

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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Most important, we need to shift the focus from talking to healthy people about what would happen should they stop breathing during a routine procedure, and toward improving conversations with people who are already seriously ill.

'When faced with death, people often change their minds' (p.3), in *The New York Times*.

Important Notice: With this, the 750th issue, publication of Media Watch is suspended. This pending a reassessment of the weekly report as an advocacy, research and teaching tool. Stay tuned.

U.S.A.

Regulators eyeing Medicare hospice spending

HOSPICE NEWS | Online – 7 January 2022 – As hospice utilization and associated costs continue to rise, federal regulators are looking more closely at providers and the services they provide. The U.S. Centers for Medicare & Medicaid Services (CMS) and the U.S. Department of Health & Human Services Officer of the Inspector General are zeroing in on longer lengths of stay, billing for services deemed unrelated to the terminal diagnosis and use of general inpatient care, among other concerns. In 2019, more than 1.6 million Medicare beneficiaries elected the hospice benefit, costing CMS \$20 billion, according to the Medicare Payment Advisory Commission (MEDPAC). This is up from about 548,000 and \$3.5 billion in 2001. The cost of care per hospice patients rose to \$12,687 in 2019 from \$11,258 in 2010, MEDPAC reported. While hospice certainly reduces healthcare spending in contrast to hospital or other high-acuity care, regulators are on the lookout for opportunities to cut costs. While CMS has no rules that limit the duration of services such as general inpatient care, the agency seeks to ensure that providers are applying appropriate criteria, as well as affirming patients' eligibility for hospice. <https://bit.ly/3r17zct>

Cancer patients often not referred to palliative, mental health care

HOSPICE NEWS | Online – 6 January 2022 – Many specialists do not refer cancer patients to palliative care (PC) or mental health care during their course of treatment, a survey of more than 240 oncologists found.¹ The physicians cited a lack of understanding of PC as a leading barrier. Among the respondents, 68% said they were aware that early access to PC correlates with better outcomes, but only 17% indicated that they refer patients to those services at the time of diagnosis. About 43% responded that clinicians

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needed more training on having goals of care conversations with cancer patients. Respondents included a mix of community-based and hospital physicians. “The results are surprising when considering that several research studies have shown that a significant portion of patients with cancer are referred to PC too late,” according to the study. A key barrier that limits access to PC include resistance to the idea from patients and families, often because of a lack of awareness of what these services are. Many mistakenly believe that PC is only available during a patient’s final days, often confusing those services with hospice. This is frequently an issue among clinicians as well, according to the surveyed oncologists. Between 25% and 50% of those physicians who indicated that some of their patients were receiving PC concurrently with curative care. About 21% said they only offered PC referrals when the patient is close to death. <https://bit.ly/3zA4F2b>

1. ‘New research with oncologist,’ Cardinal Health, December 2021, <https://bit.ly/3zB0RO0>

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

- *JCO ONCOLOGY PRACTICE* | Online – 22 December 2021 – ‘**Why are we failing to do what works? Musings on outpatient palliative care integration in cancer care.**’ In their recent study, Yeh *et al* add to the mounting evidence showing a myriad of benefits conferred by outpatient integrated palliative care (PC) in oncology.¹ However, despite this clear evidence, we have not achieved widespread PC implementation outside of trials. First, we must be clear in our terminology. The term PC is often misused and misunderstood as a euphemism for end-of-life care or hospice. Specialty PC is also different from the primary PC usually provided by the oncology team (e.g., basic symptom management and what is often called supportive care). **Full text:** <https://bit.ly/3egU9Tw>

1. ‘Different associations between inpatient or outpatient palliative care and end-of-life outcomes for hospitalized patients with cancer,’ *JCO Oncology Practice*, published online 16 December 2021. **Full text:** <https://bit.ly/3H1OxsC>

Pandemic takes heavy toll on hospice bereavement care

HOSPICE NEWS | Online – 3 January 2022 – Concerns continue to mount among hospice providers regarding their ability to reach grieving families heading into a third year of the coronavirus pandemic. Many hospices moved their bereavement care services online to keep a safe distance amid rising demand, but long-term plans are difficult to formulate given rampant uncertainty about how the outbreak will proceed. Hospice providers must offer bereavement counseling for a minimum of 13 months following a patient’s death, per U.S. Centers for Medicare & Medicaid Services requirements. Hospices often extend grief care available throughout their entire communities, regardless of whether the deceased was a patient. COVID-19 sparked a growing need for bereavement care, with many hospices seeking out ways to meet community needs by applying additional resources and new methods. Just shy of two years following the initial federal emergency declaration on 13 March 2020, the deadly virus has claimed upwards of 820,350 lives nationwide as of 29 December 2021, according to recent data from the U.S. Centers for Disease Control & Prevention.¹ <https://bit.ly/3zqMxYA>

1. ‘COVID Data Tracker,’ U.S. Centers for Disease Control & Prevention, accessed 4 January 2022. **Download at:** <https://bit.ly/3EO3nS8>



