

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

Virtual inpatient palliative care programs during a pandemic are only feasible if existing human resources can meet the increased demand for palliative care.

'Harnessing new and existing virtual platforms to meet the demand for increased inpatient palliative care services during the COVID-19 pandemic: A 5-key themes literature review of the characteristics and barriers of these evolving technologies' (p.4), in *American Journal of Hospice & Palliative Medicine*.

Canada

Parenting through terminal illness

THE NEW YORK TIMES | Online – 4 August 2021 – Andrea Warnick, a Toronto-based psychotherapist who holds a master's degree in thanatology ... has spent more than 20 years supporting grieving families and kids. While helping a grieving child can feel overwhelming, the most important elements are simple: Caregivers should work to form a secure attachment with the child and to facilitate open, honest communication. "I consistently see so many families where really hard stuff happens, and those kids are still able to thrive in the world," Ms. Warnick said. "Those kids have adults in their life who are emotionally available to them." A secure attachment, Ms. Warnick said, means that a child feels safe coming to a parent with anything that is on their mind, and that the parent accepts those questions and feelings without judgment. She said that parents who have an ill partner should strive to be as honest as possible with their

grieving kids, even when honesty is hard. But establishing free-flowing communication doesn't mean you'll magically have all the answers. Most parents who contact Ms. Warnick are looking for the right language to use with their children... "The harder job is actually being able to bear witness to our children's suffering," she added. "I think one of the most wonderful things we can do for kids is teach them about grief, and teach them that they have the capacity to survive their feelings, even the most intense ones." <https://nyti.ms/3fwZqav>

Specialist Publications

'Understanding the bereavement process: Voices of bereaved parents' (p.7), in *Illness, Crises & Loss*.

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Noted in Media Watch 2 August 2021 (#728, p.11):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 29 July 2021 – ‘**Parental death during adolescence: A review of the literature.**’ While extensive research exists on parental loss in childhood and the related psychological interventions, little has been done in the adolescent population. This review identifies a range of behavioral and emotional responses to parental death in adolescence, including depression, suicidal ideations, anxiety, insomnia, addiction and impaired function at school and home. The role of peers, school life, and family and social environment are important for the recovery from loss. More studies are required to better understand the different psychological trajectories in adolescence after parental death to tailor mental health interventions. **Full text:** <https://bit.ly/37bPIGe>

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), ‘Death of a Sibling (p.24), and ‘Death of a Parent’ (p.30) at: <http://bit.ly/2OB4Y6C>

U.S.A.

Governments, not philanthropy, should fund palliative care

DEVEX | Online – 2 August 2021 – Worldwide, philanthropy has long been a bedrock when it comes to funding care for people battling terminal illness or approaching the end of life. In the 1960s, private donations were behind the emergence of hospice and palliative care (PC) in the U.K., and ever since, charity has been the primary source of funding for PC in much of the world. However, it was the original hospice founders’ intention for the state to take over this responsibility. When ... Open Society Foundations started funding PC in Africa, the former Soviet Union, and elsewhere 20 years ago, it was with the intention of laying the foundation for governments to eventually step in to fund PC through health insurance or social security schemes. Now, 70 years later, it is long past time for governments – not philanthropy – to fund PC properly and ensure that it is available to all who need it. That’s not to say that PC hasn’t made significant strides with private support. Hundreds of thousands of people with cancer and other incurable illnesses worldwide now have access to services

that prevent needless suffering from severe pain and other symptoms. Now, many governments recognize PC as an essential health service, have incorporated it into health policies and medical education, and taken steps to ensure essential medicines, such as morphine, are available and accessible. Yet, public spending on PC services remains grossly inadequate, resulting in many providers continuing to rely on philanthropic funds. <https://bit.ly/3fn0rBR>

Specialist Publications

‘**U.S. best practice guidelines for primary palliative care in the emergency department**’ (p.5), in *Annals of Emergency Medicine*.

‘**National Comprehensive Cancer Network guidelines insights: Palliative care, Version 2.2021**’ (p.9), in *Journal of the National Comprehensive Cancer Network*.

N.B. Devex is an independent news organization.

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>



International

Terminal-illness rules “not a matter for courts”

U.K. (Northern Ireland) | *Law Society Gazette* – 6 August 2021 – The Court of Appeal in the North has overruled a decision made last year by the High Court, which found that differential treatment of social-security benefit claimants with a terminal illness was unlawful. Lorraine Cox, who is terminally ill, had brought proceedings against the Department for Communities, arguing that the rules breached her right to freedom from discrimination... In July last year, she won her case in the High Court, which ruled that she had suffered a breach of her human rights by being denied fast-tracked disability benefits because it was not clear how long she would survive. The court found that the difference in treatment – between the respondent, and individuals who had a terminal diagnosis, who were reasonably expected to die within six months, but who survived beyond that point – was not justified... The High Court decision was appealed by the Department for Communities and Department for Work & Pensions to the Court of Appeal. The Court of Appeal this week allowed the appeal, in a challenge against legislation that allows certain people with a terminal illness to receive welfare benefits without undergoing a full assessment. The Court of Appeal found that there had been a review of the rules by politicians, and that

it was not appropriate for the court to intervene with the definition of the special rules on terminal illness. Lord Chief Justice, Sir Declan Morgan, said the matter was “for the political process and not for the courts.” <https://bit.ly/3fE8bjn>

Specialist Publications

‘COVID-19 and palliative care capacity, African Region’ (p.5), in *Bulletin of the World Health Organization*.

