

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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At a time of extensive budgetary pressures and rising numbers of children with life-limiting conditions, the inability to define the benefits of a healthcare budget or argue for the value of additional funding puts the delivery of end-of-life care on the back foot, with increasing reliance falling on third sector support, which itself is struggling under the burden.

‘What does economic evaluation mean in the context of children at the end of their life?’ (p.8), in *International Journal of Environmental Research & Public Health*.

Canada

Bishops launch new palliative care toolkit

THE CATHOLIC REGISTER | Online – 19 November 2021 – Canada’s bishops have developed a new palliative care (PC) toolkit to educate and empower caregivers and those facing a terminal illness.¹ Educating and empowering caregivers, persons with terminal illness, family members supporting a terminally ill loved one, as well as anyone curious about PC and Catholic end-of-life (EoL) doctrine is the primary aim of this new online resource. Support is presented over four learning modules. The themes covered are understanding the human experience of dying and death, discerning and making decisions at the EoL, accompanying those on the journey and supporting and integrating within the wider community. Each module page features two videos.

One short film tackles the topic from a medical perspective, while the other explores ethical and theological teachings. <https://bit.ly/3qTIMZm>

Specialist Publications

‘A rapid scoping review of end-of-life conversations with frail older adults in Canada’ (p.6), in *Canadian Family Physician*.

‘Quality of end-of-life cancer care in Canada: A 12-year retrospective analysis of three provinces’ administrative healthcare data evaluating changes over time’ (p.7), in *Current Oncology*.

1. ‘Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care,’ Canadian Conference of Catholic Bishops, November 2021. **Download at:** <https://bit.ly/3CxYUSq>

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Noted in Media Watch 2 August 2021 (#728, p.3):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 July 2021 – ‘**New developments in end-of-life teaching for Roman Catholic healthcare...**’ The Vatican’s chief doctrinal body, the Congregation for the Doctrine of the Faith, recently released *Samaritanus Bonus* (“The Good Samaritan”), a letter focused on ethical obligations surrounding the care of patients who are critically ill or nearing the end of life. Historically, similar documents have had significant implications insofar as all Catholic healthcare institutions ... are bound to provide services in accordance with Catholic teaching. The authors highlight two key areas which may contribute to increased conflict between Catholic healthcare and secular society. **First page view (w. references):** <https://bit.ly/3ib3m2B>

Noted in Media Watch 10 February 2020 (#652, p.1):

- *THE CATHOLIC REGISTER* | Online – 5 February 2020 – ‘**Palliative care in Canada: Harsh facts, sad realities.**’ A guaranteed right to doctor-assisted death in Canada has still not been matched with a right to palliative care (PC) as the vast majority of Canadians continue to die among strangers in institutions, either without PC or with too little PC delivered too late in their disease trajectory. Of Canadians who died at home in 2016-2017, even though two-thirds received home care during their last year, less than one-in-six received PC, according to the Canadian Institutes of Health Information.¹ Just 22% of long-term care residents with less than six months to live received PC. Only 15% of Canadians die at home. In contrast, 40% of medical aid in dying procedures provide death at home. <http://bit.ly/3bgP1Mk>

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

New report outlines palliative care challenges in Alberta as \$11 million grant program is launched

ALBERTA | CTV News (Edmonton) – 18 November 2021 – After a year of stakeholder consultation, the province released a report outlining challenges facing Alberta’s palliative and end-of-life care (EoLC) system alongside a grant program to fund improvements.¹ The report tables four recommendations to help advance palliative and EoLC in Alberta, including: 1) Having primary and continuing care providers grant earlier access opportunities for those diagnosed with a life-threatening or life-limiting condition; 2) Integrating more training about the palliative approach into health-care and allied service provider entry-level and continuing professional development; 3) Expanding community supports and services, such as grief and bereavement services for caregivers; and, 4) Investing in research and innovation to establish more care pathways for the transition between chronic disease management and palliative care. In September 2020, the province said it would invest \$20 million into initiatives supporting palliative and EoLC. According to the province, almost \$9 million has been spent to improve education for health professionals and community hospice care projects. Now the government says it will use the remaining \$11 million to advance the recommendations tabled in the report by having healthcare providers, community and Indigenous groups submit grant applications. <https://bit.ly/3FM5FSP>

1. ‘Advancing Palliative and End-of-Life Care in Alberta: Palliative and end-of-life care engagement final report,’ Alberta Government, November 2021. **Download at:** <https://bit.ly/3CxeMo8>



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>

U.S.A.

Improving hospice diversity starts from the inside out

HOSPICE NEWS | Online – 17 November 2021 – Racial divides have long-plagued the hospice field, rising to heightened levels of concern amid the coronavirus pandemic and events leading to civil unrest in the last year. Though hospices have taken deeper dives into improving access to care among underserved populations and addressing diversity and equity in their organizations, much work lies ahead to create change from the inside out. Racial-inequity issues heightening across the country, along with continued spread of a global pandemic, have increasingly brought diversity, equity and inclusion to the forefront in healthcare. The outbreak has illuminated an imbalance in both access and utilization to end-of-life (EoL) and serious illness care. Black or African Americans have died at 1.4 times the rate of white

Americans since the pandemic's onset in the U.S., representing 15% of lives lost to COVID-19 nationwide, the U.S. Centers for Disease Control & Infection (CDC) reported.¹ Additionally, more Native American and Latino lives have been lost to the deadly virus than white populations, according to the CDC. Closing racial gaps in care at the EoL will take ongoing steps to create overall change. <https://bit.ly/3ntbUV4>

Specialist Publications

'Top ten tips palliative care clinicians should know about delivering antiracist care to Black Americans' (p.12), in *Journal of Palliative Medicine*.

