5 November 2021 – As palliative medicine concepts emerge as essential surgical education, there has been a resulting spike in surgical palliative care (PC) research. Historic surgical dogma viewed mortality and comfort-focused care as a failure of the providers' endurance, knowledge base, or technical skill. Therefore, many providers avoided consultation to a palliative medicine service until it became evident a patient could not survive or was actively dying. As the need for surgical PC grows, the identification of deficits in surgical providers' understanding of the scope of palliative medicine is necessary to direct further training and development efforts. Despite many participants training in intensive care settings, providers lack the training to carry out major discussions regarding life-limiting illness, goals of care, and end-of-life independently. **Abstract (with references):** <https://bit.ly/3ENlqlw>

Noted in Media Watch 4 October 2021 (#737, p.4):

- *AMA JOURNAL OF ETHICS*, 2021;23(10):E757-831. **'Palliative surgery.'** Palliative care (PC) is not just for dying patients. In fact, dying patients are living patients, and all patients deserve palliation. Contrary to popular belief among many patients and clinicians, palliative interventions can be invasive and include not only medical, but surgical care. In any case, PC should be defined by intention: partnering clinicians, patients, and their loved ones aim neither to cure disease nor to prolong life, but to improve the quality of a patient's life at any needed time. Quality of life is motivated by goal-elucidating conversation, counseling, and symptom management-directed intervention. This issue of the journal investigates surgical palliation specifically... **Journal contents page:** <https://bit.ly/3ip1Nh8>

Health advocacy for people experiencing homelessness

AMA JOURNAL OF ETHICS, 2021;23(11):E835-839. The National Health Care for the Homeless Council's (NHCHC) training, research, and advocacy support clinicians and the one million patients served annually in 300 Health Care for the Homeless federally qualified health centers and 100 medical respite programs. The NHCHC's work is fundamentally ethical in nature. The NHCHC community is galvanized to serve a population that is often shunned by society and large segments of the healthcare system: people experiencing homelessness. Its mission statement is expressed in moral terms: "Grounded in human rights and social justice, the National Health Care for the Homeless Council's mission is to build an equitable, high-quality healthcare system through training, research, and advocacy in the movement to end homelessness." Rights, justice, and equity are fundamentally ethical concepts. There are three reasons why we, as members of society and clinicians, are ethically obligated to offer homeless healthcare in the U.S. and to work to end homelessness: 1) Homelessness harms people's health and well-being; 2) Homelessness harms the health system and health professionals; and, finally, 3) Homelessness is a result of inequitable policies, practices, and choices our society has made. **Full text:** <https://bit.ly/3pWPUji>

N.B. The focus of the current issue of the *AMA Journal of Ethics* is healthcare for the homeless. **Journal contents page:** <https://bit.ly/3COyhK5>. Search back issues of Media Watch for additional articles on palliative and end-of-life care for the "homeless" at: <http://bit.ly/2ThijkC>

Research Matters

'Challenges and pitfalls for implementing digital health solutions in clinical studies in Europe' (p.11), in *Frontiers in Digital Health*.

'Undertaking research using online nominal group technique: Lessons from an international study' (p.11), in *Journal of Palliative Medicine*.

Publishing Matters

'Opinion: The problem with preprints' (p.11), in *The Scientist*.

Navigating medical assistance in dying from Bill C-14 to Bill C-7: A qualitative study

