

**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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**The pandemic has provided a lens that highlights a need to rapidly expand the capacity of all health professionals to deliver non-specialist palliative care.**

'Health professionals' perspectives of the role of palliative care during COVID-19: Content analysis of articles and blogs posted on Twitter' (p.5), in *American Journal of Hospice & Palliative Medicine*.

## Canada

### **Second annual report on medical assistance in dying in Canada 2020**

GOVERNMENT OF CANADA | Online – Accessed 2 July 2021 – In 2020, there were 7,595 cases of medical assistance in dying (MAiD) reported in Canada, accounting for 2.5% of all deaths in the country. The number of cases of MAiD in 2020 represents a growth rate of 34.2% over 2019. All provinces experienced a steady year-over-year growth during 2020. The total number of medically assisted deaths reported in Canada since the enactment of federal legislation in mid-2016 is 21,589. In 2020, across Canada, a greater proportion of men (51.9%) than women (48.1%) received MAiD. This gender differential is slightly greater than in 2019, although the percentage of men receiving MAiD in 2019 was still slightly higher (50.9% vs 49.1%). The average age at time of MAiD being provided in 2020 was 75.3 years. <https://bit.ly/3qJzuwF>

#### **The majority of MAiD recipients received palliative care services**

During 2020, the majority of MAiD recipients (82.8%) received palliative care (PC). Of the MAiD patients who did not receive PC during 2020, 88.5% were reported to have had access to these services had they wished to avail themselves of PC.

#### Specialist Publications

“Bare-bones” to “silver linings”: Lessons on integrating a palliative approach to care in long-term care in Western Canada’ (p.6), in *BMC Health Services Research*.

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Noted in Media Watch 21 June 2021 (#722, p.1):

- THE CONVERSATION | Online – 14 June 2021 – **‘Why is access to medically assisted death a legislated right, but access to palliative care isn’t?’** In June 2016, federal legislation gave all eligible Canadians the right to request medical assistance in dying (MAiD). Colleges of physicians and surgeons required physicians to refer people who request MAiD to services or arrange for a physician who would make the referral. Since then, every province and territory devoted resources to navigate requests and assessments for MAiD. Typically, provinces have a website for self-referral, easily found by Internet search and/or dedicated healthcare staff to help navigate the MAiD process or inform those who are MAiD-curious. By contrast, the referral process for PC is often convoluted. <https://bit.ly/3gziULA>

Noted in Media Watch 12 April 2021 (#712, p.1):

- CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS | Online – 31 March 2021 – **‘Canadian Society of Palliative Care Physicians submission to College of Physicians & Surgeons of Ontario consultation on medical assistance in dying and professional obligations and human rights policies.’** Medical assistance in dying (MAiD) is a practice distinct from the provision of palliative care (PC). PC must remain distinct from MAiD to ensure clarity and to avoid the risk of confusion and the potential for people to refuse PC services. This does not preclude people who contemplate, request or opt for MAiD from receiving PC. This is vital for people in communities that have an underlying distrust of the healthcare system who decline PC because they may confuse it with MAiD. **Download at:** <https://bit.ly/3dERsdP>

## U.S.A.

### **Centers for Medicare & Medicaid Services proposes to revamp hospice enforcement in home health rule**

*HOSPICE NEWS* | Online – 28 June 2021 – The U.S. Centers for Medicare & Medicaid Services (CMS) has proposed the creation of a Special Focus Program (SFP) with the power to impose enforcement remedies against hospices with poor performance on regulatory or accreditation surveys. The agency also has plans to implement a hospice program complaint hotline through which the public can report issues to CMS. Hospices flagged by the proposed Special Focus Program would be surveyed every six months rather than the current three-year cycle. The SFP would have the authority to impose fines, suspend reimbursement, appoint temporary management to bring the hospice into compliance, or revoke a provider’s Medicare certification altogether. If made final, the new regulations would require multidisciplinary survey teams, prohibit surveyor conflicts of interest and update the surveyor training process. The agency expects that implementation of these proposals would cost an estimated \$5.5 million annually. “In this proposed rule, we are proposing a comprehensive strategy to enhance the hospice program survey process, increase

accountability for hospice programs, and provide increased transparency to the public,” CMS indicated. “Our goals include: maintaining the public trust through addressing conflicts of interest and improving survey transparency; addressing inconsistency within the survey process through training and survey team composition and use of common hospice program deficiency reporting mechanisms; and ensuring hospice programs are held accountable for addressing identified health and safety issues.” <https://bit.ly/3iqdu8I>

#### **Specialist Publications**

**‘Grief, COVID-19, and the South: Considerations and recommendations’** (p.13), in *Omega – Journal of Death & Dying*.

**‘Engaging social justice methods to create palliative care programs that reflect the cultural values of African American patients with serious illness and their families: A path towards health equity’** (p.9), in *Journal of Law, Medicine & Ethics*.

## Illinois to become first state to approve a pediatric palliative care benefit

ILLINOIS | *Hospice News* – 28 June 2021 – The Illinois State Assembly has passed a bill to create an in-home palliative care (PC) benefit for children facing life-limiting conditions. The legislation will now go to Governor J.B. Pritzker for signature. Stakeholders told *Hospice News* that the measure could signal advancement on establishing a national PC benefit. The Pediatric Palliative Care Bill ... aims to make community-based, interdisciplinary PC services more accessible to patients and reimbursable for providers. Patients would be able to receive curative treatments in tandem with these services. The bill would allow more families in Illinois to get benefits sooner rather than later... The bill's language cited a lack of an appropriate, pediatric-focused reimbursement structure as a significant barrier for children

and their families. Should the program prove successful in Illinois, it could serve as a model for establishing a national PC benefit... Establishing a dedicated community-based PC benefit within Medicare has been a critical goal for many providers nationwide. <https://bit.ly/3AcySUE>

### Specialist Publications

'The Pediatric Palliative Improvement Network: A national healthcare learning collaborative' (p.12), in *Journal of Pain & Symptom Management*.

