

Media Watch... is intended as an advocacy, research and teaching tool. The 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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Compilation of Media Watch 2008-2022 ©

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In the last quarter century, numerous policy reports [on the provision and delivery of palliative and end-of-life care] were published through extensive consultation with stakeholders ... most of these reports “sit on a shelf and gather dust.”

‘Stakeholder perspectives towards implementing the National Framework on Palliative Care in Canada’ (p.4), in *Health Policy*.

News Media: Lead Article

The Lancet Commissions

Experts warn of increasing over medicalisation of death, call for rethink on end-of-life care

IRELAND | *The Journal* (Dublin) – 31 January 2022 – Today’s current overemphasis on aggressive treatments to prolong life, vast global inequities in palliative care access, and high end-of-life (EoL) medical costs have led millions of people to suffer unnecessarily at the EoL. A *Lancet* Commission has called for public attitudes to death and dying to be rebalanced, away from a narrow, medicalised approach towards a compassionate community model, where communities and families work with health and social care services to care for people dying. The Commission analysed how societies around the world perceive death and care for people dying, providing recommendations to policymakers, governments, civil society, and health and social care systems.¹ <https://bit.ly/3L0CpuQ>

1. ‘Report of *The Lancet* Commission on the Value of Death: Bringing death back into life,’ *The Lancet*, published online 31 January 2022. **Access full text at:** <https://bit.ly/3IOhSHU>

Related:

- ‘Kerala’s model of care transformed how people lived and died: *Lancet* Commission,’ *The Indian Express* (Noida), 1 February 2022. <https://bit.ly/3ui2tvI>

N.B. See ‘A new vision for death and dying...,’ a commentary on the Commission’s report at <https://bit.ly/3L0THYL>, and ‘The origins, development, and context of *The Lancet* Commission on the Value of Death,’ a commentary by one of the co-authors of the Commission’s report at <https://bit.ly/3ooX6XH>. Search back issues of *Media Watch* for additional articles on the “Kerala” model of EoL care at <http://bit.ly/2ThijkC>.

Government & Non-Government Organizations et al

‘What happens when palliative care is neglected as a public health priority?’ (p.4), European Association for Palliative Care.

Specialist Publications

‘Timely community palliative and end-of-life care: A realist synthesis’ (p.7), in *BMJ Supportive & Palliative Care*.

[News Media \(cont.\)](#)

The kind of death you experience has become a postcode lottery

U.K. | *The House* (London) – 31 January 2022 – One of the underreported quirks of the palliative care system is its reliance on charitable donations, with only a small proportion of funding provided directly by government. The hospice movement was not established until the mid-1950s, meaning the sector effectively missed the boat for being fully integrated within the National Health Service (NHS) when it was established in 1948. In 2022, that enduring dynamic means hospice and community nurses are often paid less than those in comparable NHS roles, creating an inevitable shortage. According to a study by King's College London, only a quarter of the new Integrated Care Systems – set to replace the current clinical commissioning groups – have identified palliative or end-of-life care as a priority. <https://bit.ly/3ANDVLX>

N.B. It is unclear to which study the author of *The House* article refers. Authors of an article published in *BMJ Supportive Care* in 2018, 'Commissioning of specialist palliative care services in England,' states that "palliative care provision is not being considered as a core service in some parts of England." <http://bit.ly/2XyQXIU>

Seriously ill children at risk due to drastic cuts to care support, charity warns

U.K. | Sky News (London) – 28 January 2022 – Seriously ill children who are being cared for at home by their families are being put at risk due to "drastic cuts to care support," a charity has warned. Research by national charity WellChild found that staff shortages were leaving parents exhausted and vulnerable, with one mother saying the situation was "an accident waiting to happen." Data, shared exclusively with Sky News, found 80% of affected families were not receiving the state-funded care support to which they are entitled. 88% said there was an expectation from care providers that parents would cover the ever-more frequent staff shortages. There are an estimated 100,000 families across the U.K. with a sick or disabled child at home. <https://bit.ly/3s0Ye4T>

[Specialist Publications](#)

'Giving a voice to the voiceless: End of life second opinions' (p.5), in *Archives of Disease in Childhood*.