BMC HEALTH SERVICES RESEARCH | Online – 4 November 2021 – Canada has made significant inroads since 2016 in adjusting the healthcare system to meet the needs of patients and families seeking a medical assistance in dying (MAiD) death. The process of MAiD has become increasingly normalized even as the gravity of the event has retained its emotional impact. MAiD assessors are developing consensus about clinical application of the legal criteria and nurses are finding ways to support a patient-centered approach to care. However, increased demand for MAiD, and a rise in the complexity of clients requesting MAiD, is putting significant strain on the system. Bill C-7 is raising complex new issues, including moral concerns about extending MAiD to new populations, access challenges to the services required to alleviate the suffering of this population, further increases in workload, and a potential shortage of assessors and providers willing to stay engaged with MAiD work. Such challenges may be partially met through the development and expansion of the coordinator/navigator role. Such individuals will require superb communication and advocacy skills, extensive knowledge of the health and social care system, and sufficient time to do this complex role well. These findings provide important insights into the practical challenges facing health systems as

they seek to create best practices around MAiD care. They provide insights for policy and healthcare decision-makers as health systems adapt to the evolution of MAiD through Bill C-7. While such insights may be specific to the immediate situation in Canada, they will have relevance for other countries considering legalizing assisted death. **Full text:** <https://bit.ly/3BOQAgO>

Extract from *BMC Health Services Research* article

This rapid development of MAiD has generated significant debate in the palliative care (PC) community. In the context of MAiD, key PC stakeholders have strongly advocated for universal access to high quality PC. A frequently cited statistic is that less than 30% of Canadians have access to high quality PC, although a recent report from the Canadian Institutes for Health Information suggested that it is difficult to obtain good information on PC accessibility, in part because of its variability across the country.¹

1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. [Noted in Media Watch 24 September 2018 (#582, p.1)]
Download at: <http://bit.ly/2MqmCYO>

Noted in Media Watch 21 June 2021 (#722, p.1):

- CANADA | *The Conversation* – 14 June 2021 – ‘**Why is access to medically assisted death a legislated right, but access to palliative care isn’t?**’ In 2016, federal legislation gave all eligible Canadians the right to request medical assistance in dying (MAiD). Colleges of physicians and surgeons required physicians to refer people who request MAiD to services or arrange for a physician who would make the referral. Since then, every province and territory devoted resources to navigate requests and assessments for MAiD. Typically, provinces have a website for self-referral, easily found by Internet search and/or dedicated healthcare staff to help navigate the MAiD process or inform those who are MAiD-curious. By contrast, the referral process for palliative care is often convoluted. <https://bit.ly/3gziULA>



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>

Natural language word embeddings as a glimpse into healthcare language and associated mortality surrounding end of life

BMJ HEALTH & CARE INFORMATICS | Online – 28 October 2021 – Discussions between doctors, patients and family in deciding what is the appropriate maximum treatment a specific patient should have based on their clinical condition is complex. Discussions, often involving expressions regarding end-of-life (EoL) care, are used to describe the maximum invasive treatments a patient should have or would want. There are a range of expressions used, many with overlapping meanings which can be confusing, not only for the patient and family, but also for doctors reading the patient's clinical notes. In this study, a computational approach using artificial intelligence (AI) to read clinical patient notes was carried out by looking at thousands of patient records from a large urban hospital. Expressions that doctors use to describe these discussions were analysed to show the associations of particular words and phrases in relation to mortality. Using a computer analysis for this study, it was possible to quantify the use of these expressions and their relation to the EoL. Through this AI-based approach, real-world use of phrases and language relating EoL can be analysed to understand how doctors and patients are communicating, and about any possible misunderstandings of language. **Full text:** <https://bit.ly/2ZP8xP8>

Care needs of dying patients and their family caregivers in hospice and palliative care in mainland China: A meta-synthesis of qualitative and quantitative studies

BMJ OPEN | Online – 5 November 2021 – Findings of this meta-synthesis reveal that dying patients and their family caregivers in mainland China have many unmet needs. Dying patients want better control of pain and symptoms, emotional and spiritual care, professional care resources and to maintain daily life, maintain autonomy, die peacefully and in a dignified manner and prepare for death. Family members expressed their wish regarding receiving information about caregiving and disease, accessible professional care resources, initiative of diagnosis notification, respite care, social support and death management. It is imperative that these care needs should be focused on, and more resources should be provided for dying patients and their family caregivers. These findings highlight the importance of promoting palliative care in future. **Full text:** <https://bit.ly/3o3Bsan>

