

**Media Watch...** is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

**Understanding the drivers of end-of-life care and knowledge of how policies may help to support better choices can improve experiences and quality of life near the end of life – and may also slow the rate of expenditure growth.**

'Health and social care near the end of life: Can policies reduce costs and improve outcomes?' (p.2), published by the European Observatory on Health Systems & Policies.

## U.S.A.

### **University of Arizona launches end-of-life medical training program**

ARIZONA | *Hospice News* – 8 December 2021 – As clinician shortages continue to plague the hospice space,<sup>1</sup> the University of Arizona Health Sciences is expanding end-of-life (EoL) medical education through its new Interprofessional End-of-Life Care Training Program. The program focuses on training students to incorporate a multicultural and interdisciplinary approach to EoL conversations with patients and their families. Faculty at the University of Arizona Center on Aging collaborated with colleges and healthcare centers to develop a curriculum that will offer age, gender and culturally sensitive training to students. The interdisciplinary program will provide guidance to doctors, nurses, pharmacists and other professionals. Medical personnel often lack adequate skills and training in EoL conversations, according to Mindy Fain MD ... chief of the Division of Geriatrics, General Internal Medicine &

Palliative Medicine, and co-director of the University of Arizona Center on Aging. The university sent surveys to all students in its health sciences schools. Their responses indicated a significant need and interest in training for EoL and serious illness care... The program includes a serious illness and EoL care curriculum toolkit with cases that faculty can integrate into their existing courses. The curriculum is designed to help transform the culture around serious illness, death and dying... <https://bit.ly/31CqBwB>

### Specialist Publications

'Differences in care provided in urban and rural nursing homes in the U.S.: Literature review' (p.8), in *Journal of Gerontological Nursing*.

1. 'The growing demand for hospice and palliative medicine physicians: Will the supply keep up?' *Journal of Pain & Symptom Management*, published online 2 February 2018. [Noted in Media Watch 5 February 2018 (#549, p.12)] **Full text:** <http://bit.ly/2CRjxwO>

## International

### **Health and social care near the end of life: Can policies reduce costs and improve outcomes?**

EUROPEAN OBSERVATORY ON HEALTH SYSTEMS & POLICIES | Online – Accessed 9 December 2021 – This brief reviews the evidence on health and social care needs and expenditures at the end of life (EoL). EoL costs are the main reason for high per person spending levels observed at older ages in many European countries. However, there is huge variation between individuals, with estimates suggesting that just 10% of people near the EoL are responsible for over 60% of total EoL health and social care expenditures. High-cost individuals tend to be frail people with multiple chronic illnesses who use considerable hospital and social care services. In most European countries, there will be large increases in annual deaths in the coming years as the “baby boom” generation ages and improved survival ultimately leads to more deaths each year. This will inevitably lead to growth in EoL needs and, ultimately, spending levels. However, there are a number of strategies available to address these challenges. Some EoL needs can be reduced

with more active public health measures and active rehabilitation, much of which can be very cost-effective. More active assessment of care needs can also significantly improve the experiences of patients and families, reduce unnecessary tests and interventions, will not shorten survival, and can help to limit the growth in costs.

**Download at:** <https://bit.ly/3EESHGd>

#### Specialist Publications

**‘Availability and quality of grief and bereavement care in pediatric intensive care units around the world, opportunities for improvement’** (p.7), in *Frontiers in Pediatrics*.

**‘Care of older people and people requiring palliative care with COVID-19: Guidance from the Australian National COVID-19 Clinical Evidence Taskforce’** (p.10), in *Medical Journal of Australia*.

### **COVID-19: How Europe’s prisons have fared in the pandemic**

GERMANY | Deutsche Welle (Berlin) – 6 December 2021 – During the pandemic, we have become accustomed to meticulously updated COVID-19 dashboards and kept a close public eye on settings vulnerable to outbreaks, such as care homes. Yet little data has been made public about the spread of the coronavirus in carceral facilities. Together with 11 newsrooms in the European Data Journalism Network, Deutsche Welle collected data from 32 countries that show how many cases and deaths were reported in prisons, how vaccinations progressed, and what measures were taken to curb the spread of the virus. Many incarcerated people have multiple factors that put them at increased risk of severe COVID-19, including conditions such as HIV and histories of smoking or other drug use. Marginalization, poverty and poor access to healthcare often take

their tolls on such populations even before incarceration, and prison conditions frequently have an exacerbating effect... Outbreaks in prisons affect not only the people who are confined or working there, but also the surrounding communities.

