

**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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Compiled & Annotated by Barry R. Ashpole

Palliative care, where the care relationship has a specific ending and family members increasingly need support, the interprofessional teamwork has special characteristics compared with other fields of care.

'Patients and family members' perceptions of interprofessional teamwork in palliative care: A qualitative descriptive study' (p.4), in *Journal of Clinical Nursing*.

**Important Notice: With this, the 751<sup>st</sup> issue, Media Watch will be published on a biweekly basis, that is, every two weeks. Feedback on the focus and content of Media Report is welcomed.**

## News Media

### **Terminally ill children suffer from neglect, say health experts**

SOUTH AFRICA | *Mail & Guardian* (Cape Town) – 16 January 2022 – South African children with terminal diseases and debilitating conditions are poorly catered for, too often enduring insufficient, impersonal and inappropriate state care, forcing non-government organizations (NGOs) to step in with super-specialist and home care, and also provide distressed families with support. So frustrated are the thinly stretched palliative care NGOs that they are considering mounting a constitutional court challenge to force improved state funding for child healthcare through the South African Children's Palliative Care Network (PatchSA). Two of the country's top paediatricians and government advisers on child health ... agreed that there are several long-standing stumbling blocks. <https://bit.ly/3rmPx4z>

**N.B.** South African Children's Palliative Care Network website: <https://bit.ly/3A44Vqm>

## Specialist Publications

'Starting of a new pediatric palliative care program in a general hospital: Characteristics of the population and use of resources' (p.8), in *Anales del Sistema Sanitario de Navarra*.

'International standards for pediatric palliative care: From the International Meeting for Palliative Care in Children, Trento (IMPACT) to Global Overview – Pediatric Palliative Care Standards (GO-PPaCS)' (p.8), in *Journal of Pain & Symptom Management*.

'The unspeakable nature of death & dying during childhood: A silenced phenomenon in pediatric care' (p.8), in *Omega – Journal of Death & Dying*.

'Palliative care across the continuum of childhood,' (p.8), in *Pediatric Annals*.

'Pediatric palliative care and end-of-life: A systematic review of economic health analyses' (p.8), in *Revista Paulista de Pediatria*.

## Time to rethink “death-care” system

AUSTRALIA | *Australian Senior News* – 14 January 2022 – The number of Australians aged 85 or over will have doubled from 2017 to over a million people. The pressures involved in caring for members of our ageing population before and after death are only set to intensify. Death-care services include a wide range of actors, from palliative care and nursing home staff to funeral and cemetery workers, chaplains, grief counsellors, and lawyers to handle wills and probate. The ways we currently handle dying, death and grief all too often result in dissatisfaction and distress, from strained last goodbyes and unsatisfying funeral services to crippling financial burdens from funeral debts. There are also troubling inequalities in who can access high-quality care and support at the end of life and in bereavement. <https://bit.ly/33joL4X>

**N.B.** The authors of this article are members of the DeathTech Research Team, a group of anthropologists, social scientists and human-computer interaction specialists based at the University of Melbourne and, in the U.K., at the University of Oxford: <https://bit.ly/3I31AKN>

## Patients with terminal illnesses “dying in pain” because of National Health Service COVID delays

U.K. | *The Telegraph* (London) – 12 January 2022 – Nearly nine in 10 hospices have revealed that patients are being referred to them with terminal illnesses as a result of COVID-related National Health Service delays in diagnosis and treatment. Marie Curie, one of the U.K.’s biggest providers of hospices, warned it meant that patients were dying in pain because delays from health service treatment backlogs meant they could not access palliative care (PC) in time. Only 17% of practitioners surveyed felt patients were being referred in a timely manner so that they could fully benefit from specialist PC. And 87% said they were seeing patients presenting as terminal because of a late diagnosis or a delay in treatment due to the backlog, according to a survey by Marie Curie and the Association of Palliative Medicine.<sup>1</sup> <https://bit.ly/3fmK7B0>

1. ‘Association of Palliative Medicine and Marie Curie survey of palliative care practitioners, 2022,’ Marie Curie and the Association of Palliative Medicine of Great Britain & Ireland, January 2022. **Download at:** <https://bit.ly/3qq0RxA>

### Related:

1. ‘Tens of thousands have died at home without adequate care during pandemic, charity warns,’ *The Independent* (London), 16 January 2022. <https://bit.ly/3fxHgF9>