'Pediatric palliative care programs in U.S. hospitals' (p.12), in *Pediatrics*.

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

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 24 March 2021 – '**A qualitative study describing pediatric palliative care in non-metropolitan areas of Illinois.**' Themes related to pediatric palliative care (PC) perceptions, availability and use of local resources and, challenges associated with travel, care coordination and finances. Participants described benefits of and limits ... including pediatric-specific issues such as attending to siblings, creating child peer-support activities, providing school guidance, and financing for pediatric PC. Recommendations included suggestions to enhance care coordination, use existing resources, improve community and provider education, develop community networks, and minimize financial challenges. **Abstract (w. references):** <https://bit.ly/3da0izS>

## International

### Terminal illness provision in social security benefits to be extended

U.K. (Northern Ireland) | *The Irish News* (Belfast) – 1 July 2021 – Communities Minister Deirdre Hargey has outlined plans to extend the terminal illness provision in social security benefits to 12 months. Currently, benefits can only be fast-tracked for an individual if a clinician states their death can "reasonably be expected within six months." The extension comes after years of calls and lobbying for a change in the provision, which had been branded "heartless." Advising Assembly members of her decision, Minister Hargey said her priority was to "reform the current rules to improve the support we provide to terminally ill people." The changes I will make will apply to all of the five social security benefits to which the special rules apply. More people who find themselves in the devastating position of being terminally ill will benefit from fast-tracked access to financial support through social security benefits. <https://bit.ly/3wenFjh>

### The National Health Service is using "soul midwives" to help people die peacefully

U.K. | *The Daily Mirror* (London) – 30 June 2021 – If you've given birth, you never forget your midwife. They're the reassuring professional you wanted to cling to, who knew the answers to your questions, and who cajoled and cheered you on through the pain as you gave birth to your child. Your midwife was with you during the most vulnerable hours of your life. But what about the other side of the equation? What if you could have a midwife to help you through the process of death – an equally confusing, often distressing, sometimes painful and always profound time? Fortunately, there are people who already do this job – soul

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midwives. Used by some National Health Service trusts and MacMillan Cancer Support, they provide a valuable service both to those who are dying and those who are being bereaved. Soul midwives are non-denominational and will work with people of any spiritual faith and none. Their role is to support someone on their journey towards dying, giving full respect to their spiritual or atheist/agnostic beliefs and practices. Soul midwives mainly work with the dying but can also help support those who are being bereaved. <https://bit.ly/3jxGOKk>

### **Palliative care for patients with COVID-19: Does ethnicity make a difference?**

U.K. | Cicely Saunders Institute – 28 June 2021 – People from ethnic minority and deprived socioeconomic groups receive suboptimal palliative and end-of-life care. People from ethnic minority groups and deprived socioeconomic backgrounds have worse outcomes from COVID-19. A small, single-centre study from the U.K. suggested that patients with COVID-19 from an ethnic minority background may have delayed referral to palliative care (PC) compared to those from White ethnic groups.<sup>1</sup> Researchers based at the Cicely Saunders Institute decided to examine associations between ethnicity and deprivation with timing of PC referral for inpatients with COVID-19. They looked at data for patients with COVID-19 who were referred to a hospital PC service across two London hospitals between February and May 2020. A total of 334 patients were included. 119 (36%) were from a non-White ethnic group; most commonly Black British (77, 23%) and Asian British (26, 8%). A longer time between admission and PC referral was associated with male gender and lower levels of socioeconomic deprivation but not ethnicity. This large service evaluation showed no evidence that patients from ethnic minority or more deprived socioeconomic groups had a longer time to PC referral. Equity in delivery of care for patients with COVID-19 is essential, especially for those groups disproportionately affected including ethnic minority groups and those from more deprived socioeconomic groups. Ongoing monitoring of meaningful data is needed to ensure equitable delivery of services. <https://bit.ly/3h2c4PV>



1. 'The association between ethnicity, socioeconomic deprivation and receipt of hospital-based palliative care for people with COVID-19: A dual centre service evaluation,' *Palliative Medicine*, published online 8 June 2021. **Full text:** <https://bit.ly/2T9XzRf>

### **New research shows U.K. faces post-pandemic bereavement crisis and lasting legacy of grief**

U.K. | Marie Curie Palliative Care Research Centre – 15 June 2021 – New research has highlighted the difficulties and distress people experienced when trying to get support after the death of a loved one during the pandemic, with more than half of people (51%) experiencing high or severe vulnerability in their grief and those seeking support facing long waiting lists or being told they are ineligible. Four in 10 participants (39%) reported difficulties in getting support from friends and family. The survey, carried out by Cardiff University's Marie Curie Palliative Care Research Centre and the University of Bristol, found that of bereaved people demonstrating high or severe levels of vulnerability, three quarters (74%) were not accessing formal bereavement services or mental health support. People also reported discomfort asking for help and were unsure how to access services. <https://bit.ly/3xg3Ppe>



