

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.

21 February 2022 Edition | Issue #753



Compilation of Media Watch 2008-2022 ©

Compiled & Annotated by Barry R. Ashpole

There are currently mounting concerns about the mental welfare of paramedics on the frontline of healthcare and we need to understand how this burnout is correlated with paramedic perception of their role, their views on organizational structure, education, and guidelines.

'What is the role of paramedics in palliative and end of life care?' (p.9), in *Palliative Medicine*.

News Media: Lead Article

Validating fears helps shift patients' palliative care expectations: Study

U.S. | *McKnights Long-Term Care News* – 16 February 2022 – Researchers explored how specialized care providers navigate difficult conversations and help patients optimize their quality of life and mitigate suffering.¹ Using six months of observational data from a hospital in a Midwestern town in the U.S., the researchers found many of the providers did not dismiss their patients' emotions or tell patients to feel differently. Rather, they validated their patients' fear, hope or guilt, and then walked them through the likely outcomes of continuing treatments. The researchers found this approach led patients to comply with the providers' suggestions for palliative care 73% of the time. The compliance rate was 43% when providers did not use this style of communication. <https://bit.ly/3JCDSGI>

1. 'Feeling rule management and relational authority: Fostering patient compliance in palliative care consultations,' *Organization Studies*, published online 7 February 2022. **Abstract:** <https://bit.ly/3JKY2ht>

News Media (cont.)

To accelerate hospice growth, it's time to embrace "the social determinants of death"

U.S. | *Hospice News* – 17 February 2022 – A commission convened by the U.K.-based research journal *The Lancet* has called on the global medical community and the public to reconsider societal attitudes about death and the care that precedes it.¹ Among the recommendations is a rethink of the over-medicalization of death and greater emphasis on hospice and palliative care. The commission of *Lancet* editors and academic scholars outlined principles to guide this process, including what they call "the social determinants of death," as well as reassessment of cultural attitudes about the end of life and strengthening networks of care for the dying and the bereaved. A key obstacle to this kind of change is simple to name but difficult to overcome: We don't want to talk about it. <https://bit.ly/3LInxSd>

1. 'Report of *The Lancet* Commission on the Value of Death: Bringing death back into life,' *The Lancet*, published online 31 January 2022. [Noted in Media Watch 7 February 2022 (#752, p.1)] **Access full text at:** <https://bit.ly/3IOhSHU>

Finding a respite: Architects discover visionary solutions for the terminally ill

U.S. | *Digital Journal* – 10 February 2022 – Among terminally ill patients, a portion of them are children, and they are oblivious to death until they reach a certain age. Tending to their physical needs is easier than talking to them about death. Most parents may choose not to talk to them about their illness, to make the situation easy for them, but children tend to come to this realization as their body changes and they receive treatments, care, and sympathy from others. ‘Respites’ an architecture competition invited sensitive design ideas for hospices for children. The competition encouraged architects and designers to put their skills and sensibilities to use, by bringing forward design solutions to improve the physical and emotional well-being of terminally ill children by providing positive environments. **Full text:** <https://bit.ly/3GHodn5>

Noted in Media Watch 24 January 2022 (#751, p.6):

- ‘Designing palliative care facilities to better support patient and family care: A staff perspective,’ *Health Environments Research & Design Journal*, published online 13 January 2022. **Abstract (w. references):** <https://bit.ly/3GtizFP>

Noted in Media Watch 9 August 2021 (#729, p.6):

- ‘The physical hospital environment and its effects on palliative patients and their families: A qualitative meta-synthesis,’ *Health Environments Research & Design Journal*, published online 6 August 2021. **Abstract (w. references):** <https://bit.ly/2VDZRJf>

N.B. Additional articles on the relationship between the architecture (i.e., the physical environment) of healthcare facilities and the quality of palliative and end-of-life care noted in Media Watch 23 November 2020 (#693, p.12).