## Jump in demand for palliative care leaves services stretched

AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 9 January 2022 – The number of Australians dying each year is expected to double by 2050, but the palliative care (PC) sector says access to services is a “postcode lottery” that must change. Demand for PC services, particularly to help people die at home, has increased significantly during the pandemic – by more than 60% in some areas. This is partly due to a reluctance to go to hospital where family might not be allowed to visit, and partly because delays to routine health checks during restrictions or lockdowns have meant people are being diagnosed in more advanced stages of disease. National data shows PC services looked after more than 30,500 patients during the first half of 2021. Five years earlier, they had 19,100 patients. <https://bit.ly/3q6s2xa>

## Palliative care is about establishing links and warmth. It became colder because of COVID

IRELAND | *The Journal* (Dublin) – 9 January 2022 – In the past two years, hospices and palliative care (PC) teams have been at the forefront of the pandemic, mostly caring for people who are at the greatest risk of dying if they contracted COVID-19. The meaning of what PC is and what hospices do has changed: though it first meant caring for people at the very end of their life, it later broadened out to include cancer patients. In more recent years, it has changed to mean caring for people at much earlier stages of their illness. Among the conditions of people who receive PC are motor neuron disease, cardiac disease, end-stage kidney disease, and dementia. But the pandemic greatly altered how PC operates: people felt safer at home, and so less people went into hospices to be cared for. <https://bit.ly/3n8AmKV>

## Government & Non-Government Organizations et al

### The number of Canadians receiving medical assistance in dying has increased annually since its introduction

CANADA | Statistics Canada – 10 January 2022 – In 2017, 2,838 medically assisted deaths were reported by Health Canada, compared with 4,478 deaths in 2018. In 2019, there were 5,425 medically assisted deaths in Canada, accounting for 1.9% of all deaths. In 2020, this increased to 7,383 deaths, representing a 36.0% increase in the number of medical assistance in dying (MAiD) recipients from 2019 to 2020. The observed increases in medically assisted deaths are consistent with those seen internationally in jurisdictions where some form of assisted dying is legal... While three-quarters of persons requesting MAiD in 2019 and 2020 ultimately received MAiD, 6.9% saw their request for MAiD denied because they did not meet the eligibility criteria when formally assessed... <https://bit.ly/3r979Rd>

#### Specialist Publications

**'Understanding why patients request euthanasia when it is illegal: A qualitative study in palliative care units on the personal and practical impact of euthanasia requests'** (p.9), in *Palliative Care in Social Practice*.

## Specialist Publications

### Taking faith seriously to improve end-of-life decision-making

*AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 5 January 2022 – Religion and spirituality may affect advanced care planning (ACP) and a patient's end-of-life (EoL) care decisions, sometimes to good effect, but sometimes adversely. As Colenda and Blazer point out in their review of the literature,<sup>1</sup> patients with the strongest connection to religious communities are less likely to receive hospice care, more likely to receive intensive EoL medical care (including less use of hospice), and more likely to experience ICU deaths. They suggest that "measures of belief, and a more nuanced assessment of 'faith' in God, might offer better explanatory or predictive value in helping us better understand ACP and EoL decisions." **Access this article at:** <https://bit.ly/3JO0Aw1>

#### Research Matters

**'Systematic reviews do not (yet) represent the "gold standard" of evidence: A position paper'** (p.11), in *European Journal of Pain*.

**'Development of guidelines to reduce, handle and report missing data in palliative care trials: A multi-stakeholder modified nominal group technique'** (p11), in *Palliative Medicine*.

#### Publishing Matters

**'Preprints: Their Evolving Role in Science Communication,'** (p.12), posted by Ithaka S+R.

1. 'Review of religious variables in advance care planning for end-of-life care: Consideration of faith as a new construct,' *American Journal of Geriatric Psychiatry*, published online 5 December 2021. **Abstract:** <https://bit.ly/3GcKZDR>

#### Related:

1. 'The physician and end-of-life spiritual care: The PALIatiVE approach,' *American Journal of Hospice & Palliative Medicine*, published online 19 January 2022. **Abstract (w. references):** <https://bit.ly/3GLx1cv>



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## Defining clinical excellence for palliative care specialists: A concept whose time has come

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE* | Online – 19 January 2022 – An interprofessional work group of palliative care (PC) specialists proposes that setting a standard for clinical excellence, applicable to PC specialists of all professions, will elevate the field in the U.S. by providing an aspirational target usable for individual assessment and self-assessment, highlighting the common ground between team roles, and promoting a deeper understanding of teamwork, utilization, and productivity. The authors call for research that utilizes inclusive methods and broad representation of diverse voices to design a vivid, practical, and evidence-based definition of clinical excellence for PC specialists. **Abstract (w. references):** <https://bit.ly/3AjtIXm>