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>

When faced with death, people often change their minds

THE NEW YORK TIMES | Online – 3 January 2022 – Since the Patient Self-Determination Act of 1990 went into effect, advance care planning (ACP) – which encourages all adults, even those in good health, to choose a surrogate to make medical decisions and to draw up an advance directive – has been promoted as the way to make sure that people receive the care they want at the end of their life. But this well-intentioned effort has not worked as promised. In a recent commentary ... a palliative care (PC) specialist, and colleagues wrote that despite decades of research on ACP, there are scant data to show that it accomplishes its goals.¹ A 2020 review of more than 60 high-quality recent studies on ACP found no impact on whether patients received the care they wanted, or how they rated the quality of their lives afterward.² When doctors talk to patients about

advance directives, they implicitly promise that the directives will help patients get the care they want and unburden their loved ones, Dr. R. Sean Morrison, a PC specialist observes. “And the reality is that we’ve been pushing a myth,” he adds. <https://nyti.ms/3JF5OKa>

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‘Shifting to serious illness communication’ (p.10), in *JAMA Network Open*.

‘End-of-life preferences in older U.S. adults – bridging the “what matters” chasm’ (p.10), in *JAMA Network Open*.

1. ‘What’s wrong with advance care planning?’ *Journal of the American Medical Association*, 2021;326(16): 1575-1576. [Noted in Media Watch 11 October 2021 (#738, p.7)] **Full text:** <https://bit.ly/3FyPlje>
2. ‘Deconstructing the complexities of advance care planning outcomes: What do we know and where do we go? A scoping review,’ *Journal of the American Geriatrics Society*, 2021;69(1):234-244. **Full text:** <https://bit.ly/3JO1wR4>

Related:

- *KAISER HEALTH NEWS* | Online – 6 January 2022 – ‘**A new paradigm is needed: Top experts question the value of advance care planning.**’ For decades, Americans have been urged to fill out documents specifying their end-of-life wishes before becoming terminally ill – living wills, do-not-resuscitate orders, and other written materials expressing treatment preferences. Now, a group of prominent experts is saying those efforts should stop because they haven’t improved end-of-life care. “Decades of research demonstrate advance care planning doesn’t work. We need a new paradigm,” said Dr. R. Sean Morrison, chair of geriatrics and palliative medicine at the Icahn School of Medicine at Mount Sinai ... and a co-author of a recent opinion piece advancing this argument...¹ <https://bit.ly/3qO0Dz8>
 1. ‘What’s wrong with advance care planning?’ *Journal of the American Medical Association*, 2021;326(16): 1575-1576. [Noted in Media Watch 11 October 2021 (#738, p.7)] **Full text:** <https://bit.ly/3FyPlje>

Noted in Media Watch 3 August 2020 (#677, p.9):

- *HEALTHCARE*, 2020;8(3):E218. ‘**Advance care planning vs. advance serious illness preparations and planning.**’ The author argues that the prevailing understanding and current practice of advance planning (ACP) ... results in patients not receiving optimal patient-centered care. Much of the problem centers on the framing of ACP around end-of-life care, the lack of use of decision support tools, and inadequate language that does not support shared decision-making. A new approach and new terminology is needed. Advance Serious Illness Preparations & Planning consists of discrete steps using evidence-based tools to prepare people for future clinical decision-making in the context of shared decision-making and informed consent. **Full text:** <https://bit.ly/30GUkAc>



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.14.

International

A path to healthier discussion: Introducing bereavement, death and grief onto the curriculum

U.K. | *Independent Education Today* – 7 January 2022 – Bereavement, death and grief are a part of life, even for young people and yet society struggles to discuss the topic openly or sometimes even at all. This perpetuates the longstanding stigma attached to death, which does a significant disservice to society as a whole. Breaking this stigma is key and by introducing the topic into the curriculum alongside other life topics, we can give young people the tools and life skills to help themselves and others now and in their future lives. One of the most important considerations for introducing the subject and teaching it proactively is the potential benefit to mental health. The taboo associated with death and dying means that people are often unprepared and conversations around the topic are reactive, making it difficult for individuals to cope with and speak about their loss. Preparing students for death in advance ensures that they are familiar with the emotions associated with grief and ways of coping.

Giving students the confidence to speak openly about death and grief will help combat the isolation and loneliness that people who have experienced bereavement very often feel. Furthermore, having the opportunity to speak freely about their feelings can play an important role in promoting positive mental health. Teachers are familiar with handling traditionally difficult subjects, such as sex and drugs, and yet death is inexplicably left off the curriculum. Given that mortality is the only certainty in life, it feels only right it should be included in education. <https://bit.ly/3f1ktRX>

Specialist Publications

'Can we talk about life without taking death into account? Early childhood educators' self-perceived ability to approach the topic of death with children' (p.13), in *Omega – Journal of Death & Dying*.

