

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

Despite preparing to assist with symptom control during a surge, the main palliative intervention addressed a pre-existing knowledge and skill gap: how to lead a values-based conversation to ensure care was aligned with goals.

'Scalable model for delivery of inpatient palliative care during a pandemic' (p.14), in *American Journal of Hospice & Palliative Medicine*.

Canada

Canadian Society of Palliative Care Physicians submission to College of Physicians & Surgeons of Ontario consultation on medical assistance in dying and professional obligations and human rights policies

ONTARIO | Canadian Society of Palliative Care Physicians – 31 March 2021 – Medical assistance in dying (MAiD) and palliative care (PC) are distinct practices. Provision of MAiD is a practice distinct from the provision of PC. PC must remain distinct from MAiD to ensure clarity and to avoid the risk of confusion and the potential for people to refuse PC services. This does not, however, preclude people who contemplate, request, or opt for MAiD from receiving PC. This is particularly vital for people in communities that have an underlying distrust of the healthcare system who decline PC because they may confuse it with MAiD. The CSPCP strongly advocates for the prioritization of, adequate investment in, and enhance-

ment of PC services as a separate service from MAiD. Without access to high quality PC, some patients who are suffering may feel that MAiD is their only option because their suffering has been inadequately addressed or they perceive that they are an excessive burden. **Download Society's brief at:** <https://bit.ly/3dERsdP>

Specialist Publications

'Models of integration of specialized palliative care with oncology' (p.9), in *Current Treatment Options in Oncology*.

N.B. College of Physicians & Surgeons of Ontario (Current Consultations): <https://bit.ly/3uwT9Rq>



Palliative Care Network
Palliative Care for Everyone, Everywhere

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Knowledge & Technology
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U.S.A.

End of life uncertainty: Terminal illness, Medicare hospice reimbursement, and the “falsity” of physicians’ clinical Judgments

CINCINNATI | *University of Cincinnati Law Review* – Accessed 10 April 2021 – If asked to visualize what “fraud” looks like, one might envision a theft, a computer hacker, or falsified signatures and documents. A doctor and an elderly man sitting in a hospice facility, on the other hand, seem like unlikely culprits. Although a hospice facility and fraud may not be an intuitive pairing, it is estimated that fraud and inaccurate billing cost the federal government’s Medicare program as much as \$60 billion dollars annually. Studies have linked hospice facilities to enrolling patients who are not terminally ill and falsifying patient documentation, among other appalling behaviors. Naturally, efforts to combat these types of behaviors have found their way into the U.S. federal courts. Questions have arisen regarding the behavior of America’s most trusted profession, medical professionals, within the hospice setting. **Full text:** <https://bit.ly/3mxOBYe>

N.B. Selected articles on fraud and malpractice within the hospice movement in the U.S. noted in Media 18 January 2021 (#700, p.3).

Around 40,000 children have lost a parent due to COVID-19, study shows

WISCONSIN | WMTV News (Madison) – 7 April 2021 – Research has found between 37,300-43,000 children had been affected by the death of a parent from the virus.¹ The researchers say Black children are disproportionately affected, making up only 14% of children in the U.S., but one-fifth of those who have lost a parent from the coronavirus. The model used to determine the results in the study estimates each COVID-19 death leaves 0.078 children aged 0 to 17 without a parent, representing a 17.5% to 20.2% increase in parental bereavement without COVID-19. As of February, 37,300 children ages 0-17 had lost at least one parent from COVID-19. When accounting for excess deaths, the researchers believe

43,000 children have had a parent die from the virus. To put this in perspective, the researchers cited that 3,000 children were left without a parent following the attacks on 11 September 2001. Children who have lost a parent are at a higher risk for traumatic grief, depression, poor educational outcomes, and even unintentional death or suicide. <https://bit.ly/31ZgILN>

[Specialist Publications](#)

‘Current grief support in pediatric palliative care’ (p.13), in *Children*.

