

**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.

## Underserved & Vulnerable Populations (1 July 2022 Supplement)



Compilation of Media Watch 2008-2022 ©

Compiled & Annotated by Barry R. Ashpole

**After 15 years and 750+ weekly issues, Media Watch ceased publication in April 2022. Periodically, however, I will be circulating a list of recent articles, studies, reports, etc., focusing specifically on end-of-life care for selected underserved and vulnerable Populations (listed below in alphabetical order). There are also sections in this “supplement” titled ‘Research Matters, ‘Publishing Matters’ and ‘Workplace Issues.’ Articles of particular interest are “flagged.” BRA**

**N.B. Search past issues of Media Watch for additional articles on the issues/topics highlighted below at: <http://bit.ly/2ThijkC>**

### Ethnically & Linguistically Diverse Communities



1. ‘A “good death” for all: The need to teach racially sensitive end-of-life care,’ *Journal of General Internal Medicine*. [Country of origin: U.S.] Posted online 16 June 2022. **Full text:** <https://bit.ly/391CMw6>

#### **Related articles from the U.S.**

- a) ‘Hispanic groups collaborate to raise awareness of end-of-life options,’ Public News Service. Posted online 27 June 2022. **Full text:** <https://bit.ly/3xXP2B7>
- b) ‘The business case for diversity, equity and inclusion in hospice care,’ *Hospice News*. Posted online 22 June 2022. **Full text:** <https://bit.ly/3A760zw>
- c) ‘Life expectancy by county, race, and ethnicity in the U.S., 2000-2019: A systematic analysis of health disparities,’ *The Lancet*. Posted online 16 June 2022. **Full text:** <https://bit.ly/3N5F71L>
- d) ‘Racial and ethnic differences in hospice use and hospitalizations at end-of-life among Medicare beneficiaries with dementia,’ *JAMA Network Open*. Posted online 9 June 2022. **Full text:** <https://bit.ly/3xDUIRS>
- e) ‘Racial and ethnic differences in informal and formal advance care planning among U.S. older adults,’ *Journal of Aging & Health*. Posted online 27 May 2022. **Abstract (w. references):** <https://bit.ly/3a35aZG>

Cont.



- f) 'Racial disparities in the provision of pediatric psychosocial end-of-life services: A systematic review,' *Journal of Palliative Medicine*. Posted online 18 May 2022. **Abstract:** <https://bit.ly/38B85Ze>
2. 'How to prepare Chinese-born nurses to care for patients at the end-of-life in Western settings: A discussion paper,' *Collegian*. [Country of origin: Australia] Posted online 25 May 2022. **Abstract (w. references):** <https://bit.ly/3M1HT7G>
3. 'Ethnicity and palliative care: We need better data – five key considerations,' *BMJ Supportive & Palliative Care*. [Country of origin: U.K.] Posted online 19 May 2022. **Full text:** <https://bit.ly/3G1rK0l>
4. 'Differences in end-of-life care between COVID-19 inpatient decedents with English proficiency and limited English proficiency,' *Journal of Palliative Medicine*. [Country of origin: U.S.] Posted online 16 May 2022. **Full text:** <https://bit.ly/3yC3mRF>

#### Related:

- a) 'End-of-life healthcare utilization and palliative care use among older adults with limited English proficiency,' *Journal of the American Geriatric Society*. Posted online 7 June 2022. **Abstract:** <https://bit.ly/3tpkt61>

### The Homeless



1. 'Evaluating the perceived added value of a threefold intervention to improve palliative care for persons experiencing homelessness: A mixed-method study among social service and palliative care professionals,' *BMC Palliative Care*. [Country of origin: The Netherlands] Posted online 23 June 2022. **Full text:** <https://bit.ly/3QD4Ku9>
2. 'Extending palliative approaches to care beyond the mainstream healthcare system: An evaluation of a small mobile palliative care team in Calgary, Alberta, Canada,' *Palliative Medicine Reports*. Posted online 1 June 2022. **Full text:** <https://bit.ly/3MS4OD1>