Members of the deaf community rally to assist those in hospice

U.S. (Illinois) | *Jacksonville Journal-Courier* – 9 February 2022 – A group of deaf advocates is returning momentum to a program that would assist hospice patients who are deaf, hard of hearing, or deaf and blind. Hospice patients often face tough, end-of-life decisions, many of them with serious health or legal consequences. Those decisions can be even tougher for the hearing impaired, who may struggle to understand everything being communicated to them. “Our goal is to make deaf people feel safe,” said Paula Chance, a volunteer deaf advocate. ASL CARES is a joint program of the Jacksonville Community Center for the Deaf and the Jacksonville Area Center for Independent Living that trains hearing-impaired volunteers to help hearing-impaired hospice patients. <https://bit.ly/3LiHte9>

Noted in Media Watch 4 April 2016 (#456, p.13):

- ‘Hearing loss in hospice and palliative care: A national survey of providers,’ *Journal of Pain & Symptom Management*, published online 1 April 2016. **Full text:** <https://bit.ly/33dIXFu>

N.B. Additional articles on the vulnerability of people living with a terminal illness who are either deaf or blind noted in the 4 April 2016 issue of Media Watch.



[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>

Do we need to reframe how we think about palliative care?

AUSTRALIA (Victoria) | Australian Broadcasting Corporation (Radio Melbourne) – 8 February 2022 – The Federal Health Minister Greg Hunt has received criticism for his description of palliative care (PC), describing it as patients who were in the “absolute latest days of their lives.” Patients, families and medical professionals say this excludes at home PC, family members caring for their relative, and accessing PC through telehealth. Those interviewed on the hour-long radio program, ‘The Conversation Hour,’ including Palliative Care Australia Chair Professor Meera Agar, shared how PC is more than end-of-life care, and must include services such as at home PC, family members caring for their relative, and accessing PC through telehealth. <https://ab.co/3HAUvBn>

[Government & Non-Government Organizations et al](#)

‘National Palliative Care and End-of-Life Care Information Priorities’ (p.4), Palliative Care Australia.

[Government & Non-Government Organizations et al](#)

Medicare payments of \$6.6 billion to non-hospice providers over 10 years for items and services provided to hospice beneficiaries suggest the need for increased oversight

U.S. | Department of Health & Human Services (Office of the Inspector General) – 14 February 2022 – The Office of the Inspector General’s analysis of trends and patterns in payments for items and services provided to Medicare beneficiaries outside the Medicare hospice benefit during a hospice period of care (which is referred to as “non-hospice payments”) demonstrate an increase in Medicare non-hospice payments for beneficiaries. Non-hospice payments for Medicare Part A services and Part B items and services totaled \$6.6 billion from 2010 through 2019. If providers bill Medicare for non-hospice items and services that potentially should be covered by hospices, Medicare could pay for the same items or services twice. **Download report at:** <https://bit.ly/354y6hy>

New national standards of Canada for long-term care

CANADA | Standards Council of Canada – Accessed 13 February 2022 – The COVID-19 pandemic has highlighted the critical importance of federal government leadership in healthcare. The pandemic’s impact has been particularly dramatic in long-term care (LTC) homes, exposing a fragmented system. Standards, and conformity to those standards, will help ensure that Canada’s LTC home settings are safe, properly supported and that the more than 250,000 residents who call them home are also receiving the quality of care they need and deserve. Standards Council of Canada, Health Standards Organization and Canadian Standards Association are collaborating to develop two new complementary National Standards of Canada for LTC. <https://bit.ly/3HM9Xe4>

Selected articles on end-of-life and palliative care in LTC in Canada:

- ‘Multi-disciplinary supportive end-of-life care in long-term care: An integrative approach to improving end of life,’ *BMC Geriatrics*, published online 22 May 2021. [Noted in Media Watch 31 May 2021 (#719, p.5)] **Full text:** <https://bit.ly/3fcD6mO>
- ‘If not now, when? Applying a palliative approach in long-term care,’ *Healthy Debate*, published online 28 December 2021. [Noted in Media Watch 4 January 2021 (#698, p.1)] **Full text:** <http://bit.ly/2Mj8ggI>
- ‘Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: A qualitative descriptive study of community-based and specialist palliative care physicians’ experiences, perceptions and perspectives,’ *BMJ Open*, published online 10 August 2020 (#678, p.9)] **Full text:** <https://bit.ly/30yzeWb>
- ‘Palliative care has been lacking for decades in long-term care,’ *Policy Options*, published online 16 July 2020. [Noted in Media Watch 20 July 2020 (#675, p.1)] **Full text:** <https://bit.ly/2B5GAXb>