1. 'COVID-19 is affecting Black, Indigenous, Latinx, and other people of color the most,' The COVID Tracking Project.' <https://bit.ly/3CsAUzW>
2. 'The Better End of Life Report 2021: Dying, Death & Bereavement During COVID-19 Research Report,' Marie Curie, April 2021. [Noted in Media Watch 12 April 2021 (#712, p.4)] **Download at:** <https://bit.ly/3mvpNWP>

N.B. See 'Achieving Racial and Ethnic Equity in U.S. Health Care: A Scorecard of State Performance,' The Commonwealth Fund, 18 November 2021. <https://bit.ly/3nrP0gF>

End-of-life care: How much should be done?

VIRGINIA | *Virginia Journal of Bioethics* – 14 November 2021 – During their last chapters of life, many patients live off of technology-breathing machines, and feeding tubes are prominent examples. The advancement of medical technology has made it possible to greatly extend the lives of critically ill patients for weeks, months, and even years. This care is costly from a financial standpoint and exerts an emotional strain on all parties involved. In the U.S., a large percentage of our government spending goes to Medicare and Medicaid, centrally controlled and taxpayer funded. The majority of patients who are elderly and/or critically ill are using these program funds, and a disproportionately high amount of these funds are spent during the final weeks of life.¹ Many patients are unable to express their wishes for care before it's too late; they are automatically granted costly, end-of-life care (EoLC). Unwanted care may be delivered at a great cost to everyone involved – most importantly the patient. Although there are many different bioethical issues to explore regarding EoLC, the central question concerns the role of the government. Should state and local governments have the power to deny precious healthcare resources to some, and give them to others? The bio-

Specialist Publications

'Are we teaching health science students in the U.S. what they need to know about death and dying coping strategies?' (p.10), in *Journal of Educational Evaluation & Health Professions*.

'Do palliative care providers use complementary and integrative medicine? A nationwide survey' (p.11), in *Journal of Pain & Symptom Management*.

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-ethical principle of nonmaleficence suggests denial of care should never be the answer. And if patients choose to continue life-sustaining care, the principle of autonomy is greatly challenged by failing to provide the requested care. This can be deemed as an act of medical malpractice. Complicating matters further, physicians are bound by an oath to “do no harm.” Withdrawing or denying wanted and needed care greatly challenges these ethical concepts. **Full text:** <https://bit.ly/3ngnDGm>

1. ‘End-of-life care, not end-of-life spending,’ *JAMA Health Forum*, published online 13 July 2018. **Full text:** <https://bit.ly/3FiWSHD>

International

Welsh Ambulance Service appoints palliative care team in U.K. first

U.K. (Wales) | ITV News (Cardiff) – 17 November 2021 – The Welsh ambulance Service has appointed its first dedicated palliative care (PC) paramedics. Currently, people nearing the end of their lives often end up in hospital, despite it not always being the most suitable place for them to receive the appropriate care they need. It is hoped the new scheme, which is thought to be the first of its kind in the U.K., will limit that need, giving patients and paramedics more options. The four-strong team will work as part of Swansea Bay University Health Board’s Specialist Palliative Care Team and divide their time between patients in the community and patients in a hospital and hospice setting. Ed O’Brian, end-of-life care lead at the Welsh Ambulance Service, said, “People associate the role of a paramedic with managing trauma patients or patients who’ve had a heart attack or stroke. Not many people realise that we also help patients approaching the end of their life due to an advanced illness, either with urgent symptom management or for a sudden deterioration. Every paramedic in Wales is trained to support these patients, but the PC paramedic role is unique in that their time will be divided between patients in the community and those in an inpatient setting. In the community, they’ll respond to palliative emergencies – essentially, they’re the bridge between the home and hospital for patients in the last days of life.” <https://bit.ly/3Hpj5FT>

Specialist Publications

‘Pediatric oncology palliative care programs in Central America: Pathways to success’ (p.7), in *Children*.

‘COVID-19 pandemic: End-of-life experience in Australian residential aged care facilities’ (p.8), in *Internal Medicine Journal*.

‘Implementation and knowledge of the clinical practice guide for palliative care in the Ecuadorian primary care level’ (p.9), in *International Journal of Environmental Research & Public Health*.