‘Lessons learned from introducing Last Aid courses at a University Hospital in Germany’ (p.6), in *Healthcare*.

‘Variations in end-of-life practices in intensive care units worldwide: A prospective observational study’ (p.10), in *The Lancet Respiratory Medicine*.

‘Attitudes and preferences towards palliative and end of life care in patients with advanced illness and their family caregivers in Latin America: A mixed studies systematic review’ (p.11), in *Palliative Medicine*.

Royal College of Physicians COVID-19 study provides insight into pandemic hospital care

U.K. (England) | Royal College of Physicians – Accessed 2 August 2021 – The College conducted the largest study to date of the quality of care given to patients in the U.K. with COVID-19 to identify learnings from the pandemic. This study recruited a sample and demographic representative of English hospitals’ experience of the COVID-19 pandemic. The study gathered information about the quality of care delivered from 19 organisations in England, which between them accounted for a population of almost 10.5 million people exposed to the COVID-19 virus. These organisations collectively looked after over 26,000 cases of COVID-19 in 2020 with over 6,000 patients dying with the condition in their care. They reviewed 510 patients and their care. Care judged to be poor overall was very uncommon and occurred in only 3.5% of the total sample.

When it did occur, it was related to end-of-life care issues, nosocomial infections (those acquired in hospital), delays in assessment and the two linked issues of poor communication and poor documentation. <https://bit.ly/3rNhtyd>

Extract from the report on the Royal College of Physicians’ study

The study looked at significant variations between hospitals when it came to end-of-life care experiences, assessment, documentation and communication, senior review, do not attempt resuscitation decisions and discharge planning. This revealed both excellent care and care that could have been improved.

Demand for end-of-life doulas on the rise as palliative care need increases

AUSTRALIA | ABC News – 1 August 2021 – The increase in doulas comes as a concerning palliative care (PC) shortage begins to emerge Australia-wide. According to the Australian Institute of Health & Welfare, this is because the nation's population is ageing fast, and rates of cancer and other chronic diseases are on the rise.¹ There are only 270 PC physicians registered in Australia – just 50% of what the country needs. And with Australia's ageing population tipped to reach 30 million people by 2030, this is only expected to get worse. "We're concerned we haven't got sufficient funding invested for the future," Palliative Care Australia chief executive Camilla Rowland said. The majority of residential aged care facilities don't have PC services employed – or even visiting. Rowland said funding from both state and federal governments – and more discussions around who was responsible – was needed to address this. Under-served populations such as Aboriginal and Torres Strait Islander and culturally and linguistically diverse groups are also being left behind. <https://ab.co/3j9ooOr>

1. 'Palliative Care Services in Australia,' Australian Institute of Health & Welfare, May 2021. [Noted in Media Watch 31 May 2021 (#719, p.2)] <https://bit.ly/3il1bh5>

N.B. additional articles on death doulas noted in Media Watch 14 December 2020 (#696, p.11).

Specialist Publications

Harnessing new and existing virtual platforms to meet the demand for increased inpatient palliative care services during the COVID-19 pandemic: A 5-key themes literature review of the characteristics and barriers of these evolving technologies

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 August 2021 – Overall, telepalliative care does appear to have the capacity to meet the increased demand for safe and accessible inpatient palliative care (PC) during a pandemic. While virtual inpatient PC is not perfect and some challenges exist, this service allows patients to have meaningful interactions with their extended care team and family while isolated in hospital or in hospice, and feel more supported as they approach EoL. Patients are generally satisfied with virtual visits and value the healthcare team's efforts, regardless of which devices are used. PC patients, however, are a complex, heterogenous population with differing needs. A one-size-fits all model will not suit this line of care, not even during a pandemic. Thus, redesigning hospice delivery systems should be done thoughtfully and in consideration of when in-person versus virtual visits are most appropriate, as well as take into account a community's cultural values and socioeconomic barriers to digital HC. The decision for which patients receive what format of care should remain an individual choice for both the patient and the family and staff supporting them. **Full text:** <https://bit.ly/3jvvj4E>

Dying alone during a pandemic

JOURNAL OF PALLIATIVE MEDICINE | Online – 4 August 2021 – The coronavirus disease 2019 (COVID-19) pandemic is an unprecedented experience that has had profound impact and consequences for healthcare providers, visitation policies, and procedures. Hospitals and healthcare facilities were forced to implement changes to visitation policies, in an effort, to minimize transmission of the virus, which unfortunately had negative impact on patients' and family members' well-being as well as moral distress for the staff. The authors present a case illustration of the impacts of such a response to the pandemic situation, including challenges for uniformly implementing such a change along with suggestions to support patients during these difficult times. Healthcare facilities should make efforts to maintain balance between safety precautions and minimizing potential negative impacts on patients, families, and staff by implementing innovative measures to support ongoing communication and access to family support. **Full text:** <https://bit.ly/37mSCrO>

N.B. Addition articles on "harnessing new and existing virtual platforms" in PC noted in Media Watch 12 July 2021 (#725, p.6).