<https://bit.ly/3Drh0FZ>

#### **Prison Hospice: Backgrounder (Updated 1 November 2021)**

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 weekly report can be downloaded from the Palliative Care Network website: <http://bit.ly/2RdegnL>



Share this issue of Media Watch with a colleague.

## National Health Service report shows confusion over do not resuscitate decision

U.K. (England) | This is Local London – 5 December 2021 – A report by the National Health Service Learning Disability Mortality Review programme (LeDeR) raised concerns that the conditions, which cannot be direct causes of death, had been listed on death certificates of people in Essex by medics. The findings, included in a West Essex Clinical Commissioning Group (CCG) report, also found a small number of decisions to not resuscitate had “learning disability,” “wheelchair user” or “Down’s syndrome” given as the reason. But the report continues to say these were “turned around” by learning disability liaison nurses, who then raised safeguards. A section read: “There is still much confusion around how a do not attempt resuscitation [order] fits with advanced care planning. “The majority are made when the person is in hospital very close to death.” West Essex CCG did not respond to comment when approached. This is the part of a death certificate which should document the disease or condition that led directly to the death. LeDeR has recommended the way deaths are recorded for people with cerebral palsy, and Down’s syndrome be reviewed. <https://bit.ly/31v2d0d>

## Specialist Publications

### Advance care planning and healthcare utilization in patients with amyotrophic lateral sclerosis: A retrospective chart review

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 December 2021 – Amyotrophic lateral sclerosis (ALS) is a progressive neuromuscular disorder resulting in functional decline and death. Despite recent emphases on advance care planning (ACP), low rates of documentation of ACP are seen in this population. This study aimed to determine rates of advance directive (AD) documentation and whether having a documented AD or ACP discussion affects healthcare utilization for ALS patients. Overall rates of AD documentation in the electronic medical record were low at only 29.2%. Rates of PEG placement, tracheostomy placement, hospitalization within 2 weeks of death, death in hospital, and hospice utilization did not vary between patients with and without AD documentation; however, patients with a documented ACP conversation were more likely to have a percutaneous endoscopic gastrostomy placed and to utilize hospice. The findings of this study indicates that while having a documented AD is not correlated to differences in healthcare utilization in patients with ALS, the benefit of ACP in this population is in having a dedicated conversation with patients and caregivers rather than focusing on completion of a static document. **Abstract (w. references):** <https://bit.ly/3ozaEjE>

### The Evolving Specialty of Neuropalliative Care

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Blog

– 15 November 2021 – The focus of this posting is on the evolving specialty that is neuropalliative care with summaries of a representative sample

of journal articles on the subject published during the past year or so. Included are articles on Parkinson’s disease, **amyotrophic lateral sclerosis**, multiple sclerosis, motor neurone disease, Huntington’s disease, dementia, epilepsy and neuro-ICU (neurosciences intensive care unit). There is a short selection of articles on neuropalliative care in the context of the COVID-19 pandemic, from the family caregivers’ perspective, and **advance care planning** (including advance directives and goals-of-care). <https://bit.ly/3cdwyIS>

**N.B.** This posting is part of a series on neuro-palliative care developed in partnership with the EAPC Neurology Reference Group: <https://bit.ly/3rge50A>



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### Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.12.