N.B. Search back issues of Media Watch for additional articles on the role of “paramedics” in end-of-life care at: <http://bit.ly/2ThijkC>

Exploratory Review of Palliative Care Assessment Tools

AUSTRALIA | Australian Government (Department of Health) – 16 November 2021 – The ‘Exploratory Review of Palliative Care Assessment Tools’ project was undertaken by the Australian Commission on Safety & Quality in Health Care... The literature review explored the evidence base for clinical assessment tools indicating or predicting the likely death of people within one year, and the key enablers and barriers to the successful use of the tools. Several of the clinical assessment tools identified were in development and had not been tested in clinical settings. In addition, while there are many tools widely available and in use, the evidence to support their implementation in clinical settings remains limited. Studies specifically examining the use of mortality risk-prediction tools in prompting clinicians to initiate end-of-life discussions with patients and their families or carers are particularly lacking. It is apparent that development work in relation to a variety of tools targeting

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different conditions, patient populations and clinical settings, is continuing in this area. Within this review, the evidence base to support the use of most of the tools was relatively poor. The studies included in the review contained similar enablers and barriers; however, they contained little discussion of key implementation issues including the training, time and clinical expertise required to administer these tools in practice. The studies also provided limited insight into the practical and operational aspects of using tools prospectively in clinical settings. Much of the literature identified in the review related to new tools that were largely under development. Hence, these studies provided limited insight into the operational aspects associated with implementation of these tools in clinical settings and the practical and resource constraints that may influence clinicians' ability to utilise them. **Download at:** <https://bit.ly/3wP1CBQ>

Palliative paucity: Millennials predicted to be bad deaths of the future

NEW ZEALAND | Stuff.com.nz (Auckland) – 15 November 2021 – Many millennials are forecast to die badly with reports of a palliative care (PC) system already struggling on dwindling fundraising and experts saying we already have a “postcode lottery” determining who dies in pain. It comes as the new End-of-Life Choice Act means people with a terminal illness, and who meet exacting criteria, can end their own lives in a fully-funded system. But, if they want PC, to end their lives naturally and in comparative comfort, much of that funding comes from the likes of selling strawberries and second hand clothes. “Looking to the future is a nerve-wracking experience, as we see costs increasing, but no sign of a commitment from Government to help us with the additional costs,” Mary Potter Hospice chief executive Brent Alderton said. “It is ironic that the new end-of-life-choice service is fully funded, and our hospice care funded less than 50%.” <https://bit.ly/3cbwzGT>

Noted in Media Watch 8 November 2021 (#742, p.4):

- NEW ZEALAND | *Scoop* (Wellington) – 31 October 2021 – **‘Euthanasia and palliative care funding: “Horribly distorted.”**” 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. <https://bit.ly/3nJKRM>

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>

“Everyone is entitled to a dignified death”: Fears over care for people dying at home

U.K. (England & Wales) | *The Telegraph* (London) – 13 November 2021 – Figures from the Office for National Statistics ... show that in 2020 nearly 30% more people died at home than in 2019.¹ And that trend continued in January to June of this year. The increase is thought to be down to a range of factors: from disruption to health services to patients’ reluctance to go to hospital or a care home over fears of catching COVID or restrictions on visiting. Even pre-pandemic there was a growing trend for more people to die at home, but there are fears the surge in numbers means many are not getting the support to have a “good death.” A survey by charity Marie Curie of nearly 1,000 people who cared for a dying loved one at home during the pandemic showed that 75% felt they did not get the support and care they needed.² Some 64%

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reported being unable to get help to manage pain and other symptoms, and 65% said they had problems getting support at night and over the weekend. Ruth Driscoll, director of policy and public affairs at Marie Curie, says the pandemic was a “stress test” for the end-of-life (EoL) care system – a test that the system failed. Dr. Sarah Holmes, palliative care consultant and medical director of Marie Curie Hospice Bradford, says for those who have never experienced death, caring for someone at the EoL can be daunting. Most people do not know what normal dying looks like, she says. <https://bit.ly/3wM48sD>

1. ‘Number of people dying at home is highest in 20 years,’ *The Telegraph*, 10 November 2021. [Noted in Media Watch 15 November 2021 (#743, p.2)] <https://bit.ly/2YFbllS>

Specialist Publications

A rapid scoping review of end-of-life conversations with frail older adults in Canada

CANADIAN FAMILY PHYSICIAN, 2021;67(11): e298-e305. In terms of having end-of-life (EoL) conversations with frail older adults, this study found that many clinicians do not often and adequately discuss frailty and impending death with their older patients. Moreover, patients and their care partners do not have enough knowledge about frailty and death to make informed EoL decisions, leading to patients choosing more aggressive therapies instead of care focused on symptom management. In terms of barriers to EoL discussions, common barriers included a lack of trust between clinician and patient, inadequate EoL training for clinicians, and ineffective clinician communication with patients and families. Recommendations for improving EoL conversations include regular screening for frailty to prompt conversations about care and the use of an interprofessional approach. More empirical research is needed that uses exploratory methods to shed light on the contextual factors that may act as a barrier to EoL conversations. More research is also needed on the roles and responsibilities of interprofessional teams in screening for frailty and engaging in EoL conversations. There is a need to better understand how frail older patients and their families want EoL conversations to unfold and what best facilitates these conversations. **Full text:** <https://bit.ly/3wMI7cR>

A goal-directed model of collaborative decision-making in hospice and palliative care

JOURNAL OF PALLIATIVE CARE | Online – 17 November 2021 – Hospice and palliative care (PC) teams face numerous barriers to the meaningful involvement of patients and families in medical decision-making, which limits opportunities for exploration of the very values, preferences, and goals that ideally inform serious illness care. Researchers who develop and test interventions to address these barriers have noted the complementary utility of two existing models in supporting collaborative relationships between hospice and PC teams and the patients and families they serve: 1) The social problem-solving model; and, 2) The integrative model of shared decision-making in medical encounters. The authors describe the integration and extension of these two highly synergistic models, resulting in a goal-directed model of collaborative decision-making in hospice and PC. Directions for practice innovation and research informed by the model are discussed...