U.S. best practice guidelines for primary palliative care in the emergency department

ANNALS OF EMERGENCY MEDICINE | Online – 2 August 2021 – The growing palliative care (PC) needs of emergency department (ED) patients in the U.S. have motivated the development of ED primary PC principles. An expert panel convened to develop best practice guidelines for ED primary PC to help guide frontline ED clinicians based on available evidence and consensus opinion of the panel. Results include recommendations for screening and assessment of PC needs, ED management of PC needs, goals-of-care conversations, ED PC and hospice consults, and transitions of care. **Abstract (w. references):** <https://bit.ly/3jrg7W9>

N.B. Additional articles on PC in the ED noted in Media Watch 2 August 2021 (#728, p.7).

COVID-19 and palliative care capacity, African Region

BULLETIN OF THE WORLD HEALTH ORGANIZATION, 2021;99(8):542-542. In the authors' recent review of African COVID-19 case management guidelines, they found few palliative care (PC) approaches and a focus on clinical management to the neglect of important psychosocial and spiritual stressors affecting morbidity and outcomes. Health systems' allocation of resources to COVID-19 has severely weakened services for other serious conditions, such as cancer and HIV infection. PC patients who contract COVID-19 are at risk of poorer outcomes, yet African PC providers have little COVID-19 preparedness and response capacity, as shown by a survey of African countries. Community outreach efforts to improve access to PC have been suspended. Furthermore, COVID-19 restrictions that hinder appropriate care delivery to the dying add to the distress of patients and their families, while social distancing and the ban on group gatherings disrupt the normal experience of grief and communal bereavement practices. In Africa, little has been done to develop the evidence base and adapt PC interventions to improve grief and bereavement outcomes. Research is required to address the evidence gaps and ensure that bereaved families receive appropriate support. **Full text:** <https://bit.ly/3yzzRNM>



Noted in Media Watch 22 February 2021 (#705, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 February 2021 – ‘**Do the clinical management guidelines for COVID-19 in African countries reflect the African quality palliative care standards? A review of current guidelines.**’ The authors set out to critically appraise the case management guidelines for COVID-19 in Africa for their palliative care (PC) content and evaluate the adequacy of this against African Palliative Care Association standards for quality PC provision across Africa. The majority of the countries with specific sections on PC are in Southern and Eastern Africa. This reflects the development of PC in these countries with strong advocacy networks and well-developed services and national policies. **Full text:** <https://bit.ly/3ubMH2J>

Psychologists in pediatric palliative care: Clinical care models within the U.S.

CLINICAL PRACTICE IN PEDIATRIC PSYCHOLOGY | Online – Accessed 2 August 2021 – Pediatric psychologists are not currently recognized as core members of interdisciplinary pediatric palliative care (PPC) teams, which aim to reduce physical, psychological, social, practical, and spiritual suffering for children with chronic illnesses. However, the authors' findings suggest that pediatric psychologists provide important services to enhance the care of children with life-limiting conditions, including psychological assessment and treatment for patients and families, support for healthcare staff, supervision and mentorship of trainees, and skills in conducting research. This article outlines the roles and scope of services provided by psychologists within the purview of PPC and potential strategies for improving systematic inclusion of psychologists in PPC to advance holistic care for youth with serious illness and their families. **Abstract:** <https://bit.ly/2Vokbht>



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The physical hospital environment and its effects on palliative patients and their families: A qualitative meta-synthesis

HEALTH ENVIRONMENTS RESEARCH & DESIGN JOURNAL | Online – 6 August 2021 – People with a life-limiting illness may receive palliative care to improve their quality of life (QoL) in hospital and may have multiple admissions as their illness progresses. Yet, despite a preference for a death at home, more than half of the dying population will receive end-of-life (EoL) care in hospital. The physical hospital environment consists of ambiance, aesthetics, and architectural factors, and it is well known that the hospital's acute wards are not a homely environment. Demand is increasing for the physical environment to be improved to better meet the needs and demands of palliative and EoL patients and their families. Findings of this study resulted in the development of the SSAFeR Place approach that incorporates the concepts that are important to palliative and EoL patients and their families by describing an environment within the acute or PC units that feels safe, is private, customizable, and accommodates family; is a space to share with others, is homelike in ambiance and aesthetics, and is conducive for reflection. The concepts of identity, belonging, and safety are connected to the notions of home. To provide person-centered care and to move the focus toward the palliative approach of comfort and QoL, attention to room size, layout, aesthetics, and ambiance is needed. **Abstract (w. references):** <https://bit.ly/2VDZRJf>