## Related:

- *AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 3 December 2021 – **‘Review of religious variables in advance care planning for end-of-life care: Consideration of faith as a new construct.’** This commentary reviews the history and current national trends of advance care planning (ACP) activities for end of life (EoL) ... and describes the characteristics and challenges associated with research instruments used, religious variables influencing ACP, and EoL preferences. Higher levels of religiosity, reliance on religious coping, belief in God’s control over life’s length, divine intervention, and conservative faith traditions are factors in lower levels of ACP and more intensive EoL care preferences, although the provision of spiritual care at EoL mitigates intensive EoL care. **Abstract:** <https://bit.ly/3IE8iOH>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 December 2021 – **‘Building on sand: Digital technologies for care coordination and advance care planning.’** Approaches using digital technologies to support advance care planning (ACP) and care coordination are being used in palliative and end-of-life care. While providing opportunities to facilitate increases in the completeness, sharing and availability of care plans, the evidence base underpinning their use remains limited. The authors outline an approach that continues to be developed – Electronic Palliative Care Coordination Systems. Stages governing its optimal use are outlined alongside unanswered questions with relevance across technology-mediated approaches to ACP. **Abstract:** <https://bit.ly/3EDFwoK>
- *CHILD: CARE, HEALTH & DEVELOPMENT* | Online – 6 December 2021 – **‘Initiation of paediatric advance care planning: Cross sectional survey of health professionals reported behaviour.’** Paediatric advance care planning is viewed positively; however, initiation practices are found to be influenced by wide ranging diagnoses and disease trajectories. While some tools and protocols exist, they are not used in a systematic manner and initiation behaviour is often not guided by them. Initiation is unstandardised, individually led, guided by intuition and experience and based on a range of prerequisites. Such behaviour, combined with inconsistencies in professional development, resulted in varying practice when managing clinical deterioration. **Abstract:** <https://bit.ly/31DD03J>
- *JOURNAL OF MULTIDISCIPLINARY HEALTHCARE* | Online – 9 December 2021 – **‘Multidisciplinary clinicians and the relational autonomy of persons with neurodegenerative disorders and an advance care plan: A thematic analysis.’** The author found that doctors prioritised engagement with family for consent to treatment, usually without reviewing the advance care planning (ACP). In essence, doctors practice relational autonomy when they envisage that families understand the person’s likely wishes, and collectively, doctors and family partner in contemporaneous healthcare decision on patients’ behalf. Doctors’ protective concern for family, and their tendency to prioritise active treatment, forms a limitation to realisation of patient agency through ACP. **Full text:** <https://bit.ly/3pGVs3B>
- *PALLIATIVE MEDICINE* | Online – 6 December 2021 – **‘Using advance and emergency care plans during transfer decisions: A grounded theory interview study with care home staff.’** Advance care planning (ACP) has attracted widespread policy support... A wide range of activities may be referred to (in academic literature and clinical practice) as “advance care planning”; however, there is a distinction between ACP (written by individuals, detailing wishes, priorities and preferences for future care) and emergency healthcare plans (written by professionals, containing clinical recommendations). Existing research focuses on experiences of engaging in care planning discussions, but much less is known about how these plans are used during in-the-moment decision-making... **Full text:** <https://bit.ly/3dmy99m>

### [Research Matters](#)

‘Building strong clinician-researcher collaborations for successful hospice and palliative care research’ (p.10), in *Journal of Hospice & Palliative Nursing*.

### [Publishing Matters](#)

‘Canadian academics’ use of predatory journals’ (p.11), in *Journal of the Canadian Health Libraries Association*.

## Caregiver challenges seen from the perspective of certified home hospice medical directors

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 December 2021 – Hospice medical directors (HMDs) play an important role as part of the interdisciplinary hospice team. Family caregivers (FCGs) play a critical role in caring for patients receiving home hospice care. Understanding the challenges HMDs face when working with FCGs is important when addressing potential gaps in care and providing quality end-of-life care for the patient/FCG dyad. Semi-structured phone interviews with certified HMDs were conducted. Participants' responses regarding the major issues HMDs faced when working with FCGs were categorized into six themes: 1) Assessing FCG competency; 2) FCG financial burden; 3) Physical burden of caregiving; 4) Managing FCG expectations; 5) FCGs denial of patient's terminal condition; and, 6) FCGs unwilling or unable to engage with providers about their needs or the patient's needs. HMDs confirmed the important role FCGs play in providing care to home hospice patients. Future studies are needed to explore solutions to the issues identified in this study to better support FCGs in the home setting.

**Abstract (w. references):** <https://bit.ly/3dr0rzl>

### Related:

- *CANCER* | Online – 7 December 2021 – ‘**A lay navigator-led, early palliative care intervention for African American and rural family caregivers of individuals with advanced cancer (Project Cornerstone): Results of a pilot randomized trial.**’ Very few programs have been developed to support under-resourced cancer family caregivers (FCGs). To address this need, the authors successfully pilot-tested an early palliative care program, called Educate, Nurture, Advise, Before Life Ends Cornerstone, for African American and rural FCGs of individuals with advanced cancer. Cornerstone is led by specially trained lay people and involves a series of weekly phone sessions focused on coaching caregivers to manage stress and provide effective support to patients with cancer. **Abstract:** <https://bit.ly/3Dy29tp>