N.B. Selected articles on bereavement training for teachers noted in Media Watch 13 September 2021 (#734, p.3). See also 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) and 'In the Classroom' (p.37) at: <http://bit.ly/2OB4Y6C>

COVID-19: Hospices “may have to close beds and cut services” amid 40% drop in fundraising

U.K. | Sky News (London) – 3 January 2022 – Doctors and nurses working in hospices across the U.K. are calling on the government to provide more funding to ensure they can continue providing critical care. The hospice sector saw demand for its services increase significantly during the pandemic, as many centres were able to alleviate pressure on hospitals by treating patients at home. Hospices rely on fundraising to cover their costs, but during the pandemic this was made much more difficult as charity shops closed and it was harder to host fundraising events. According to Hospice UK data, this led to a 40% drop in fundraising and income levels still haven't fully recovered.¹ A spokesperson for the Department of Health & Social Care told Sky News: “We are incredibly grateful to the hospice sector for their tireless efforts throughout the pandemic and we are working closely with the sector. “Hospices received an additional £257 million of grant funding in 2020-2021, as part of the COVID-19 response to provide additional services and support discharge from hospitals.” But Dr. Corinna Midgely, a consultant at Saint Francis Hospice in Romford, Essex, said this cash boost has long run out and hospices are now facing immense challenges. <https://bit.ly/3sSK-MCb>

1. ““Jenga-like” funding model undermining capacity of hospices,” Hospice UK, accessed 3 January 2022. <https://bit.ly/32lo70A>

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Noted in Media Watch 15 March 2021 (#708, p.4):

- U.K. (England) | *Charity Today News* – 8 March 2021 – ‘**Charity urges government to end hospice funding crisis.**’ Sue Ryder ... commissioned an independent report looking into the rise in demand and cost for end-of-life (EoL) care services over the next ten years.¹ 245,000 people in the U.K. are expected to receive PC in the coming year. This is expected to increase to 379,000 people per year by 2030. Independent hospices only receive around one-third of the money required to fund their EoL services from the government. The running costs of the PC sector are estimated to be £947 million a year between now and 2030, and if government funding remains the same, the hospice sector will be required to fund-raise £597 million every year in order to keep hospices open. <http://bit.ly/3bvKOM1>

1. ‘Modelling demand and costs for palliative care services in England. A final report for Sue Ryder,’ London Economics, February 2021. **Download/view report at:** <http://bit.ly/3v29izf>

N.B. Selected articles on the U.K.’s funding of hospice crises noted in Media Watch 23 November 2020 (#693, pp.5-6).

[Specialist Publications](#)

Perinatal palliative care

ANALES DE PEDIATRIA | Online – 6 January 2022 – At present, congenital diseases and malformations that may lead to the death of the patient during gestation, birth or in childhood are usually diagnosed antenatally. In spite of this, affected foetuses and pregnant women are rarely offered specialised palliative care (PC). When a potentially life-limiting malformation or disease is diagnosed prenatally, the American College of Obstetricians & Gynecologists and the American Academy of Pediatrics recommend informing pregnant women of the different options available to them along with their risks and benefits, promoting their autonomy and freedom to choose. Therefore, in addition to detailed documentation on different options for voluntary termination of pregnancy based on gestational age, pregnant women and their partners should be given information on pediatric palliative care, an emergent field focused on the complex management of foetal diseases and the overwhelming circumstances experienced by affected families, offering interdisciplinary care to those families that choose to seek it. Follow-up care should also be offered to parents that choose to terminate the pregnancy, including psychological support, if necessary. **Full text:** <https://bit.ly/34u1oGb>



N.B. English language article. Search back issues of Media Watch for additional articles on perinatal palliative care at: <http://bit.ly/2ThijkC>

What to consider when implementing a tool for timely recognition of palliative care needs in heart failure: A context-based qualitative study

BMC PALLIATIVE CARE | Online – 4 January 2022 – Needs assessment tools can facilitate healthcare professionals (HCPs) in timely recognition of palliative care (PC) needs. Despite the increased attention for implementation of such tools, most studies provide little or no attention to the context of implementation. The aim of this study, from The Netherlands, was to explore factors that contribute positively and negatively to timely screening of PC needs in advanced chronic heart failure (CHF). Several factors were perceived to play a role, such as perception and knowledge about PC, awareness of PC needs in advanced HF, perceived difficulty when and how to start PC, limited acceptance to treatment boundaries in cardiology, limited communication and collaboration between HCPs, and need for education and increased attention for PC in advanced CHF guidelines. This study clarified critical factors targeting patients, HCPs, organisations to implement a needs assessment tool for timely recognition of PC needs in the context of advanced CHF. A multifaceted implementation strategy is needed which has attention for education, patient empowerment, interdisciplinary collaboration, identification of local champions, CHF specific guidelines and culture. **Full text:** <https://bit.ly/3pQR2Z0>

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Noted in Media Watch 4 October 2021 (#737, p.7):

- *HEART, LUNG & CIRCULATION* | Online – 27 September 2021 – ‘**Elements of integrated palliative care in chronic heart failure across the care continuum: A scoping review.**’ Individuals with chronic heart failure (CHF) experience high symptom burden, reduced quality of life and high healthcare utilisation. Although there is growing evidence a palliative approach, provided concurrently with usual treatment improves outcomes, the method of integrating palliative care (PC) for individuals living with CHF across the care continuum remains elusive. This review identifies 4 key strategic elements: 1) Clinical; 2) Professional; 3) Organisational; and, 4) System-level integration. Implementing strategies across these elements facilitates integrated PC for individuals with CHF. **Abstract (w. references):** <https://bit.ly/2ZIMAAZ>

N.B. Selected articles on the role of PC for patients living with CHF noted in Media Watch 13 September 2021 (#734, p.7) and 6 September 2021 (#733, pp.8-9).