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

Lessons learned from introducing Last Aid courses at a University Hospital in Germany

HEALTHCARE, 2021;9(7):906. In recent years, so called “Last Aid courses”, concerning end-of-life care for people dying, have successfully been established in community settings in several European countries, Australia, and South-America. To date, they have not been evaluated in hospital settings, where educational needs (concerning care of the dying) are especially high, and may differ from the general population. To evaluate if Last Aid courses are feasible in hospital settings, and if informational needs of hospital staff are met by the curriculum, the authors introduced Last Aid courses at a university hospital. Five courses were offered; participants of courses 1 and 2 completed surveys with open-ended questions; the answers were used to develop the evaluation questionnaire employed in courses 3-5. In these three courses, 55 of the 56 participants completed an evaluation survey to explore their learning goals and obtain feedback. Courses were fully booked; participants were heterogeneous with regard to their professional background. The most prevalent learning goals were “preparation for emotional aspects in care of dying,” “preparation for medical/care aspects in care of dying,” and “knowledge of supportive services and facilities.” **Full text:** <https://bit.ly/37xxPBz>

Noted in Media Watch 15 February 2021 (#704, p.12):

- *PUBLIC HEALTH* | Online – 5 February 2021 – ‘**First experiences with online Last Aid courses for public palliative care education during the COVID-19 pandemic.**’ The Last Aid course aims to teach public palliative care (PC) by increasing public awareness and empowering people about the role of the individual in the death of loved ones. The COVID-19 pandemic, however, has altered educational methods prohibiting classroom settings. Therefore, an online course was created to enable continued and safe public PC education. The online platform enabled course participation from people previously unable or unwilling to attend, namely caregivers to dying relatives and younger people. Instructors displayed an ability to teach online. **Full text:** <http://bit.ly/3q9cSot>

Noted in Media Watch 4 February 2019 (#600, p.10):

- *HEALTHCARE* | Online – 28 January 2019 – ‘**Last Aid Course. An education for all citizens and an ingredient of compassionate communities.**’ Knowledge in palliative care (PC) is very limited or totally absent in most communities, and information about the effects of educational procedures in teaching non-professionals in basic PC is sparse. In the Last Aid courses, the public knowledge approach and the initial experiences from the implementation process are described. In addition, a review of the literature on educational efforts regarding PC for non-professionals and the existing literature on courses is provided. An international working group has established a curriculum for Last Aid courses based on four teaching hours (45 minutes each). **Full text:** <http://bit.ly/2Bem43h>

Understanding the bereavement process: Voices of bereaved parents

ILLNESS, CRISIS & LOSS | Online – 3 August 2021 – Analysis of in-depth qualitative interviews with 20 bereaved parents and 11 service providers revealed a more holistic conceptualization of the bereavement process for parents who have lost a child. Holistic “states” included: “helplessness prior to the death,” “fog,” “turmoil,” “transition,” “new beginnings,” and “stability.” Findings of this study showed that loss and restorative processes are characteristic of more than one state, the bereavement narrative starts prior to the death, there is often a downturn after the bereaved parent seemingly is doing better, and the process never ends but may include a continuing bond with the deceased and reoccurring moments of extreme grief. Recommendations for direct practice, program development, and future research are presented. **Full text:** <https://bit.ly/3xm0m7F>

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), at: <http://bit.ly/2OB4Y6C>

“I was not able to keep myself away from tending to her immediate needs”: Primary care physicians’ perspectives of serious illness conversations at community health centers

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 29 July 2021 – Initiatives that promote serious illness (SI) conversations in community health centers (CHCs) can reach broad, diverse patient populations. This study explored the experiences of primary care physicians in conducting SI conversations at CHCs in order to understand challenges and needs in this setting. Eight themes emerged: 1) Structured approaches to SI conversations are useful even in longstanding patient-doctor relationships; 2) Discussion of prognosis is meaningful, but difficult; 3) Emotional work is humanizing, but draining; 4) Poverty and underinsurance are high priorities; 5) Social context affects patient readiness; 6) Communication barriers take multiple forms; 7) Patient characteristics make it “easier” or “harder” to initiate the SI conversation; and, 8) Time constraints limit the ability to meet multiple patient needs. **Abstract (w. references):** <https://bit.ly/3lg16sM>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 August 2021 – ‘**Goals-of-care discussions over the course of a patient’s end-of-life admission: A retrospective study.**’ As deaths in hospitals increase, clear discussions regarding resuscitation status and treatment limitations, referred to as goals-of-care (GOC), are vital. GOC may need revision as disease and patient priorities change over time. There is limited data about who is involved in GOC discussions, and how this changes as patients deteriorate in hospital. In this study, as patients deteriorated, family and senior clinician involvement in GOC discussions increased, but patient involvement did not. Junior doctors were most heavily involved in discussions. **Abstract (w. references):** <https://bit.ly/3Cor6Z9>
- *PEDIATRIC BLOOD & CANCER* | Online – 6 August 2021 – ‘**Broaching goals-of-care conversations in advancing pediatric cancer.**’ Presently, the communication strategies used by pediatric oncologists to approach goals-of-care (GoC) conversations are not well understood. The authors recorded disease re-evaluation conversations between pediatric oncologists, patients, and parents, capturing 141 conversations for 17 patients with advancing illness across the study period. They conducted content analysis to identify strategies for broaching GoC conversations and found five distinct communication approaches, which were not mutually exclusive. Further research is needed to explore patient and family views on best practices for broaching discussions about GoC. **Abstract:** <https://bit.ly/3jAD21a>