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

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 9 December 2021 – Community-based and home-based palliative and end-of-life care (EoLC) services, often underpinned by primary care provision, are becoming increasingly popular. One of the key challenges associated with them is their timely initiation. The latter requires an accurate enough prediction of how close to death a patient is. Numerous palliative and EoLC policies and programmes are embedded in a framework of Preparation and Planning for Death and Dying, with identification of the dying stage setting in motion key systems and services. This is challenged by: 1) Accumulated evidence demonstrating low accuracy of prognostic judgements; 2) Many individuals' orientation towards living and hope; 3) Expanding grey zones between palliative and curative care; 4) The complexity of referral decisions; 5) The loss of pertinent information in hierarchical relationships; and, 6) The ambiguous value of having “more time.” Palliative and EoLC programmes in primary care and community settings are here to stay and grow. A realist perspective centred around the concepts of contexts-mechanisms-outcomes offers a promising way of understanding and improving their workings. Once again, however – after decades of seeking to expand palliative care outside of the realm of cancer – we may need a significant rethinking of the reach of palliative and EoLC programmes. A significant pool of evidence on prognosis suggests that current EoLC policy in England and any other country which relies strongly on “timely identification” is nothing short of hubristic in its expectations of working out death's timings. And while the day may come, for better or worse, when we are able to perfect the latter, for now we will achieve more if we focus on other ways of improving the EoLC we provide, no matter how brief or how long we are providing it for. **Full text:** <https://bit.ly/3dAvBoi>



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**Palliative Care Network**

*Palliative Care for Everyone, Everywhere*

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

## Related:

- *MEDICAL REVIEW OF LIEGE*, 2021;76(12):879-883. ‘How to recognize a patient with palliative needs: “Surprise” question to prevent bad surprises.’ In Belgium, a Royal Decree sets the criteria to identify patients with palliative needs. For that purpose, the Palliative Care Indicators Tool (PICT) is proposed. This 3-step identification tool designed for physicians begins with the so-called surprise question: “Would you be surprised if your patient died in the next 6 to 12 months?” The second and third steps examine the fragility and incurability criteria, respectively. The surprise question intends to encourage the clinician to trust his/her intuition and to promote a reflection on patient’s needs. The PICT facilitates communication between caregivers. **Abstract:** <https://bit.ly/3yeW7wR>

N.B. French language article.

## Before I die: Death positivity and the community nursing contribution

*BRITISH JOURNAL OF COMMUNITY NURSING* | Online – 8 December 2021 – This article explores the contextual backdrop of the death-positive movement that inspired the discussion group Before I Die: Worcestershire, along with the motivations behind its creation. It explores the balance between practical, planning discussions and open-ended talks held by the group, emphasising the importance of creativity when responding to the topics of death and dying. The collaborative efforts between Before I Die: Worcestershire and other groups and persons involved in the death-positive movement are also highlighted. This article considers the potential of grassroots community movements to engage people to make plans for their dying, regardless of circumstances and background. It argues that death-positive movements, projects and initiatives can be a valuable way for community nurses to engage with the population they serve. **Abstract:** <https://bit.ly/31lqek7>

## Implementation and evaluation of clinical supervision for support workers in a paediatric palliative care setting

*CLINICAL CHILD PSYCHOLOGY & PSYCHIATRY* | Online – 5 December 2021 – Support workers represent a large proportion of the National Health Service workforce [in the U.K.] and yet their supervisory needs are often overlooked. This study focused specifically on a cohort of support workers in a community paediatric palliative care setting. Peer supervision was implemented for this group, initially face to face and then virtually. The experiences of clinical supervision for this group were investigated through responses to an online survey and two focus groups. The following themes and sub-themes were developed from transcribed focus groups: 1) Barriers to engagement; 2) Being listened to; and, 3) What worked well: Logistics. Overall, delivery of supervision was effective to a mixed degree – though support workers appreciated a space to be listened to, their distrust of colleagues and other barriers impeded the capacity of supervision to achieve more than support and catharsis for this group. Future projects should focus on introducing more preliminary interventions to promote reflection and peer support for these groups as well as continue to consider the supervisory needs of support workers. **Abstract (w. references):** <https://bit.ly/3ls4nhP>



### [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>

## Availability and quality of grief and bereavement care in pediatric intensive care units around the world, opportunities for improvement