## Specialist Publications

### **The human rights of older people with mental health conditions and psychosocial disability to a good death and dying well**

*AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 30 May 2021 – The human right to a good death and dying well is as important as the right to life. At stake at the end of life (EoL) are human rights to dignity, autonomy, self-determination and respect for will and preferences, equitable access to quality healthcare that is needs-based, and respect for family and relationships. Older people with dementia, those with serious mental illness, and those with intellectual disability are vulnerable to “bad deaths” due to violations of these rights. The authors of this article explore why this is so and examine existing and potential solutions. A human rights-approach to EoL care and policy for older persons with mental health conditions and psychosocial disability is one that is needs-based, encompassing physical and mental health, palliative care, social, and spiritual support services provided in the context of inclusive living. Most importantly, EoL care must be self-determined, and not “one size fits all.” An important remedy to existing violations is to strengthen human rights frameworks to cater specifically to older persons’ needs with a United Nations’ convention on the rights of older

persons. Finally, as health professionals we have important contributions to make at the coalface by accepting our responsibilities in the area of death and dying. With the concept of the palliative psychiatrist gaining traction and recognition that death is our business, the authors add that human rights is also psychiatrists’ business. **Abstract:** <https://bit.ly/3A5DdsW>

#### Research Matters

**‘Alternative consent models in pragmatic palliative care clinical trials’** (p.14), in *Journal of Pain & Symptom Management*.

#### Publishing Matters

**“Evidence-based checklists” for identifying predatory journals have not been assessed for reliability or validity: An analysis and proposal for moving forward’** (p.14), in *Journal of Clinical Epidemiology*.

**N.B.** Selected articles on palliative and hospice care for individuals living with serious mental illness noted in Media Watch 21 June 2021 (#722, p.2).

### **Health professionals’ perspectives of the role of palliative care during COVID-19: Content analysis of articles and blogs posted on Twitter**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 June 2021 – This study highlights that some health professionals (HPs) felt that they do not have the skills required to provide quality end-of-life care (EoLC) and require more education and training in order to do so. This gap in practice can be addressed by equipping HPs with skills to conduct goals-of-care (GoC) conversations and improving their knowledge of palliative care (PC). This may help to alleviate the existing demand for PC due to a shortage of a specialist PC physicians. Current evidence suggests that the healthcare workforce does not receive adequate PC education during medical training. This viewpoint is shared by students who suggest that medical schools are not adequately preparing future HPs to conduct EoLC conversations. The inherent emotionality, stigma and taboo surrounding death and dying is a challenge. As a priority, undergraduate health professional courses should prepare graduates to effectively communicate topics surrounding grief and loss, existential issues and changing GoC. In addition, HPs need to appreciate the diverse clinical responses that occur throughout illness trajectories, to understand the palliative principles for assessing and managing care needs and the ability to self-reflect on one’s own professional and personal experiences. The experiences of HPs, as reflected in this study, highlight the need for increased PC education for the emerging and current healthcare workforce. **Full text:** <https://bit.ly/3qJkori>

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## Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 July 2021 – ‘**As the pandemic recedes, will moral distress continue to surge?**’ Palliative care (PC) practitioners have encountered morally distressing situations during the COVID-19 pandemic, and have supported their colleagues experiencing moral distress. Familiarity with the concept of moral distress and with COVID-specific causes of moral distress may help PC practitioners recognize moral distress in themselves and in their colleagues. This essay provides a brief review of the concept of moral distress, a list of potential COVID-19 specific causes of moral distress, and a list of organizational, team, and individual interventions to promote resilience. **Abstract (w. references):** <https://bit.ly/3hjnoWY>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 June 2021 – ‘**Expanding the palliative care workforce during the COVID-19 pandemic: An evaluation of core palliative care skills in health social workers.**’ Besides palliative care (PC) physicians or advanced practice providers, health social workers (SWs) were the next most common group to lead goals-of-care conversations for high-mortality risk patients. With minimal training, health SWs were able to increase their use of the following core PC skills: “identify or document a healthcare proxy or surrogate decision-maker,” “assess prognostic understanding” and “coordinate care between medical teams.” Further education has the potential to increase the frequency of health SWs in these conversations. **Full text:** <https://bit.ly/3h6L6a4>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 June 2021 – ‘**The prevalence of palliative care consultation in deceased COVID-19 patients and its association with end-of-life care.**’ The authors evaluated the frequency of palliative care (PC) consultation, as well as its association with healthcare utilization for 203 deceased patients during the early COVID-19 pandemic in a single academic institution. They reviewed differences in invasive procedures, mechanical ventilation, continuous renal replacement therapy, ICU admissions, and code status at time of death. The most important finding was that only a little over half of the deceased patients received PC consultations during their hospital stay. **Full text:** <https://bit.ly/2TiogTW>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 June 2021 – ‘**Virtual interinstitutional palliative care consultation during the COVID-19 pandemic in New York City.**’ It was feasible to provide palliative care (PC) consultations virtually by providers from across the U.S. in the peak weeks of the COVID-19 surge. Despite the concerns of consultants’ availability (virtual consultants were volunteering their time in addition to their duties in their home institutions) or institutional, cultural, and legal differences regarding PC, PC consultation was provided to 34 seriously ill patients under very challenging circumstances. Positive effects of using telemedicine to deliver PC have been reported previously, but those studies are mainly in the community setting, where patients are at home. **Full text:** <https://bit.ly/3xdRLVm>

## “Bare-bones” to ‘silver linings’’: Lessons on integrating a palliative approach to care in long-term care in Western Canada