1. ‘Estimates and projections of COVID-19 and parental death in the U.S.’ *JAMA Pediatrics*, published online 5 April 2021. **Full text:** <https://bit.ly/3fRVoku>



[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>

Poll: Despite pandemic, less than half of older adults have formally recorded what they want if they get seriously ill

INSTITUTE FOR HEALTHCARE POLICY & INNOVATION | Online – 6 April 2021 – As the toll of COVID-19 continues to climb, newly released poll data suggest an opportunity to use the pandemic as a prompt for discussing and documenting older adults' wishes for their care, if they get seriously ill... 59% of the 50- to 80-year-olds polled said they had had a conversation with loved ones about their preferences in case they became severely ill. That percentage was even higher – 70% -- among those over age 65. Just 7% of all older adults polled said COVID-19 had motivated them to have such conversations. When it came to documenting their preferences in a legally binding way that can guide families and care teams, 46% of those polled said they had completed at least one of two legal documents that could help their loved ones make decisions for them if they can't do it for themselves. The poll asked about medical durable powers of attorney, and advance directives, often called "living wills." Among the 7% of older adults who had completed one or both of these forms in the early months of the pandemic,

one-third said COVID-19 had motivated them to do so ... a very small percentage – just 1% -- of the entire poll sample. <https://bit.ly/31RFb0g>

Extract from Institute for Healthcare Policy & Innovation's report

The new poll confirms past research finding that just bringing up the topic of end-of-life care and medical decision-making is uncomfortable or hard to broach for older adults. Nearly a quarter of the poll respondents who hadn't yet had a conversation about their wishes said they don't like talking about such things, and 56% said they hadn't gotten around to it.

[Specialist Publications](#)

'Advance care planning for Medicare beneficiaries increased substantially, but prevalence remained low' (p.6), in *Health Affairs*.

Noted in Media Watch 18 January 2021 (#700, p.2):

- INSTITUTE ON HEALTHCARE DIRECTIVES | Online – 13 January 2021 – **'New research reveals patient safety concerns and medical errors of 50% with critical end-of-life documents needed in this pandemic to protect patients.'** As the nation and world are facing the COVID-19 pandemic ... new research calls into question the tools utilized to document patient wishes for current and end-of-life care.¹ Research reveals medical providers often incorrectly provide the wrong level of care and both under and over treat patients despite their documented wishes. This now places vulnerable at-risk patients in situations where they have no one to advocate for them. Physicians, who are essentially medical strangers to these patients, now are left to guess patient wishes from confusing documents. <http://prn.to/2KfFm05>

1. 'Utilizing simulation to evaluate the living will and POLST ability to achieve goal concordant care when critically ill or at end of life: The realistic interpretation of advance directives,' *Journal of Healthcare Risk Management*, published online 10 December 2020. **Abstract:** <https://bit.ly/3bCnUOA>

When patients choose to end their lives

THE NEW YORK TIMES | Online – 5 April 2021 – At a time when so many are dying against their will, it may seem out of sync to discuss the option of having a doctor help people end their lives when they face intolerable suffering that no treatment can relieve. It's less a question of uncontrollable physical pain, which prompts only a minority of requests for medical aid in dying, than it is a loss of autonomy, a loss of dignity, a loss of quality of life and an inability to engage in what makes people's lives meaningful. Intractable suffering is defined by patients, not doctors. Patients who choose medical aid in dying want to control when they die and die peacefully, remaining conscious almost to the very end, surrounded by loved ones and able to say goodbye. Most people who seek medical aid in dying would prefer to live but have an illness that has in effect stripped their lives of meaning. Though often – and, proponents say, unfortunately – described as "assisted suicide," the laws hardly give carte blanche for doctors to give people medication that would end their lives quickly and painlessly. The patient has to be terminally ill (usually with a life expectancy of less than six months), professionally certified as of sound mind, and able to self-administer the lethal medication without assistance. That can leave out people with advanced dementia or, in some cases, people with severe physical disabilities... <https://nyti.ms/3cRHfva>