Noted in Media Watch 15 March 2021 (#708, p.8):

- *MEDED PORTAL* | Online – 10 March 2021 – ‘**Effective goals-of-care conversations: From skills training to bedside.**’ The authors created a simulation-based learning experience to teach one aspect of serious illness communication – the late goals-of-care conversation when a person is close to end of life. This training included breaking difficult news, sitting with strong emotion, matching priorities with treatment preferences, and recommending hospice care. Residents reflected on why these emotional, challenging conversations matter; recognized turning points in an illness signaling the need to pause and assess a patient’s goals and priorities; and, understood and applied an evidence-based serious illness conversation guide in skills practice with standardized patients. **Full text:** <https://bit.ly/3ez1r6s>

Social model hospice home: A concept analysis

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 27 July 2021 – The term *social model hospice* first appeared late in the 20th century as a label for a complementary model to medical hospice care. Two decades later, the term is inconsistently defined and used by scholars, healthcare providers, public consumers, and those within the movement. The purpose of this review is to trace the development of the concept and confirm an evolving definition... Unique antecedents include presence of a resource crisis, unmet needs falling outside the scope of medical hospice care, and desire to experience death outside the medical system and/or personal home. Attributes include a dedicated home, round-the-clock, individualized end-of-life care (EoL) care; care option when dying at home becomes unmanageable; collaboration with medical hospice services; nonprofit organization funded by community philanthropy; environment to support loved ones; and, community volunteer involvement. Noted consequences are effective EoL care for dying patients and their families, innovative healthcare design, nationwide network of like-minded providers, and platform for EoL community education. Clarity of the concept will facilitate access to EoL care, further the model's development, formalize research endeavors, and foster community education. **Abstract:** <https://bit.ly/37bNlxx>

Noted in Media Watch 14 September 2015 (#427, p.12):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2015;17(5):456-461. 'An introduction and overview of social model hospice care.' The social model hospice is an option for families facing the harsh realities of caring for a loved one at the end of life as well as addressing the gap that exists between desired and actual place of death for hospice patients. Honoring the individual's values, goals, and informed preferences, the model complements and enhances traditional medical hospice care. It is provided in a community home, utilizing a network of volunteers and paid staff, in combination with traditional medical hospices, addressing the lack of resources and the burden often accompanying care of the dying. **Abstract:** <https://bit.ly/3rNLeyK>

End-of-life care for people living with neurodegenerative disorders

Advance care plans and the potentially conflicting interests of bedside patient agents: A thematic analysis

JOURNAL OF MULTIDISCIPLINARY HEALTHCARE, 2021;14:2087-2100. This study provides insights into the potentially conflicting interests experienced by bedside patient agents who seek to represent the best interests of neurodegenerative disorders (PWND). Although bedside patient agents endeavour to respect patient choices, doctors feel conflicted about relying on advance care planning (ACP) as sources of truth. Doctors do not appear conflicted by patient agency when doctors and families agree with the decisions within the ACP. Generally doctors perceive that family cannot be excluded from a temporal decision-making partnership, elevating the needs of doctors and family beyond the agency of the PWND. Whilst not all ACPs are legally persuasive, doctors engage families and make decisions on behalf of PWND regardless of ACP legal status, thus placing bedside agents and patient agency in potential conflict. It appears that there are substantial limitations to the effectiveness of PWND's agency expressed through ACP, and that bedside agents can experience considerable intra and interpersonal conflict. The complex interplay between healthcare systems and the realisation of agency through ACP warrants further research. **Full text:** <https://bit.ly/3rWqc0Y>

N.B. Search back issues of Media Watch for articles on end-of-life care for people living with "neurodegenerative" disorders" and "neuropalliative" at: <http://bit.ly/2ThijkC>

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Related:

- *CURRENT MEDICAL RESEARCH & OPINION* | Online – 30 July 2021 – ‘**Integration of palliative care in Parkinson’s disease management.**’ Analysis of various existing literature has demonstrated promise in timely palliative care (PC) integration for patients with Parkinson’s disease (PD), which has shown improvement in the quality of life (QoL) of PD patients. It also strives to alleviate caregivers’ stress and improve their QoL, although insufficient research exists to support this. PC in PD is a growing area of interest, evidently demonstrating the potential to expand among the current approaches. Understanding the connections between the themes surrounding PC is crucial for successful integration in PD management. **Abstract:** <https://bit.ly/3C39NfP>