*BMC HEALTH SERVICES RESEARCH* | Online – 28 June 2021 – Immediate efforts should be made to ensure holistic, palliative approaches to care (PAC) become the standard for usual care in these settings. Strategic investments in staff and training are minimum requirements to support quality of life (QoL) for residents and workers. In a perfect world, there would be adequate fiscal resources and financial rewards to support addressing human resource shortages, and expanding care teams, and ensuring access to effective and ongoing education and training. There is a desperate need for reforms and incentives to ensure a strong and steady supply of trained professional, and non-licensed workers are drawn to this field of caring. Supportive leadership ... is essential to build and support a strong and common vision, and creative solutions to the enactment and embedding of PAC. Deeply concerning is the potential scenario of nothing changing, and of even more limited resources being infused in long-term care (LTC) than in the past, as governments strain to adapt and evolve in a post-COVID world. This means that it will take all existing human and financial resources, as well as all of ingenuity and creativity to mobilize the current skills and expertise of care team members, residents, families and volunteers to promote the QoL of residents. It is too be hoped that resources will come soon, and that the lack of resources meantime, will help to catalyze a re-orientation of care towards whole-person integrated PAC in LTC. Being able to capitalize on care team member strengths in different ways, and with better outcomes, while supporting them more fully in the work they do must be pursued vigorously and doggedly. **Full text:** <https://bit.ly/3y6kmMo>

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Noted in Media Watch 31 May 2021 (#719, p.5):

- *BMC GERIATRICS* | Online – 22 May 2021 – ‘**Multi-disciplinary supportive end-of-life care in long-term care: An integrative approach to improving end of life.**’ Interventions to optimize supportive end-of-life (EoL) care in Canadian long-term-care (LTC) facilities include changes in clinical practice, communication and culture, and organizational policy. Clinician educators can use the authors’ findings to support the provision of palliative education and skills training, as well as mentorships. Administrators should explore opportunities to reconfigure LTC culture through communication changes, as well as the physical environment through facility design modifications. Residents and family caregivers should also be engaged in research and change efforts to optimize EoL care within LTC. **Full text:** <https://bit.ly/3fcD6mO>

**Related:**

- *BMC PALLIATIVE CARE* | Online – 26 June 2021 – ‘**NUrsing Homes End-of-Life Care Program (NUHELP): Developing a complex intervention.**’ Twenty-two interventions were selected to enable the attainment of five objectives in the intervention program... This program aimed to improve the basic PC provided at the different nursing homes by modifying their clinical and organizational practice as well as their relationship with the public health system, presenting PC as a necessity at these centers and providing tools for successful PC delivery. The NUHELP program could also be used as an example of complex intervention development when designing other programs at nursing homes or other types of facilities. **Full text:** <https://bit.ly/3h8Knnp>

**N.B.** Search back issues of Media Watch for additional articles on palliative and EoL care in “long-term” care facilities and nursing homes at: <http://bit.ly/2ThijkC>

**Perceptions of healthcare professionals towards palliative care in internal medicine wards: A cross-sectional survey**

*BMC PALLIATIVE CARE* | Online – 30 June 2021 – The authors believe this survey of physician and nurse perceptions of palliative care (PC) in internal medicine in Singapore General Hospital reflects a wider gap in understanding of PC in Singapore, given the presence of corroborative findings on gaps in communication and prognostication skills and a general misunderstanding of PC’s role amongst physicians and nurses. Given such wide ranging knowledge and skill gaps and misconceptions, the authors opine that there is a need for a concerted national education program to target these barriers to PC’s effective use as they likely persist across clinical settings. This program must focus on increasing communication skills and cultural sensitivity even as government led initiatives on educating the public to PC’s wider role continue. At the same time, data from this survey also lends weight to efforts by local medical and nursing schools to increase awareness of PC. **Full text:** <https://bit.ly/3hmvNc2>



**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>

## Single-center quality improvement report

### **Incorporating early palliative medicine consultation into daily morning huddle in the ICU**

*CRITICAL CARE EXPLORATIONS* | Online – 25 June 2021 – Prior studies have shown a benefit of palliative medicine (PM) consultation by proactively screening high-risk patients by a research team. However, this approach, albeit effective research methodology, may not be pragmatic in the busy daily ICU workflow. A change in daily behavior, like in the morning huddle, can be more beneficial in the long term by imbedding a new culture to the fabric of the ICU care. Despite the known benefits of an early PM consultation, it remains underused. Prompting the consultation based on known trigger criteria at the beginning of the day may be an efficient way to involve the PM team in the ICU. This efficiency is especially important in the setting of a national shortage of PM provider and an aging population with increasing amounts of medical comorbidities. In this study, case managers identified patients with early PM consultation trigger as they are a part of the morning huddle and screen ICU patients for other needs. However, identifying patients who may benefit from an early PM consult can be done by any caregiver and can be done during

rounds as well. This is especially important in hospitals that may be understaffed or do not have a formal huddle. A future direction can be using a clinical decision support system in the electronic medical records to identify these patients for the provider. Additionally, this process should be monitored as hospitals may have different patient populations with different needs to ensure the best use of available PM resources. **Full text:** <https://bit.ly/3627D1n>

#### **The morning huddle**

...is a multidisciplinary team meeting with a focus on the current status of multiple aspects of patient care. In the ICU, team huddle can facilitate patient transfer, reduce length of stay, improve patient outcomes, as well as bridge the deficits of communication between the multilayered patient care. In theory, it represents a perfect spot in the busy ICU workflow to present the caregivers a reminder for necessary interventions, including a timely PM consult.