Being a safe place: A qualitative study exploring perceptions as to how a rural community hospice could respond to enactment of voluntary assisted dying legislation

BMC PALLIATIVE CARE | Online – 4 January 2022 – There is a lack of research to guide the implementation of voluntary assisted dying (VAD) legislation within a hospice setting [in Western Australia]. Furthermore, there is limited published information related to the expectations of the community and staff to assist decision-making regarding VAD in a community hospice. The aim of this study was to explore the expectations of staff, volunteers and members of the community as to how a rural Australian community hospice could respond in relation to imminent enactment of VAD legislation. Sixty-three hospice staff and volunteers and community members participated in 11 workshops. While there was not a consensus view on community expectation, there was agreement among the participants for respect for a patient’s individuality and choices. Furthermore, care offered in hospice needs to remain non-judgemental and patient focused regardless of whether VAD policy was implemented or not. Both opportunities and risks associated with implementation were identified by the participants. There was common ground around the respect for the dying person and the ideal of a “safe place” despite opposing views on what this may mean in practice. There is a need for clarity in organisational responses around policy, risk management, education, and staff support. **Full text:** <https://bit.ly/3sV8X2J>



Noted in Media Watch 19 April 2021 (#713, p.7):

- *BMC PALLIATIVE CARE* | Online – 12 April 2021 – ‘**Hospice care providers’ experiences of grappling with medical assistance in dying in a hospice setting: A qualitative descriptive study.**’ The introduction of medical assistance in dying (MAiD) in Canada represents a new and evolving choice for end-of-life care which has affected the dynamic of care within the hospice environment. The experience of navigating MAiD within a non-provider context challenged care providers to rethink and redefine their roles and left some uncertain about how best to support their patients and others. Care providers worked to navigate the uncharted territory of the MAiD trajectory within a non-provider hospice setting and sought to remedy the moral complexities... **Full text:** <https://bit.ly/3sgHEvP>

Verbalizing spiritual needs in palliative care: A qualitative interview study on verbal and non-verbal communication in two Danish hospices

BMC PALLIATIVE CARE | Online – 4 January 2022 – Spiritual care (SC) is highly relevant to study especially in a secular setting like Denmark, where spiritual matters rarely are addressed in public and institutional contexts. Through the step-by-step, interpretive analysis, three themes emerged: 1) When death becomes present; 2) Direction of the initiative; and, 3) Bodily presence and non-verbal communication. The relation between patient and HCP is greatly influenced by sensing, decoding, and interpretation. The patient’s perception and bodily experience of the HCP seems to be crucial to whether they move forward toward the HCP and initiate a conversation about spiritual matters. This study hypothesizes that the same

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seems to apply to the HCPs. Overarching the authors found an ontological flow from 1. Sensory to verbal aspects of SC as well as from 2. Secular to more spiritual aspects of SC and 3. From biomedical to spiritual care and that SC must be viewed in its entirety as an aspect of palliative care. Thus, the non-verbal dimension becomes a prerequisite for the verbal dimension of spiritual communication to develop and unfold. The same holds for the sense of connection: The perceived connectedness between the patient and the HCP is of great importance as to how the patient experiences the relationship with the HCP. The way patients sense and decode the HCPs has impact on whether, and how patients open up to the HCPs about thoughts and needs of a spiritual nature and thereby initiates a conversation. Therefore, the dilemma surrounding the direction of the initiative and how the spiritual conversation can be initiated is essential. The HCP's perception and non-verbal communication are a prerequisite for being able to meet patient's spiritual needs with care and verbal communication. The authors argue that the behavior of the HCPs, the way they move and touch the patient, is just as important and inviting as the verbal conversation about spiritual matters when it comes to SC. HCP can create a connection to the patient through bodily and relational presence, and the HCP should let their sensing and impressions guide them, when meeting with the patient about conversations and matters of a spiritual nature. **Full text:** <https://bit.ly/3zsJ0J1>

Which human factors design issues are influencing system performance in out-of-hours community palliative care? Integration of realist approaches with an established systems analysis framework to develop mid-range programme theory

BMJ OPEN | Online – 3 January 2022 – In the U.K., around 30% of people receiving palliative care have contact with out-of-hours services. Interactions between emotions, cognition, tasks, technology and behaviours must be considered to improve safety. After sharing experiences, workshop participants were presented with analyses of 1,072 National Reporting & Learning System incident reports. Discussion was orientated to consider priorities for change. Complex interacting configurations explain relational human-mediated outcomes where cycles of thought and behaviour are refined and replicated according to prior experiences. Five such configurations were identified: 1) Prioritisation; 2) Emotional labour; 3) Complicated/complex systems; 4a) System inadequacies and 4b) differential attention and weighing of risks by organisations; 5) Learning. Underpinning all these configurations was a sixth: 6a) Trust and access to expertise; and 6b) isolation at night. By developing a mid-range programme theory, the authors have created a framework with international relevance for guiding quality improvement work in similar modern health systems. **Full text:** <https://bit.ly/3FTF9XT>

Noted in Media Watch 13 September 2021 (#734, p.6):