The role of palliative care in COPD

CHEST | Online – 2 November 2021 – Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death in the U.S. and is a serious respiratory illness characterized by years of progressively debilitating breathlessness, high prevalence of associated depression and anxiety, frequent hospitalizations, and diminished wellbeing. Despite the potential to confer significant quality-of-life benefits for patients and their care partners and to improve end-of-life (EoL) care, specialist palliative care (PC) is rarely implemented in COPD and when initiated it often occurs only at the very EoL. Primary PC delivered by frontline clinicians is a feasible model, but is not routinely integrated in COPD. In this review, the authors discuss: 1) The role of specialist and primary PC for patients with COPD and the case for earlier integration into routine practice; 2) The domains of the National Consensus Project Guidelines for Quality Palliative Care applied to people living with COPD and their care partners; and, 3) Triggers for initiating PC and practical ways to implement PC using case-based examples. This review solidifies that PC is much more than hospice and EoL care and demonstrates that early PC is appropriate at any point during the COPD trajectory. The authors emphasize that PC should be integrated long before the EoL to provide comprehensive support for patients and their care partners and to better prepare them for the EoL. **Abstract:** <https://bit.ly/3H55hQP>

N.B. Search back issues of Media Watch for additional articles on COPOD in palliative and end-of-life care at: <http://bit.ly/2ThijkC>



Closing the Gap Between
Knowledge & Technology
<http://bit.ly/2DANDFB>

Health professionals palliative care education for older adults: Overcoming ageism, racism, and gender bias

CURRENT GERIATRIC REPORTS | Online – 30 October 2021 – Most aging Americans lack access to specialist palliative care (PC) aimed at those experiencing serious illness and/or high symptom burden at end of life. The curricula used by training programs for all healthcare professions should focus on helping learners develop the primary PC skills and competencies necessary to provide compassionate bias-free care for adults with serious illness. There is much opportunity to improve this landscape via the incorporation of PC competencies throughout generalist healthcare professional programs. Several recent publications highlight multiple issues with recruitment and retention of diverse students and faculty into healthcare professional training programs. There are also concerns that the curricula are reinforcing age, race, and gender biases. Due to these biases, healthcare professionals graduate from their training programs with socialized stereotypes unquestioned when caring for older adult minority patients and caregivers. Important lessons must be incorporated to assure that bias against age, race, and gender are discovered and openly addressed in healthcare professionals' education programs. This review highlights these three types of bias and their interrelationships with the aim of revealing hidden truths in the education of healthcare professionals. The authors offer targeted recommendations of focus for programs to address implicit bias within their curricula. **Full text:** <https://bit.ly/3wh6WxF>

N.B. Search back issues of Media Watch for additional articles on “ageism,” “racism,” and “gender” bias in palliative and end-of-life care at: <http://bit.ly/2ThijkC>

Clinical presentation, complications, and outcomes of hospitalized COVID-19 patients in an academic center with a centralized palliative care consult service

HEALTH SCIENCE REPORTS | Online – 2 November 2021 – Palliative care (PC) is a critical component of the response of a healthcare system to a pandemic. The authors present risk factors associated with mortality and highlight an operational PC consult service in facilitating early identification of risk factors to guide goal-concordant care and rational utilization of finite healthcare resources during a pandemic. In this case series, 100 consecutive patients admitted to hospital with COVID-19 in Seattle, presenting clinical characteristics and laboratory indices associated with more severe disease and mortality, were identified. During the initial stages of the COVID-19 pandemic, recognition of risk factors associated with poor prognosis, in conjunction with a systematic PC response plan, played an important role in the provision of goal-concordant care while maintaining functional resilience, rational utilization of finite medical resources, and sustainability of the healthcare system. The provision of an operational PC response plan will be critical for healthcare systems to respond appropriately and effectively to not only the ongoing COVID-19 pandemic but also other pandemics that will arise inevitably in the future. **Full text:** <https://bit.ly/3k5G8LV>