National Palliative Care and End-of-Life Care Information Priorities

AUSTRALIA | Palliative Care Australia – 27 January 2022 – The Australian Institute of Health & Welfare, in collaboration with the Palliative Care & End of Life Data Development Working Group, has recently published the ‘National Palliative Care and End-of-Life Care Information Priorities’ document. This important advocacy document sets out the strategic priorities for information development in government-funded palliative care (PC) and support services over the next decade. The document is intended to guide planning, investment and action by governments and other stakeholders. It recognises that a large volume of PC and end-of-life care related activity occurs outside of specialised PC settings. **Download (scroll down to ‘National Palliative care...’ at: <https://bit.ly/33eojVy>**

Related:

- ‘Steps towards equitable care: Creating webpages to highlight diversity for Australia’s aged care and end-of-life care workforce,’ *Australian Journal of Primary Health*, published online 12 February 2022. **Abstract:** <https://bit.ly/3HFLXcB>

Specialist Publications

Palliative care for rural growth and wellbeing: Identifying perceived barriers and facilitators in access to palliative care in rural Indiana

BMC PALLIATIVE CARE | Online – 19 February 2022 – In the U.S. state of Indiana, an estimated 6.3 million people are living with one or more chronic illnesses, a large proportion of them reside in rural areas where there is limited access to palliative care (PC)... Study findings provide insights into several barriers and facilitators to PC access from the perspectives of providers who serve rural Indiana. Within the context of inpatient PC, findings are evident that barriers to PC access among rural populations were critical. PC, as a newer specialty that comprises end-of-life care or hospice, has not gained adequate familiarity among both clinicians and the public in rural Indiana. However, community hospice care has gained more familiarity as it has been long-standing and well covered under Medicare. **Full text:** <https://bit.ly/35cH4tj>

N.B. Selected articles on PC in rural U.S. noted in Media Watch 13 December 2021 (#747, pp.8-9).

Research Matters

‘**Barriers to recruitment into emergency department-initiated palliative care: A sub-study of a multi-site, randomized controlled trial**’ (p.11), in *BMC Palliative Care*.

‘**What can we learn from controlled clinical trials in palliative care?**’ (p.11), *European Association for Palliative Care*.

‘**Understanding complexity in care: Opportunities for ethnographic research in palliative care**’ (p.11), in *Journal of Palliative Care*.

‘**Family carers research: What progress has been made?**’ (p.11), in *Palliative Medicine*.

‘**Community-based participatory research and public health palliative care**’ (p.12), in *Progress in Palliative Care*.

Specialist palliative care classification: Typology development

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 8 February 2022 – The authors of this article developed a refined classification of specialist palliative care (PC) in Germany, which for the first time allows for a comprehensive description and categorisation of services on a conceptual, polyhierarchical basis. Increasing economisation and rising quality requirements in the health sector require services to be presentable in-depth and unambiguously. Along with previously developed characteristics from PC contexts in other countries, this improved understanding of characteristics also facilitates international contextualisation. Enhancing the systematic comparison of processes through benchmarks will prospectively allow for measurement of quality and efficiency and facilitate quality development. **Full text:** <https://bit.ly/3sskc0T>

The Quebec Observatory on End-of-Life Care for People with Dementia: Implementation and preliminary findings

CANADIAN JOURNAL ON AGING | Online – 9 February 2022 – End-of-life care (EoLC) for people with dementia is difficult to investigate because of the many methodological challenges, but is critical to study in order to identify deficiencies in care quality, their impact on resident outcomes, and areas for improvement. To this end, the first Observatory on End-of-Life Care for People with Dementia was successfully implemented in Quebec, and pilot data were used to draw a preliminary portrait of this population. The newly implemented Observatory could prove useful for assessing the impact of urgently needed long-term care reforms and the effects of innovative interventions in dementia EoLC, for which the evidence base is currently very limited. **Full text:** <https://bit.ly/3gzKvwj>

N.B. Search back issues of Media Watch for additional articles on EoLC for people living with dementia at: <http://bit.ly/2ThijkC>

Palliative care in the face of racism: A call to transform clinical practice, research, policy, and leadership

HEALTH AFFAIRS | Online – 9 February 2022 – Available across the life course and serious illness continuum, palliative care (PC) is a values-driven approach to providing holistic care for patients and their families in the setting of life-threatening illness and injury. Despite its benefits related to optimizing quality of life and relieving suffering, equity in PC for racially and ethnically minoritized communities is lacking. There remain important gaps in the availability, accessibility, appropriateness, and understanding of these services across diverse and racially minoritized populations... The authors discuss strategies for PC clinical practice and training, and recommendations for research, policy, and leadership, to mitigate the impact of racism in PC and re-center historically excluded populations. **Access full text at:** <https://bit.ly/3HDf7Ji>