International

Palliative care at home “compromised” during pandemic, Marie Curie survey finds

U.K. | Home Care Insight – 8 April 2021 – Three quarters of people who died at home during the pandemic struggled to get the care and support they needed at the end of their lives. The revelation has been made in a new report published by Marie Curie,¹ which says quality of palliative and end-of-life care (EoLC) across the U.K. was compromised by shortages of personal protection equipment, essential medicines, and equipment, because these services were not seen as “front-line National Health Service.” Unpaid carers surveyed by the charity said their loved one received no support (8%), very little support (18%), some support (28%) or most (22%) of the support they needed. The remaining 24% said they received all the support they needed and 1% answered “prefer not to say.” The survey, which ran for two weeks last month, was conducted on 995 people who were involved in caring for someone who died at home from March 2020 to date. Respondents revealed their loved ones didn’t get all the help they needed with pain management (64%), personal care (61%) and out-of-hours support (65%) before they passed away. The findings have are released alongside Marie Curie’s inaugural ‘Better End of Life’ report [a collaboration between Marie Curie, King’s College London Cicely Saunders Institute, Hull York Medical School, University of Hull, and the University of Camb-

ridge], which says that quality of palliative and EoLC across the U.K. was compromised due to it not being recognised as a frontline, essential service. <https://bit.ly/3upR2yK>

Specialist Publications

‘Palliative care in general practice: A questionnaire study on the GPs role and guideline implementation in Norway’ (p.5), in *BMC Family Practice*.

‘Global perspectives on palliative care for cancer patients: Not all countries are the same’ (p.9), in *Current Oncology Reports*.

‘Palliative care in high- and low-resource countries’ (p.8), in *Current Pediatric Reviews*.

‘Comparison of end-of-life care for people living in home settings versus residential aged care facilities: A nationwide study among Australian general practitioners’ (p.5), in *Health & Social Care in the Community*.

‘The influence of geography, religion, religiosity and institutional factors on worldwide end-of-life care for the critically ill...’ (p.8), in *Journal of Palliative Care*.

1. ‘The Better End of Life Report 2021: Dying, Death & Bereavement During COVID-19 Research Report,’ Marie Curie, April 2021. **Download/view at:** <https://bit.ly/3mvpNWP>

Specialist Publications

Shared death experiences: A little-known type of end-of-life phenomena reported by caregivers and loved ones

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 5 April 2021 – Anecdotal evidence suggests that some loved ones and caregivers of dying patients undergo a type of end-of-life phenomena known as a shared death experience or SDE, whereby one feels that one has participated in a dying person’s transition to a post-mortem existence. Anecdotal evidence also suggests that SDEs can have a range of profound psycho-spiritual-emotional effects. However, SDEs have been all but ignored in hospice

Research Matters

‘The impact of international research collaborations on the citation metrics and the scientific potential of South American palliative care research: Bibliometric analysis’ (p.14), in *Annals of Global Health*.

‘Factors affecting recruitment and participation of bereaved parents in research: A brief report’ (p.15), in *Journal of Pain & Symptom Management*.

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and palliative medicine, leaving professional bereavement services uninformed about SDEs and leaving individuals who report SDEs without adequate professional support to process and integrate them. To better understand the features and effects of SDEs, an inductive content analysis was performed on written accounts and transcripts of semi-structured interviews with 107 persons reporting a total of 164 SDEs. Analysis revealed four distinct though non-exclusive modes of an SDE: remotely sensing a death, witnessing unusual phenomena, feelings of accompanying the dying, and feelings of assisting the dying. Analysis also revealed three major domains of SDE effects: changes in belief, the reconciliation of grief, and the perception of continued relational bonds with the deceased. Interviews highlighted both difficulties and therapeutic value in people openly discussing their experiences with health professionals. Integration of information about SDEs offers an opportunity to add to the breadth and quality of psychological, spiritual, and bereavement care. **Abstract (w. references):** <https://bit.ly/3fLwJZU>