*FRONTIERS IN PEDIATRICS* | Online – 15 November 2021 – The authors assessed how pediatric intensive care units (PICUs) around the world implement grief and bereavement care (GBC). The study included 34 PICUs from 18 countries. Questionnaires with multiple-choice and open-ended questions focusing on unit infrastructure, personnel, policies, limited patient data, and practices related to GBC for families and healthcare professionals (HCPs) were completed by on-site researchers, who were HCPs on the direct care of patients. PICU fulfillment of GBC goals was evaluated using a custom scoring based on indicators developed by the Initiative for Pediatric Palliative Care. The authors compared average total and individual items fulfillment scores according to the respective country's World Bank income. Patient characteristics and details of unit infrastructure were also evaluated as potential predictors of total GBC fulfillment scores. The authors found statistically significant differences in GBC fulfillment scores between high-income countries and upper middle-income countries (specifically, HCP grief support), and between HICs and LMICs (specifically, family grief support and HCP grief support). PICUs world-wide provide some GBC, independent of income, but barriers include lack of financial support, time, and training, overall unit culture, presence of a palliative care consultation service, and varying cultural perceptions of child death. Dis-

parities in GBC for families and HCPs exist and were related to the native countries' income level. **Full text:** <https://bit.ly/3EqFCjA>

### Children living with the dying or death of a family member

#### **Development and psychometric evaluation of the Concerns of Grieving Caregivers Scale with two clinical samples**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 5 December 2021 – Understanding the concerns of bereaved caregivers is valuable within clinical settings that provide support to grieving families, as well as within the academic literature. As caregivers' concerns can either mitigate or intensify their interactions with, and their access to supports for their bereaved children, this ultimately influences the grieving child's psychosocial outcomes, as well as those of the caregiver. Examination of the newly generated Concerns of Grieving Caregivers Scale across two samples, a hospice and a community grief center [in Ontario, Canada], provided preliminary support for construct and criterion validity, as well as internal consistency reliability. The scale likely has utility in both clinical and non-clinical academic contexts to promote the advancement in our understanding of the concerns that grieving caregivers may have and how these concerns may influence their own and their child(ren)'s emotional wellbeing. **Full text:** <https://bit.ly/31FJWEh>

Noted in Media Watch 4 October 2021 (#2021, p.11):

- *HOSPITAL PEDIATRICS* | Online – 1 October 2021 – ‘**An interdisciplinary hospital-based committee to improve pediatric bereavement care.**’ The death of a child can significantly jeopardize the physical, psychosocial, and emotional health of surviving parents, caregivers, and family members. Researchers have only recently begun to explore the trajectory of pediatric bereavement care needs. As an ongoing public health concern, healthcare institutions and related organizations must partner with interdisciplinary care providers and bereaved families to design effective and sustainable bereavement supports in their communities. This article describes the development ... of an interdisciplinary bereavement committee at a children's hospital within an academic medical center. **Abstract:** <https://bit.ly/3kZHyrZ>

## Bereaved caregivers perspectives of negative communication experiences near the end of life for adolescents and young adults with cancer

*JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY* | Online – 6 December 2021 – High-quality communication is a standard of palliative care for adolescents and young adults (AYAs) with cancer. Yet, few studies have characterized the negative communication experiences of AYAs near the end of life (EoL). Overall, 23/27 (85%) caregivers [i.e., study participants] described at least one negative communication experience related to one of three themes: 1) Insensitivity to patients' needs, preferences, and values; 2)

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Insufficient discussions of prognosis and/or EoL; and, 3) Loss of support from the clinical team near EoL. Both clinician- and patient-related factors contributed to limited EoL discussions. Lack of care continuity related to both clinician factors and systems of care that required new or changing clinical care teams near the EoL. Caregivers report a desire for clinician sensitivity to their needs and values, information about the future, and longitudinal connections with individual clinicians. Clinicians might improve caregivers' EoL experiences by eliciting patient preferences, engaging in EoL discussions, adapting to the AYA's developmental and emotional needs, and demonstrating a commitment to AYAs and caregivers as they approach the EoL. **Abstract:** <https://bit.ly/3oE2o1V>

**Related:**

- *BMC PALLIATIVE CARE* | Online – 8 December 2021 – ‘**Communicating with patients and families about illness progression and end of life: A review of studies using direct observation of clinical practice.**’ This rapid review synthesises direct evidence of ways experienced clinicians manage challenging discussions about illness progression and end of life (EoL). The identification of common types of communicative practices used across these diverse clinical settings increases confidence that the findings of this review are transferrable to the discussions about illness progression and EoL that clinicians may need to have across a variety of clinical settings. Increasingly clear evidence has emerged to inform this poignant part of clinical practice. **Full text:** <https://bit.ly/3pJQUtk>