Related:

- 'Lack of racial diversity within the palliative medicine workforce: does it affect our patients?' *BMJ Supportive & Palliative Care*, published online 17 February 2022. **Full text:** <https://bit.ly/3BuRzEd>
- 'Race roundtable series: Structural racism in palliative care,' *Journal of Pain & Symptom Management*, published online 10 February 2022. **Abstract (w. references):** <https://bit.ly/3Bc1Epy>

N.B. Search back issues of Media Watch for additional articles on “disparities” and “racism” in the U.S. healthcare system in the context of palliative and end-of-life care at: <http://bit.ly/2ThijkC>



Media Watch: Access Online – Updated 7 February 2022

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.13.



Search Back Issues of Media Watch
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Understanding the policy landscape surrounding medical assistance in dying in Canada's federal prison system

JOURNAL OF CORRECTIONAL HEALTHCARE | Online – 10 February 2022 – Medical assistance in dying (MAiD) has been legal in Canada since 2016, and the implementation of MAiD for people who are incarcerated has raised ethical and procedural concerns. The authors review the current Correctional Service Canada guideline on MAiD alongside a joint report by the Office of the Correctional Investigator (OCI) and the Canadian Human Rights Commission (CHRC) on aging and dying in prison. They echo concerns raised by the OCI and the CHRC about the limits of adequate end-of-life care currently provided to those in custody and offer our analysis of the procedural guideline for MAiD in prison, which they argue to be inadequate in support for patient-centered care and equality in access to healthcare. **Abstract:** <https://bit.ly/3sBy2xZ>

Nurse-led telephonic palliative care: A case-based series of a novel model of palliative care delivery

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 11 February 2022 – This article discusses a nurse-led telephonic palliative care (PC) program, part of the Emergency Medicine Palliative Care Access Project ... comparing outpatient PC with nurse-led telephonic case management after an emergency department visit. Telephonic nurses discuss patients' goals, fears, hopes, and concerns regarding their illness and its trajectory that inform decisions for future interventions and treatments. They share this information with patients' surrogate decision-makers and clinicians to facilitate care coordination and symptom management. Nurses' abilities and expertise, as well as the difficulties of providing care through in-person models of PC delivery, make a nurse-led telephonic model an optimal option. **Abstract:** <https://bit.ly/3gEDYk7>

Related:

- 'Barriers and facilitators to nurse-led advance care planning and palliative care practice change in primary healthcare: A qualitative study,' *Australian Journal of Primary Health*, published online 8 February 2022. **Full text:** <https://bit.ly/3GANEXp>
N.B. The Advance Project website: <https://bit.ly/3sstBp3>
- 'Power of palliative care: How oncology nurses can increase referrals,' *Oncology Nursing News*, published online 11 February 2022. **Full text:** <https://bit.ly/3oLr9cl>
- 'Quality of palliative nursing care: Meaning, death anxiety, and the mediating role of well-being,' *Palliative & Supportive Care*, published online 10 February 2022. **Abstract (w. references):** <https://bit.ly/3HO738l>

"If you built it, they could come"

Opportunities to expand access to palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 February 2022 – There are growing calls to broaden palliative care (PC) access to more populations, diseases, and care settings and to earlier in the disease



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

Cont.

process; yet, supply of specialty PC is not likely to keep pace with demand. This article discusses possible solutions by which to bridge the gap between limited PC supply and demand: 1) Specialist workforce development; 2) Alternate models of care; 3) Triage systems; and, 4) Telemedicine. Education/training, research, and policy mechanisms could operationalize these solutions. With the solutions in hand, the field may be able to increase the reach, sustainability, and equity of PC, thereby improving access and enabling a multitude of positive patient, family, and healthcare system outcomes. **Abstract:** <https://bit.ly/3Hwg3ix>

Experiences of staff providing specialist palliative care during COVID-19: A multiple qualitative case study