Palliative care in general practice: A questionnaire study on the GPs role and guideline implementation in Norway

BMC FAMILY PRACTICE | Online – 7 April 2021 – Regular general practitioner (RGP) participation in the palliative care trajectory is important to achieve the goals set by the Norwegian health authorities. Still, the RGPs display low adherence to the national guideline and have not adopted the working methods recommended in PC. Reluctance towards symptom assessment forms and advance care plans despite judging them useful, may indicate something more than unawareness of guideline content. The guideline recommendations, inherently based on the specialists' view of best practice, may not correspond with the existing working methods of general practice, making them difficult to adopt in the clinical reality of the RGP. Clinical experience is important, and the mismatch between guideline and practice in this study may thus be at least partially explained by the fact that the RGPs have too few clinical cases over time to maintain skills at a complex and specialized level. The competence requirement posed on the RGPs in this specific guideline, may thus be difficult to implement in general practice. It is also a paradox that as much as half of the RGPs see themselves as central, at the same time as public evaluations see them as missing in the trajectories. **Full text:** <https://bit.ly/2POsLUa>

Related:

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 6 April 2021 – ‘**Comparison of end-of-life care for people living in home settings versus residential aged care facilities: A nationwide study among Australian general practitioners.**’ We have little knowledge of differences in end-of-life care between home settings and residential aged care facilities where people spend most of their last year of life. A study was conducted with GPs from Western Australia, Queensland and Victoria. There were no significant differences between the two patient groups for seven out of the eight assessed symptoms... GPs' perceived roles in caring for patients and levels of their involvement in provision of common palliative care services were comparable between the two groups. **Abstract:** <https://bit.ly/3dOPnvZ>

Prevalence of advance care planning practices among people with chronic diseases in hospital and community settings: A retrospective medical record audit

BMC HEALTH SERVICES RESEARCH | Online – 5 April 2021 – International literature suggests that a consensus on the definition of advance care planning (ACP) and understanding how to measure successful ACP are fundamental for policymakers and health service providers to monitor ACP policy and effectiveness of interventions, but it has been a challenge globally due to the lack of uniform definition and clarity of what entails ACP. This retrospective medical record audit was conducted to examine the prevalence of ACP within the local definition and legislative framework in New South Wales (NSW), Australia. Despite the policy, legislative framework and resources available to promote ACP, its prevalence remains very low in both hospital and community settings in NSW. In addition to this, healthcare professionals record keeping reflects a poor understanding and possible lack of commitment, and the current medical record systems appear ill-equipped to correctly record ACP practices and advance care directive (ACD) documents in real

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time. Having an ACD or Enduring Guardian in place is only useful if the treating healthcare professionals know where and how to access the information. To ensure the benefits for all involved, both patients and healthcare professionals need to be educated, and ACP needs to be promoted with a whole-system approach. This may become plausible and feasible with the normalisation of ACP service provision supported by enhanced processes and system to store, locate, access and execute ACP practices and ACD documents. **Full text:** <https://bit.ly/3dK0t5w>

Related:

- *HEALTH AFFAIRS*, 2021;40(4):613-621. ‘**Advance care planning for Medicare beneficiaries increased substantially, but prevalence remained low.**’ Examining fee-for-service Medicare claims, the authors found a substantial increase in outpatient advance care planning (ACP) claims between 2016 and 2019, although prevalence remained below 7.5% for all patient subgroups analyzed. Roughly half of beneficiaries with ACP claims received the service at an annual wellness visit; the remainder received it at a different outpatient visit. Among those with claims, Black, Hispanic, and Medicaid dual-eligible patients and patients with comorbidities were less likely to have a claim at an annual wellness visit, largely because they have fewer such visits overall. **Abstract:** <https://bit.ly/3cUbRMF>

The hospice as a learning space: A death education intervention with a group of adolescents