- *BRITISH JOURNAL OF GENERAL PRACTICE* | Online – 6 September 2021 – ‘**Out-of-hours services and end-of-life hospital admissions: A complex intervention systematic review and narrative synthesis.**’ This review provides evidence as to why issues experienced during out-of-hours may lead to end-of-life (EoL) hospital admissions, how such admissions occur, and by whom they are instigated. Importantly, although the findings may be unsurprising to many clinicians and EoL care researchers, this review highlights significant gaps in the evidence. Knowledge on how the identified factors interact with each other is currently lacking. Also lacking is evidence of effective interventions to improve care to prevent potentially avoidable EoL hospital admissions. **Full text:** <https://bit.ly/38UkGDl>

Noted in Media Watch 30 November 2020 (#694, p.11):

- *PALLIATIVE MEDICINE* | Online – 21 November 2020 – ‘**Effectiveness and cost-effectiveness of out-of-hours palliative care: A systematic review.**’ While out-of-hours (OoH) palliative care is a recognised priority for patients and policymakers, no evidence base exists on which services are beneficial for patients and worthy of healthcare funding. The lack of evidence underscores the need for future studies to incorporate measurement of the effectiveness and/or cost-effectiveness of OoH services. In principle there are two ways that such evaluations might be initiated. Consistent with other areas of palliative and end-of-life care research, this agenda will have to be flexible and pragmatic in matching methodological approaches to specific problems. **Full text:** <https://bit.ly/3nNIU7P>

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Noted in Media Watch 26 August 2019 (#628, p.4):

- HEALTH RESEARCH BOARD (Dublin, Ireland) | Online – 21 August 2019 – ‘**Out-of-hours specialist and generalist palliative care service provision. An evidence review.**’ Inadequate community supports and deficiencies in access to services outside of regular office hours have been linked to poor outcomes for patients with life-limiting illness. Policymakers, researchers, providers, patients, and carers in Ireland have all identified out-of-hours (OoH) care as a key deficit in current service provision. The Department of Health commissioned this review to inform the revision of national palliative care (PC) policy and address the recognised challenges in providing OoH PC. The purpose of this review was to synthesise evidence regarding the provision of OoH PC... **Download/view at:** <http://bit.ly/2L4gPYh>

Family carer needs in advanced disease: Systematic review of reviews

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 7 January 2022 – The findings presented here provide an insight into the broad range of carer needs reported across disease groups. It is important to consider how these findings can be applied in the current public health context and with regards to established priorities in family carer research. Resourcing support services to sufficiently meet the needs of family carers is an ongoing challenge. Although comprehensive in scope and included literature, the nature of this systematic review of reviews means that our results can only serve as an aid for broad-based planning and generalised approaches to carer provision. However, the review has identified the commonly expressed carer needs and preferred ways to source this information, which can inform the development of priority information to support carers and enable access through preferred mechanisms to meet carer needs. **Full text:** <https://bit.ly/3t4Hf3H>

Fostering palliative care through digital intervention: A platform for adult patients with hematologic malignancies

FRONTIERS IN DIGITAL HEALTH | Online – Accessed 3 January 2022 – The diversity of cancer patient needs for palliative care (PC) is enormous. A patient-centered approach for PC should take into account many aspects, such as the spectrum of symptoms and clinical manifestations of the particular disease, the patient’s age and overall physical condition (including comorbidities), the treatment aim (e.g., cure vs. disease control), the medication plan and its impact in quality of life and life expectancy, lifestyle and exposures (including concomitant medication) as well as patient preferences, health literacy, etc. Some of the above aspects, such as the experience of adverse drug effects, are dynamic by nature, adding further difficulties in adequately addressing the individual patient needs for PC. MyPal aspires to provide such a patient-centered approach for PC of cancer patients in capturing more accurately their symptoms/conditions and communicating them in a seamless and effective way to their healthcare providers. While there are various patient reported outcomes systems available, they typically lack the required flexibility to address the individual patient needs, hampering their potential due to their inherent “one-size-fits-all” approach. MyPal focused on the thorough understanding of the varying patient needs across disease trajectories and designed a comprehensive, adaptive intervention to accommodate these needs. MyPal successfully developed and deployed a digital intervention for PC cancer patients overcoming several technical challenges with the continues collaboration of the clinical and technical partners of the project. Apart from the technical challenges of such an effort, one must be prepared for unpredictable parameters, such as COVID-19, and provide flexible solutions. **Full text:** <https://bit.ly/3pOzGMI>

N.B. MyPal “aims to foster PC for people with cancer by leveraging patient reported outcome systems through their adaptation to the personal needs of the person with cancer and his/her caregiver(s).” Project website: <https://bit.ly/3bpDSdp>

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

Noted in Media Watch 10 May 2021 (#716, p.6):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 April 2021 – ‘**Perceptions of hematology among palliative care physicians: Results of a nationwide survey.**’ Respondents to a 44-item survey reported comfort managing symptoms in leukemia (84.0%), lymphoma (92.1%), multiple myeloma (92.9%), and following hematopoietic stem cell transplant (51.6%). Fewer expressed comfort with understanding disease trajectory ... and discussing prognosis... In exploring perceptions of hematology-PC relationships, three themes were identified: misperceptions of PC, desire for integration, and lacking a shared model of understanding. These data inform efforts to integrate PC into hematologic care-at-large, echoing previous studies of hematologist perspectives. **Abstract (w. references):** <https://bit.ly/3tkL55m>

N.B. Selected articles on supportive and PC in hematology noted in Media Watch 19 April 2021 (#713, pp.9-10).