### Related:

1. 'Patients and family members' perceptions of interprofessional teamwork in palliative care: A qualitative descriptive study,' *Journal of Clinical Nursing*, published online 10 January 2022. **Full text:** <https://bit.ly/3zM7m0t>
2. 'Referral relationship: Illuminating the ways palliative care creates a holding environment for referring clinicians,' *Journal of Palliative Medicine*, published online 11 January 2022. **Abstract:** <https://bit.ly/3zT52os>

## Delivering mental healthcare to patients with a depressive disorder alongside a life-limiting illness

*BJPSYCH BULLETIN* | Online – 7 January 2022 – Mental illness is a substantial source of morbidity for patients receiving end-of-life care and is often underdiagnosed and undertreated. It can be difficult for palliative care (PC) teams to know where to get support for people living with physical and mental health needs, and there is evidence that these patients occupy a significant amount of multidisciplinary team discussion time. Assessing response to any intervention is difficult given time limitations and the heterogeneity of this population. It is essential that mental health services offer flexibility in approaching the care of those with both palliative and psychiatric diagnoses; realistically, supporting PC teams to offer interventions may be the most pragmatic approach. **Full text:** <https://bit.ly/3qUDyuu>

### Noted in past issues of Media Watch:

1. 'Co-design of an evidenced informed service model of integrated palliative care for persons living with severe mental illness: A qualitative exploratory study,' *Healthcare*, 2021;9(12):1710. [Noted in Media Watch 3 January 2022 (#749, p.17)] **Full text:** <https://bit.ly/3e5pecC>
2. 'Adapting the collaborative care model to palliative care: Establishing mental health-serious illness care integration,' *Palliative & Supportive Care*, published online 21 October 2021. [Noted in Media Watch 25 October 2021 (#740, p.13)] **Full text:** <https://bit.ly/3B2hJfN>
3. 'End-of-life care for people with severe mental illness: Mixed methods systematic review and thematic synthesis,' *Palliative Medicine*, published online 3 September 2021. [Noted in Media Watch 6 September 2021 (#733, p.12)] **Full text:** <https://bit.ly/3tfatuB>

## Communication in the face of death and dying. How does the encounter with death influence the patient management competence of medical students? An outcome-evaluation

*BMC MEDICAL EDUCATION* | Online – 10 January 2022 – As part of an elective course, the Interdisciplinary Centre for Palliative Medicine at Duesseldorf University Hospital in Germany offers medical students the opportunity to personally meet and talk to a seriously ill patient on one or more occasions. The future physicians are provided with an opportunity to broaden their professional competence, i.e., their knowledge and skills in patient-centred communication at the end of life, and enhance their personal competence, for example in how to professionally handle their own emotions. A topical e-learning module helps the students to prepare for the meetings, and writing a reflection paper forms the basis for a concluding reflection seminar. **Full text:** <https://bit.ly/3fai4Ev>

## Caring for depression in the dying is complex and challenging: Survey of palliative physicians

*BMC PALLIATIVE CARE* | Online – 16 January 2022 – This is the first study that captures palliative physicians' practices and perceptions regarding depression care specifically in people with very poor prognoses of only days to weeks. As demonstrated by the survey, encountering depression in patients with very poor prognoses was common to palliative physicians. However, despite the high prevalence of depression (up to 50%) in this population and the frequency of clinical encounters, only 40% of clinicians reported to screen for depression, with all clinicians reported to have experienced uncertainty when assessing the cause of depression. This is reflected by the current study finding of the perceived challenging complexity of depression care in the very poor prognosis setting by clinicians. **Full text:** <https://bit.ly/3roKEYG>

## Improving primary palliative care: A Delphi consensus study on measures for general practice in Germany

*BMC PRIMARY CARE* | Online – 17 January 2022 – After having developed, tested and evaluated 26 practical measures for GP practices to improve their primary palliative care (PC), a Delphi consensus study among GPs took place. At least 20 of these measures achieved consensus on relevance and feasibility and were included in a final intervention package. The main results showed an acceptance of measures focussing on strategies to prevent and prepare for emergency situations in primary PC patients. An expert group emphasised the importance of personal experience in identifying patients with PC needs. However, they also confirmed the value of using systematic tools such as the Supportive & Palliative Care Indicators Tool to support their professional assessment. **Full text:** <https://bit.ly/3tPWRIS>

## How do we get around the barriers to integrating palliative care in oncology?

*BULLETIN DU CANCER* | Online – 13 January 2022 – Supported by numerous scientific publications showing its clinical benefits, early palliative care (PC) has become a gold standard in oncology since 2017, recommended for patients with advanced cancer by the major societies of oncology. Nevertheless, PC team integration is still too late in France and the intervention of PC teams in oncology is still often limited to the management of patients and their relatives at the end of life. The authors look at the main obstacles: the lack of staff in PC teams and the complex functioning of PC identified beds; also, the difficulties of communication with the patient and his relatives for the introduction of PC. They then discuss the prospects for development, moving from the concept of early PC to integrated PC. **Abstract:** <https://bit.ly/3KjMJ0z>