**Differences in care provided in urban and rural nursing homes in the U.S.: Literature review**

*JOURNAL OF GERONTOLOGICAL NURSING*, 2021;47(12);48-56. Despite evidence acknowledging disadvantages in care provided to older adults in rural nursing homes (NHs) in the U.S., since 2010, no literature review has focused on differences in care provided in urban versus rural NHs. The authors examined these differences by searching U.S. English-language peer-reviewed articles published after 2010 on differences in care quality in urban and rural NHs. They conducted full-text abstraction of 56 articles, identifying ten relevant studies. Metric specification of urban/rural location varied, and care quality measures were wide-ranging, making it difficult to interpret evidence. Limited evidence supported that rural NHs, compared to urban NHs, provided sparse mental health support and limited access to hospice care after controlling for facility and resident characteristics. This review highlights the need for more research examining differences in quality of care between urban and rural NHs and raises several issues in current research examining urban/rural NH differences where future work is needed. **Abstract:** <https://bit.ly/3lCeQxb>

Noted in Media Watch 29 November 2021 (#745, p.10):

- *JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED*, 2021;32(4):2167-2180. ‘**Defining rurality in hospice research: Evaluation of common measures.**’ Inconsistency in identifying rural hospices has biased research findings and policy analysis. The authors conducted a comprehensive evaluation of eight rural-urban classifications against the gold standard of the Office of Budget & Management to determine the utility of alternative measures in hospice research. These classifications included: Urban-Rural Classification Scheme for Counties, Urban Influence Codes, Rural-Urban Continuum Code, Federal Office of Rural Health Policy, Index of Relative Rurality (IRR), the U.S. Census Bureau, Rural-Urban Commuting Area codes, and Frontier & Remote. **First page view:** <https://bit.ly/3HPDSCs>

Noted in Media Watch 15 November 2021 (#743, p.8):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 November 2021 – ‘**Developing successful palliative care teams in rural communities: A facilitated process.**’ Developing palliative care (PC) programs in rural settings is challenging due to limitations on training, staff, resources, and reimbursement. Employing established frameworks and processes can assist rural communities in developing quality PC programs. Results of a prospective, observational, quality improvement initiative implemented over 18-24 months demonstrate that a structured facilitated planning process can help rural communities develop and implement PC services, despite barriers. Additional resources and support are needed to continue to expand access to high-quality PC services in rural communities... **Full text:** <https://bit.ly/3onU98X>

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Noted in Media Watch 3 May 2021 (#715, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 April 2021 – ‘**Examining barriers and facilitators to palliative care access in rural areas: A scoping review.**’ Access to palliative care (PC) remains challenging for rural Americans... Given the demand and benefits of PC, a comprehensive view of PC access would inform policymakers in developing PC services in rural areas. The findings of this review highlight the need for funding support to increase provider competency, service availability and accessibility, and the public knowledge and awareness of PC in rural areas. A holistic and tailored PC model that standardizes care delivery, referral and coordination, including family caregiver support programs, can improve care access. **Abstract (w. references):** <https://bit.ly/2R0dslp>

### **Education in palliative and end-of-life care pediatrics: Curriculum use and dissemination**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 8 December 2021 – The majority of seriously ill children do not have access to specialist pediatric palliative care (PC) services nor to clinicians trained in primary pediatric PC. The Education in Palliative & End-of-Life Care (EPEC-Pediatrics) curriculum and dissemination project was created in 2011 in response to this widespread education and training need. Since its implementation, EPEC-Pediatrics has evolved and has been disseminated worldwide. This article describes findings from a global survey of clinicians who received EPEC-Pediatrics training over a nine-year period, including the impact the course had on their knowledge, attitudes, skills, and teaching of others. The course had a positive impact internationally, and importantly, was perceived as improving care of children with serious illness. **Abstract (w. references):** <https://bit.ly/31LRl8K>



### **Identifying core domains to assess the “quality of death”: A scoping review**

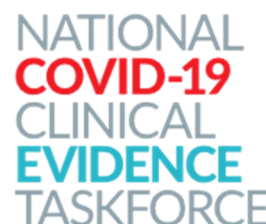
*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 December 2021 – This scoping review provides an extensive list of the domains and sub-domains identified as pertinent to the delivery of better end-of-life (EoL) care through a health systems lens. The integrated results linking health systems level structure and individual level experience can substantially contribute to ongoing efforts to examine the design and performance of EoL care systems. The overarching theme of the seven domains identified is the promotion of security and confidence to cope with death-related vulnerability and the need for various types of support to address the complexity of dying and death. The stark uncertainty of death and the need for specialized caregiving that is sensitive to and responsive of this is a unique concern during the EoL period as compared to non-EoL stages of care. It is reflected in the heightened concern across various domains at the EoL around avoidance of suffering related to isolation and medical abandonment. The health system has a critical role in the ongoing facilitation of and involvement in core actions that address suffering at the EoL, including from clinical management of symptoms to resources for management of existential distress of facing life’s end and addressing related emotional, psychological, and social impact. As such, this review highlights the need to shift EoL care from merely focusing on treatment of biological aspects of disease to a holistic biopsychosocial-spiritual model of care that seeks to alleviate serious health-related suffering across its dimensions (physical, psychological, social, and spiritual) to realize a “good death.” Moreover, it emphasizes the functional and foundational role of accessibility to and quality of information exchange in ensuring quality of care across all care sub-domains. This results in separation of quality of communication as a distinct domain from quality of care. **Full text:** <https://bit.ly/31EYvkk>