N.B. WellChild website: <https://bit.ly/3s0YwbZ>

Study: U.S. ranks 43rd in end-of-life care quality

U.S. | *Hospice News* – 26 January 2022 – The U.S. ranks 43rd in end-of-life care (EoLC) quality among 81 countries according to a recent study...¹ Worldwide, much improvement is needed in the realm of caring for terminally ill patients, researchers found. For the purposes of this study, researchers defined EoLC as any healthcare services received by terminally ill patients in their final days, including but not limited to hospice. Globally most of these patients die in pain, under significant psychological distress, and not in the place of their choice. Dying patients also often express regret about the treatment they received, particularly high-cost, high-acuity services that are of little benefit at that stage of their illness. The families of these patients are also often left with medical debt that can lead to bankruptcy. <https://bit.ly/31IKXog>

1. 'Cross-country comparison of expert assessments of the quality of death and dying 2021,' *Journal of Pain & Symptom Management*, published online 21 December 2021. [Noted in Media Watch 3 January 2022 (#749, p.8)] Full text: <https://bit.ly/3yMBVCU>



Media Watch: Access Online

Media Watch (or a link to the report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.14.

Death doulas used to be rare. The COVID-19 pandemic changed that

U.S. | *Time Magazine* – 26 January 2022 – Since COVID-19 emerged in early 2020, organizations that support and train U.S. death doulas have seen significant spikes in membership and enrollment. The National End-of-Life Doula Alliance grew to more than 1,000 members in 2021, from just 200 in 2019. More than 600 people enrolled in the University of Vermont’s end-of-life doula program in 2021, compared with fewer than 200 in 2017 when the program began. Some training groups say enrollment has more than tripled during the pandemic, as has the number of people seeking help for themselves and others facing imminent death. Since doulas do not administer or prescribe medication, the industry is unregulated and does not require a license. <https://bit.ly/3H7puot>

Specialist Publications

‘When “being there” is disallowed: Disruptions to knowing and caring during COVID-19 visitor restrictions’ (p.10), in *Journal of Social Work in Palliative & End-of-Life Care*.

N.B. The U.S. death toll at the time the *Time Magazine* article was published exceeding 850,000. Latest statistics are available at: <https://bit.ly/3B0uokP>

Noted in Media Watch 15 November 2021 (#743, p.6):

- ‘Unbefriended, uninvited: How end-of-life doulas can address ethical and procedural gaps for unrepresented patients and ensure equal access to the “good death,”’ *Clinical Ethics*, published online 11 November 2021. **Abstract (w. references):** <https://bit.ly/3FbdQIO>

Noted in Media Watch 27 September 2021 (#736, p.12):

- ‘End-of-life doulas: Documenting their backgrounds and services,’ *Omega – Journal of Death & Dying*, published online 22 September 2021. **Abstract (w. references):** <https://bit.ly/3AEu9eg>

Advance planning hasn’t improved end-of-life care, some experts say. They’re getting pushback

U.S. (Pennsylvania) | *The Philadelphia Inquirer* – 23 January 2022 – For decades, Americans have been urged to fill out documents specifying their end-of-life (EoL) wishes before becoming terminally ill... Now, a group of prominent experts says those efforts ... haven’t improved EoL care.¹ The reasons are varied and documented in dozens of research studies: People’s preferences change as their health status shifts; forms offer vague and sometimes conflicting goals for EoL care; families, surrogates and clinicians often disagree with a patient’s stated preferences; documents aren’t readily available when decisions need to be made; and, services that could support a patient’s wishes ... simply aren’t available. But this critique of advance care planning is highly controversial and has received considerable pushback. <https://bit.ly/3nPGFn7>

Specialist Publications

‘Advance and future care planning: Strategic approaches in Wales’ (p.7), *BMJ Supportive & Palliative Care*.

‘Cultural adaptation of a community-based advance serious illness planning decision aid to the Quebec context involving end-users’ (p.7), in *Health Expectations*.

‘Surrogate decision-makers need better preparation for their role: Advice from experienced surrogates’ (p.10), in *Journal of Palliative Medicine*.

1. ‘What’s wrong with advance care planning?’ *Journal of the American Medical Association*, 2021;326(16): 1575-1576. [Noted in Media Watch 11 October 2021 (#738, p.7)] **Full text:** <https://bit.ly/3FyPIje>

Noted in Media Watch 3 August 2020 (#677, p.9):

- ‘Advance care planning vs. advance serious illness preparations and planning,’ *Healthcare*, 2020;8(3): E218. **Full text:** <https://bit.ly/30GUkAc>



Share this issue of Media Watch with a colleague.

Government & Non-Government Organizations et al

What happens when palliative care is neglected as a public health priority?