N.B. Search back issues of Media Watch for additional articles on PC in “Parkinson’s” disease management at: <http://bit.ly/2ThijkC>

National Comprehensive Cancer Network guidelines® insights: Palliative care, Version 2.2021

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2021;19(7):780-788. This article highlights recent updates to the 2021 version of the Network’s guidelines for palliative care. Several recommendations were made by the expert panel to enhance the quality of life of patient/family/caregivers throughout the disease trajectory. These include effectively assessing and addressing psychosocial distress, promoting adaptive coping strategies for patients/family/caregivers, and emphasizing the need for holistic cancer care plans that include patient/family/caregiver education and support. The panel acknowledged and recommended describing the PC team as “interprofessional” to emphasize its collaborative nature. Updates also included suggestions for a multimodal approach to the management of anorexia/cahemia. **Full text:** <https://bit.ly/3rQ81Ko>

Related:

- *BRITISH JOURNAL OF CANCER* | Online – 2 August 2021 – ‘**Communication around palliative care principles and advance care planning between oncologists, children with advancing cancer and families.**’ In medical oncology, palliative care (PC) principles and advance care planning (ACP) are often discussed later in illness, limiting time for conversations to guide goal-concordant care. In pediatric oncology, the frequency, timing and content of communication about PC principles and ACP remains understudied. Communication strategies for navigating these conversations can inform development of educational and clinical interventions to encourage earlier dialogue about OC principles and ACP for children with high-risk cancer and their families. **Abstract (w. references):** <https://go.nature.com/3yuVeQb>

Parental decision-making for children with medical complexity: An integrated literature review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 4 August 2021 – Children with medical complexity (CMC) have multiple significant chronic health conditions that result in functional limitations and high healthcare utilization. The population of CMC is increasing and parent decision-making for this population is nuanced. A comprehensive, systematic approach was undertaken with the goal of identifying emergent themes in the existing literature as well as implications for clinical practice and future research. The search yielded 300 unique manuscripts; including 32 empirical articles incorporated in this review. The synthesized findings were broken down into three main sections: 1) Types of decisions that parents of CMC face; 2) Key factors that influence parental decision-making for CMC; and, 3) Reasons that the decision-making process for parents of CMC is unique. The findings suggest that parents should be considered experts in their child’s care and should be incorporated in shared decision-making in a culturally appropriate manner. CMC should have their personhood valued and providers require specialized training in communication. **Abstract (w. references):** <https://bit.ly/3rRcQTX>



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.13.

Palliative care education for surgical residents: Current practices and future directions

JOURNAL OF SURGICAL EDUCATION | Online – 1 August 2021 – Despite the benefits and increased clinical application of primary palliative care (PC) principles within surgery, PC education among surgical trainees remains varied and poorly defined. Through a survey of general surgery program directors, this perspective highlights current PC educational practices of general surgery residencies and existing curricula. Although program directors deemed PC education important to surgical training, barriers to improving resident education included limited overall educational time, few available PC experts, and the lack of a dedicated curriculum. There is a need for a surgical PC educational toolkit that is validated, easily available, incorporates local experts, and adjustable to the variety of educational practices of surgical programs and their residents. **Abstract:** <https://bit.ly/3yldknu>

Noted in Media Watch 29 March 2021 (#710, p.12):

- *SURGERY* | Online – 18 March 2021 – ‘**Palliative medicine and end-of-life care in surgery.**’ Surgeons are privileged to offer treatments that often cure disease. Optimizing comfort for those who cannot be cured is also a core part of every clinician’s duty; surveys repeatedly tell us that when death is approaching, people value quality of life above length of survival. Recognizing when someone is dying can be difficult. Tools exist to help; it is worth noting that emergency presentation with life-threatening symptoms can be a marker of poor prognosis. Clear, effective communication is crucial: understanding the patient’s perspective and expectations is vital before attempting to offer information that allows future care planning. **Abstract:** <http://bit.ly/319k3ID>

Noted in Media Watch 30 November 2020 (#694, p.5):

- *THE AMERICAN SURGEON* | Online – 24 November 2020 – ‘**Surgical palliative care: Where are we in 2020?**’ Dr. Balfour Mount, a retired urologic surgeon is considered the father of North American palliative care (PC). Dr. Geoffrey P. Dunn, a retired general surgeon and hospice and palliative medicine (PM) specialist along with other like-minded surgical colleagues were instrumental in developing the field of surgical PC in the U.S. Dr. Olga Jonasson, championed the American Board of Surgery becoming one of the sponsoring boards of the hospice and PM certifying exam. Dr. Anne Mosenthal advocated for PC to be integrated as parallel clinical aims so espoused in the ‘Trauma Quality & Improvement Program Palliative Care Best Practice Guidelines.’ **Abstract (w. references):** <https://bit.ly/2V0IGyZ>