Change in perception of the quality of death in the intensive care unit by healthcare workers associated with the implementation of the “well-dying law”

INTENSIVE CARE MEDICINE | Online – 1 January 2022 – The South Korean government implemented the “well-dying law” [i.e., the Hospice, Palliative Care & Life-sustaining Treatment Decision-Making Act] in 2018, which enables patients to refuse futile life-sustaining treatment (LST) after being determined as terminally ill. This study is the first to identify the effect of the well-dying law on the quality of death in ICUs. As expected, there was a significant improvement in the quality of dying (QODD) after the well-dying law implementation. In addition, the concordance rate of the medical staff’s opinion of the best action and actual action for the LST withdrawal was significantly increased after the implementation of the law. The time between receiving a do not resuscitate order and death increased from 2.5 to 5 days following the implementation of the law. This implies that the “well-dying” law provides an extended opportunity to communicate about death and withdrawal of LST between medical staff and the caregiver/patient much earlier than the point of death. Moreover, the concordance rate of the staff’s opinion of the best action and actual action for LST withdrawal showed a 20% increase after the implementation of the law. These findings reflect that the ethical and legal issues around LST withdrawal have been improved by the well-dying law, enabling physicians to act according to their clinical judgment to limit futile LST, thereby leading to an increased concordance between the opinion and the action of LST withdrawal. **Full text:** <https://bit.ly/3zktsXV>

Noted in Media Watch 25 January 2021 (#701, p.4):

- SOUTH KOREA | *The Korea Times* (Seoul) – 18 January 2021 – ‘**Over 130,000 terminal patients choose to forgo life-prolonging treatment over 3 years: Data.**’ The number of patients who opted to die with dignity stood at 134,945 at the end of December last year, according to the data from the National Agency for Management of Life-Sustaining Treatment. The law took effect on 4 February 2018, allowing terminal patients to sign up to forgo a “meaningless extension of life” by stopping or postponing four life-sustaining treatments. The four treatments – cardiopulmonary resuscitation, artificial respiration, hemodialysis and anti-cancer drug administration – are only meant to prolong the lives of terminally ill patients without giving any treatment from the start. <http://bit.ly/3sl1b9N>

Noted in Media Watch 19 October 2020 (#688, p.4):

- *BMC MEDICAL ETHICS* | Online – 16 October 2020 – ‘**Forgoing life-sustaining treatment: A comparative analysis of regulations in Japan, Korea, Taiwan, and England.**’ The analysis offers five important legal and philosophical points: 1) Defining the terminal stage and associated criteria for clinical judgment; 2) Discussion on withdrawing life-sustaining treatment in persistent vegetative state or motor neurone disease patients who are not terminal; 3) (Re)considering any moral and legal differences between withholding and withdrawing treatments (this is disputed particularly in Asian countries); 4) Ascertaining the family’s role in end-of-life decision-making; and, 5) Devising ways to deal with incompetent patients who lack family or advance directives. **Full text:**

Planning for implementation success of an electronic cross-facility health record for pediatric palliative care using the Consolidated Framework for Implementation Research

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online – 1 January 2022 – Pediatric palliative care (PPC) patients require years of care across professions and sectors. Sharing treatment-related information and communicating among different PPC professionals is critical to ensure good quality of care. In Germany, this communication is mostly paper-based and prone to errors. Therefore, an electronic cross-facility health record (ECHR) was participatorily designed with users, wherein information can be shared and PPC professionals can communicate with each other. As this form of electronic health record differs from existing models in Germany, there is a need for successful implementation to ensure a positive impact. Therefore, the facilitators and barriers to the implementation of ECHR in PPC were examined. Using the consolidated framework for implementation research (CFIR), transcripts of 32 interviews, 3 focus groups, and 20 think-aloud studies with PPC professionals were analyzed. CFIR indicated that the ECHR-design was viewed positively by users and can be a facilitator for implementation. Barriers exist, mainly due to the fact that the implementation is not planned, the use of the ECHR involves effort, costs are not covered, and all users must be motivated to use the ECHR for functionality. CFIR helps uncover the crux of the issues that need to be considered when planning ECHR implementation to improve care in PPC. **Full text:** <https://bit.ly/3qUWpWI>

Shifting to serious illness communication

JAMA NETWORK OPEN | Online – 7 January 2022 – Although facing challenging circumstances, patients who have engaged in serious illness communication can better understand difficult prognostic information, recalibrate hopes and priorities, and, when the time comes, make medical decisions consistent with their values. These patients might make a transition to comfort care, or they might choose intensive care. By engaging patients with serious illness and their loved ones in iterative conversations that build trust and an awareness of illness, clinicians could enhance the person-centeredness of care and enable values-based medical decision-making. This Viewpoint focuses on a related emerging construct and promising intervention, serious illness communication, and describes its components, presents evidence supporting the approach, and discusses areas for further research. **Full text:** <https://bit.ly/3GftyCU>

Related:

- *JAMA NETWORK OPEN* | Online – 5 January 2022 – ‘**End-of-life preferences in older U.S. adults – bridging the “what matters” chasm.**’ The first M of the 4Ms Framework for Age-Friendly Healthy Systems ... refers to understanding the values of older adults and establishing their preferences for care across the continuum. For older U.S. adults at the end of life (EoL), a “what matters” chasm has formed between the estimated 70% who express a preference to die at home and the 30% who actually do. This discordance could be attributable in part to the variable access to, and underfunding of, home and EoL care across the U.S. An increasing number of people growing older with serious illnesses and dying at home will need home and community-based services (HCBS) to help with activities of daily living and staying independent. **Full text:** <https://bit.ly/3G4kBMk>

Impact of pediatric primary palliative care education and mentoring in practice

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2022;24(1):22-29. Primary palliative care (PC) education and mentoring strengthens frontline clinicians' confidence and competence in pediatric PC, and potentially mitigates their moral distress. The project aims were to improve the knowledge, attitudes, and skills of frontline interdisciplinary clinicians in caring for children with serious conditions and their families. The authors undertook an intensive educational initiative... Outcomes included: 93.3% of participants reported comfort in discussing death, suffering, spirituality, and hope with families, and increased comfort in end-of-life care (89.5%), increased knowledge (94.7%) and skills (100%), improved communication (100%), and being better pre-



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pared to discuss and access PC resources (100%). Secondary outcomes included 33% increase in specialty pediatric PC consults and 98% increase in the integration of specialty PC for patients with high-risk cancers. Specialty pediatric PC referral became standard for patients with cystic fibrosis, high-risk solid and brain tumors, heart failure, and patients receiving a stem cell transplant. Clinician self-reported moral distress decreased by 30%. This project improved primary PC knowledge, attitudes, and confidence in skills, access to care, and family satisfaction, and decreased clinician self-reported moral distress. **Abstract:** <https://bit.ly/3qMNXsn>

Learner experiences matter in interprofessional palliative education: A mixed methods study

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 5 January 2022 – In this study involving, over 3,000 participants, a large majority of professionals (75% to 99%) across several professions – including physicians, nurses, pharmacists, social workers and other allied health professionals – rated this interprofessional continuing professional development (CPD) palliative care course highly across several facets related to the learning experience. These results are encouraging, support the Learning Essential Approaches to Palliative care (LEAP) course's interprofessional approach and confirm that interprofessional learning is possible. Designing an interprofessional CPD curriculum can be challenging as common and diverging learning needs across the professions need to be taken into consideration. Designing for large scale national deployment adds another layer of complexity. Intentional instructional design is required to, among others, address varying scopes of practice and different lenses used by different professions in their clinical and learning activities. To this end, Pallium Canada's LEAP courses incorporate instructional strategies such as integrating cases that resonate with and solicit input from various professions, facilitator training to support interprofessional education, and interprofessional curriculum and facilitator teams. Satisfaction with the learning experience across different facets, while overall favourable across professions, did show variability between profession groups. **Full text:** <https://bit.ly/3HDMbk3>



N.B. Selected articles on Pallium Canada's LEAP courses noted in Media Watch 23 August 2021 (#731, pp.10-11).

(Don't) leave me alone: Attachment in palliative care

JOURNAL OF PALLIATIVE MEDICINE, 2022;25(1):9-14. In this article, the authors discuss attachment – the system by which people form bonds in relationships. The different styles that people have in navigating relationships such as clinician-patient relationships develop from early life onward. Attachment styles are not pathological. But they are helpful to understand because they are a relatively stable factor that impacts how people relate to caregivers like clinicians. Our patients all express unique relational needs to us; some of our patients need closeness and reassurance to feel comfortable, others value independence and space. These needs are highly significant to palliative care clinicians; they inflect our patients' goals of care and values, they modulate our patients' psychosocial needs, and they elucidate the ways our patients respond to a range of therapeutic interventions. Understanding attachment gives us a window into these individual care needs and empowers us to tailor the care we provide for a wide range of patients. **Abstract:** <https://bit.ly/31uhgHC>

Pandemic lessons: Resilience and hope

JOURNAL OF PSYCHOSOCIAL NURSING & MENTAL HEALTH SERVICES | Online – 1 January 2022 – In the U.S., the coronavirus disease 2019 pandemic took a heavy toll on older adults, particularly those residing in long-term care facilities who were reduced to extended periods of isolation from families, friends, and healthcare providers. The concepts of resilience and hope became extremely relevant in the context of pandemic-related restrictions that exacerbated loneliness across all age groups. A review of evidence indicates that resilience is defined as an on-going, conscious process of adaptation in the face of adversity, whereas hope is defined as a resilience moderator through its process of making sense of a difficult situa-

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tion. Cognitive-behavioral therapy and life review interventions were found to effectively enhance hope, thus contributing to increased resilience in older adults diagnosed with depression, bereavement, and/or medical conditions. Mental health providers at any level of practice should assess older adults for levels of loneliness, isolation, resilience, and hope and consider interventions to boost resilience and hope. **Full text:** <https://bit.ly/3mTtBMl>

Related:

- *BRITISH JOURNAL OF GENERAL PRACTICE, 2022;72(714):6-7. 'Palliative and end-of-life care in primary care during the COVID-19 pandemic and beyond,'* The COVID-19 pandemic has been associated with the highest death rate in the U.K. for over 10 years. There has been a marked shift of place of death into the community across the U.K... Deaths at home increased by 67% during the first wave of the pandemic. There was a sustained increase of 33% above expected between the first two waves, and 43% above expected in the second wave. Nationally reported data identifies large changes in where people are dying, but little is understood about the circumstances of these deaths, the quality of end-of-life care in the community ... or the services received. **Introduction:** <https://bit.ly/3eSAv0t>

Neuro-oncology and supportive care: the role of the neurologist

NEUROLOGICAL SCIENCES | Online – 5 January 2022 – The diagnosis of a brain tumor is a life-changing event for patients and their families. Despite numerous treatment advances, malignant brain tumors are universally incurable and long-term survival is limited. Treatment response, prognosis, and survival depend on underlying histopathology and recently defined molecular features. Patients suffer from a disproportionately high symptom burden throughout the disease trajectory and at the end of life (EoL). Pronounced neurologic decline and psychological distress significantly impair quality of life (QoL) and impose high supportive care needs relative to other systemic cancers. Palliative interventions addressing brain tumor-specific symptoms, such as seizures, cognitive dysfunction, and headaches, are paramount to maintaining QoL. In the terminal phase of illness, most brain tumor patients lose the ability to communicate and participate in EoL decision-making. The benefits of advance care planning (ACP) and early integration of specialized palliative care are well-established in other systemic cancers and have received wider recognition in neuro-oncology. The authors review how to approach neurological symptoms in brain tumor patients, as well as address prognosis and ACP with the goal of improving QoL for patients and caregivers. **Abstract (w. references):** <https://bit.ly/3GgY6Us>

The Evolving Specialty of Neuropalliative Care

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Blog – 15 November 2021 – The focus of this posting is on the evolving specialty that is neuropalliative care with summaries of a representative sample of journal articles on the subject published during the past year or so. Included are articles on Parkinson's disease, amyotrophic lateral sclerosis, multiple sclerosis, motor neurone disease, Huntington's disease, **dementia**, epilepsy and neuro-ICU (neurosciences intensive care unit). There is a short selection of articles on neuropalliative care in the context of the COVID-19 pandemic, from the family caregivers' perspective, and advance care planning (including advance directives and goals-of-care). <https://bit.ly/3cdwyIS>

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



Can we talk about life without taking death into account? Early childhood educators' self-perceived ability to approach the topic of death with children

OMEGA – JOURNAL OF DEATH & DYING | Online – 6 January 2022 – The current explorative cross-sectional study evaluated the knowledge, attitudes, and practices of early childhood educators towards death education and their self-perceived comfort to approach the topic of death in the classroom. One hundred eight (108) early childhood educators participated in the study. The study was promoted through early childhood educators' support groups and social networks. Demographic characteristics, an *ad hoc* questionnaire, and the Greek version of the Death Attitude Profile-R questionnaire were used to assess the educators' comfort and attitudes. Results showed that participants' self-perceived ability to approach the topic of death in the classroom was affected by gender and personal attitudes towards death (specifically death avoidance and fear of death). Overall, this study emphasized early childhood educators' role in extreme situations which their students may face as death. **Abstract (w. references):** <https://bit.ly/3HKs9Eq>



The Crossroads of Grief:
Understanding Grief &
Diversity

<http://bit.ly/2OB4Y6C>

N.B. See 'Children's
Understanding of Dying
& Death' (pp.5-7)

Polish Association for Palliative Care

Organizational standards for specialist palliative care for adult patients: Recommendations of the Expert Group of National Consultants in Palliative Medicine & Palliative Care Nursing

PALLIATIVE MEDICINE IN PRACTICE | Online – 30 December 2021 – The study aimed to develop organizational standards for specialist palliative care (PC) for adult patients in Poland. The work was done in three stages: 1) Literature analysis and [review of] legislation on PC; 2) Questionnaire development ... and survey of 120 respondents in two rounds using the Delphi method; and, 3) Analysis of the results by the Expert Group during remote meetings and determination of the final version of the organizational standards for specialist PC for adult patients. PC was divided into two types: PC elements (PC approach) and specialist PC. In the latter home, inpatient and outpatient care was distinguished with ensuring public funding for all their organizational units by the State, including the integration into the guaranteed benefits. Requirements and procedures for all organizational units of specialist PC were depicted. Three specialist inpatient PC referral levels were offered taking into account complexity of services for patients, under- and post-graduate education. Principles of qualifying patients for PC, the development of research and education in palliative medicine and PC nursing were presented. **Full text (click on PDF icon):** <https://bit.ly/3EULwsy>

N.B. English language article.



European Association for Palliative Care Blog

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



Prison Hospice: Backgrounder Next Update: 1 February 2022

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded from the Palliative Care Network website: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk, Philadelphia, PA

Media Watch: Editorial Practice

EACH LISTING IN MEDIA WATCH represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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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.

[Search Back Issues of Media Watch @ http://bit.ly/2ThijkC](http://bit.ly/2ThijkC)

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3IH8oz0>

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

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

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[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU>]

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

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Australia

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

Canada



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

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



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>

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

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

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

Europe



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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <https://bit.ly/3wwL5RW>

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

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

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