Noted in Media Watch 28 June 2021 (#723, p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 June 2021 – ‘**What affects adoption of specialty palliative care in intensive care units: A qualitative study.**’ The authors identified three types of specialty palliative care (PC) adoption in ICUs, representing different phases of buy-in. The “nascent” phase is characterized by the need for education about PC services and clarification of which patients may be appropriate for involvement. During the key “transitional” phase, use of specialists depended on development of “comfort and trust.” In the critical “mature” phase, ICU and PC clinicians worked to strengthen their existing collaboration, but further adoption was limited by the availability and resources of the PC team. **Abstract (w. references):** <https://bit.ly/3gSJSin>

#### **Related:**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 July 2021 – ‘**Seeking Excellence in End of Life Care (SEE Care): A multi-centered acute hospitals service evaluation.**’ There are significant unmet specialist palliative care needs within the hospital inpatient population. Prospective multi-centered service evaluation was conducted through four snapshots across four acute National Health Service hospital trusts. All patients identified as dying in each hospital were included. End-of-life care plans were completed for 73%, symptom-focused prescribing present in 96%. Symptoms were not well managed for 22%... Specific intervention was triggered in 56% of patients, consisting of prescribing advice and holistic support. **Abstract (w. references):** <https://bit.ly/3hmCZFm>



**Palliative Care Network**

*Palliative Care for Everyone, Everywhere*

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



## **Talking about death when a parent with dependent children dies of cancer: A pilot study of the Family Talk Intervention in palliative care**

*DEATH STUDIES* | Online – 2 July 2021 – This study focused on families with dependent children who participated in the Family Talk Intervention and lost a parent during the intervention or directly thereafter. The aim was to explore how they perceived information and communication about the imminent death during the illness trajectory and after the loss. Seven families from palliative homecare settings in Sweden participated. This study suggests that it is important to support family communication when a parent is dying, since communication in this situation is unlike everyday family communication, as they enter a complex and existentially unfamiliar area, hard to initiate on their own. **Abstract:** <https://bit.ly/3wgYA7g>

Noted in Media Watch 21 June 2021 (#722, p.21):

- *SUPPORTIVE CARE IN CANCER* | Online – 18 June 2021 – “‘**Don’t forget the children**’: **A qualitative study when a parent is at end of life from cancer.**’ While parents often feel ill-equipped to prepare their children for the death of a parent from cancer and desire supportive guidance from healthcare teams, this is a challenging aspect of care for health and social care professionals (HSCP) to provide. There is a need for HSCP to reassure parents that by involving the children early in the end-of-life experience, when the ill-parent is “well enough” to parent, enables them to be actively involved in supporting their child through one, if not the greatest life changing event. This enables the sharing of sadness, providing love and support that only a parent can. **Full text:** <https://bit.ly/3gyDrAZ>

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

## **Engaging social justice methods to create palliative care programs that reflect the cultural values of African American patients with serious illness and their families: A path towards health equity**

*JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 29 June 2021 – Cultural values influence how people understand illness and dying, and impact their responses to diagnosis and treatment, yet end-of-life care is rooted in white, middle class values. Faith, hope, and belief in God’s healing power are central to most African Americans, yet life-preserving care is considered “aggressive” by the healthcare system, and families are pressured to cease it. **Abstract (w. references):** <https://bit.ly/3wbfh3Z>

**N.B.** Search back issues of Media Watch for articles on ethnic and racial “disparities” and “inequities” in the provision and delivery of PC and hospice in the U.S. at: <http://bit.ly/2ThijkC>

## **Shades of hope: Marcel’s notion of hope in end-of-life care**

*MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 25 June 2021 – This article examines the compatibility and relevance of Gabriel Marcel’s phenomenology of hope in interdisciplinary research on the role of hope in end-of-life (EoL) care. The authors’ analysis is divided into three thematic topics which examine the various shades of hope observed in Marcel’s phenomenology of hope and in the collection of twenty EoL studies on hope as experienced by adult palliative care (PC) patients, healthcare professionals (HCP) and parents of terminally ill children. The three topics defining the shades of hope are: 1) The meaning of hope in its dynamic aspects; 2) The dialectics of hope and despair; and, 3) The transcendent facets of hope. The authors analyse how Marcel’s understanding of hope is reflected in EoL studies, and how this perception can enrich the philosophy of PC and significantly deepen and broaden HCPs’ understanding of hope. Despite terminological differences between Marcelian phenomenology and the concepts of hope in the twenty EoL studies, hope emerges as a resourceful movement towards being. Implementing Marcelian hope within communication in EoL care could help in HCPs’ interpersonal approach to patients as his concept harbors a holistic perception of the existential situation of a person. Equally, introducing Marcel’s phenomenology of hope into the clinical encounter could play a beneficial role in improving the ability of patients to adapt to the difficult conditions of their disease and PC treatment. **Full text:** <https://bit.ly/3w6mhzq>

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Noted in Media Watch 5 April 2021 (#711, p.9):

- *PALLIATIVE MEDICINE* | Online – 30 March 2021 – ‘**The effectiveness of hope-fostering interventions in palliative care: A systematic review and meta-analysis.**’ The concept of hope is an important theme in chronic illness and palliative care (PC) and has been associated with increased psycho-spiritual well-being and quality of life. Psycho-spiritual interventions have been described in this population, but no systematic review of hope-enhancing interventions or hopelessness-reducing interventions has been conducted for persons with PC diseases. Thirty-five studies (24 randomized controlled trials, 5 quasi-experimental, 6 pre-post studies) involving a total of 3,296 PC patients were included. Overall, quality of evidence across the included studies was rated as low. **Abstract (w. references):** <https://bit.ly/3u8q52n>