Abstract (w. references): <https://bit.ly/3qIXphR>

Noted in Media Watch 20 September 2021 (#735, p.11):

- *PALLIATIVE MEDICINE* | Online – 13 September 2021 – ‘**Identifying older adults with frailty approaching end-of-life: A systematic review.**’ Clear implications for end-of-life (EoL) policy and practice are hindered by the lack of evidence that relates to older adults explicitly identified as frail. Frailty trajectories, measures of physical fitness and assessment of malnutrition may all be helpful to indicate entry into the EoL phase, but the evidence is limited. There is also a paucity of evidence for appropriate interventions. Future research could helpfully adopt explicit measurement and reporting of frailty among study populations. In view of the challenges to identification of frailty and EoL, a focus on models of care that incorporate a palliative care approach within frailty is critical. **Full text:** <https://bit.ly/398p0yZ>

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Noted in Media Watch 10 May 2021 (#716, p.8):

- *PALLIATIVE MEDICINE* | Online – 3 May 2021 – ‘**The importance of living well now and relationships: A qualitative study of the barriers and enablers to engaging frail elders with advance care planning.**’ The population of frail elders is growing, and due to their vulnerability to sudden deterioration, advance care planning (ACP) is particularly important. However, ACP is uncommon for multiple reasons, some of which are linked to the perceptions of frail elders and their families. Key barriers identified in this study were: ACP is unclear, in terms of meaning and the language used; lack of relevance, with frail elders preferring to focus on living well now; and, the importance of family, relationships and home, and the influence of relationship on end-of-life decision-making. **Full text:** <https://bit.ly/3xDrlrz>

Pediatric oncology palliative care programs in Central America: Pathways to success

CHILDREN | Online – 10 November 2021 – Cultural and financial barriers to palliative care (PC) in oncology patients occur in all countries, and those located in Central America are no exception. In this article, the authors summarize how the programs participating in the Asociación de Hemato-Oncólogos Pediátricos de Centro America (AHOPCA) have developed dedicated oncology PC programs. The experience in Guatemala, El Salvador, Costa Rica, Panama, Dominican Republic and Haiti is detailed, with a focus on history, the barriers that have impeded progress, and achievements. Future directions, which, of course, may be impacted by the COVID-19 pandemic, are described as well. Every single country which came together for the foundation of AHOPCA has found a way to start their very own programs to very successfully offer local support. It is certain that in Central America, although PC practice has just begun in some countries, many patients, families, and teams have benefited from the improved quality of life that is only possible through an integrated, holistic approach to care. **Full text:** <https://bit.ly/3DdmeG8>

Noted in Media Watch 29 March 2021 (#710, p.7):

- *CHILDREN* | Online – 23 March 2021 – ‘**Quality indicators in pediatric palliative care: Considerations for Latin America.**’ Pediatric palliative care (PC) is a growing field in which the currently available resources are still insufficient to meet the PC needs of children worldwide. Specifically, in Latin America, pediatric PC services have emerged unevenly and are still considered underdeveloped when compared to other regions of the world. A crucial step in developing pediatric PC programs is delineating quality indicators; however, no consensus has been reached on the outcomes or how to measure the impact of pediatric PC. Additionally, Latin America has unique socio-cultural characteristics that impact the perception, acceptance, enrollment and implementation of PC services. **Full text:** <https://bit.ly/3rkvJwm>

Quality of end-of-life cancer care in Canada: A 12-year retrospective analysis of three provinces’ administrative healthcare data evaluating changes over time

CURRENT ONCOLOGY | Online – 12 November 2021 – This retrospective cohort study of cancer decedents during 2004-2015 examined end-of-life (EoL) cancer care quality indicators (QIs) in the provinces of British Columbia (BC), Ontario, and Nova Scotia (NS). These included: emergency department use, in-patient hospitalization, intensive care unit admissions, physician house calls, home care visits, and death experienced in hospital. Ontario saw the greatest 12-year decrease in in-hospital deaths from 52.8% to 41.1%. Hospitalization rates within 30 days of death decreased in Ontario, increased in NS, and remained the same in BC. Ontario’s usage of aggressive EoL measures changed very little, while BC increased their utilization rates. Supportive care use increased in both NS and Ontario. Those who were male or living in a lower income/smaller community (in Ontario) were associated with a decreased likelihood of receiving supportive care. Despite the shift in focus to providing hospice and home care services, approximately 50% of oncology patients are still dying in hospital and 11.7% of patients overall are subject to aggressive care measures that may be out of line with their desire for comfort care. Supportive care use is increasing, but providers must ensure that Canadians are connected to palliative services, as its utilization improves a wide variety of outcomes. **Full text:** <https://bit.ly/3x3R3L4>