**N.B.** French language article.

### Noted in Media Watch 3 January 2022 (#749, p.8):

1. 'Why are we failing to do what works? Musings on outpatient palliative care integration in cancer care,' in *JCO Oncology Practice*, published online 22 December 2021. **Full text:** <https://bit.ly/3egU9Tw>

### Related:

1. 'Unnecessary use of radiotherapy persists in end-of-life patients,' *Medscape*, 18 January 2022. **Full text:** <https://wb.md/3rw3iO6>



### 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>



## Designing palliative care facilities to better support patient and family care: A staff perspective

*HEALTH ENVIRONMENTS RESEARCH & DESIGN JOURNAL* | Online – 13 January 2022 – The receipt of palliative care (PC) differs from other inpatient experiences owing to its distinct philosophy of care, longer lengths of stay, a greater presence of family members, and more frequent end-of-life events. While research regarding the optimal design of PC environments recognizes these differences, this knowledge has been slow to exert change on the guidelines and procurement processes that determine the design solutions possible within these settings. The authors' findings illustrate that the implications of privacy and homeliness extend far beyond the patient room and that homeliness is about more than an aesthetic of comfort. **Abstract (w. references):** <https://bit.ly/3GtizFP>

### Noted in a past issue of Media Watch:

1. '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. [Noted in Media Watch 9 August 2021 (#729, p.6)] **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 PC noted in Media Watch 23 November 2020 (#693, p.12).

## The 'Time Moving' exhibit: Exploring perceptions of time in end-of-life experiences

*HEALTH EXPECTATIONS* | Online – 22 January 2022 – Death and dying is a sensitive topic that is often avoided in everyday conversation. To open these conversations, the authors designed 'Time Moving,' a participatory exhibit that probed the public's experiences with death and how these experiences related to the perception of time. The outcome was a tapestry of responses that illustrate a diversity of perception of time and of death and dying. The contributions of participants may appear chaotic, ambiguous and overwhelming, mirroring the experience of end of life (EoL). Exploring and acknowledging the disorientation that comes with EoL experiences, this study contributes examples of perceptions of time useful for practitioners facilitating EoL conversations and communicating with family members. **Full text:** <https://bit.ly/3AkIkXJ>

### "That little bit of time"

## Transition-to-hospice perspectives from hospice staff and bereaved family

*INNOVATION IN AGING* | Online – 18 January 2022 – Patients are often referred to hospice without clear prognostic understanding, at times placing staff in the uncomfortable position of breaking difficult news. Stigma may make patients and families fearful of enrolling in hospice and misconceptions about hospice are common. Caregivers emphasize the need for increased attention to their emotional needs. Staff revealed the emotional challenges they experience conducting admissions. Both staff and caregivers indicate that the transition to hospice is often emotionally and logistically burdensome, especially when discharging home from the hospital. Both subgroups report insufficient caregiver preparation for taking care of a dying patient at home, particularly regarding medication management. **Abstract:** <https://bit.ly/3rTgqNR>

### Related:

1. 'Fast-track hospital end-of-life discharge pathway: Is it actually fast? National clinical audit,' *BMJ Supportive & Palliative Care*, published online 12 January 2022. **Abstract:** <https://bit.ly/3KashPO>



### 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 beginning on p.13.

## **Editorial**

### **Updates on palliative medicine in the COVID-19 era**

*JOURNAL OF CLINICAL MEDICINE* | Online – 9 January 2022 – A recent multinational survey ... showed a significant increase in activity in palliation and hospice, making it clear the need is expanding.<sup>1</sup> The ongoing COVID-19 pandemic will continue to pose a considerable challenge for palliative patients and their caregivers and personnel ... [for example] ... constant changes in healthcare provisions, new variants and the resulting misinformation or inadequate information about them, burnt-out healthcare workers, scarce resources, and the influx of complex medical cases in an already overstressed healthcare system. Within this whirlwind of challenges, palliative patients need more than just professional compassion; they need personalized care strategies that must be carried out even in lockdown. **Full text:** <https://bit.ly/324DeBg>

1. 'Change in activity of palliative care services during the COVID-19 pandemic: A multinational survey,' *Journal of Palliative Medicine*, published online 20 December 2021. **Full text:** <https://bit.ly/3riMA4V>