Variations in end-of-life practices in intensive care units worldwide: A prospective observational study

THE LANCET RESPIRATORY MEDICINE | Online – 5 August 2021 – End-of-life (EoL) practices vary among intensive care units worldwide. Differences can result in variable use of disproportionate or non-beneficial life-sustaining interventions across diverse world regions. This study investigated global disparities in EoL practices. In this prospective, multinational, observational study, consecutive adult ICU patients who died or had a limitation of life-sustaining treatment (withholding or withdrawing life-sustaining therapy and active shortening of the dying process) during a 6-month period between 1 September 2015 and 30 September 30 2016, were recruited from 199 ICUs in 36 countries. The primary outcome was the EoL practice as defined by the EoL categories: withholding or withdrawing life-sustaining therapy, active shortening of the dying process, or failed cardiopulmonary resuscitation. Patients with brain death were included in a separate predefined EoL category. Data collection included patient characteristics, diagnoses, EoL decisions and their timing related to admission and discharge, or death, with comparisons across different regions. Patients were studied until death or 2 months from the first limitation decision. Limitation of life-sustaining therapies is common worldwide with regional variability. Withholding treatment is more common than withdrawing treatment. Variations in type, frequency, and timing of EoL decisions were observed. Recognising regional differences and the reasons behind these differences might help improve EoL care worldwide. **Full text:** <https://bit.ly/3lDXmBI>

Cont.

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 August 2021 – ‘**Trends in palliative care consultations in critically ill patient populations, 2013-2019.**’ Critically ill patients have important palliative care (PC) needs in the intensive care unit (ICU), but specialty PC is often underutilized. Across 39,515 ICU patients seen by a PC team, overall numbers of consultations from the ICU increased each year. PC referrals in ICU patients with cancer are decreasing, while those for cardiovascular disease are increasing. Reasons for referrals in the ICU are commonly for goals-of-care (GoC); other reasons, like pain control are uncommon. Early GoC conversations and further training in advance care planning should be emphasized in the ICU setting. **Abstract (w. references):** <https://bit.ly/3CdPWec>

Noted in Media Watch 5 July 2021 (#724, p.8):

- *CRITICAL CARE EXPLORATIONS* | Online – 25 June 2021 – ‘**Incorporating early palliative medicine consultation into daily morning huddle in the ICU.**’ Case managers identified patients with early palliative medicine (PM) 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. 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>

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>

Attitudes and preferences towards palliative and end-of-life care in patients with advanced illness and their family caregivers in Latin America: A mixed studies systematic review

PALLIATIVE MEDICINE | Online – 2 August 2021 – Achieving universal access to palliative care (PC) is considered a global and equity priority. Understanding patients and caregivers’ attitudes and preferences towards palliative and end-of-life (EoL) care in Latin America is essential to develop person-centred services in the region. Forty-five articles were included, comprising 7 countries and a total of 1,220 patients and 965 caregivers (26.8% non-cancer-related participants). Data were organized around seven themes: 1) Symptom management and nutrition; 2) EoL medical decisions; 3) Communication patterns; 4) Place of EoL care and death; 5) God and religious community as source of hope and support; 6) Caregiver’s role; and, 7) Mixed understandings of PC. Main findings include; conflicted views around PC and pain relief; patients’ preference to be informed about their condition contrasting with caregivers’ reluctance to discuss this with patients; common preference for shared decision-making; and, overburdened caregivers lacking professional home-care support. **Abstract (w. references):** <https://bit.ly/2WDcC78>

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**Prison Hospice: Backgrounder
Updated 1 August 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 at the Palliative Care Network website: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk, Philadelphia, PA

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 4 August 2021 – ‘**How universal is palliative care in Colombia? A health policy and systems analysis.**’ The authors’ analysis shows that the country’s failure to integrate palliative care (PC) most likely is a result of limited health worker education. Advocacy efforts should include deans of schools and provosts, in addition to policymakers and regulators. Other possible factors affecting uptake and implementation of existing national policies are civil unrest and limited collaboration between government offices. Additional research is needed to evaluate the impact of these and other related factors on PC integration in Colombia. **Abstract (w. references):** <https://bit.ly/3jyfBWx>

Noted in Media Watch 7 June 2021 (#720, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 May 2021 – ‘**Palliative care in Latin America: Are we making any progress? Assessing development over time using macro indicators.**’ The authors conducted a secondary analysis of data collected for the 2012 and 2020 editions of the ‘Atlas of Palliative Care in Latin America’ using indicators on policy, education, access to medicines and service provision.^{1,2} The number of countries with a national palliative care (PC) plan increased from 5 to 9; percentage of medical schools with PC as an independent subject at the undergraduate level grew from 4.2 to 17.1%; distributed opioid morphine equivalence increased from 6.6 to 7.1 mg/capita; and, number of services increased from 1.5 to 2.6 million. **Abstract (w. references):** <https://bit.ly/3vEj1eU>

1. ‘Atlas de Cuidados Paliativos de Latinoamérica,’ Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch 7 January 2013 (#287, p.8)] **Download at:** <https://bit.ly/3ldpJmu>

N.B. Click on pdf icons to access either Portuguese, Spanish or English language editions of the Atlas.