Parents' experiences of initiation of paediatric advance care planning discussions: A qualitative study

EUROPEAN JOURNAL OF PEDIATRICS | Online – 16 November 2021 – This qualitative study ... explored parents' experience of the initiation of their child's advance care planning (ACP), to help provide an understanding to inform future practice. Single interviews were undertaken with 17 non-bereaved and bereaved parents. Parents reported they had engaged with future thinking but needed time before initiating this with clinicians. They identified the need for a trusted professional and time for private, thorough, non-judgemental discussion without feeling clinicians were "giving up." Parents reported that discussions were not always aligned to the dynamics of family life. They felt that health professionals (HPs) were responsible for initiating ACP conversations according to the families' individual requirements. There was an apparent lack of standardised protocols to assist paediatric ACP initiation. Initiating ACP is a complicated process that needs to be tailored to the specific parent and child situation. HPs need to appreciate that parents are key contributors to initiate engagement with ACP, but that they also require support and care, recognising this may facilitate the building of trust, identified as a key corner stone, of paediatric ACP initiation and engagement.

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

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

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 September 2021 – '**Participatory development of a modular advance care planning program in pediatric palliative care.**' This study aimed at developing a pediatric advance care planning program meeting specific needs of children, parents and health professionals. The overall focus of participants in this study was on the children's quality of life and an individualized interdisciplinary communication process along the disease trajectory. The program was conceptualized in modular design with fixed modules at the beginning (to build a trustful relationship and frame the process) and at the end (to summarize results and prepare implementation)
Full text: <https://bit.ly/3ihR7ka>

COVID-19 pandemic: End-of-life experience in Australian residential aged care facilities

INTERNAL MEDICINE JOURNAL | Online – 16 November 2021 – This research was undertaken to explore and better understand the effects of the pandemic on the experience of next-of-kin and carers who encountered the death of a loved one who resided within a residential aged care facilities RACF during the pandemic. Forty-one telephone interviews [with next-of-kin or carers of residents who died within 30 days] were analysed. Themes identified included: 1) COVID-19 pandemic; 2) Communication and technology; 3) Death and dying experience; 4) Bereavement and grief; and, 5) Social supports and external systems. Findings from this study identify the many COVID-19 pandemic related challenges faced by participants and their dying loved one in RACFs. Access to palliative care and bereavement support is crucial for dying residents and for grieving that has been made more difficult by the pandemic. **Abstract:** <https://bit.ly/3nnn6Cv>

What does economic evaluation mean in the context of children at the end of their life?

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH, 2021;18(21): 11562. Failure to consider the costs or benefits of the range of end-of-life care (EoLC) packages in children has contributed to inconsistent provision of care throughout the National Health Service (NHS) in England, and internationally. Furthermore, at a time of extensive budgetary pressures and rising numbers of children with life-limiting conditions the inability to define the benefits of a healthcare budget or argue for the value of additional funding puts the delivery of EoLC on the back foot, with increasing reliance falling on third sector support, which itself is struggling under the burden. However, the unsuitability of the "conventional framework" of cost-effectiveness analysis and the potentially impossible challenge of identifying a framework, which weighs the different costs and outcomes falling across stakeholders into a single statement of cost-effectiveness, has led to what little applied research exists focusing on costing alone. The resultant blind spot of research able to sufficiently inform policy deliberations directly impacts the children and their families who feel failed by the promises of universal healthcare, with a parent representative to this research

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commenting: “Something I always find useful to consider here is the principle of universal healthcare: To protect people from the catastrophic consequences/costs of ill health. The NHS [in England] does not do that, as anyone with a disabled child will tell you.” Methods such as impact inventory evaluation frameworks may represent an important turning point in undertaking economic evaluations in EoLC, especially in children and young people. **Full text:** <https://bit.ly/3DmYkIA>

Implementation and knowledge of the clinical practice guide for palliative care in the Ecuadorian primary care level

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH, 2021;18(21): 11573. This study intended to analyze the impact of implementing the Clinical Practice Guide for Palliative Care in Ecuador’s Health Zone 7, since its approval in 2014. To such end, physicians and nurses involved in palliative care (PC) were asked about their knowledge and professional experience. Likewise, the managers of the health centers involved were also included. Insufficient implementation of the Clinical Practice Guide for Palliative Care guide is evidenced, despite approval of the 2015-2017 Palliative Care National Plan, where all health establishments are compelled to apply it, which does not necessarily lead to putting it into practice to ensure provision of the service. This phenomenon has been observed in several studies and, perhaps, the most notorious is the one by the World Health Organization in 2015, which concludes that, in order to have successful PC programs, universal access to the essential PC medications is required, as well as generalized education and implementation, in line with the results found in this study. In addition, adequate funding and political commitment are required. Nine out of 10 administrative managers stated that the demand for PC among the population of their health centers was less than or equal to 50 individuals, although chronic diseases in advanced stages are the most prevalent in Ecuador. This can be due to the fact that they are not properly identified or that they are only considered at the end of the chronic process, instead of at early stages, as currently recommended. **Full text:** <https://bit.ly/3DaUli1>