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – 26 January 2022 – The COVID-19 pandemic has exposed and magnified many of the weaknesses of our healthcare systems, including the lack of access to palliative care (PC) for patients dying alone with COVID-19. It is striking how little we have heard in the general media about PC in this pandemic, a symptom of how it is under-valued as a public health priority... COVID-19 has a major impact on people, not only physically, but also mentally. Once someone is ill, there is uncertainty about the course of the disease, the symptom burden and the treatment. If an infected person has the misfortune to need hospitalisation, and the good fortune to receive it, a terrible period follows on the ward or, worse, in intensive care. <https://bit.ly/3uR-qXJJ>

Specialist Publications

'Revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care: A Delphi study' (p.12), in *Palliative Medicine*.

Noted in Media Watch 28 September 2020 (#685, p.14):

- 'Rethinking palliative care in a public health context: Addressing the needs of persons with non-communicable chronic diseases,' *Primary Health Care Research & Development*, published online 15 September 2020. **Full text:** <https://bit.ly/3r0YZLH>

Noted in Media Watch 20 July 2020 (#675, p.11):

- 'COVID-19, palliative care and public health,' *European Journal of Cancer*, 2020;136(9):95-98. **Full text:** <https://bit.ly/2OhJTG>

Noted in Media Match 25 February 2019 (#603, p.12):

- 'Palliative care and public health: An asymmetrical relationship?' *Palliative Care: Research & Treatment*, published online 20 February 2019. **Full text:** <http://bit.ly/2Xhk1oG>

Noted in Media Watch 4 February 2019 (#600, p.9):

- 'Unpacking "the cloud": A framework for implementing public health approaches to palliative care,' *Health Promotion International*, published online 27 January 2019. **Abstract:** <http://bit.ly/2RrPpgd>

Specialist Publications: Lead article

Stakeholder perspectives towards implementing the National Framework on Palliative Care in Canada

HEALTH POLICY | Online – 24 January 2022 – Organizations genuinely support the Framework.¹ However, three-quarters of organizations were not confident in their abilities to strongly influence national palliative care (PC) policies. Barriers to collaboration include differences in governance models and funding arrangements, a lack of resources and divergent priorities. Homogeneous stakeholder cohorts and in-depth analysis of stakeholder characteristics resulted in recommendations to support targeted engagement strategies. Implementation of national PC policies requires a large-scale coordinated approach... Recommendations are centered on the premise that targeted and tailored stakeholder engagement needs to be coordinated and is superior to a one-size fits all approach. **Abstract:** <https://bit.ly/3IECDWs>

1. 'Framework on Palliative Care in Canada,' Health Canada, 2018. [Noted in Media Watch 10 December 2018 (#593, p.1)] **Download/view at:** <http://bit.ly/2AVEghF>

Cont.

Noted in Media Watch 22 November 2021 (#744, p.7):

- '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*, published online 12 November 2021. **Full text:** <https://bit.ly/3x3R3L4>

Noted in Media Watch 21 September 2020 (#684, p.6):

- 'Framework on palliative care in Canada: Do we have a broad enough lens?' *Canadian Family Physician*, 2020;66(9):642-643. **Full text:** <https://bit.ly/2FHthhD>

Noted in Media Watch 4 November 2019 (/658, p.1):

- 'Action Plan on Palliative Care,' Health Canada, August 2019. **Download/view at:** <http://bit.ly/2Jno3Xa>

Noted in Media Watch 24 September 2018 (#582, p.1):

- 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, Ottawa, Ontario, September 2018. **Download/view at:** <http://bit.ly/2MqmCYO>

N.B. Noted in past issues of Media Watch: Nine key studies on end-of-life care in Canada, published between 1995-2014 see (#389, p.4), and 'Right to Care: Palliative care for all Canadians,' Canadian Cancer Society (#445, p.1).

[Specialist Publications \(cont.\)](#)

Giving a voice to the voiceless: End of life second opinions

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 28 January 2022 – The Royal College of Paediatrics & Child Health (RCPCH) has published an ethical framework setting out in rigorous, scholarly and humane documents the principles by which life-sustaining treatment may be withheld or withdrawn from a child,¹ and important principles for giving a second opinion have also been published. This Viewpoint is set within the framework of previous guidance and relates to the practicalities of giving a second opinion when such a course of action is contemplated; it does not seek to challenge any aspect of the RCPCH principles, nor unfortunately does it provide a panacea for resolving disagreements in which usually both sides genuinely perceive themselves as having the best interests of the child at heart. **Access at:** <https://bit.ly/3g9ultr>

[Research Matters](#)

An economic research agenda for palliative care' (p.13), in *JAMA Health Forum*.