Noted in Media Watch 17 August 2020 (#679, p.6):

- *MORTALITY* | Online – 9 August 2020 – ‘**Hospice care: Between existential and medical hope.**’ The authors consider hospice managers’ perspectives on hospice care in the complex between values related to hospice philosophy and a specialised medical approach to hospice care. This study contributes to further understanding of the complexity of navigating hospice care in the impasse between an existential hope focused on meaning at the end of life and a medical hope for control of the dying body. Hospice care appeared as pulled between these dimensions of hope. The hospice managers took a pragmatic approach to medicalisation but their emphasis on dying as an existential event also points to a role for hospices as a critical voice against over-medicalisation of dying. **Abstract:** <https://bit.ly/2DLRfru>

### **Ethical reflections on filming death in end-of-life documentaries**

*MORTALITY* | Online – 25 June 2021 – The end-of-life documentaries that focus on natural death struggle with the question as to whether cinematic technology is able to express death as an event and whether it should even aspire to do so. In the process of filming dying people, questions of vulnerability, privacy, and empowerment become important, and each filmmaker makes ethical choices about how to approach the topic. By interviewing 14 documentary directors, using one audio commentary, and analysing 14 of their documentary films, the author recognised two main approaches to filming death. Most documentaries exclude the moment of death, which becomes a private event outside the public eye. These films narrate the experiences of living people and use metaphorical means to communicate the moment of death. They respect the physical vulnerability of the dying people, and protect the viewer from potentially shocking images. Occasionally, some documentaries include deathbed scenes that confront physical aspects of dying. These films create an affective and embodied connection to death and dying in ways that invite the viewer to co-experience the process. The author of this article discusses the ethical approaches related to these two approaches through questions of consent, the films’ content, and viewer’s responsibility. **Full text:** <https://bit.ly/3A34gVS>

### **How doctors actually (do not) involve families in decisions to continue or discontinue life-sustaining treatment in neonatal, pediatric, and adult intensive care: A qualitative study**

*PALLIATIVE MEDICINE* | Online – 28 June 2021 – The main implication of this study is that even though tailoring doctors’ communication to the families’ preferences and needs is advocated, it does not seem to be integrated into actual practice in the neonatal, pediatric, and adult intensive care. To allow for true tailoring, doctors’ awareness regarding their communicative behaviors is key. For this purpose, two simple questions can be helpful: 1) “Which communicative behaviors do/did I use in this situation?” and, 2) “Why do/did I use these behaviors?” Two important factors to consider in answering the latter question are: “how gray is the decision?” and “does my approach fit this family’s communication preferences and needs?”. In order to create more awareness, peer-to-peer coaching in which doctors can observe and discuss their practices in and over their intensive care settings is a helpful tool. The same holds true for organizing recurring mirror interviews with families about their experiences regarding their involvement in the decision-making process for their critically ill family member. **Full text:** <https://bit.ly/3quy4pX>



Would the *Palliative Medicine* article be of interest to a colleague?

## Culturally sensitive palliative care in humanitarian action: Lessons from a critical interpretive synthesis of culture in palliative care literature

*PALLIATIVE & SUPPORTIVE CARE* | Online – 29 June 2021 – There is growing recognition of the importance of increasing preparedness for and the provision of palliative care (PC) in humanitarian crises. The primary objective of this review is to interpret the existing literature on culture and PC to query the recommendation that humanitarian healthcare providers, teams, and organizations integrate PC into their practice in ways that are attentive to and respectful of cultural differences. 112 articles covering 51 countries and 9 major worldviews met inclusion criteria. This literature describes culture as it influences perspectives on death and dying, expectations of PC, and challenges to providing culturally sensitive care. A key pattern highlighted in articles with respect to the culture and PC literature is that culture is invoked in this literature as a sort of catch-all for non-white, non-Christian, indigenous practices, and preferences for PC. It is important that humanitarian healthcare providers and organizations aiming to enact their commitment of respect for all persons through attention to potential culturally specific approaches to pain management, suffering, and dying in specific crisis settings do so without reproducing othering and reductionistic understandings of what culturally sensitive care in humanitarian crises settings involves. This article clarifies and unpacks the diverse influences of culture in PC with the goal of supporting the preparedness and capacity of humanitarian healthcare providers to provide PC. In doing so, it aids in thinking through what constitutes culturally sensitive practice when it comes to PC needs in humanitarian crises. Providing such care is particularly challenging but also tremendously important given that healthcare providers from diverse cultures are brought together under high stress conditions. **Abstract (w. references):** <https://bit.ly/3jr2GHa>

Noted in Media Watch 22 March 2021 (#709, p.6):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 March 2021 – ‘**End-of-life care in natural disasters including epidemics and pandemics: A systematic review.**’ Although end-of-life (EoL) and palliative care (PC) are considered essential components of disaster planning and response, there are gaps in understandings about their real-life application, and how natural disasters impact EoL care. Natural disasters impact profoundly on EoL care, representing a stark departure from a PC approach. Using models, policies and practices already developed in PC, involving those most impacted in disaster planning and anticipating barriers, such as resource shortages, enables development of EoL care policies and practices that can be rapidly implemented during natural disasters. **Abstract:** <http://bit.ly/3vHqUYr>

**N.B.** Additional articles on the provision and delivery of PC during humanitarian crises or natural disasters noted in Media Watch 10 December 2020 (#593, p.11).