Noted in Media Watch 8 June 2020 (#669, p.8):

- *INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH* | Online – 30 May 2020 – ‘**Knowledge, attitudes and expectations of physicians with respect to palliative care in Ecuador: A qualitative study.**’ In Latin America, only Cuba and Uruguay, include palliative care (PC) in pre-graduate courses as a mandatory discipline in their medical schools. The need for PC is high, especially in mid-income countries like Ecuador, where the percentage of patients receiving such care is small due to the scarcity of infrastructure and specialized personnel and to the unequal distribution in the country. Strategies are needed which intensify the training of medical professionals in PC, as well as develop the human resources and materials for providing it. **Full text (click on pdf icon):** <https://bit.ly/2TSkrBB>

N.B. Noted in Media Watch 9 August 2021 (#729, p.12): ‘Atlas de Cuidados Paliativos de Latinoamérica (2nd Edition),’ Asociación Latinoamericana de Cuidados Paliativos, 2020. **Download Spanish language edition at:** <https://bit.ly/3c5PQtr>

The Evolving Specialty of Neuropalliative Care

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Blog – 15 November 2021 – The focus of this posting is on the evolving specialty that is neuropalliative care with summaries of a representative sample of journal articles on the subject published during the past year or so. Included are articles on Parkinson’s disease, Amyotrophic Lateral Sclerosis, Multiple Sclerosis, Motor Neurone disease, Huntington’s disease, Dementia, Epilepsy and Neuro-ICU (neurosciences intensive care unit). There is a short selection of articles on neuropalliative care in the context of the COVID-19 pandemic, from the family caregivers’ perspective, and advance care planning (including advance directives and goals-of-care). This posting is part of a weekly series developed in partnership with the European Association for Palliative Care Neurology Reference Group. <https://bit.ly/3cdwyIS>



Palliative care organization and staffing models in residential hospices: Which makes the difference?

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – 13 November 2021 – The number of patients using palliative care (PC) services, particularly residential hospices, is increasing. Policymakers are urging these services to reflect on the most effective organizational strategies for meeting patients' complex care needs. This study showed the exact skill-mix composition and proportions of PC team able to ensure optimal control of patients' symptoms. The added value of physicians and nurses with a qualification in PC in terms of better patient outcomes reaffirmed the importance of education in guaranteeing quality care. Hospices with 12-25 beds, and recruitment methods guaranteeing at least 12-day stay ensured the most propitious organizational environment for optimal management of clinically significant symptoms. The transferability of these results mainly depends on whether the skills of health professionals in our "ideal" model are present in other contexts. The findings of this study provide policymakers and hospice managers with specific, evidence-based information to support decision-making processes regarding hospice staffing and organization. Further prospective studies are needed to confirm the positive impact of this "optimal" organizational framework on patient outcomes. **Abstract:** <https://bit.ly/3cqdvEM>

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

JOURNAL OF THE AMERICAN COLLEGE OF SURGEONS, 2021;233(5):S106. Historic surgical dogma viewed mortality, comfort care, and end-of-life (EoL) therapy as failures of providers' knowledge and technical skill. This created an atmosphere to defer consultation to palliative care (PC) service until the latest stages of EoL care. New surgical initiatives demonstrate the need for EoL care, death with dignity, and the need for palliative services. As this need grows, deficits in surgical providers' knowledge of PC is necessary to direct further training and development efforts. Less than half of participants in this study reported training in withdrawal of care conversations, while 55% reported receiving training in pain management and 64% reported receiving training in delivery of bad news. Fifty-four percent reported being involved in 5 or more EoL discussions in the last year, with trainees reporting fewer EoL discussions than non-trainees; 67% of trainees reported 0 to 4 discussions, while 23% of non-trainees reported more than 20 discussions. Although most of the study participants train and work in intensive care settings, many providers lack the training to carry out PC discussions, including withdrawal of care conversations, pain management, and delivery of bad news. Such training may benefit providers and patients in the future. **Abstract:** <https://bit.ly/30ER3Wg>

Related:

- *BMC MEDICAL EDUCATION* | Online – 17 November 2021 – '**Future palliative competence needs: A qualitative study of physicians' and registered nurses' views.**' Seamless cooperation between palliative care (PC) services and educational institutions is recommended to ensure that undergraduate and postgraduate education of physicians and registered nurses is based on a continuous assessment of competence requirements within the field of PC. Therefore, online multi-professional simulations, for example, could be used to enhance future competencies within PC; undergraduate medical, nursing and allied healthcare students as well as postgraduate PC professionals and experts of experience could work together during simulations. **Full text:** <https://bit.ly/30BOFyZ>
- *JOURNAL OF EDUCATIONAL EVALUATION & HEALTH PROFESSIONS* | Online – 11 November 2021 – '**Are we teaching health science students in the U.S. what they need to know about death and dying coping strategies?**' Of the 93 students who had already started their clinical rotations, 55 stated they had not received death and dying education before starting clinical courses. Of the 38 who had received death and dying education, only 17 students believed the training was effective. It is imperative that health science educational programs implement death and dying education and training into the curriculum, and that criteria for evaluating effectiveness be an essential part of death and dying education and training in order to ensure effectiveness. **Abstract:** <https://bit.ly/3Hm2suB>