1. 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A framework for practice,' Royal College of Paediatrics & Child Health. **Download at:** <https://bit.ly/3ragpWy>

Noted in Media Watch 27 September 2021 (#736, p.5):

- 'Parents' perspectives on conflict in paediatric healthcare: A scoping review,' *Archives of Disease in Childhood*, published online 17 September 2021. **Abstract:** <https://bit.ly/3lJPLjs>

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

- 'Hearing the voices of children diagnosed with a life-threatening or life-limiting illness and their parents' accounts in a palliative care setting: A qualitative study,' *Palliative Medicine*, published online 26 March 2021. **Abstract (w. references):** <https://bit.ly/3rpxecl>

Cont.

Related:

- 'Ethical quandaries at end of life: Navigating real-world case examples as a pediatric psychologist,' *Clinical Practice in Pediatric Psychology*, accessed online 1 February 2022. **Abstract:** <https://bit.ly/3HrilQg>
- 'End-of-life care in patients with cancer 16-24 years of age,' *Current Oncology Reports*, published online 25 January 2022. **Full text:** <https://bit.ly/3r2tEbN>
- 'End-of-life palliative home care for children with cancer: A qualitative study on parents' experiences,' *Scandinavian Journal of Caring Sciences*, published online 24 January 2022. **Full text:** <https://bit.ly/3r9nerb>

Impact of home healthcare on end-of-life outcomes for people with dementia: A systematic review

BMC GERIATRICS | Online – 27 January 2022 – Different care needs at various stages in the disease trajectory towards the end-of-life (EoL) among people living with dementia urge more integrated services with effective components to respond to their demand better. Effects of advance care planning, multidisciplinary approach, integration between health and social care, and coordination between primary home healthcare (HHC) and specialists' support in local healthcare networks for better continuity of care at home should be emphasised in clinical practice and policy-making. Population-based large databases may provide opportunities to examine more clearly the long-term impact of HHC and its synergy with other clinical services on EoL outcomes in a longitudinal study design. **Full text:** <https://bit.ly/3g42U4c>

N.B. Search back issues of Media Watch for additional articles on palliative and EoL care for people living with “dementia” and “neuropalliative” care at: <http://bit.ly/2ThijkC>

Using routine databases to evaluate Electronic Palliative Care Co-ordination Systems

BMJ EVIDENCED-BASED MEDICINE | Online – 19 January 2022 – In response to the government's drive to expand Electronic Palliative Care Co-ordination Systems (EPaCCS) across England by 2020, further evidence for this intervention needs to be established quickly. With palliative and end-of-life care research being an underfunded area, the availability and lower costs of routine databases make it an attractive resource to integrate into studies evaluating EPaCCS without jeopardising research quality. Routine databases can be used to address the current paucity of high-quality evidence; they can be used in a range of study designs, including randomised controlled trials and quasi-experimental designs, and may also be able to contribute quality of life or patient-reported outcome measures. **Abstract:** <https://bit.ly/3lsypkx>

N.B. Additional articles on EPaCCS noted in Media Watch 19 April 2021 (#713, p.8).

Metaphors that shape parents' perceptions of effective communication with healthcare practitioners following child death: a qualitative U.K. study

BMJ OPEN | Online – 25 January 2022 – The findings illuminate the ways parents experienced communication with healthcare professionals (HCPs) surrounding the death of a child. Good communication with HCPs following the death of a child should acknowledge parental identity (and that of their child as an individual) and offer opportunities for them to enact this; taking account their emotional and physical experiences; and, accommodate their altered experiences of time. HCPs when communicating with bereaved parents need to recognise, and seek to comprehend, the ways in which the loss impacts on an individual's identity as a parent, the “physical” nature of the emotions that can be unleashed and the ways in which the death of a child can alter their metaphorical conceptions of time. **Full text:** <https://bit.ly/349bf46>

N.B. Selected articles on the use of metaphors in palliative and end-of-life care noted in Media Watch 25 November 2019 (#641, p.12).

Cont.

Related:

- 'Attending to child agency in paediatric palliative care consultations: Adults' use of tag questions directed to the child,' *Sociology of Health & Illness*, published online 28 January 2022. **Full text:** <https://bit.ly/3r9p7Ed>

Timely community palliative and end-of-life care: A realist synthesis

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 2 February 2022 – Palliative and end-of-life (EoL) care programmes in primary care and community settings are here to stay and grow. However, after decades of seeking to expand palliative care outside of the realm of cancer, we may need a significant rethinking of the reach of palliative and EoL care programmes. A significant pool of evidence on prognosis suggests that current EoL care policy in England and any other country which relies strongly on “timely identification” is nothing short of hubristic in its expectations of working out death’s timings. And while the day may come, for better or worse, when we are able to perfect the latter, for now we will achieve more if we focus on other ways of improving the EoL care we provide... **Full text:** <https://bit.ly/3L72kB9>