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE | Online – 8 February 2022 – Constraints related to COVID-19 infection control policies and practices were central to experiences of moral distress by prohibiting and/or diluting staff's capacity to provide care that was aligned to their professional caring values. Experiences of moral distress had a detrimental impact on the well-being of staff causing "moral injuries" in which participants experienced feelings of sadness, stress, anger, guilt, frustration and fatigue. These feelings crescendoed over time whereby the impacts of moral distress had a cumulative effect that worsened as the pandemic progressed. Various individual, team, organisational and community strategies were drawn on to address the impacts of moral distress. **Full text:** <https://bit.ly/34JmgZT>

Reducing burnout and promoting professional development in the palliative care service

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 3 February 2022 – Previous research suggests healthcare providers working with issues of death and dying may experience increased stress and risk of burnout. Despite previous research on the problem of burnout faced by palliative care (PC) providers, there have been few interventions studied to prevent further burnout. Research does support allowing time away from a stressful healthcare environment to promote wellness and to decrease burnout. This study ensured each PC advanced practice provider received an 8-hour day monthly to work on professional development activities remotely. **Abstract:** <https://bit.ly/336FVTq>

Related:

- 'An ethical framework for visitation of inpatients receiving palliative care in the COVID-19 context,' *Journal of Bioethical Inquiry*, published online 17 February 2022. **Full text:** <https://bit.ly/3JTLILV>
- 'The lived experience of physical separation for hospice patients and families amid COVID-19,' *Journal of Pain & Symptom Management*, published online 18 February 2022. **Full text:** <https://bit.ly/3JyC0y6>
- 'Patient-family experience at the onset of COVID-19: Interviews with ten palliative chaplains,' *Journal of Palliative Medicine*, published online 10 February 2022. **Full text:** <https://bit.ly/3HDU21r>

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

- 'End-of-life experiences for cancer patients dying in hospital with COVID-19,' *Journal of Patient Experience*, published online 28 January 2022. **Full text:** <https://bit.ly/3ruSjG8>

Dying is never beautiful, but there are beautiful moments: Qualitative interviews with those affected on the subject of "good dying"

MORTALITY | Online – 8 February 2022 – It became clear in this study that the process of dying has not only a physical, but also a psychological, a social and a spiritual dimension. For those affected, dying is never beautiful, but there are beautiful moments that are linked to elevating moral emotions. This study shows that the views of those affected differ significantly from those we hear in the public discourse. The authors conclude that the public debate on "good dying" should give a voice to those affected: to terminally ill and elderly people and to their informal carers. The academic discourse can make a contribution by differentiating between various perspectives and by researching the points of view of those concerned. **Full text:** <https://bit.ly/33cawPs>

Triggers for referral to specialized palliative care in advanced neurologic and neurosurgical conditions: A systematic review

NEUROLOGY CLINICAL PRACTICE | Online – 8 February 2022 – The results suggest that several published referral triggers for specialized neuropalliative care are based on expert consensus. However, there is a growing body of literature providing evidence-based condition-specific triggers for multiple sclerosis, Parkinsonism, amyotrophic lateral sclerosis and dementia. There is a growing body of research that outlines evidence-based referral triggers for neuropalliative care. The ambiguity of nomenclature surrounding referral triggers in the current literature and field of neuropalliative care was a limitation to this study. The authors suggest that condition-specific triggers are likely to be the most effective for identifying the appropriate patients and timing for referral to specialist palliative care. **Abstract:** <https://bit.ly/3Jsk08r>

N.B. Search back issues of Media Watch for additional articles on “neuropalliative” care at: <http://bit.ly/2ThijkC>. See also European Association for Palliative Care series on the evolving specialty of neuropalliative care at: <https://bit.ly/3rge50A>.

Children and adolescents’ preferences for support when living with a dying parent: An integrative review

NURSING OPEN | Online – 13 February 2022 – Children and adolescents strive for control and balance regarding involvement in the sick parent’s care and treatment, as well as time spent in the home when living with the dying parent. They preferred emotional support from their families, especially from parents, and from friends they wanted opportunities to socialize, to do things together with other children and adolescents. A consistent perception was that support from healthcare professionals (HCPs) was mainly for the sick parent. However, they wanted HCP to show compassion and adjusted information on their own terms. Challenges for HCP are to identify vulnerable children and adolescents with a weak social network and provide timely individually adapted support. **Full text:** <https://bit.ly/3JoFhjB>