What is a good death? A choice experiment on care indicators for patients at end of life

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 14 November 2021 – The authors developed a discrete choice experiment survey with 13 key indicators related to patients' experience in the last 6 weeks of life. They fielded the survey to a web-panel of caregiver proxies for recently deceased care recipients and obtained 250 responses in each of 5 countries: India, Singapore, Kenya, the U.K. and the US. Latent-class analysis was used to evaluate preference weights each indicator within and across countries. Results reveal that not all aspects of end-of-life care (EoLC) are equally valued. Not accounting for these differences would lead to inappropriate conclusions on how best to improve EoLC. **Abstract (w. references):** <https://bit.ly/3cbT8Lu>

Do palliative care providers use complementary and integrative medicine? A nationwide survey

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 14 November 2021 – Given the high prevalence of burdensome symptoms in palliative care (PC) and increasing use of complementary and integrative medicine (CIM) therapies, research is needed to determine how often and what types of CIM therapies providers recommend to manage symptoms in PC. Survey respondents were mostly female (71.3%), physicians (74.9%), and cared for adults (90.4%). Providers recommended CIM an average of 6.82 times per month and used an average of 5.13 out of 10 CIM modalities. Respondents recommended mind-body medicines (e.g., meditation, biofeedback) most, followed by massage, and acupuncture/acupressure. The most targeted symptoms included pain; followed by anxiety, mood disturbance and distress. Recommendation frequencies for specific modality-for-symptom combinations ranged from little use (e.g., aromatherapy for constipation) to occasional use (e.g., mind-body interventions for psychiatric symptoms). Finally, recommendation rates increased as a function of pediatric practice, non-inpatient practice setting, provider age, and proportion of effort spent delivering PC. To the best of the authors' knowledge, this is the first national survey [in the U.S.] to characterize PC providers' CIM recommendation behaviors and assess specific therapies and common target symptoms. Providers recommended a broad range of CIM but do so less frequently than patients report using CIM. **Abstract (w. references):** <https://bit.ly/3ow44JJ>

Noted in Media Watch 1 November 2021 (#741, p.9):

- *PALLIATIVE CARE IN SOCIAL PRACTICE* | Online – 26 October 2021 – '**Implementation and outcomes of complementary therapies in hospice care: An integrative review.**' This integrative review of quantitative studies ... focused on implementation and outcomes of complementary therapy (CT) as a component of hospice care. The majority of studies had positive results; however, 40% had both significant and non-significant findings indicating that while there is evidence to support the use of some CTs for specific symptoms, it is not consistent, and improvements may not be sustained over time. In addition, a number of methodological issues should be considered related to study design and sample, implementation of the CT interventions, and data measurement and analysis. **Full text:** <https://bit.ly/3nvcnF1>

Noted in Media Watch 26 April 2021 (#714, p.11):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 April 2021 – '**Characteristics of provider-focused research on complementary and integrative medicine in palliative care: A scoping review.**' The authors identified 34 studies that were conducted primarily in the U.S. and the U.K., focused mostly on nurse and physician providers, and employed questionnaires or qualitative methods. Studies investigated 58 complementary and integrative medicine (CIM) modalities. Study outcomes included perceived benefits of CIM and types of CIM modalities that providers offer. Uncommonly studied phenomena included referral patterns, facilitators of provider recommendation of CIM, and rates of CIM use. **Abstract (w. references):** <https://bit.ly/3xjzc2F>

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Palliative Care Network

Palliative Care for Everyone, Everywhere

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Related:

- *PALLIATIVE MEDICINE* | Online – 16 November 2021 – ‘Arts engagement facilitated by artists with individuals with life-limiting illness: A systematic integrative review of the literature.’ A growing body of evidence suggests that arts engagement facilitated by artists promotes well-being. However, no synthesis of the literature exists to describe arts engagement delivered by artists with individuals receiving palliative care. Seven reviewed studies explored literary, performing, and visual arts engagement in hospitals, hospice and community settings... Themes identified across studies associated arts engagement with: 1) A sense of well-being; 2) A newly discovered, or re-framed, sense of self; 3) Connection with others; and, 4) Challenges associated with practice. **Abstract (w. references):** <https://bit.ly/3DhMwHk>

Anxiety, depression, quality of life, caregiver burden, and perceptions of caregiving-centred communication among Black and White hospice family caregivers

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 November 2021 – Anxiety, depression, and reduced quality of life (QoL) are common problems for hospice family caregivers (FCGs), but it is unknown if disparities in these experiences exist among Black and White caregivers. Despite demographic and socioeconomic differences, Black and White hospice FCGs [i.e., study participants] experience similarly high levels of anxiety, depression, burden, and perceptions of hospice communication. Interventions to support hospice FCGs across racial groups and research that identifies factors that mediate social determinants of health in this population are needed. The development and validation of culture-concordant mental health screening tools in racially diverse populations is recommended. **Abstract:** <https://bit.ly/3nyoPFfe>