Palliative care and legal issues in geriatric psychiatry

INDIAN JOURNAL OF PSYCHOLOGICAL MEDICINE, 2021;43(5):S31-S36. There is an increased risk of debilitating illnesses that often have no curative treatment with aging. The mainstay of treatment in many such conditions is palliative care (PC): a holistic approach focused on preventing and relieving physical, psychosocial, legal, ethical, and spiritual problems. It involves the facilitation of end-of-life care decisions aimed at relieving distress and improving quality of life. In this article, the authors discuss the role of mental health professionals in legal issues related to PC in the elderly around decision-making, right to autonomy, euthanasia, and advanced directive. The cognitive decline associated with aging and mental health issues in the PC setting of an individual such as dementia, depression, and hopelessness, and impact on the family members like burnout may influence the overall capacity of that individual to make decisions about their treatment. While an individual has a right to self-determination and autonomy, withholding or withdrawing treatment has many legal and ethical implications, more so in those with incapacity, especially in India due to the absence of uniform legislation. The decision to withhold or withdraw treatment might be a

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restrictive choice due to limited options in a setting with a lack of PC options, poor psychosocial support, non-address of mental health issues, and lack of awareness. As the right to health is a constitutional right, and the right to mental health is legally binding under Section 18 of India's Mental Health Care Act 2017, systematic efforts should be made to scale up services and reach out to those in need. **Full text:** <https://bit.ly/3CTeqcw>

Noted in Media Watch 23 August 2021 (#731, p.8):

- *FOCUS* | Online – 18 August 2021 – '**Palliative care: Critical concepts for the geropsychiatrist.**' Psychiatrists can make a significant contribution to improving quality end-of-life care (EoLC) for their 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. 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. **Abstract:** <https://bit.ly/3D7r7AQ>

N.B. Selected articles on the interface between geriatric and palliative medicine noted in Media Watch 9 August 2021 (#729, p.13).

Expressing grief through metaphors: Family caregivers' experience of care and grief during the COVID-19 pandemic

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH & WELL-BEING | Online – 29 October 2021 – The COVID-19 pandemic has disrupted thousands of individuals' experience of caregiving and grief. This qualitative study aimed to gain in-dept understanding of family caregivers' lived experiences of caregiving and bereavement in the context of the COVID-19 pandemic in Quebec, Canada. The study also aimed at providing new insight about caregiving and bereavement by analysing the metaphors family caregivers use to report their experiences. Results indicate that bereaved family caregivers lived and understood their experience in terms of metaphoric cut-offs, obstructions and shockwaves. Metaphors represented the grief process and the bereaved's quest for social connection, narrative coherence and recognition. By identifying the meaning of the bereaved's metaphors and the quest they reveal, our study underlines the singularity of pandemic grief and points to the value and meaning of caregiving with regard to the grieving process. **Full text:** <https://bit.ly/3CAqfLa>



Centre for Research and Intervention
on Suicide, Ethical Issues and
End-of-Life Practices

Related:

- *PEDIATRICS* | Online – 26 October 2021 – '**Supporting transition to the bereaved community after the death of a child.**' Whether a child dies suddenly or after a long battle against a serious illness, the entire family is forced to make an unimaginably painful transition. This new reality may involve an adjustment in one's identity, a loss of community, and an entrance into a new community of bereaved families. The goal of effective bereavement care is to help families heal and process a child's death while making the difficult transition to functioning with their grief and still finding joy in life and relationships. Yet feelings of abandonment persist, suggesting the healthcare system needs to do a better job supporting families facing this devastating transition. **Full text:** <https://bit.ly/3brYeTG>

Comparison of end-of-life care between recent immigrants, long-standing residents in Canada