Advance and future care planning: Strategic approaches in Wales

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 1 February 2022 – In Wales, the term advance care planning now falls under the wider umbrella term “future care planning,” which also includes patients with diminished mental capacity and their significant others, to engage in deciding and planning future care. Advance and future care planning is an approach with many different facets. In Wales, some patients prefer a clearly set out, legally binding ‘Advance Decision to Refuse Treatment’ to guide their care, while others prefer a softer, guiding approach captured through an ‘Advance Statement.’ All these formats are available to patients, carers and healthcare professionals, together with explanatory guidance notes, through a central Welsh website.¹ **Full text:** <https://bit.ly/3giowtL>

1. ‘Advance & Future Care Planning,’ National Health Service Wales: <https://bit.ly/3J0rkbw>

Related:

- ‘Cultural adaptation of a community-based advance serious illness planning decision aid to the Quebec context involving end-users,’ *Health Expectations*, published online 2 February 2022. **Full text:** <https://bit.ly/3gsKKJu>

Medical assistance in dying in hospice: A qualitative study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 25 January 2022 – The modern hospice movement has historically opposed assisted dying. The 2016 legalisation of medical assistance in dying (MAiD) in Canada has created a new reality for Canadian hospices. There have been few studies examining how the legalisation of MAiD has affected Canadian hospices. The authors objective was to identify the challenges and opportunities hospice workers think MAiD brings to a hospice. They constructed five themes. These themes detailed participants’ beliefs in the abilities of hospice care, and how they felt MAiD challenged these abilities. Participants felt that MAiD itself created challenging situations for patients and families, and that local policies and practices led to additional institutional challenges. **Abstract:** <https://bit.ly/3AAy5hd>

N.B. Selected articles on MAiD in hospice noted in Media Watch 10 January 2022 (#750, p.6).

Themes of end-of-life care in memorable cases of medical health professionals: A mixed methods approach

CURRENT PSYCHOLOGY | Online – 18 January 2022 – Little is known regarding memorable cases and their impact on the personal and professional well-being of medical health professionals (MHP). 163 MHP at a leading tertiary pediatric medical center in Israel answered an open-ended question recalling a memorable case and the influence it had on them. Three key findings are presented: 1) The prominence of end-of-life care (EoLC) among the memorable cases and its cross-disciplinary impact among professionals; 2) The importance of social support for professionals providing EoLC; and, 3) The high influence attributed by the MHP to their memorable case resulting in multiple short and long-term effects, negative and positive, effecting quality of life and professional performance. **Abstract (w. references):** <https://bit.ly/3KEImOQ>

One last effort. Are high out-of-pocket payments at the end of life a fatality?

EUROPEAN JOURNAL OF HEALTH ECONOMICS | Online – 31 January 2022 – Few studies outside of the U.S. address the issue of out-of-pocket payments (OoP) at end of life (EoL) because of a lack of data. The authors use an exclusive dataset from a major French health insurance company, including claim data, both mandatory and voluntary health insurance details, income and individual characteristics, for individuals aged 65 or older who died in 2017. They address three main issues: 1) What is the magnitude of OoP in France at the EoL; 2) How are OoP distributed, and do they present a financial risk to patients; 3) What are the determinants of OoP and what health system reforms could reduce them. The French system is successful in protecting individuals from catastrophic OOP. **Abstract:** <https://bit.ly/3L8xR5M>

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

Editorial

The role of policy and law in shaping the ethics and quality of end-of-life care in intensive care

INTENSIVE CARE MEDICINE | Online – 22 January 2022 – Policies regarding end-of-life care (EoLC) exist across a spectrum. Policies that restrict options have the potentially harmful effect of hindering ethically and clinically appropriate practices around limiting unwanted or non-beneficial life-sustaining treatment. Policies that provide the flexibility, clarity, and transparency to act ethically can improve the quality of EoLC and promote high-quality palliative care. Policymakers and clinicians must work together to create policies that promote ethical decision-making while refraining from overly restrictive policies that can be harmful to high-quality and ethical EoLC. The experiences in France and South Korea suggest policy interventions have the power to change the culture around EoLC for the better.^{1,2} **Full text:** <https://bit.ly/3tNCewN>

1. ‘An interprofessional process for the limitation of life-sustaining treatments at the end of life in France,’ *Journal of Pain & Symptom Management*, 2022;63(1):160-170. **Abstract (w. references):** <https://bit.ly/3rBm0UA>
2. ‘Change in perception of the quality of death in the intensive care unit by healthcare workers associated with the implementation of the “well-dying law,”’ *Intensive Care Medicine*, published online 1 January 2022. [Noted in Media Watch 10 January 2022 (#750, p.9)] **Full text:** <https://bit.ly/3zksXV>