### The Homeless: Selected Postings

1. Calgary Allied Mobile Palliative Program [Alberta, Canada] <https://bit.ly/3mkDhPV>
2. Canadian Virtual Hospice: <https://bit.ly/3t8lnCK>
3. Centre to Advance Palliative Care [Icahn School of Medicine, New York City]: <https://bit.ly/3GD6miG>
4. European Association for Palliative Care: <https://bit.ly/3PWwyck>
5. Hospice UK: <https://bit.ly/3zd4k7k>
6. Marie Curie [U.K. (Scotland)]: **Download at:** <https://bit.ly/3uGvGg2>
7. Palliative Care Australia: <https://bit.ly/3t4zBWf>
8. Palliative Education & Care for the Homeless [Inner City Health Associates Toronto, Canada]: <https://bit.ly/3PQ3O5f>
9. Palliative Outreach Resource Team [University of Victoria, Canada] <https://bit.ly/3mn7MEP>
10. Scottish Partnership for Palliative Care: <https://bit.ly/3agYqHJ>
11. Worldwide Hospice Palliative Care Alliance: <https://bit.ly/3m5qVek>

## Humanitarian Aid

1. 'The Rome Declaration of Palliative Care for Children in Ukraine,' eHospice. Posted online 15 June 2022. **Full text:** <https://bit.ly/3OfLZuz>

### **Related:**

- a) '99th day of the Russian invasion of Ukraine,' eHospice. Posted online 7 June 2022. **Full text:** <https://bit.ly/3O0YsIB>
2. 'Healthcare in conflict zones,' *AMA Journal of Ethics*, 2022;24(6):E453-E541. [Country of origin: U.S.] **Contents page:** <https://bit.ly/3NMcO9p>
3. 'Neonatal palliative care in low-resource humanitarian settings: Engaging mentoring session reaching a global audience of humanitarian healthcare workers,' eHospice. [Country of origin: Bangladesh] Posted online 2 June 2022. **Full text:** <https://bit.ly/3m7g0kh>
4. 'First steps: Integrating palliative and end-of-life care in South Sudan,' *Palliative Care in Humanitarian Aid Situations & Emergencies*. Posted online 29 April 2022. **Full text:** <https://bit.ly/3NqfMka>

### **Related:**

- a) 'A quiet revolution bringing palliative care to Sudan,' eHospice. Posted online 11 June 2022. **Full text:** <https://bit.ly/3O9XvaK>

## Immigrants

1. 'What support for requests to return to the country of origin of migrant patients in a palliative situation?' *Cancer Newsletter*. [Country of origin: France] Posted online 17 June 2022. **Full text:** <https://bit.ly/3OtVPct>
2. 'When a child dies: Racialized [immigrant] father's experiences of objectification during hospital care,' *Omega – Journal of Death & Dying*. [Country of origin: Canada] Posted online 26 April 2022. **Full text:** <https://bit.ly/3LptsLj>
3. '52 Days: A discussion on unauthorized immigrants and end-of-life care,' *Lynchburg Journal of Medical Science*, 2022;4(2). [Country of origin: U.S.] **Abstract:** <https://bit.ly/3IKbV5d>

## The Incarcerated

1. 'Louisiana State Penitentiary: A textual analysis of correctional staff views on end-of-life care,' *Journal of Correctional Health Care*. [Country of origin: U.S.] Posted online 31 May 2022. **Abstract:** <https://bit.ly/3tbSQ04>

### **Related:**

- a) 'Older Adults' perspectives on death and dying in prison,' *Journal of Criminal Justice*. [Country of origin: U.S.] Posted online 31 May 2022. **Abstract (w. extracts from the full text):** <https://bit.ly/3mlYdWs>
- b) 'Compassionate release for aging prisoners isn't enough,' National Public Radio. [Country of origin: U.S.] Posted online 24 May 2022. **Full text:** <https://wbur.fm/3NnOQBk>
- c) 'Bereavement behind bars: Grief support groups with and without therapy dogs for incarcerated females,' *Bereavement*, 2022;1:1-8. [Country of origin: U.S.] **Full text (click on pdf icon):** <https://bit.ly/3LyF0v0>

2. 'Ensuring the quality of palliative care in Australia's prisons,' Deeble Institute for Health Policy Research (Australian Healthcare & Hospitals Association). Posted online 10 May 2022. **Download at:** <https://bit.ly/3Pf8hOk>

**Related:**

- a) 'The aged-care crisis in prisons,' *The Saturday Paper*. [Country of origin: Australia] Posted online 18 June 2022. **Full text:** <https://bit.ly/3OaEq96>

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the report [2018-2022] can be downloaded from the Palliative Care Network website: <http://bit.ly/2RdegnL>.