Clinician perspectives guiding approach to comprehensiveness of palliative care assessment

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 November 2021 – National Consensus Project for quality palliative care (PC) guidelines emphasizes the importance of a comprehensive assessment of all care domains, including physical, psychosocial, and spiritual aspects of care, for seriously ill patients. However, less is known about how real-world practice compares with this guideline. Nineteen out of 25 invited clinicians (physicians, nurse practitioners, and physician assistants) completed a survey. A majority (62%) reported that, although some elements of assessment were mandatory, their usual practice was to tailor the focus of the consultation. Time limitations and workload received the highest mean scores as reasons for tailored assessment, followed by beliefs that comprehensive assessment is unnecessary, and absence of the full interdisciplinary team. All participants cited symptom acuity, and 91% cited reason for consult as factors influencing a tailored approach. Among domains “always” assessed, physical symptoms were reported most commonly (81%) and spiritual and cultural factors least commonly (24% and 19%, respectively). Although a majority of clinicians reported usually tailoring their consultations, mean importance scores for almost all assessment elements were high; however, there was some variation based on reason for consult. Spiritual elements received lower importance scores relative to other elements. Although clinicians placed high importance on most elements included in comprehensive PC, in practice they often tailored their consultations, and the perceived relative importance of domains shifted depending upon the type of consultation. **Abstract:** <https://bit.ly/3oGaRk3>

Top ten tips palliative care clinicians should know about delivering antiracist care to Black Americans

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 November 2021 – Racial disparities, including decreased hospice utilization, lower quality symptom management, and poor-quality end-of-life care have been well documented in Black Americans. Improving health equity and access to high-quality serious illness care is a national palliative care (PC) priority. Accomplishing these goals requires clinician reflection, engagement, and large-scale change in clinical practice and health-related policies. In this article, the authors provide an overview of key concepts that underpin racism in healthcare, discuss common serious illness disparities in Black Americans, and propose steps to promote the delivery of antiracist PC. **Abstract:** <https://bit.ly/3FsSKEZ>

Prognostication, ethical issues, and palliative care in disorders of consciousness

NEUROLOGIC CLINICS, 2022;40(1):59-75. Advances in the care of severe acute brain injury (SABI) have enabled the survival of patients in states of diminished consciousness. Recent research has offered an increasingly complex picture of the possible inner lives of these patients and their potential for recovery. This shift opens new ethical questions and intensifies the challenges facing patients' surrogate decision-makers, who in the acute period of SABI are tasked with making life-or-death decisions in the face of profound uncertainty. **Access article at:** <https://bit.ly/3CLy5dL>

Research Matters

Palliative care clinical trials: Building capability and capacity

JOURNAL OF PALLIATIVE MEDICINE | Online – 17 November 2021 – Clinical trials are a key component of expanding the evidence base in palliative care (PC). A key strategic objective of the Victorian Comprehensive Cancer Centre (VCCC), a multisite cancer center alliance [in Melbourne, Victoria, Australia], was to increase PC clinical trial expertise. The PC services within the VCCC alliance presented substantial trial development opportunities with large number of patients and established relationships, but few trial-active centers. In the two years of implementation, the “Building Capability in Palliative Care Clinical Trials” program resulted in the establishment and conduct of several Phase 4 post-marketing pharmacovigilance studies, nine Phase 2 and 3 trials across five PC services, and a Phase 1 clinical trial. During the program, 150 patients were recruited to clinical trials, and 258 prospective pharmacovigilance monitoring cases were recorded. Clinicians reported that undertaking clinical trials had increased attention to the evidence base of care provision, and increased service research activity more broadly. Long-term sustainability remains a challenge, particularly in the context of the COVID-19 pandemic. Clinical trials in PC services are feasible, acceptable, and result in increased attention to the evidence base of care. The strategies detailing the framework, activities, and outcomes have been collated to facilitate implementation of clinical trials in other sites and with other trial-naive disciplinary groups. **Abstract:** <https://bit.ly/3Dve9gi>

Successful strategies and areas of improvement-lessons learned from design and conduction of a randomized placebo-controlled trial in palliative care, ‘Palliative-D’

LIFE | Online – 15 November 2021 – Clinical trials in palliative care (PC) are challenging to design and conduct. Burden on patients should be minimized, while gatekeeping by professionals and next-of kin needs to be avoided. Clinical deterioration due to disease progression affects attrition unrelated to intervention, and different care settings complicate comparisons and reduce the generalizability of the results. The aim of this review is to provide advice for colleagues planning to perform clinical trials in PC based on the authors' experiences from performing the Palliative-D study and by a thorough literature review on this topic. In this article, the authors discuss challenges in PC research based on lessons learned from the ‘Palliative-D’ trial regarding successful strategies as well as areas for improvement. **Full text (click on pdf icon):** <https://bit.ly/3CFWQYM>



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



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