Related:

- ‘End-of-life decisions, nurses, and the law,’ *Australian Critical Care*, 2022;35(1):1-2. **Abstract (w. references):** <https://bit.ly/3tUo64I>

Assessment of clinical palliative care trigger status vs actual needs among critically ill patients and their family members

JAMA OPEN NETWORK, 2022;1(5):e2144093. Palliative care (PC) consultations in ICUs are increasingly prompted by clinical characteristics associated with mortality or resource utilization. However, it is not known whether these triggers reflect actual PC needs. In this cohort study, the authors found that the presence of clinical PC triggers was not associated with higher levels of unmet PC need and was no better than chance in identifying the most serious needs. In contrast, needs were associated with person-centered outcomes and could represent a novel foundation for improving PC delivery. These findings raise questions about the increasingly common practice of prompting PC specialist consultation in ICU settings based on characteristics associated with death or resource utilization. **Full text:** <https://bit.ly/3rKV8Se>

Related:

- 'Palliative care exposure relative to predicted risk of 6-month mortality in hospitalized,' *Journal of Pain & Symptom Management*, published online 23 January 2022. **Abstract (w. references):** <https://bit.ly/3tW8Swe>

Palliative care utilization among non-Western migrants in Europe: A systematic review

JOURNAL OF IMMIGRANT & MINORITY HEALTH, 2022;24(1):237-255. A systematic review in accordance with PRISMA guidelines was conducted in June 2020. Studies included empirical research published between 2011 and 2020. Twenty nine qualitative and six quantitative studies were included. Four main themes were identified: 1) Communication and language; 2) Knowledge and awareness; 3) Patient preferences, cultural and religious issues; and, 4) Lack of resources at different levels of palliative care (PC) service provision. Migrants' access to PC is impeded at system, community and individual levels, yet, recommendations are mostly at the individual level. Closer attention is required to these different levels when designing future palliative interventions for migrants. **Abstract (w. references):** <https://bit.ly/3LiVZp>

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

Brain death determination and communication: An innovative approach using simulation and standardized patients

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 2 February 2022 – Palliative medicine clinicians in hospital settings are often involved in the care of patients dying in critical care settings, with a subset from brain death. Brain death is a complex concept, not only for families, but also for clinicians. There is wide variability in adhering to formalized guidelines for brain death determination. In addition, communication techniques regarding brain death determination are distinct from those used in shared decision-making. There is a need to obtain knowledge and practical skills in brain death determination, including examination and communication. Simulation can provide a low-stakes setting to practice the process of brain death determination and communication. **Abstract (w. references):** <https://bit.ly/3ASbvAE>

What's in the sauce? The specific benefits of palliative care for Parkinson's disease

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 30 January 2022 – Increasing evidence demonstrates the benefits of palliative care (PC) among individuals with Parkinson's disease and related disorders (PDRD), but the critical components that contribute to therapeutic effects are not well understood. The main trial was a pragmatic comparative effectiveness trial of outpatient integrated PC compared to standard care among participants with PDRD, showing significantly higher patient quality of life at six months and lower care partner burden at twelve months. Specific benefits of an integrated palliative approach in PDRD include improvement in patient holistic self-impressions, care partner self-efficacy, and non-motor symptoms. **Abstract (w. references):** <https://bit.ly/34944sN>

N.B. Search back issues of Media Watch for additional articles on PC for people living with "Parkinson's" disease and also "neuropalliative" care: <http://bit.ly/2ThijkC>

Turning the lens inward: The psychological elements of clinician well-being

JOURNAL OF PALLIATIVE MEDICINE | Online – 27 January 2022 – Psychological elements of palliative care also impact clinician well-being. The PEPC are bidirectional: we impact patients, but patients also impact us. The reactions that we have to patients and the boundaries we set around the care we provide are two examples of psychological factors of care that can influence our well-being. Creating spaces to explore and reflect on the psychological impact of the clinical care we provide is a key component of well-being. Such spaces vary in their configuration, but all share the opportunity to self-reflect and to experience emotional validation, normalization, and reality testing from peers or mentors. In mental health training, clinical supervision is one common format for creating such a space. **Abstract:** <https://bit.ly/3KQyG2K>

N.B. This article is the seventh entry in the journal's 'Psychological Elements of Palliative Care' series. Journal's website: <https://bit.ly/3rbznfu>