BMC PALLIATIVE CARE | Online – 7 April 2021 – The study confirmed that death education (DE) does not produce negative consequences, but rather promotes existential reflection, as evidenced by previous literature. The authors found that psychometric scores generally remained stable over time – namely those relating to ontological representations of death, personal meaning attributed to life and spirituality. Instead, alexithymia scores decreased ... suggesting that the DE project improved these students’ ability to recognise and express their own emotions and those of others. The students appreciated the different experiential and theoretical activities in the course and the warmth, humanity and competence conveyed by the hospice professionals and guests who held the meetings. Students highlighted the particular importance of the hospice experience, which reassured them about their capacity to manage the end of life. This protected space offered them the opportunity to face death as a natural and necessary event in life that can be managed with sensitivity, generosity and serenity. Participants’ responses in the qualitative part of the study revealed that they had discovered a deeper meaning in their lives and developed better coping skills to deal with loss, empowering them with more confidence to talk about the subject. In addition, some participants reported a change in their death representations from death as total annihilation to death as a passage, suggesting that they had gotten closer to a spiritual and transcendental dimension. For some, spirituality was a positive discovery, while for others, it simply confirmed their faith. From this, the authors conclude that it is important and desirable to invest in new DE programs, as they have proven to be effective in addressing and reducing the denial of death. **Full text:** <https://bit.ly/39Oss2H>

N.B. See ‘Grieving or Bereaved Children: Literature Review, 2015-2018’ (‘Children’s Understanding of Dying & Death,’ pp.5-8), Children & Youth Grief Network, Canada. **Download/view at:** <http://bit.ly/2OB4Y6C>

Noted in Media Watch 29 March 2021 (#710, p.8):

- *DEATH STUDIES* | Online – 24 March 2021 – ‘**“Death education’s “period of popularity””: Lessons for contemporary P-12 schools in the U.S. during the COVID-19 pandemic.**’ As students return to P-12 classrooms in the U.S. during and after the COVID-19 pandemic, they will have faced and been inundated with images of death at unprecedented levels. Teachers, administrators and other school personnel will be challenged with assisting students in processing these encounters with death. While death education (DE) is no longer a formal component of the American curriculum, DE took on a prominent role in the curriculum during its “period of popularity” (1968-1977). Lessons from this period can guide educators in bringing back needed components of ED to P-12 classrooms today. **Abstract:** <https://bit.ly/3d3TDHr>

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Noted in Media Watch 2 November 2020 (#690, p.10):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 28 October 2020 – ‘**Death education for children and young people in public schools.**’ Nursing students partnered with a local palliative care team to examine death education for children. The nursing students focused on children’s understandings of death and their coping abilities, the lack of appropriate discussions about death with children, and the implementation of death education in public schools. Three online death education resources were identified and evaluated for use in public schools. This project fueled preliminary local discussions and advocacy efforts in the provision of death education for children. In the future, death education will need to be incorporated into education plans at local schools, **Abstracts:** <https://bit.ly/37KQaN7>

N.B. Additional articles on including death education in the public school curriculum noted in Media Watch 14 September 2020 (#683, p.7).

Triggers for palliative care referral in pediatric oncology

CANCERS, 2021;13(6). Oncologists have identified specific reasons to consult palliative care (PC), including disease, therapy and symptom-related triggers. The authors looked at 931 patients, 94% of whom had at least 1 pre-identified trigger, and yet only 52 patients (5.6%) were referred to PC. The triggers most frequently associated with PC consultation were disease type, poor prognosis, high risk or relapsed disease, intense therapy, bone marrow transplant, phase 1 enrollment, and significant symptoms which seem to prompt PC consultation most consistently, albeit inconsistently. With an overall PC consultation prevalence of 5.6%, this study suggests that PC remains extremely underutilized despite its noted potential to improve the physical, emotional and spiritual well-being of a child undergoing treatment for a life-threatening illness. Additionally, it was not until patients reached four or more documented triggers that PC was consulted. Demographics such as age or gender did not play a role in PC referral practices in the findings of this study, although have been previously cited as triggers for PC consultation. Of note, the age range in this patient population reflects the institution’s practice of caring for all pediatric cancers in patients aged 0-26 years. Interestingly, patients with central nervous system tumors, which generally carry a poor prognosis, or who were found to be deceased at the time of review had extremely low rates of PC consultation, for which further exploration with future studies may be helpful. Together, the findings of this study suggest that a starting point for increasing PC involvement is a trigger-based tool to help pediatric oncology providers improve the integration of PC into the care of children with cancer. **Full text:** <https://bit.ly/2Pqfb9H>