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

- ‘Parent’s with incurable cancer: “Nuts and bolts” of how professionals can support parents to communicate with their dependent children,’ *Patient Education & Counseling*, published online 16 July 2021. **Abstract:** <https://bit.ly/3er1kJp>
- ‘Bereavement and children’s mental health: Recognising the effects of early parental loss,’ *Nursing Children & Young People*, published online 19 July 2021. **Abstract:** <https://bit.ly/3hMNEdE>

N.B. See literature review at ‘The Crossroads of Grief: Understanding Grief & Diversity,’ published by the Children & Youth Grief Network, Ontario Canada.’ In particular, ‘Children’s Understanding of Death & Dying’ (p.5), ‘Parental Illness, Dying & Death’ (p.13), and ‘Death of a Parent’ (p.30) at: <http://bit.ly/2OB4Y6C>

Perceptions of hope among bereaved caregivers of cancer patients who received early palliative care: A content and lexicographic analysis

THE ONCOLOGIST | Online – 4 February 2022 – Oncologists’ fear of taking away hope from patients when proposing early palliative care (PC) is a barrier to the implementation of this model. This study focussed on hope perceptions by bereaved primary caregivers of cancer patients who received early PC as a standard clinical practice. Contrary to intuitions regarding the scant possibility of hope in the clinical context of incurable onco-hematologic illnesses, they reported developing hope and maintaining it until the death of their loved ones. They connected the finding of hope to the adoption of early PC treatments and to the inspiring relationships they were able to develop with the healthcare team. A crucial factor in this positive dynamic seems to be the connection between hope, truth, and trust... **Full text:** <https://bit.ly/3LoumZ4>



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Introducing the special collection on palliative care for LGBTQ2S+ individuals and families

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 11 February 2022 – This special collection of *Palliative Care & Social Practice* features the work of top scholars in the fields of LGBTQ2S+ (lesbian, gay, bisexual, transgender, queer, and two-spirit) aging, health, and palliative care (PC). The articles in the collection approach the topic of PC for LGBTQ2S+ individuals from a variety of perspectives and collectively introduce readers to key issues facing this population near the end of life. Improving the quality of care provided to LGBTQ2S+ individuals and their families requires a multifaceted approach to understanding their needs and lived experiences and then educating their care teams on how best to address those needs more fully. **Full text:** <https://bit.ly/368FGIz>

N.B. List of references includes links to the articles cited in this editorial.

Related:

- 'A rapid review of end-of-life needs in the LGBTQ+ community and recommendations for clinicians,' *Palliative Medicine*, published online 17 February 2022. **Full text:** <https://bit.ly/3JkSpX>

What is the role of paramedics in palliative and end of life care?

PALLIATIVE MEDICINE | Online – 17 February 2022 – Paramedics are the frontline of the emergency response to urgent palliative and end-of-life care. The scope of practice for paramedics in the ambulance service has radically changed in the last 20 years, with paramedics now having a high level of clinical knowledge and autonomy giving them the ability to treat patients at home rather than providing a patient transport service to hospital... The question that we must therefore ask is does this make paramedics a suitable solution to fill the out-of-hours gap in community palliative care (PC) provision? Advancements in medical procedures and the many interventions now available often make the deciphering of PC disease trajectories complex for generalist clinicians such as paramedics. **Full text:** <https://bit.ly/3sMUwMp>

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

Good medicines management: From describing problems to a vision for change

PALLIATIVE MEDICINE | Online – 14 February 2022 – Effective palliation can be disrupted by untimely prescribing, unavailability of medicines or professionals for administration, incorrect opioid selection or conversion of doses, ineffective set-up and use of syringe pumps, and failure of continuity as patients move between care settings. When discussing medicines management, patients, carers and healthcare professionals share common narratives of “concern,” “pressure,” “fear,” “feeling uncomfortable,” “feeling scared,” “anxiety,” “burden,” “challenge” and “strain.” The worry and concern of hastening death and being responsible for “the last injection” is expressed by both family carers and nursing staff who administer anticipatory medications. **Full text:** <https://bit.ly/3LYkmw9>

Posttraumatic growth in palliative care patients and its associations with psychological distress and quality of life

PALLIATIVE & SUPPORTIVE CARE | Online – 14 February 2022 – Fifty-six percent of study participants reported moderate to very high posttraumatic (PTG) levels. These results highlight the importance of considering PTG in the psychological care of palliative patients, which offers the possibility of “living a life at a deeper level of personal, interpersonal, and spiritual awareness.” Interventions geared towards fostering growth, including narrative and expressive therapies, may thus represent promising avenues to improve the experience of individuals in palliative care. To maximize the potential of such interventions, we must first gain a better understanding of the patterns and dynamics underlying PTG processes. A study utilizing a life narrative approach to this effect is currently in preparation. **Full text:** <https://bit.ly/3GRj4sK>

Cont.