Related

- 'The burden in palliative care assistance: A comparison of psychosocial risks and burnout between inpatient hospice and home care services workers,' *Palliative & Supportive Care*, published online 26 January 2022. **Abstract (w. references):** <https://bit.ly/3nZDWre>

Surrogate decision-makers need better preparation for their role: Advice from experienced surrogates

JOURNAL OF PALLIATIVE MEDICINE | Online – 24 January 2022 – Little is known about what surrogates may need to adequately prepare for their role, and few resources exist to prepare them. Five themes and advice were identified: 1) Lack of, but needing, surrogates' own preparation and guidance; 2) Initiate advance care planning (ACP) conversations; 3) Learn patient's values and preferences; 4) Communicate with clinicians and advocate for patients; and, 5) Make informed surrogate decisions. Experienced surrogate decision-makers emphasized the importance of ACP and advised that surrogates need their own preparation to initiate ACP conversations, learn patients' values, advocate for patients, and make informed surrogate decisions. **Abstract:** <https://bit.ly/3AFUqKa>

Noted in Media Watch 28 June 2021 (#723, p.10):

- 'What surrogates understand (and don't understand) about patients' wishes after engaging advance care planning: A qualitative analysis,' *American Journal of Hospice & Palliative Medicine*, published online 25 June 2021. **Abstract (w. references):** <https://bit.ly/3vVoKfQ>

Noted in Media Watch 14 June 2021 (#721, p.9):

- "'She's not ready to give up yet!": When a family member overrides the patient's medical decisions,' *Journal of Pain & Symptom Management*, published online 8 June 2021. **Abstract (w. references):** <https://bit.ly/351byLx>

When "being there" is disallowed: Disruptions to knowing and caring during COVID-19 visitor restrictions

JOURNAL OF SOCIAL WORK IN PALLIATIVE & END-OF-LIFE CARE | Online – 23 January 2022 – The study goal was to understand how palliative care providers experienced and responded to the significant change in family presence when visitors were restricted to slow the spread of the virus. Identified was the loss and disruption of important forms of knowing including observational and embodied knowing. Family members' knowledge of how their person was faring was curtailed, as was providers' capacities to know families personally. Family members' less obvious needs did not come forward as readily in the absence of informal encounters with providers. Constraints on knowing and embodied actions often meant phone and video meetings failed to provide meaningful connection. **Abstract:** <https://bit.ly/3fPuty6>

Death and dying in carceral America: The prison hospice as an inverted space of exception

MEDICAL ANTHROPOLOGY QUARTERLY | Online – 30 January 2022 – In America’s prisons, long-term incarceration carries fears that one could die in prison alone and abandoned. Death by incarceration looms as inescapable for myriad inmates who are terminally ill or “graying” in prison. These realities inform this study of a prison-based hospice program staffed by male inmate volunteers in a mixed medium/maximum security facility. Of special concern are the experiences of the men who sit by the bedside of others who are dying. The author of this article begins with the assumption that prisons loom as states of exception, epitomized by the realities of substandard prison medicine, the devaluation of care as anathema to prison survival, and the persistent neglect of the ill and aging. **Abstract:** <https://bit.ly/3uewmN6>

N.B. The *Medical Anthropology Quarterly* article did not “surface” until after the latest update of the ‘Prison Hospice: Backgrounder’ (see sidebar).

Editorial: End-of-life care in Romania

Lack of quality of (palliative) care: The way out

PALIAȚIA, 2022;15(1):3. It should be well-known: palliative care (PC) is not just dealing with end-of-life decisions. It is also to relieve suffering and optimize quality of life. Despite the efforts of many doctors, nurses and others, PC is still inequitably accessible, underutilized, and often introduced (too) late in the care of patients, also in Romania. The lack of PC services in Romania is still not recognised by policymakers as is the lack of quality in healthcare services generally (partly due to the lack of qualified healthcare managers). This neglect (or is it denial?) of PC harms Romanian citizens, and more specific patients, especially patients with cancer (see the article in this issue: ‘What are the palliative care needs of cancer patients in Romania?’¹ **Full text (click on pdf icon):** <https://bit.ly/3fNsOZU>

1. ‘What are the palliative care needs of cancer patients in Romania?’ *Paliatja*, 2022;15(1):3. **Full text (click on pdf):** <https://bit.ly/33LU5tf>

Related:

- ‘Lack of knowledge about palliative care among healthcare providers,’ *Paliatja*, 2022;15(1):22-24. **Full text (click on pdf):** <https://bit.ly/3rGU6XA>

Noted in Media Watch 29 November 2021 (#745, p.7):

- ‘Challenges of paediatric palliative care in Romania: A focus groups study,’ *BMC Palliative Care*, published online 18 November 2021. **Full text:** <https://bit.ly/3kSstlb>

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



Prison Hospice: Backgrounder Updated 1 February 2022

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

Photo: Lori Waselchuk, Philadelphia, PA



Reader feedback on the focus and content of Media Watch is welcomed.

Revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care: A Delphi study

PALLIATIVE MEDICINE | Online – 3 February 2022 – This revision to the European Association for Palliative Care recommendations on standards and norms in palliative care (PC) identified that there remains a high consensus amongst European experts with the original recommendations. The core principles of PC are fully endorsed, along with shared understanding about definitions of PC and how these are articulated in specialist PC services. It has highlighted the emergence of new areas of specialisation in PC including neonatal PC, geriatric and dementia services. These attest to the needs of patients across the life span as recommended by WHO. There is greater awareness of the need to improve access to better information transfer and the role of digital health technologies including... **Full text:** <https://bit.ly/3AUKkoV>

N.B. See the authors' discussion of the Delphi study on the Association's blog at: <https://bit.ly/3HrJm5Z>

Overtreatment at the end of life in oncology

THERAPEUTISCHE UMSCHAU, 2022;78(1):53-60. Over the last two decades numerous studies, mainly in the U.S. of America and Europe, have shown that the use of anticancer treatments at the end of life has increased considerably. Moreover, the overuse of chemotherapy or targeted therapeutic agents as well as radiotherapy in terminally ill cancer patients in the last months of life was associated with an increased risk of undergoing cardiopulmonary resuscitation, mechanical ventilation or both and of dying in an intensive care unit. More recently, early provision of palliative care for patients with incurable cancer has gained increased attention as a feasible and efficacious approach for improving quality of life. Therefore, the doctor-patient communication is central for the avoidance of overtreatment. **Abstract:** <https://bit.ly/3gh1XWj>

N.B. German language article. Recent articles on end-of-life care in oncology noted in Media Watch 10 January 2022 (#750, pp.1-2) and 24 January 2022 (#751, p.5).

Related:

- 'The prognostic value of the 12-, 6-, 3- and 1-month 'Surprise Question' in cancer patients: A prospective cohort study in three hospitals,' in *European Journal of Cancer Care*, published online 26 January 2022. **Full text:** <https://bit.ly/3Hbzddu>

N.B. Search back issues of Media Watch for additional articles on the "surprise" question at: <http://bit.ly/2ThijkC>

Palliative care's role in austere medicine

WILDERNESS & ENVIRONMENTAL MEDICINE | Online – 24 January 2022 – The rapid growth of the global population has seen a concurrent increase in the number of people living, working, traveling, and recreating in areas that are considered austere, or resource limited, environments, requiring the medical community to adapt and grow with the challenge of caring for patients in these settings. Palliative care (PC) is an integral aspect of quality medical care that has been expanding into austere medical settings over the past decade. The information presented in this article will clarify what PC is and how its inclusion in care delivery in austere settings such as the wilderness, humanitarian crises, and low- and middle-income countries is beneficial for both patients and providers. **Full text:** <https://bit.ly/3rVprWr>

N.B. Search back issues of Media Watch for additional articles on PC during "humanitarian" crises and natural "disasters" at: <http://bit.ly/2ThijkC>



Palliative Care Network
Palliative Care for Everyone, Everywhere

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

Research Matters

An economic research agenda for palliative care

JAMA HEALTH FORUM | Online – 28 January 2022 – Policymakers and the U.S. public are largely aligned on the need to improve care for patients with serious illness while curtailing wasteful spending and easing burdens on family caregivers. By one estimate, the value of unpaid U.S. family caregiving for people with serious illness exceeds \$300 billion annually. Studies to date suggest that palliative care (PC) could help increase the value, defined as some combination of better quality and lower costs, of U.S. healthcare spending. PC ... improves care quality. However, without robust economic evidence to calculate the value equation, including costs and benefits, the current paradigm of high costs, poor outcomes, and growing inequities will persist for people with serious illnesses. **Full text:** <https://bit.ly/3unzJBu>



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>

Media Watch: Editorial Practice

EACH LISTING IN MEDIA WATCH represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The biweekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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.

Media Watch: Access on Online

International



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

[Scroll down to 'Media Watch: social Workers']

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

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

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

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

Asia



Asia Pacific
Hospice Palliative
Care Network

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

[Scroll down to 'Media Watch']

Australia

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

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

Canada



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/3wwL5RW>

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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