Noted in Media Watch 13 July 2020 (#674, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 8 July 2020 – ‘**A tool for the evaluation of clinical needs and eligibility of pediatric palliative care: The validation of the ACCAPED Scale.**’ This study presents the validation of the Accertamento dei bisogni Clinico-Assistenziali Complessi in PEDIatria (ACCAPED) scale. Results show a very high concordance between the evaluation of clinical vignettes through the ACCAPED scale and the evaluation by the clinical experience for experts in pediatric palliative care (PPC) and pediatricians. A less favorable grade of concordance has been recorded for healthcare professionals not involved in PPC, suggesting that educational efforts to improve basic knowledge of PPC within the medical community are needed. **Abstract:** <https://bit.ly/321UjZV>



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 p.16.

Palliative care in high- and low-resource countries

CURRENT PEDIATRIC REVIEWS | Online – 5 April 2021 – Palliative Care (PC) is well developed in most high income countries; however, in most low income settings, where approximately 80% of patients with cancer requiring PC care for advanced disease live, PC services are still uncommon. Health indicators monitoring global PC development are policy, education, use of medicines, service provision and professional activity. Globally PC development may be categorized as: Group 1 (no known hospice-PC activity); Group 2 (capacity-building activity); Groups 3a (isolated PC provided), and 3b (generalized PC provided); 4a (hospice-PC services at a stage of integration into regular service provision), and 4b (hospice-PC services at a stage of advanced integration into regular service provision). Spirituality is an essential element of PC. The use of complementary and traditional medicine in Middle Eastern countries is widespread. There are wide discrepancies in cancer care and PC in many regions in the world. The Individualized Care Planning & Coordination Model is designed to facilitate the advance care planning with continuity of all the measures like symptom control or emotional, social and spiritual care of both the patient and the family during the disease steps like relapse or end of life. **Abstract:** <https://bit.ly/3s0BZtS>

Noted in Media Watch 10 October 2020 (#688, p.3):

- *WORLDWIDE HOSPICE PALLIATIVE CARE ALLIANCE* | Online – 13 October 2020 – ‘*Global Atlas of Palliative Care (2nd edition)*.’ This edition of the Global Atlas reveals some of the changes that have occurred since the first edition was published in 2014. For instance, there is now a better idea of how many people need palliative care (PC) worldwide. In the 1st edition a conservative estimate of 40 million has now been more accurately estimated as over 56.8 million, including 25.7 million in the last year of life. More patients are now receiving PC than six years ago, increasing from 16,000 services caring for 3 million patients to over 25,000 services caring for over 7 million patients. Still this is only about 12% of the need being met. **Download/view at:** <https://bit.ly/370atWq>

Noted in Media Watch 5 October 2020 (#686, p.7):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 September 2020 – ‘**Estimating the number of patients receiving specialized palliative care globally in 2017.**’ Significant disparities in palliative care (PC) access exist both by region and income group. The European and Pan-American regions had most while the Eastern Mediterranean, Southeast Asian, and African regions had least. Much more needs to be done to develop and deliver PC in low and middle-income countries (LMICs) where 80% of the need for PC exists. With about 70% of operating PC services in high income countries and only 30% in LMICs, a major effort to develop PC in these settings is urgently needed. If every country had a PC registry, we would have more accurate numbers... **Full text:** <https://bit.ly/3l4f2CX>

The influence of geography, religion, religiosity and institutional factors on worldwide end-of-life care for the critically ill...