## Indigenous Peoples

### Australia



1. 'Building capacity in those who deliver palliative care services to Aboriginal and Torres Strait Islander peoples,' *Medical Journal of Australia*. Posted online 5 June 2022. **Full text:** <https://bit.ly/3H0urAb>

**Related:**

- a) 'Healthcare workers' understanding of and barriers to palliative care services to Aboriginal children with cancer,' *Journal of Paediatrics & Child Health*. Posted online 30 April 2022. **Abstract:** <https://bit.ly/3y9TLRU>

### U.S.

2. 'Factors influencing palliative care access and delivery for Great Plains American Indians,' *Journal of Pain & Symptom Management*. Posted online 23 May 2022. **Abstract (w. references):** <https://bit.ly/3a6cFiy>

**Related:**

- a) "Calling the Spirit back:" Spiritual needs among Great Plains American Indians,' *Journal of Pain & Symptom Management*. Posted online 22 May 2022. **Abstract (w. references):** <https://bit.ly/3sR3OYR>

### Canada

3. 'Integrative review of the needs and challenges of indigenous palliative care in rural and remote settings,' *Journal of Advance Nursing*. [Country of origin: Canada] Posted online 16 May 2022. **Abstract:** <https://bit.ly/3sHygEm>

## The Intellectual, Developmental & Physically Disabled

1. 'A comparative case study of hospice and hospital end-of-life care for aging adults with developmental disabilities,' *Global Qualitative Nursing Research*. [Country of origin: U.S.] Posted online 11 May 2022. **Full text:** <https://bit.ly/38wvuvv>

## Lesbian, Gay, Bisexual, Transgender Communities



1. 'Milestone House: The story of a hospice for people with HIV/AIDS,' *Journal of the Royal College of Physicians of Edinburgh*. Posted online 9 June 2022. **Full text:** <https://bit.ly/3NTw2KJ>
2. 'Providing home hospice care for LGBTQ+ patients and caregivers: Perceptions and opinions of hospice interdisciplinary care team providers,' *Palliative & Supportive Care*. [Country of origin: U.S.] Posted online 19 May 2022. **Abstract (w. references):** <https://bit.ly/39ZZTCc>

## Low- & Middle- Income/Resource Countries

1. "Estimating the impact of inpatient palliative care consultations on healthcare costs in a low- and middle-income country, *Journal of Palliative Medicine*. [Country of origin: Lebanon] Posted online 22 June 2022. **Abstract:** <https://bit.ly/3nhZyhv>
2. 'Face and content validity, acceptability, feasibility, and implementability of a novel outcome measure for children with life-limiting or life-threatening illness in three sub-Saharan African countries,' *Palliative Medicine*. Posted online 2 June 2022. **Abstract (w. references):** <https://bit.ly/3aFhj7F>

**N.B.** Kenya, South Africa, and Uganda.

3. 'Development of palliative care services at a tertiary care teaching hospital in Pakistan: Retrospective analysis of existing palliative care program,' *Journal of Pain & Symptom Management*. Posted online 15 May 2022. **Abstract (w. references):** <https://bit.ly/39pWe0q>
4. 'Romanian Palliative Care Foundation Hospice "Casa Speranței" receives public utility status,' Romanian-Insider.com. Posted online 5 May 2022. **Access online at:** <https://bit.ly/3KNjlic>
5. 'Place of death and associated factors in 12 Latin American countries: A total population study using death certificate data,' *Journal of Global Health*. Posted online 30 April 2022. **Full text:** <https://bit.ly/3kvhFzq>

**N.B.** Argentina, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Mexico, Paraguay, Peru, and Uruguay.

6. 'Progress update: Development of palliative care from 2017 to 2020 in five countries in Eurasia,' *Journal of Pain & Symptom Management*. Posted online 27 April 2022. **Full text:** <https://bit.ly/3kifQG0>

**N.B.** Armenia, Georgia, Moldova, Tajikistan, and Ukraine.

7. 'Implementation science of paediatric palliative care in lower- middle- income countries in Southeast Asia: An integrative review,' *Indian Journal of Palliative Care*, 2022;28(1);80-87. **Full text:** <https://bit.ly/3mAfxHI>