2. ‘Atlas de Cuidados Paliativos de Latinoamérica,’ Asociación Latinoamericana de Cuidados Paliativos, 2020. **Download Spanish edition at:** <https://bit.ly/3c5PQtr>

Quality and cost outcomes of an integrated supportive care program

SUPPORTIVE CARE IN CANCER | Online – 1 August 2021 – Palliative care (PC) services have become increasingly available over the past two decades. Recent reports suggest that half of all hospitals [in the U.S.] with > 50 beds, and as much as 90% of hospitals with > 300 beds, now have some type of PC program. As programs have grown, so too has the evidence base of the improvements in patient outcomes associated with PC. However, most reports document outcomes either within very specific, disease-oriented categories (e.g., stroke, heart failure, and lung cancer) or have been limited in the type of outcomes measured. This pragmatic demonstration project confirmed the clinical benefits of an integration of supportive care for patients with advanced cancer, although no reduction in costs was found. **Full text:** <https://bit.ly/37tZzaB>

Making your geriatric and palliative programs a strength: Trauma Quality Improvement Project guideline implementation and the Verification, Review & Consultation perspective

TRAUMA SURGERY & ACUTE CARE OPEN | Online – 15 July 2021 – In this article, the implementation of geriatrics and palliative principles in trauma centers is discussed. In addition to the discussion of how quality metrics can be tracked and used for performance improvement and leveraged as a strength for trauma verification from the perspective of the American College of Surgeons’ Verification, Review & Consultation, three examples of how palliative and geriatric focused measures have been successfully implemented were provided. These three institutions performed gap analysis and then implemented organization-specific initiatives tailored to the environment in which they were achieved. Some of the key takeaways from these experiences is the realization that geriatric and palliative care (PC) principles can be incorporated into existing educational forums and structure and can be customized to the needs of the institution. Taking advantage of existing strengths and collaborative stakeholders and identifying champions will create programs and approaches that will be successful and sustained. Opportunities such as those described earlier provide thoughtful and evidence-based treatment for older patients, including geriatric-focused medical care and dedication to PC principles. **Full text:** <https://bit.ly/3ilvIY4>

Cont.

Noted in Media Watch 19 April 2021 (#713, p.4):

- **AGE & AGEING** | Online – 9 April 2021 – ‘**Examining the role of specialist palliative care in geriatric care to inform collaborations: A survey on the knowledge, practice and attitudes of geriatricians in providing palliative care.**’ This was a voluntary anonymous online survey distributed to all full members of the Australian & New Zealand Society of Geriatric Medicine. Geriatricians overwhelmingly believed they should coordinate care and derived satisfaction from providing palliative care (PC). Regarding knowledge, participants scored an average of 13.5 correct answers out of 18 in a Modified Palliative Care Knowledge Test. Geriatricians find reward in providing generalist PC to their patients; however, potential exists for improved collaborations with specialist PC services. **Full text:** <https://bit.ly/3g0MLO9>

Noted in Media Watch 15 February 2021 (#704, p.7):

- **JOURNAL OF THE AMERICAN GERIATRIC SOCIETY** | Online – 13 February 2021 – ‘**Geriatrics and palliative medicine leadership is needed now more than ever: What are the training gaps?**’ Geriatrics and palliative medicine (PM) specialists are uniquely trained to provide expert coordinated care for older adults and seriously ill and complex patients. Health system leadership geared towards this patient population is critically important as Society ages. To assess the leadership training needs of geriatrics and PM fellowship graduates, the authors conducted a needs assessment to identify: 1) Early career leadership trajectories and challenges; and, 2) Knowledge and skills deemed essential for effective leadership. **Abstract:** <https://bit.ly/3qikTHv>

Noted in Media Watch 8 February 2021 (#703, p.9):

- **EUROPEAN GERIATRIC MEDICINE** | Online – 1 February 2021 – ‘**Palliative care competencies for geriatricians across Europe: A Delphi consensus study.**’ Early identification of patients in need of palliative care (PC) becomes crucial in particular for older patients with chronic conditions. The Delphi process described enabled the development of a European specific core competency catalogue to improve competencies of geriatricians to enable them to guide their patients through the last period of life. The current version of the PC competency catalogue represents an important step in the development of effective PC education within the training of geriatricians, which is essential given the condition’s increasing relevance to twenty-first century healthcare. **Full text:** <https://bit.ly/36wpzSo>

[Media Watch: Access on Online](#)

International



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

[Scroll down to ‘Media Watch: At-home Care’]

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

PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

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Asia



ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2SWdYWP>

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Australia

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PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to ‘Useful Resources in Palliative Care Research’]

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Canada



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>

South America

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

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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.

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