JOURNAL OF PALLIATIVE CARE | Online – 5 April 2021 – Twenty-two end-of-life (EoL) issues consisting of 35 definitions and 46 statements were evaluated in 32 countries in North America, South America, Eastern Europe, Western Europe, Asia, Australia and South Africa. A multidisciplinary, expert group from specialties treating patients at the EoL within each participating institution assessed the association between 7 key statements and geography, religion, religiosity and institutional factors likely influencing the development of consensus. Mean age of respondents was 45 ± 9 years and 55% were females. Consensus was obtained for 77 of 81 definitions and statements. There was a significant difference in responses across geographical regions. South African and North American respondents were more likely to encourage patients to write advance directives. Fewer Eastern European and Asian respondents agreed with withdrawing life-sustaining treatments without consent of patients or surrogates. While respondent’s religion, years in practice or institution did not affect their agreement, religiosity, physician specialty and responsibility for EoL decisions did. Variability in agreement with key consensus statements about EoL care is related primarily to differences among providers, with provider-level variations related to differences in religiosity and specialty. **Abstract (w. references):** <https://bit.ly/3sTRlvP>

Models of integration of specialized palliative care with oncology

CURRENT TREATMENT OPTIONS IN ONCOLOGY | Online – 8 April 2021 – Evidence from randomized controlled trials (RCTs) and meta-analyses has shown that early integration of specialized palliative care (PC) improves symptoms and quality of life (QoL) for patients with advanced cancer. There are various models of early integration, which may be classified based on setting of care and method of PC referral. Most successful RCTs of early PC have used a model of specialized teams providing in-person PC in free-standing or embedded outpatient clinics. During COVID-19, telehealth has become a prominent model for PC delivery. This model of care has been well received by patients and PC providers, although evidence to date is limited. Despite evidence from trials that routine early integration of PC into oncology care improves patient outcomes, referral to PC still occurs mostly according to the judgment of individual oncologists. This hinders equitable access to PC and to its known benefits for patients and their caregivers. Automated referral based on triggering criteria is being actively explored as an alternative. In particular, routine technology-assisted symptom screening, combined with targeted needs-based automatic referral to outpatient PC, may improve integration and ultimately increase QoL. **Full text:** <https://bit.ly/3dOxmhd>

Related:

- *CURRENT ONCOLOGY REPORTS* | Online – 8 April 2021 – ‘**Global perspectives on palliative care for cancer patients: Not all countries are the same.**’ Palliative care (PC) is developing around the globe and yet PC specific for cancer patients is in its infancy. Cancer care professionals should recognize the gaps that exist and develop strategies to successfully integrate PC into cancer care. To begin this integration, clinicians should understand the epidemiologic cancer differences that exist globally and the impact this has on PC. Next, clinicians need to examine their personal healthcare clinics and environments to begin asking how they can facilitate this integration. This could involve obtaining more education on PC or could involve proposing models and for integration. **Full text:** <https://bit.ly/2Q8eaTF>

Beyond the corporatization of death systems: Towards green death practices

ILLNESS, CRISIS & LOSS | Online – 7 April 2021 – One less explored area of research concerns the response to the ecological crisis through environmentally sustainable death practices, which the authors broadly define in this article as “green death practices.” Interdisciplinary research and scholarship are utilized to critically analyze death practices, and to demonstrate how contemporary Westernized death practices such as embalming, traditional burial, and cremation can have harmful environmental and public health implications. The authors also investigate the multi-billion-dollar funeral industry, and how death systems which place economic growth over human wellbeing can be socially exploitative, oppressive, and marginalizing towards recently bereaved persons and the environment. Death-care as corporatized care is explicitly questioned, and the authors provide a new social vision for death systems in industrialized Western societies. Ultimately, the authors advocate for how green death practices may offer new pathways for honoring our relationships to the planet, other human beings, and even our own deepest values. **Full text:** <https://bit.ly/3d3mXyW>

Noted in Media Watch 26 March 2018 (#556, p.2):