Photo: Lori Waselchuk. Philadelphia, PA

### Prison Hospice: Backgrounder

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 at the Palliative Care Network website: <http://bit.ly/2RdegnL>



### 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 beginning on p.15.

## Pediatric palliative care programs in U.S. hospitals

*PEDIATRICS* | Online – 28 June 2021 – Pediatric palliative care (PC) is integral to the care of children living with serious illnesses. Despite the growth in the number of established PC programs over the past decade, little is known about the current operational features of pediatric PC programs across the country. The National Palliative Care Registry collects annualized data on PC programs' structures, processes, and staffing. Using data from the 2018 registry survey, the authors report on the operational features of inpatient pediatric PC programs across the U.S. Fifty-four inpatient pediatric PC programs submitted data about their operations. Programs reported a median of 3.8 full-time equivalent staff per 10,000 hospital admissions ... across the core interdisciplinary team, yet few (37%) met the minimum standards of practice for staffing. Programs provided more annual consults if they were longer-standing, had more interdisciplinary full-time equivalent staff, offered 24/7 availability for patients and families, or were at larger hospitals. The majority of programs reported concern for burnout (63%) and an inability to meet clinical demand with available staffing (60%). There is considerable variability in pediatric PC program operations and structure in hospitals. This study affirms the need for updated program standards and guidelines, as well as research that describes how different care delivery models impact outcomes for patients, families, staff, and healthcare systems. Future studies that further define the clinical demand, workload, and sustainability challenges of pediatric PC programs are necessary to foster the provision of high-quality pediatric PC and maintain a vital clinical workforce. **Abstract:** <https://bit.ly/3dnBgdy>

### **The Pediatric Palliative Improvement Network: A national healthcare learning collaborative**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 June 2021 – Although multiple national organizations have created consensus guidelines and metrics for pediatric palliative care (PC), standardized implementation and measurement has been challenging. In 2016, six pediatric PC physician-experts in program development and quality improvement (QI) formed a healthcare learning collaborative network entitled the Pediatric Palliative Improvement Network (PPIN). The PPIN now includes 146 members representing 51 organizations. In 2019 the group completed a national collaborative QI project focused on pain assessment at the time of initial consult, demonstrating a national increase in pain assessment from 75.8% to >90% over 12 months. The PPIN has hosted two national QI workshops training more than 50 pediatric PC clinicians in QI... Monthly calls since 2017 provide QI methods “refreshers,” share local works in progress, and provide infrastructure for future collaborative projects. The PPIN has become a sustainable organization which improves the quality of pediatric PC through focus on national QI methods training, successful collaborative projects, and the creation of a learning and peer support community with regular calls. With the advent of the Palliative Care Quality Collaborative in 2020, the PPIN provides critical educational and organizational infrastructure to inform ongoing quality efforts in PPC, now and in the future. **Abstract (w. references):** <https://bit.ly/3y0MZuC>

**N.B.** 'Challenges and priorities for pediatric palliative care research in the U.S. and similar practice settings: Report from a Pediatric Palliative Care Research Network Workshop,' *Journal of Pain & Symptom Management*, published online 21 August 2019. [Noted in Media Watch 26 August 2019 (#628, p.12)] **Full text:** <http://bit.ly/2MxyM8r>

Noted in Media Watch 10 September 2018 (#580, p.5):

- *CHILDREN* | Online – 31 August 2018 – **'Delivering pediatric palliative care: From denial, palliphobia, pallilalia to palliative.'** In the U.S., more than 42,000 children die every year... Advanced interdisciplinary pediatric palliative care (PC) for children with serious illnesses is now an expected standard of pediatric medicine. In many institutions there remain significant barriers to achieving optimal care related to lack of formal education, reimbursement issues, the emotional impact of caring for a dying child, and the lack of interdisciplinary pediatric PC teams with sufficient staffing and funding. The authors address common myths and misconceptions which may pose clinical obstacles to effective pediatric PC delivery and discuss the four typical stages of pediatric PC program implementation. **Full text:** <https://goo.gl/rvFUJ8>

Cont.

Noted in Media Watch 5 November 2018 (#588, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 November 2018 – ‘**Comparing healthcare provider-perceived barriers to pediatric palliative care fifteen years ago and today.**’ Study findings were similar between 2002 and 2017, particularly in the extremes of the most and least commonly cited barriers. Barriers to palliative care (PC) for hospitalized children persist and commonly include perceptions that families deny, prefer, or have discomfort with forgoing life-sustaining treatments. Increasingly, studies have shown that families can be simultaneously hopeful and aware of their child's worsening health. Further PC education and research about these barriers and their impacts are necessary to support seriously ill children and their families. **Abstract:** <https://goo.gl/wGNPX7>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 November 2018 – ‘**Provision of palliative and hospice care to children in the community: A population study of hospice nurses.**’ A clear malalignment exists between the needs of children with serious illness in the community and the availability of trained providers. Each year, approximately 50,000 children in the U.S. die in the context of life-limiting illnesses, yet only 1 in 10 of these children receive hospice services. and this preference is supported by the majority of clinicians. Yet fewer than 1 in 5 hospice programs in the U.S. offer formal pediatric palliative care services with specialized staff, and nearly one-third of existing hospices in the region have policies in place prohibiting provision of care to pediatric patients. <https://goo.gl/mhEkV4>