**N.B.** Cambodia, Indonesia, Lao People's Democratic Republic, Myanmar, the Philippines, Timor-Leste, and Vietnam.



### 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.0.

## Residents of Long-Term Care, Nursing Homes & Residential Care



1. Delivering person-centred palliative care in long-term care settings: Is humanism a quality of healthcare employees or their organisations?' *Ageing & Society*. [Country of origin: Canada] Posted online 9 June 2022. **Full text:** <https://bit.ly/3NPWm8D>
2. 'End-of-life care in U.K. care homes during the COVID-19 pandemic: A qualitative study,' *BMC Palliative Care*. Posted online 1 June 2022. **Full Text:** <https://bit.ly/3NKjwg4>

### **Related:**

- a) 'Nursing home palliative care during the pandemic: Directions for the future,' *Innovation in Aging*. [Country of origin: U.S.] Posted online 9 May 2022. **Full text (click on pdf icon):** <https://bit.ly/3N5oxzL>

### **Report of the *Lancet* Commission on the Value of Death: Bringing death back into life (Extract)**

*The Lancet*, 2022;399(10327):837-884. Care homes, which are called nursing, assisted living, long-term care, or rest homes in some settings, are increasingly the place of dying for many around the world. This presents a challenge. Care homes must tread a careful line between being a home and being places for rehabilitation, health-care, safety, and dying. Care homes have been described as the hospices of the future, but achieving equity in provision of care at the end of life (EoL) is a formidable challenge. Issues such as staff training and turnover, support with clinical decision making at the EoL, access to medical or specialist support, and high workloads can make provision of holistic care at the EoL difficult. **Full text:** <https://bit.ly/3IOhSHU>

## Rural & Remote Regions

1. "It sort of has the feel of being at home': Mixed-methods evaluation of a pilot community-based palliative end-of-life service in a regional setting,' *Australian Journal of Rural Health*. Posted online 24 June 2022. **Full text:** <https://bit.ly/3u7CJ4e>
2. 'Where you live may shape your access to hospice care,' *Medical Xpress*. [Country of origin: U.S.] Posted online 15 June 2022. **Full text:** <https://bit.ly/3Ok8nmM>

### **Related:**

- a) "Hard to say goodbye over iPad": Experiences of palliative care providers and lessons learned during the COVID-19 pandemic in rural communities of Indiana...,' *Journal of Hospice & Palliative Nursing*, 2022;24(3):E94-E100. **Full text:** <https://bit.ly/39FzSIh>
3. 'Access to virtual care highlights urban/rural divide,' *Healthy Debate*. [Country of origin: Canada] Posted online 5 May 2022. **Full text:** <https://bit.ly/3L6sG58>
  4. 'Home visits in rural general practice: What does the future hold?' *Rural & Remote Health*, 2022;22(2):6767. [Country of origin: Ireland] **Full text:** <https://bit.ly/3MD5jBi>



### Barry R. Ashpole

MY INVOLVEMENT IN HOSPICE AND PALLIATIVE CARE DATES FROM 1985. As a communications consultant and educator, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current focus is advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. See biosketch on the International Palliative Care Resource Center website: <http://bit.ly/2RPy9b>

## Socio-economically Disadvantaged Populations



1. 'New research finds 90,000 people die in poverty in the U.K. each year,' Centre for Research in Social Policy, Loughborough University. Posted online 12 May 2022. **Download Centre's report at:** <https://bit.ly/3sK5pQ4>

### **Related:**

- a) 'Northern Ireland's terminally ill "poverty crisis is truly shameful," says end of life charity,' ITV News. Posted online 19 June 2022. **Full text:** <https://bit.ly/3HARyBL>
2. 'Socio-economic disparity trends in end-of-life care for cancer and non-cancer patients: Are we closing the gap?' *Clinical Epidemiology*. [Country of origin: Denmark] Posted online 7 May 2022. **Full text:** <https://bit.ly/38ZxtHU>

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## Research Matters



1. 'Palliative care research, why it has to change,' eHospice. [Country of origin: U.K.] Posted online 5 June 2022. **Full text:** <https://bit.ly/3NUyOPD>
2. 'Meeting ethical challenges with authenticity when engaging patients and families in end-of-life and palliative care research...', *BMC Palliative Care*. [Country of origin: U.S.] Posted online 16 May 2022. **Full text:** <https://bit.ly/3yW18gr>
3. 'Improving research integrity: A framework for responsible science communication,' *BMC Research Notes*. [Country of origin: U.S.] Published online 15 May 2022. **Full text:** <https://bit.ly/3wz3Tm1>
4. 'Attitudes of palliative care practitioners towards enrolling patients in clinical trials,' *Journal of Palliative Care*. [Country of origin: Australia] Posted online 12 May 2022. **Abstract (w. references):** <https://bit.ly/3Mm1IHU>

### **Palliative care research and practical application: Have they stalled?**

*INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE NEWSLETTER*, June 2022. When Barry Ashpole sent a letter to Media Watch users in April, signalling its end after 15 years, he broke his rule against expressing personal opinions by noting the "disturbing repetition of subject matter" and asked "What *real* progress has been made at the bedside?" "The quality of research has deteriorated significantly," he noted in our interview.