JAMA OPEN NETWORK | Online – 2 November 2021 – In this population-based cohort study of Ontario residents who died between 2013 and 2016, the authors recent immigrants were 1.2-fold more likely to use acute care services at the end of life and 1.1-fold more likely to die in acute care settings compared with long-standing residents. In the last 90 days of life, despite a greater percentage of recent immigrants receiving palliative physician services, recent immigrants spent a mean of 1.1 to 1.8 more days using inpatient

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care services (ICU and non-ICU) and emergency department services. More than half of recent immigrants died in hospital settings, compared with 45% of long-standing residents. The variation in places of care observed in this study could be partially attributed to immigrant status, influenced by the region of origin and time since immigration. The disproportionate use of acute care among immigrants is corroborated by a previous study that found that Canadian immigrants were significantly more likely to receive aggressive care and die in an ICU compared with long-standing resident.¹ **Full text:** <https://bit.ly/3EBvjJd>

1. 'Association between immigrant status and end-of-life care in Ontario, Canada,' *Journal of the American Medical Association*, published online 2 October 2017. [Noted in Media Watch 9 October 2017 (#533, p.2)] **Full text:** <https://bit.ly/2LhvDHe>

Top ten tips palliative care clinicians should know about prognostication in children

JOURNAL OF PALLIATIVE MEDICINE, 2021;24(11):1725-1731. Pediatric palliative care (PC) is different from PC for adults. However, conceptualizing pediatric PC remains cumbersome due to the high heterogeneity of often rare diseases, the high diversity of disease trajectories, and the particular difficulty to predict the future of an individual, severely ill child. This article aims to provide an overview and critical reflection of different aspects of prognostication in children with PC needs. This includes different diseases from neurology to oncology, from the unborn baby to the young adult, new approaches in treatment, advance care planning, and, most important, communication with the affected child as well as parents. **Abstract:** <https://bit.ly/3EM9RkZ>

Noted in Media Watch 7 June 2021 (#720, p.13):

- *PEDIATRICS* | Online – 1 June 2021 – '**Prognostic communication between oncologists and parents of children with advanced cancer.**' How oncologists disclose information about disease progression and incurability and how prognostic communication impacts parental understanding of prognosis are poorly understood. The authors characterize communication strategies used by pediatric oncologists to share prognostic information across a child's advancing illness course, and explore relationships between different communication approaches and concordance of oncologist-parent prognostic understanding. When oncologists provided direct statements about incurability, prognostic understanding appeared to improve. **Abstract:** <https://bit.ly/34CJw8Y>

Enhancing a community palliative care service with telehealth leads to efficiency gains and improves job satisfaction

JOURNAL OF TELEMEDICINE & TELE CARE, 2021;27(10):625-630. Telepalliative care services enable clinicians to provide essential palliation services to people with a life-limiting illness in or closer to home. This study aimed to explore the costs, service activity and staff experiences resulting from the introduction of telehealth in a community palliative care (PC) service in Queensland, Australia. Pre- and post-activity and cost data from the 2016-2017 and 2019-2020 financial years were examined and staff members interviewed. Accounting for inflation and standard wage increases, the labour costs before and after the addition of telehealth were approximately equal. There were small variations in non-labour costs, but these were not directly attributable to the expansion of the telehealth services. Overall, the service activity increased by 189% for standard doctor and nurse consultations, due to the increased efficiency of telehealth compared to the previous outreach (travel) model. Thematic analysis of the staff interview data generated an overarching theme of increased job satisfaction which staff attributed to the patient-centred nature of the telepalliative care service, the increased peer support, and increased professional development. Compared with the traditional in-person service, the new telehealth-supported model resulted in equivalent costs, greater efficiency by allowing PC to reach more patients and improved staff job satisfaction. **Full text:** <https://bit.ly/3mHYRyR>

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Related:

- *JOURNAL OF TELEMEDICINE & TELE CARE*, 2021;27(10):631-637. ‘**Virtual care in end-of-life and palliative care: A rapid evidence check.**’ Generally, studies reported similar or favourable quality-of-life outcomes to face-to-face palliative care (PC), especially when virtual care was used as a supplement rather than a substitute for face-to-face care. Positive attitudes for perceived usefulness and helpfulness were reported by patients, caregivers and healthcare providers. Challenges identified related to technology limitations, trust, ethical concerns, administrative burden and evidence gaps. Overall, most studies found virtual care modalities to be safe and effective in end of life and PC with no detrimental adverse outcomes, when used as a supplement to face-to-face care. **Full text:** <https://bit.ly/3wfiwcC>

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

Research Matters

Challenges and pitfalls for implementing digital health solutions in clinical studies in Europe

FRONTIERS IN DIGITAL HEALTH | Online – Accessed 31 October 2021 – The increasing number of digital solutions developed for use in clinical healthcare settings is accompanied by new challenges to develop and conduct clinical studies that include eHealth technologies. Clinical study implementation plans often disregard or underestimate the necessity of additional administrative and logistic tasks required at clinical sites as well as ethical aspects to test digital solutions. Experiences made in the run-up of an observational clinical feasibility study at three international clinical sites in the framework of the MyPal project result in recommendations to avoid delays and barriers in the planning of such prospective studies in clinical and also palliative care for increased efficiency. **Full text:** <https://bit.ly/3nlUNxw>

N.B. MyPal “aims to foster palliative care for people with cancer by leveraging patient reported outcome systems through their adaptation to the personal needs of the person with cancer and his/her caregiver(s).” Project website: <https://bit.ly/3bpDSdp>

Undertaking research using online nominal group technique: Lessons from an international study

JOURNAL OF PALLIATIVE MEDICINE | Online – 1 November 2021 – This brief report demonstrates that adapting nominal group technique (NGT) to an online format is feasible and acceptable to participants. It also adds to the literature that uses online/technical innovations to support the continuation of research inquiry during the COVID-19 pandemic, but with implications for the future conduct of research. NGT meetings are an ideal way to establish foundations for policy, clinical guidelines, and research priorities in palliative care. NGT meetings can successfully be conducted online and may, in turn, increase inclusivity and participation, especially when social restrictions limit in-person interactions due to the COVID-19 pandemic. **Full text:** <https://bit.ly/2ZMd6dj>

Publishing Matters

Opinion: The problem with preprints

THE SCIENTIST | Online – 1 November 2021 – Preprints aim to bridge the time gap between submission and publication in a peer-reviewed journal, something that becomes even more crucial as humans navigate a global public health crisis; but they also run the risk of spreading shoddy research. Preprints also stand to disrupt traditional science publishing if researchers see them as an end product rather than a stepping stone to peer review. Fewer than one-half of COVID-19 preprints posted to arXiv, bioRxiv, and medRxiv ... achieved peer-reviewed publication nine months later; fewer than one in five preprints posted in the whole

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study period reached full publication by October. This low rate could reflect the time required for peer review and revision. Usually this takes several weeks to a few months, depending upon manuscript quality, reviewer responsiveness, editorial decisions, and author revision speed. The low speed and high rigor of peer review are not the only causes of orphan preprints. Some authors choose to stop with the preprint with no attempt at further publication. Preprints give authors a permanent digital object identifier, and preprints are immediately searchable and citable. These features create incentives for preprint authors to skip the scrutiny of peer review. If the preprint becomes the end product (or a “no-print,” or no formal publication) for some authors, we risk a flood of publications of low quality. **Full text:** <https://bit.ly/31hHi01>

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International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3FtoV7X>

[Scroll down to 'End-of-Life Medications']

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

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

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Asia



Asia Pacific
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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



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>

[Scroll down to 'Are you aware of Media Watch?']

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



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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Something Missed or Overlooked?

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

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Barry R. Ashpole, Ontario CANADA

e-mail: BarryRAshpole@bell.net