Related:

- 'Associations between the cause of loved one's death, mourner's psychological distress and ongoing relationship with the deceased, and mourner's posttraumatic growth,' *Omega – Journal of Dying & Death*, published online 16 February 2022. **Abstract (w. references):** <https://bit.ly/357kkKW>

'Playlist for Life' at the end of life: A mixed-methods feasibility study of a personalised music listening intervention in the hospice setting

PILOT & FEASIBILITY STUDIES | Online – 7 February 2022 – The aim of this study was to evaluate the feasibility, acceptability and practicality of using 'Playlist for Life' for adults at the end of life (EoL), family members and hospice staff in a hospice inpatient unit setting in Scotland. Given that many people with life-threatening illnesses will continue to have increased needs that could be met through the provision of palliative care as their condition progresses, it is important that interventions that may facilitate and shape future care are used during a time when input from individuals approaching the EoL is possible. The 'Playlist for Life' intervention enabled participants to leave their loved ones a legacy which could help bereaved individuals to cope with their grief after their loved ones death. **Full text:** <https://bit.ly/3JfIOSd>

N.B. 'Playlist for Life' website: <https://bit.ly/34JlKu6>

"I dressed her up in her best dress"

The experiences of the dead body for bereaved relatives in the context of palliative care

QUALITATIVE RESEARCH IN HEALTH | Online – 12 February 2022 – Preparedness for the death in palliative care for family members encompasses diverse emotional and practical challenges for healthcare personnel. Discussing what happens after the death adds to these challenges and requires a recognition of the complexity of individual, relational, and contextual aspects of choice about being with body after death. Discussions about the aftermath of the death to explore options about what is possible and preferences for time with the body of their relative may be of help. Post-death care of the body could also be discussed either before or after the death to ascertain family members' wishes or preferences about preparation of the body... **Full text:** <https://bit.ly/3gTp3CO>

Vulnerable persons, partners or warriors? How relatives perceive their roles in palliative care

ZEITSCHRIFT FUR EVIDENZ, FORTBILDUNG UND QUALITAT IM GESUNDHEITSWESEN | Online – 8 February 2022 – Relatives play a very important role in palliative care (PC). Whilst previous research has investigated this role from the perspective of health professionals, this article focuses on the perspectives of the relatives of palliative patients. This article demonstrates that well-trained health personnel in the field of PC and a common understanding of the roles within the PC team are central to supporting relatives. These findings can help inform good collaboration between relatives and professionals in PC (e.g., general practitioners, nurses, specialized doctors, such as oncologists and specialized nurses) and to encourage families to feel comfortable with the care their loved ones receive. **Abstract:** <https://bit.ly/3rJns8G>

N.B. German language article.

End-of-Life Aid Skills for Everyone in Scotland

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 15 February 2022 – Families, friends and communities have an important role to play in providing informal support when someone is faced with deteriorating health, caring responsibilities, death or bereavement. However, people can lack the confidence, skills and opportunities to offer this support. Public education is an example of a public health approach to palliative care that can help to develop individual skills and knowledge relating to these issues. The Scottish Partnership for Palliative Care has developed a public education course, which aims to enable people to be more comfortable and confident supporting family/community members with issues they face during dying, death and bereavement. **Full text:** <https://bit.ly/3Bq7Z0E>

N.B. Scottish Partnership for Palliative Care website: <https://bit.ly/3GZlvt7>

Cont.