#### **Related:**

1. 'Bereavement during the COVID-19 pandemic in the U.K.: What do we know so far?' *Bereavement*, published online 13 January 2022. **Full text:** <https://bit.ly/3rFRetL>
2. 'Overcoming adversity: Insights into an acute hospital service of supported viewing for families bereaved during the COVID-19 pandemic,' *Bereavement*, published online 6 January 2022. **Full text:** <https://bit.ly/3KwYYXN>
3. 'Sacrifice and solidarity: A qualitative study of family experiences of death and bereavement in critical care settings during the pandemic,' *BMJ Open*, published online 19 January 2022. **Full text:** <https://bit.ly/3kAord>
4. 'Do not attempt cardiopulmonary resuscitation decisions during COVID-19: An empirical and analytical study,' *Medical Law Review*, published online 14 January 2022. **Full text:** <https://bit.ly/33wZST6>

### **Caregivers' view of socio-medical care in the terminal phase of amyotrophic lateral sclerosis. How can we improve holistic care in ALS?**

*JOURNAL OF CLINICAL MEDICINE* | Online – 4 January 2022 – Based on first-hand information from the caregivers of deceased ALS patients, there are several clear messages: 1) Specialized palliative care does what it is supposed to, providing a higher quality of dying in the absence of burdening symptoms and at home, if so desired, and reducing hospitalizations; 2) There are significant deficits in socio-medical care in the terminal stage, affecting not only patients, but also their caregivers (The authors identified problems with health insurance, a lack of psychological and practical caregiver support, and problems with professional caregivers); and, 3) Caregiver burden at least partly depends on modifiable aspects of socio-medical care in ALS. **Full text:** <https://bit.ly/31P16yO>

**N.B.** See European Association for Palliative Care (EAPC) series on the evolving specialty of neuropalliative care at: <https://bit.ly/3rge50A>. The series includes a representative sample of journal articles, etc., including several on ALS (posted on the EAPC blog 15 November 2021), noted in past issues of Media Watch at: <https://bit.ly/3cdwylS>



**Palliative Care Network**

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## International standards for pediatric palliative care: From the International Meeting for Palliative Care in Children, Trento (IMPACT) to Global Overview – Pediatric Palliative Care Standards (GO-PPaCS)

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 January 2022 – Since the publication of the IMPACT project, much effort has been made in the development of new approaches to pediatric palliative care (PC). It is time to redefine the standards in pediatric PC. The authors have expanded and updated the previously published IMPACT standards to include new practices (e.g., advance care planning) and new standards for applying pediatric PC in perinatal care, in humanitarian crises, and in other specific settings and conditions (e.g., intensive care). The present document, developed with the contribution of an international group of experts from different countries, experiences and models of care, provides standards for a wider implementation of pediatric PC worldwide. **Full text:** <https://bit.ly/3HUmFHR>

**N.B.** IMPACT Standards for Paediatric Palliative Care in Europe: <https://bit.ly/3njqTQY>

### Related:

1. 'Starting of a new pediatric palliative care program in a general hospital: Characteristics of the population and use of resources,' *Anales del Sistema Sanitario de Navarra*, published online 17 January 2022. **Full text (via PubMed):** <https://bit.ly/3lqsJtQ>  
**N.B.** Spanish language article.
2. 'Palliative Care in paediatric oncology: An update,' *Current Oncology Reports*, published online 21 January 2022. **Full text:** <https://bit.ly/3qMD76N>
3. 'The ongoing impact of Covid-19 pandemic on children with medical complexity: The experience of an Italian pediatric palliative care network,' *Italian Journal of Pediatrics*, published online 18 January 2022. **Full text:** <https://bit.ly/3tDCSN9>
4. 'Exploring parental decision-making for a child with a life-limiting condition: An interpretive description study,' *Journal of Hospice & Palliative Nursing*, published online 12 January 2022. **Abstract:** <https://bit.ly/3GM0umK>
5. 'The unspeakable nature of death & dying during childhood: A silenced phenomenon in pediatric care,' *Omega – Journal of Death & Dying*, published online 14 January 2022. **Full text:** <https://bit.ly/3flzokB>
6. 'Palliative care across the continuum of childhood,' *Pediatric Annals*, 2022;51(1):e40-e46. **Abstract:** <https://bit.ly/3fkCVVN>