### **Top ten tips palliative care clinicians should know about spirituality in serious illness**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 December 2021 – Assessment of spiritual suffering and provision of spiritual care (SC) are a central component of palliative care (PC). Unfortunately, many PC clinicians, like most medical providers, have received limited or superficial training in spirituality and spiritual distress. This article, written by a group of SC providers, and other PC and hospice clinicians, offers a more in-depth look at religion and spirituality to help to enhance readers’ current skills while offering a practical roadmap for screening for spiritual distress and an overview of partnering with colleagues to ensure patients receive values-aligned SC provision. **Abstract:** <https://bit.ly/3lsuiWM>

## Care of older people and people requiring palliative care with COVID-19: Guidance from the Australian National COVID-19 Clinical Evidence Taskforce

*MEDICAL JOURNAL OF AUSTRALIA* | Online – 5 December 2021 – Older people living with frailty and/or cognitive impairment who have COVID-19 experience higher rates of critical illness. There are also people who become critically ill with COVID-19 for whom a decision is made to take a palliative approach to their care. The need for clinical guidance in these two populations resulted in the formation of the Care of Older People & Palliative Care Panel of the National COVID-19 Clinical Evidence Taskforce in June 2020. This specialist panel consists of nursing, medical, pharmacy and allied health experts in geriatrics and palliative care (PC) from across Australia. The panel was tasked with developing two clinical flow charts for the management of people with COVID-19 who are: 1) Older and living with frailty and/or cognitive impairment; and, 2) Receiving PC for COVID-19 or other underlying illnesses. The flow charts focus on goals-of-care, communication, medication management, escalation of care, active disease-directed care, and managing symptoms such as delirium, anxiety, agitation, breathlessness or cough. The Taskforce also developed living guideline recommendations for the care of adults with COVID-19, including a commentary to discuss special considerations when caring for older people and those requiring PC. The practice points in the flow charts emphasise quality clinical care, with a focus on addressing the most important challenges when caring for older individuals and people with COVID-19 requiring PC. The adult recommendations contain additional considerations for the care of older people and those requiring PC. **Full text:** <https://bit.ly/3DuJX3Q>



### Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 December 2021 – ‘**Hospital-based palliative and end-of-life care in the COVID-19 pandemic: A scoping review.**’ This review highlights the increased awareness and knowledge of palliative and end-of-life care provided in hospitals. The COVID-19 pandemic and subsequent increased admission to hospitals has led to increased referral rates to these services, which in turn has the potential to improve patients and family care and assist with greater interaction and consultation with specialist palliative care (PC) in the future. The review also highlights the rapid response of hospital-based PC teams to an evolving crisis, within the context of developed health systems under sustained and overwhelming pressure. **Full text:** <https://bit.ly/3iYs3AH>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 December 2021 – ‘**The virulence of grief in the pandemic: Bereavement overload during COVID.**’ The authors present three cases encountered in their health system during the COVID-19 pandemic amongst a family member, a patient, and a healthcare provider. In each case the palliative care team worked closely with these individuals to identify COVID-associated bereavement overload and helped them reconcile their unresolved grief to be able to move forward. These cases reflect only a fraction of those who experienced loss during the pandemic, but they illustrate how grief can be complicated by the pandemic for everyone involved. **Abstract (w. references):** <https://bit.ly/3ychq1X>

## Research Matters

### Building strong clinician-researcher collaborations for successful hospice and palliative care research

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 6 December 2021 – Hospice and palliative care (PC) research aim to build a knowledge base to guide high-quality care for people with serious illness and improve their quality of life. Considering its focus on patient and family caregiver’s experiences, hospice and PC research activities primarily take place in real-world clinical settings where seriously ill patients and their family caregivers receive care (e.g., nursing homes, clinics, inpatient units). Conducting research in these settings poses many challenges because researchers, clinicians, and administrators may have different priorities – and scientific control is difficult. Therefore, clinician-researcher-administrator collaboration