Palliative care, he added, has not been well served despite a flourishing number of journals specific to the topic, because too many fail to ensure that the research is rigorous. "Predatory journals that get paid to publish is a huge issue." Research is too often based on too few participants, and it can be repetitive because authors have failed to do a comprehensive search before embarking, he said. **Full text:** <https://bit.ly/3xCjFNz>

## Publishing Matters



1. 'Predatory journals and the use and abuse of special issues,' *Information Polity*. [Country of origin: U.K.] Posted online 21 June 2022. **Abstract:** <https://bit.ly/3OMm2TS>
2. 'Perceptions on the prevalence and impact of predatory academic journals and conferences: A global survey of researchers,' *Learned Publishing*. [Country of origin: U.S.] Posted online 15 June 2022. **Abstract:** <https://bit.ly/3HyDRmO>
3. 'Predatory journals that publish shoddy research put people's lives at risk,' *Scientific American*. Posted online 1 June 2022. **Full text:** <https://bit.ly/3Mnj7Af>

4. 'A randomized trial alerting authors, with or without co-authors or editors, that research they cited in systematic reviews and guidelines has been retracted,' *Accountability in Research*. Posted online 30 May 2022. [Country of origin: U.K. (Scotland)] **Full text:** <https://bit.ly/3zfgRY4>
5. 'Supporting the pursuit of quality improvement publication: What your organization can do now,' *Quality Management in Health Care*. Posted online 27 May 2022. [Country of origin: U.S.] **Full text:** <https://bit.ly/3z5gKya>
6. 'Predatory journals: Revisiting Beall's research,' *Publishing Research Quarterly*. Posted online 24 May 2022. [Country of origin: U.K.] **Abstract (w. references):** <https://bit.ly/3GsuyUY>

## Workplace Issues

1. 'Hospices pay a high price for physician burnout,' *Hospice News*. [Country of origin: U.S.] Posted online 6 June 2022. **Full text:** <https://bit.ly/3GUXUeV>

### **Related:**

- a) 'Workforce, workforce, workforce: A wellbeing crisis without resolution,' *Journal of Royal Society of Medicine*. [Country of origin: U.K.] Posted online 26 May 2022. **Full text:** <https://bit.ly/3z7Gz0x>
- b) 'Moral distress amongst palliative care doctors working during the COVID-19 pandemic: A narrative-focussed interview study,' *Palliative Medicine*. [Country of origin: U.K. (Scotland)] Posted online 12 May 2022. **Full text:** <https://bit.ly/39uiHsV>
- c) 'Exploring the impact and lived experiences of hospice staff working in end-of-life care: An interpretative phenomenological analysis,' *Omega – Journal of Death & Dying*. [Country of origin: U.K. (Wales)] Posted online 26 April 2022. **Full text:** <https://bit.ly/3LpxXWr>



2. 'Hospices need a "huge catapult" to replenish workforce,' *Hospice News*. [Country of origin: U.S.] Posted 1 June 2022. **Full text:** <https://bit.ly/3z8NkPD>
3. 'Children's hospices in England facing staffing crisis almost twice as severe as National Health Service,' ITV News. Posted online 12 May 2022. **Full text:** <https://bit.ly/3w6Wpqj>

**N.B.** See 'Children's palliative care nursing workforce in crisis,' Together for Short Lives. Posted online 1 May 2022. <https://bit.ly/39OHrFH>



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WORLD HOSPICE & PALLIATIVE CARE DAY **8 OCT 2022**

## Media Watch: Access on Online

### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/381La4b>

[Scroll down to 'Media Watch: Advice on Conducting Research']

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> ]

### 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 'Links: International Palliative Care Resource Center']



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

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

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

[Scroll down to 'General Resources' and 'Media Watch']

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

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

### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <https://bit.ly/3wvL5RW>

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



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