### Pediatric palliative care and end-of-life: A systematic review of economic health analyses

*REVISTA PAULISTA DE PEDIATRIA* | Online – Accessed 12 January 2022 – The economic outcomes analyzed were length and place of stay at the end of life (EoL)..., diagnostic and therapeutic procedures performed, and health-related costs. The authors found evidence of direct economic benefits, such as reduced health costs, indirect savings, and protection of patients from undergoing invasive procedures, surgeries, and costly therapies, which cause greater suffering at the EoL. Therefore, participating in a palliative care (PC) program saved financial and technological resources, besides increasing the frequency of deaths at home and improving the quality of life. Public and private policies to promote PC represent better efficiency when allocating available healthcare resources. **Abstract:** <https://bit.ly/3K67xbN>

**N.B.** Portuguese language article.



## **A novel scale to assess palliative care patient experience of feeling heard and understood**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 8 January 2022 – Patient experience of palliative care (PC) serves as an important indicator of quality and patient centeredness. The authors of this article developed a novel patient-reported scale measuring ambulatory PC patients' experience of feeling heard and understood by their providers. They used self-reported patient experience data collected via mixed-mode survey administration. Combining psychometric information with the expert ratings, the authors established the final four-item scale, which was reliable and had good convergent validity. This novel multi-item Feeling Heard & Understood Scale can be used to measure and improve ambulatory PC patient experience. **Abstract (w. references):** <https://bit.ly/32WO90m>

### **Noted in a past issue of Media Watch:**

1. 'Feeling heard and understood: A patient-reported quality measure for the inpatient palliative care setting,' *Journal of Pain & Symptom Management*, published online 17 November 2015. [Noted in Media Watch 23 November 2015 (#437, p.13) **Full text:** <https://bit.ly/3zHkvb2>

### **Related:**

1. 'Intelligent palliative care based on patient-reported outcome measures,' *Journal of Pain & Symptom Management*, published online 10 January 2022. **Full text:** <https://bit.ly/3Gi1UF3>

## **Factors influencing the quality of life of the primary caregiver of a palliative patient: Narrative review**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 January 2022 – The quality of life (QoL) of the caregiver can be improved by social and relaxation techniques, reduction of insecurity or anxiety. Furthermore, the caregiver's QoL increases through an adequate communication of diagnosis, a proper conducted treatment, and education over the care maneuvers. The factors that influence the QoL can be distributed into four areas: 1) Social; 2) Psycho-emotional; 3) Financial; and, 4) Physical. The disruption of daily routine, non-existent financial resources, multiple responsibilities, and psychological tension reduce the caregiver's QoL. Family involvement, knowledge about disease and treatment, abilities to communicate patient and the team and optimistic attitude improve caregiver's QoL. **Abstract:** <https://bit.ly/3qez8Q6>

## **The significance of the distinction between “having a life” vs. “being alive” in end-of-life care**

*MEDICINE HEALTH CARE & PHILOSOPHY* | Online – 11 January 2022 – The distinction between the capacity for living life (having a life) vs. basic physical survival (being alive) could play a significant role in end-of-life care. This distinction assists patients to have their decisions respected and supported with clinicians' responsibilities of beneficence and non-maleficence. By separating these often-conflated, but differing kinds of existing, patients and surrogates can better identify which they regard as more valuable. Facilitating conversations between patients and families in identifying values, interests and preferences helps clinicians provide clinical expertise and information. The distinction between the capacity for living life vs. basic physical survival supports the shared decision-making process... **Full text:** <https://bit.ly/3K4cBNX>

## **Understanding why patients request euthanasia when it is illegal: A qualitative study in palliative care units on the personal and practical impact of euthanasia requests**

*PALLIATIVE CARE IN SOCIAL PRACTICE* | Online – 10 January 2022 – Some patients in palliative care (PC) units request euthanasia regardless of legislation. A request for euthanasia appears to be a willful means to remove oneself from the impasse of an existence paralyzed by suffering. It creates a space for discussion, which promotes negotiation with patients on care practices and therapeutics, and strengthens patients' sense of autonomy. Investigating the relationship between the evolution of euthanasia requests within the PC setting could be beneficial. It is important to encourage healthcare professionals to adopt a readiness to listen by interacting with patients in a way that is not momentarily action-oriented but rather focused on proactive discussion. **Full text:** <https://bit.ly/34w0HMo>

## Out-of-pocket costs near end of life in low- and middle-income countries: A systematic review

*PLOS GLOBAL PUBLIC HEALTH* | Online – 6 January 2022 – Inadequate government spending on health is a recurring feature in low- and middle-income countries (LMICs). Weak health infrastructure leads to delays in diagnosis and resulting late disease presentations, heavy reliance on out-of-pocket payments and catastrophic health expenditures. As out-of-pocket spending is inversely proportional to life expectancy, earlier diagnoses through improved screening programs would likely result in more treatable disease, at lower cost. Policies aimed at bolstering socioeconomic resilience and financial protection are greatly needed in LMICs. A better understanding of early versus late drivers of medical impoverishment is an urgent research priority, as this would inform these strategies. **Full text:** <https://bit.ly/3A0bc6w>