### **Bereavement care for ethnic minority communities: A systematic review of access to, models of, outcomes from, and satisfaction with, service provision**

*PLOS ONE* | Online – 30 June 2021 – This review reveals a stark lack of evidence about bereavement care for ethnic minority populations. There is no research literature outlining the role of family, friends and existing networks, other than the suggestion that this type of support, including the role of religious communities and faith, is especially important. From the limited evidence available, there are barriers at each level of the three identified components of bereavement care outlined by the National Bereavement Alliance for ethnic minority groups, limiting accessibility. In particular, issues relating to the availability, awareness and dissemination of information were identified, which ideally should be available on a universal basis; furthermore, barriers at components one and two may also impact on awareness and access to bereavement counselling. A lack of relevant, culturally competent training for healthcare professionals can limit access and awareness of potential support services. Additionally, these services may not be structured in a way which meets the needs of ethnic minority groups. For example, practical, legal and financial support may be needed and deemed more important by users during the initial bereavement period. A shortage in reporting of facilitators to care was notable, although ensuring readily available information and inclusive approaches (e.g., broad invitations to groups and events) were found to improve accessibility. There were few examples of existing models of care, a real absence of evidence about outcomes and levels of satisfaction for those from an ethnic minority background who receive bereavement care and no identified studies which focused on users who were children. **Full text:** <https://bit.ly/3692y7z>

#### **Related:**

- *MORTALITY* | Online – 25 June 2021 – ‘**“It was the easiest way to kind of announce it”**: Exploring death announcements on social media through a dramaturgical lens.’ This article addresses how online death announcements (ODAs) – where bereaved people use social media platforms to share news of a loved one's death – are extending beyond the role of public death notification previously limited to newspaper-published obituaries. ODAs are social performances embodying a diverse range of grief responses and offer a significant new direction in death scholarship. ODAs go beyond purely information-sharing devices and are, instead, complex performances which benefit mourners in a number of ways and are governed by tacit “rules” of permission and content. **Abstract:** <https://bit.ly/3jqyQm6>
- *OMEGA | JOURNAL OF DEATH & DYING* | Online – 1 July 2021 – ‘**Grief, COVID-19, and the South: Considerations and recommendations.**’ COVID-19 has devastated the U.S. One of the more notably impacted areas is the South. Compared to the rest of the U.S., the South is characterized by increased rurality, lowered access to healthcare, older populations, and higher religiosity, all of which might predispose its residents to more detrimental effects of COVID-19, including COVID-related fatalities. As such, the authors of this article, members of the faculty at the University of Alabama, provide important considerations for individuals engaging in work with Southern, rural Americans dealing with COVID-related grief and loss. **Full text:** <https://bit.ly/2UhF1Pc>

## Research Matters

### **Alternative consent models in pragmatic palliative care clinical trials**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2021;62(1):183-191. Palliative care (PC) research raises a host of ethical concerns. Obtaining informed consent from seriously ill patients and their families is often perceived as an additional burden. Alternative approaches to traditional written informed consent reflect the changing nature of modern trial design, embracing real-world effectiveness and pragmatic clinical trials with those who are seriously ill. Ethicists, clinical investigators, and regulatory bodies have acknowledged the challenges to rigorous, meaningful, and generalizable research across diverse patient populations in real-world settings. The purpose of this article is to describe how these clinical trial designs have driven innovation in methods for achieving informed consent, with a focus on PC research. In this article, the authors describe and provide examples of consent waivers and three types of alternative approaches to consent, including broadcast notification and integrated and targeted consent. They also present their experiences in an ongoing PC clinical trial, specifically using broadcast notification. Working with participants and regulatory oversight organizations, investigators can address the limits of traditional written informed consent and adopt innovative consent models to advance the science of PC. Research is now needed to determine the impact of these differing consent models on clinical trial recruitment, enrollment, and retention, as well as participants' informed understanding of their research participation using such models. **Abstract (w. references):** <https://bit.ly/2Tez84V>

## Publishing Matters

### **“Evidence-based checklists” for identifying predatory journals have not been assessed for reliability or validity: An analysis and proposal for moving forward**

*JOURNAL OF CLINICAL EPIDEMIOLOGY* | Online – 24 June 2021 – The authors identified evidence-based checklists (EBCs) to detect predatory journals (PJs) and critically examined each item in each EBC identified. They identified a total of four EBCs and compared them against a published methods guideline for scale development outlined in nine steps and found that no checklist even fully completed step one. A number of reasons can explain this finding, the most notable being that all these checklists were developed prior to the publication of a consensus definition of predatory journals and publishers (PJPs) which was published in late 2019. The authors compared all items from each of the four EBCs against the five components of a recently published consensus definition of PJPs, and a list of items to be considered in the creation of a composite checklist to identify PJs was generated. With the recent consensus definition, checklists now have a clearer target, can make adjustments, and proceed to address methods standards for measurement scales; future work should involve creating and assessing a composite checklist that eliminates non-discriminating items. **Abstract (w. references):** <https://bit.ly/3dojP0k>

### 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.

### 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 weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly 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.

Cont.

### 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 the weekly report 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

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/2RBj7VW>

[Scroll down to 'Media Watch']

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

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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  
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### **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**



CSPCP SCMSP  
Canadian Society of  
Palliative Care Physicians Société canadienne des  
médecins de soins palliatifs

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>

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**Europe**



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): [HTTPS://BIT.LY/3WVL5RW](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>

**South America**

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

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