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in planning and conducting studies is critical for successful hospice and PC research. For an effective collaboration, clinicians, researchers, and site administrators must be considered equal partners. Each collaborator brings their unique expertise, knowledge, and skills that when combined can strengthen scientific rigor, feasibility, and success of the project, as well as have study outcomes that are more translatable to real-world practice; however, little guidance exists to give actionable steps to build collaborative partnerships for hospice and PC researchers. The purpose of this article is to describe the process of forming successful clinician-researcher-administrator collaborations through five phases of the research life cycle: 1) Idea generation; 2) Partnership; 3) Proposal writing; 4) Research process; and, 5) Dissemination. Exemplars are drawn from the authors' experiences conducting collaborative research and highlight strategies and resources for successful hospice and PC collaborations. **Abstract:** <https://bit.ly/3oseU4C>

## [Publishing Matters](#)

### Canadian academics' use of predatory journals

*JOURNAL OF THE CANADIAN HEALTH LIBRARIES ASSOCIATION*, 2021;42(3):140-153. Predatory journals have been acknowledged as an increasing concern in the scholarly literature over the last decade, but research on the subject has been sparse. Research that has focused on predatory journals in the Canadian context has been even rarer, and limited to work focused on a single university. This study explores publishing trends in predatory journals by authors affiliated with Canadian universities. Articles published by authors at 30 Canadian universities ... were pulled from select predatory journals. Key data including author affiliation, article type, discipline, and grant information were extracted from the articles. All universities in the study were found to have publications in predatory journals. The health sciences accounted for 72% of the publications, and the sciences for 20%. Research articles accounted for 50% of the articles. Opinion, editorial, or commentary pieces accounted for 24% and 19% were review articles. Grant funding was indicated in 34% of the articles, with Natural Sciences & Engineering Research Council of Canada (NSERC) and Canadian Institutes of Health Research (CIHR) being top funders. The research-intensive U15 universities [an asso-

ciation of 15 Canadian public research universities] were found to publish more in predatory journals than their non-U15 compatriots, even when the universities were of similar size. Canadian scholars were found to publish in predatory journals, particularly those scholars from the health sciences and research-intensive U15 universities. Grant funding was common, and often came from high profile funders like NSERC and CIHR. **Full text:** <https://bit.ly/338Fis7>

#### **Extract from Journal of the *Canadian Health Libraries Association* article**

This study has provided a first look into patterns of use of predatory journals by Canadian scholars at U15 and non-U15 universities. It has highlighted disturbing trends that warrant further investigation, notably high usage of predatory journals by scholars in the health sciences and at U15 universities. It has raised questions to be addressed in future studies and by policymakers. Predatory journals remain an issue in scholarly publishing that is heavily discussed, but scarcely researched. This paper adds insight to the Canadian dimension of predatory publishing.

Noted in Media Watch 23 March 2020 (#658, p.13):

- *UNIVERSITY AFFAIRS* | Online – 20 March 2020 – ‘**How Ottawa’s Centre for Journalology is tackling the scourge of predatory publishers.**’ Predatory journals deviate from accepted editorial procedures (by not doing peer reviews, for example) and engage in unethical practices (such as neglecting to archive studies). To bring attention to the problem, Dr. Kelly Cobey and her colleagues at the centre recently published a definition of predatory journals,<sup>1</sup> and kicked off a series of initiatives that will make publishers and academics’ published research more transparent, ethical and open. In a world where predatory or deceptive journals likely outnumber legitimate journals, scholars will need all the support they can get: worldwide, there are about 13,000 deceptive journals... **Full text:** <https://bit.ly/2J6pMzy>

1. ‘Defining predatory journals and responding to the threat they pose: A modified Delphi consensus process,’ *BMJ Open*, published online 9 February 2020. [Noted in Media Watch 17 February 2020 (#653, p.17)] **Full text:** <http://bit.ly/2SdQaNr>

## 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 weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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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.

**IPCRC.NET** International Palliative  
Care Resource Center

Search Back Issues of Media Watch  
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## Media Watch: Access on Online

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3CX3lr3>

[Scroll down to 'Media Watch: a Potpourri']

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: <http://bit.ly/2SWdYWP>

[Scroll down to 'Media Watch']

Cont.

## 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

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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