## Use of telehealth in the provision of after-hours palliative care services in rural and remote Australia: A scoping review protocol

*PLOS ONE* | Online – 13 January 2022 – Across Australia, there are 242 specialists palliative care (PC) services, and they were mostly located in major cities and large urban areas. People living in rural and remote communities in Australia often experience poor access to PC especially during after-hours. Poor access to PC services especially after-hours can be very distressing for both patients and families especially. This can lead to patients' symptoms not being managed in a responsive way that meets patients' and families' needs. By enabling communities in rural and remote communities in Australia to have access to immediate after-hours PC services, telehealth can be useful in servicing these communities and overcoming issues of access and availability. **Full text:** <https://bit.ly/3qsW4LR>

## Provision of end-of-life care in primary care: A survey of issues and outcomes in the Australian context

*BMJ OPEN* | Online – 19 January 2022 – End-of-life (EoL) care for many patients could be improved with the successful management of symptoms such as fatigue, loss of appetite and depression in the last stages of the patient's life. These findings – in conjunction with low rates of palliative care training and a lack of confidence in some aspects of EoL care among GPs – suggest the need for applied training programmes in EoL at undergraduate and postgraduate levels of medical training. More extensive collection of clinical data from GPs is required. This would allow further exploration of the findings from this study, provide additional insights into the scope of primary care management of EoL patients, and support the indispensable contribution of GPs to community-based EoL care. **Full text:** <https://bit.ly/3FFf5Pq>

### Related:

1. 'Telemedicine in palliative care during the COVID-19 era: A review of the literature,' *Journal of Holistic Nursing Science*, published online 14 January 2022. **Abstract:** <https://bit.ly/3nAz6Ao>

**N.B.** Search back issues on Media Watch for additional articles on “telehealth” and “telemedicine” in PC at: <http://bit.ly/2ThijkC>

### Editorial

## The therapeutic potential of psychedelic substances in hospice and palliative care

*PROGRESS IN PALLIATIVE CARE* | Online – 15 January 2022 – The healthcare field and society at large are witnessing a resurgence of interest in the effects and applications of psychedelic therapies in a wide range of settings. Primarily in the fields of hospice and palliative care, assisted psychedelic therapies have been investigated as a potential novel therapeutic modality due to preliminary evidence suggesting their profound impact on psychological, existential, and spiritual outcomes in patients with serious diseases. Results indicate that psychedelic experiences, in a controlled setting, can catalyze psychological processes associated with illness and fear of death, promoting therapeutic effects that impact the physical, mental, and spiritual spheres... **Full text:** <https://bit.ly/3nunK0E>

**N.B.** Selected articles on psychedelic-assisted therapies in palliative and end-of-life care noted in Media Watch 3 January 2022 (#749, p.9).

## Measuring effectiveness in community-based palliative care programs: A systematic review

*SOCIAL SCIENCE & MEDICINE* | Online – 19 January 2022 – Community-based palliative care (CBPC) programs increase the likelihood that seriously ill patients in their community have their place of death as home, with fewer hospitalizations, fewer emergency department visits, decreased hospital length of stays, improved quality of life, and lower healthcare costs. There was, however, evidence showing certain programs were unsuccessful in improving the stated outcomes. There is a paucity of research examining CBPC program impact on vulnerable and key populations across the globe. Although findings generally support the notion CBPC programs are a cost-effective way to improve end-of-life quality, further research is needed examining the characteristics of the more successful programs. **Abstract:** <https://bit.ly/3GPpdX2>

### Related:

1. “Well, what do you want to do?” A case study of community palliative care programme: ‘Heidi’s Have a Go,’ *Omega – Journal of Death & Dying*, published online 20 January 2022. **Abstract (w. references):** <https://bit.ly/32kdTU1>
2. ‘A social capital perspective on social-medical collaboration in community end-of-life care in Hong Kong,’ *Omega – Journal of Death & Dying*, published online 6 January 2022. **Full text:** <https://bit.ly/3r9WpBV>

## Research Matters

### Systematic reviews do not (yet) represent the “gold standard” of evidence: A position paper

*EUROPEAN JOURNAL OF PAIN* | Online – 8 January 2022 – The low quality of included trials, insufficient rigour in review methodology, ignorance of key pain issues, small size, and over-optimistic judgements about the direction and magnitude of treatment effects all devalue systematic reviews, supposedly the “gold standard” of evidence. Available evidence indicates that almost all systematic reviews in the published literature contain fatal flaws likely to make their conclusions incorrect and misleading. Only 3 in every 100 systematic reviews are deemed to have adequate methods and be clinically useful. Examples of research waste and questionable ethical standards abound: most trials have little hope of providing useful results, and systematic review of hopeless trials inspires no confidence. **Abstract:** <https://bit.ly/3Gcb7i5>