Related:

- ‘How companions speak on patients’ behalf without undermining their autonomy: Findings from a conversation analytic study of palliative care consultations,’ *Sociology of Health & Illness*, published online 14 February 2022. **Full text:** <https://bit.ly/3sGne1E>
- “‘I think that she would have wanted. . .’: Qualitative interviews with bereaved caregivers reveal complexity in measuring goal-concordant care at the end of life,’ *Palliative Medicine*, published online 15 February 2022. **Abstract (w. references):** <https://bit.ly/3sOEylc>

Research Matters

Barriers to recruitment into emergency department-initiated palliative care: A sub-study of a multi-site, randomized controlled trial

BMC PALLIATIVE CARE | Online – 15 February 2022 – By providing greater insight into why patients with advanced illness refuse to participate in palliative care (PC) research, the authors explored the ways in which to successfully engage this patient population. In particular, misconceptions related to PC may prevent patients from enrolling in PC programs, so it is essential that patients have a clear understanding of the role of PC. This requires a strong training infrastructure for research coordinators. Furthermore, engagement with PC physicians and ongoing communication across recruitment sites are essential in order to overcome enrollment challenges. Future studies with PC populations must design programs that meet the needs of this population, which may include some form of telemedicine. **Full text:** <https://bit.ly/3LAfBIX>

What can we learn from controlled clinical trials in palliative care?

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – 14 February 2022 – Being able to personalise the care that we offer is critical to the continued improvements in outcomes for people with life-limiting illnesses. As we think about controlled clinical trials (CCT), who benefits? Getting our interventions right the first time requires us to have a much more nuanced understanding of each person that we serve. Much of this can only be refined through CCT where causality of benefits and harms can be attributed. At a personal level, people participating in clinical studies often have more contact with clinicians – something that patients and their families value. For patients subsequently, well designed, CCT will help to refine care, whether studies are positive or negative. <https://bit.ly/3uRqXJJ>

Understanding complexity in care: Opportunities for ethnographic research in palliative care

JOURNAL OF PALLIATIVE CARE | Online – 15 February 2022 – Ethnographic methods focuses on behaviour in the “natural” setting of participants, to create theoretical descriptions of events, cultures, interactions and experiences. In palliative care (PC) these methods may provide nuanced understandings of illness, relationships and teams, communication, medical education, complex care provision, and novel or changing health practices. Of particular importance is the potential of these methods to understand complex practices and processes, and engage with under-represented population groups who may be excluded from interview research. Ethnography offers important opportunities for future research in PC and should be considered as part of the “research toolbox”... **Abstract (w. references):** <https://bit.ly/36j5fqu>

Family carers research: What progress has been made?

PALLIATIVE MEDICINE | Online – 17 February 2022 – The provision of end-of-life care in the home continues to be a priority and is where the majority of family caregiving takes place. This may become even more important in a post-pandemic environment, where shifts in place of death may be influenced by restrictions on visiting or limited resources in institutional settings such as hospitals and hospices. The rapid increase in digital health interventions may offer new forms of support for carers or alternatively may exacerbate their feelings of isolation; we do not yet know. Whilst the increase in research activity is encouraging; unless gaps in diversity and rigorous intervention and implementation research are addressed, there is a significant risk that needs of numerous carers will not be adequately met. **Full text:** <https://bit.ly/3GXW8lj>

Community-based participatory research and public health palliative care

PROGRESS IN PALLIATIVE CARE | Online – 12 February 2022 – While much has been developed and refined in terms of theoretical basis and practice methods, there is an increasing need to consider the research agenda and methods employed to evaluate outcomes and strengthen the evidence base for public health approaches to palliative and end-of-life care. In particular, promoting the participation of underserved and vulnerable populations and understanding the influence of power structures on their representation in research is imperative. There is scope to complement traditional research methodologies with new public health approaches that are participatory and directly informed by communities' lived experience, expressed needs, and aspirations for care. **Full text:** <https://bit.ly/3HPznHJ>

Selected articles on palliative and end-of-life care as a public health issue:

- 'What happens when palliative care is neglected as a public health priority?' European Association for Palliative Care, posted online 26 January 2022. [Noted in Media Watch 7 February 2022 (#752, p.4)] <https://bit.ly/3uRqXJJ>
- '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. [Noted in Media Watch 28 September 2020 (#685, p.14)] **Full text:** <https://bit.ly/3r0YZLH>
- 'COVID-19, palliative care and public health,' *European Journal of Cancer*, 2020;136(9):95-98. [Noted in Media Watch 20 July 2020 (#675, p.11)] **Full text:** <https://bit.ly/2OhJTG>

Media Watch: Editorial Practice

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Something Missed or Overlooked?

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

[Media Watch: Access on Online – Updated 7 February 2022](#)

International



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[Scroll down to 'Media Watch: Telehealth']

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

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[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?']

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

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

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