### Development of guidelines to reduce, handle and report missing data in palliative care trials: A multi-stakeholder modified nominal group technique

*PALLIATIVE MEDICINE* | Online – 17 January 2022 – Seven main recommendations for reducing missing data, nine for handling missing data and twelve for reporting missing data were developed. The top five recommendations were: 1) Train all research staff on missing data; 2) Prepare for missing data at the trial design stage; 3) Address missing data in the statistical analysis plan; 4) Collect the reasons for missing data; and, 5) Report descriptive statistics comparing the baseline characteristics of those with missing and observed data. Reducing missing data, preparing for missing data and understanding the reasons for missing data were greater priorities for stakeholders than how to deal with missing data once they had occurred. **Full text:** <https://bit.ly/3A3iFSg>

### Noted in Media Watch 3 January 2022 (#749, p.17):

1. ‘Handling missing data and drop out in hospice/palliative care trials through the estimand framework,’ *Journal of Pain & Symptom Management*, published online 22 December 2021. **Abstract (w. references):** <https://bit.ly/3JgL5fD>

“There’s this big fear around palliative care because it’s connected to death and dying”

## **A qualitative exploration of the perspectives of undergraduate students on the role of the speech and language therapist in palliative care**

*PALLIATIVE MEDICINE* | Online – 17 January 2022 – Research literature has highlighted that undergraduate palliative care (PC) education in speech and language therapy is inconsistent and inadequate. However, limited research has been carried out to date in relation to student speech and language therapists and PC. This study revealed that undergraduate student speech and language therapists collectively agree that there is a role for speech and language therapy in PC. Although students acknowledged that speech and language therapists can make a positive difference to patients’ lives, and academic lectures were positively received, insufficient exposure to PC has resulted in fear, uncertainty and a lack of confidence amongst student speech and language therapists. **Abstract (w. references):** <https://bit.ly/34Mj5AL>

## **Publishing Matters**

### ***Preprints: Their Evolving Role in Science Communication***

ITHAKA S+R | Online – 12 January 2022 – This briefing discusses the history and role of preprints – scholarly manuscripts posted by the author(s) to a repository or platform to facilitate open and broad sharing of early work without any limitations to access – in the biological sciences within the evolving open science landscape. The focus is on the explosive growth of preprints as a publishing model and the associated challenges of maintaining technical infrastructure and establishing sustainable business models. Currently there are more than 60 preprint servers representing different subject and geographical domains, each developing at a different pace based on adoption patterns and disciplinary ethos. This briefing offers invaluable help to those who wish to understand this rapidly evolving publishing model. <https://bit.ly/31T6EIB>

### **Noted in past issues of Media Watch:**

1. ‘Opinion: The problem with preprints,’ *The Scientist*, published online 1 November 2021. [Noted in Media Watch 8 November 2021 (#742, p.11)] **Full text:** <https://bit.ly/31hHi01>
2. ‘Preprint: Already the bride or still the bridesmaid?’ *Postgraduate Medical Journal*, published online 19 August 2021. [Noted in Media Watch 23 August 2021 (#731, p.14)] **Abstract:** <https://bit.ly/3y62MI5>
3. ‘Opinion: The rise of preprints is no cause for alarm,’ *The Scientist*, published online 14 April 2021. [Noted in Media Watch 19 April 2021 (#713, p.16)] **Full text:** <https://bit.ly/3sjanQE>



### European Association for Palliative Care Blog

‘Abstract Watch’ highlights selected articles, noted in past issues of Media Watch, on a wide range of issues specific to palliative and end-of-life care. Past postings, for example, focus on the hospice and palliative care workforce, palliative and end-of-life care for patients living with intellectual and developmental disabilities, paediatric palliative care and transition to adult care, advance care planning and advance directives, and neuropalliative care. **Access at:** <https://bit.ly/3wvL5RW>

## 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.

### Distribution

MEDIA WATCH IS DISTRIBUTED AT NO COST to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of Media Watch is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
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: Updated 01.15.2022

### **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']

Cont.



## Canada



BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION <https://bit.ly/3two4xX>

[Grief & Bereavement & Mental Health Summit 2021 'Resource Page.' Scroll down to 'International Palliative Care Resource Center']



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

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

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

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

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

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

## Europe



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

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

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

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