- *THE NEW YORK TIMES* | Online – 22 March 2018 – ‘**Thinking about having a “green” funeral? Here’s what to know.**’ A typical American funeral usually involves a few hallmarks we’ve come to expect: an expensive coffin, lots of flowers, an embalming for the deceased and a number of other add-ons. But how necessary are those embellishments? Enter the “green burial.” The specifics of a green burial vary widely, but typically they require far fewer resources for the care of the body and skip a number of the traditional steps, making them better for the environment. Plus, they can save families on funeral costs. Interest in these pared-down, eco-friendly options has grown as people look for ways to cut their carbon footprint. Nearly 54% of Americans are considering a green burial... <https://nyti.ms/3wFstzN>

Influence of social interactions, professional supports and fear of death on adults' preferences for life-sustaining treatments and palliative care

INTERNATIONAL JOURNAL OF NURSING PRACTICE | Online – 7 April 2021 – End-of-life (EoL) preferences can be shaped not just by knowledge, values and individuals' attitudes, but rather a host of social influences. Few studies with theoretical frameworks or models in the literature are available to provide a comprehensive understanding of factors contributing to responses at the EoL. The findings of this study advances the knowledge of the influence of social interactions, healthcare services' support, palliative care (PC) understanding and fear of death on adults' preferences for life-sustaining treatments and PC. The identified relationships in the context of life-sustaining treatments and PC provide practical guidelines, which can help to inform appropriate supportive interventions for EoL care planning. Healthcare services that provide a mediating structure where a person belongs should focus on enhancing community resources regarding EoL healthcare planning, knowledge about PC and reinforcing life and death education. The social support network and emotional ties with a person's significant others should also be taken into consideration to facilitate EoL healthcare planning and to promote good quality of life at EoL. **Abstract:** <https://bit.ly/31U41fX>

Influence of physical activity on pain, depression and quality of life of patients in palliative care: A proof-of-concept study

JOURNAL OF CLINICAL MEDICINE, 2021;10(5). Palliative patients often or very often experience limitations in the performance of daily activities. The examined group of survey respondents in the majority of cases lead a limited lifestyle and report problems in the sphere of independence, even performing basic activities of everyday life. After completing an educational program for a useful physical activity, the majority of patients declared a reduction of limitations in routine everyday activities. The derived effect was an increase in the quality of life of the examined group of palliative patients, including reduction of pain and mood improvement. The original educational program for physical activity generated a positive response among patients in palliative care (PC), both in a hospice or at home, and their caregivers. The implementation of this project in the everyday management of PC patients would need little additional efforts, in terms of personnel, and would provide good results, if those obtained with this pilot study are confirmed by further studies. **Full text:** <https://bit.ly/3uqowNv>

Noted in Media Watch 6 January 2020 (#647, p.4):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 30 December 2019 – '**Rehabilitation in palliative care: A qualitative study of team professionals.**' The concept of rehabilitative palliative care (PC) has been advocated to help patients preserve function and independence, through greater patient enablement and self-management. Such an approach requires engagement from all members of the PC team. The objective of this research was to explore hospice-based PC professionals' understanding and perceptions of rehabilitation. Overall, participants in this study clearly articulated the underlying values and benefits of rehabilitative PC. Emphasis was placed on ensuring that rehabilitation was appropriately tailored to each individual patient. **Abstract:** <http://bit.ly/2Qb5BF8>

Noted in Media Watch 28 October 2019 (#633, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 September 2019 – '**Top ten tips palliative care clinicians should know about physical medicine and rehabilitation.**' This article, written by a team of physical medicine and rehabilitation (PM&R) and palliative care (PC) specialists, aims to help the PC team ... expand their toolkit for treating musculoskeletal and neurological symptoms, improve prognostication for patients with brain and spinal cord injuries, and decide when patients may benefit from PM&R consultation and support. There is significant overlap between the populations treated by PM&R and PC. Better integration between these specialties will help patients to maintain independence as well as advance excellent patient-centered care. **Abstract:** <http://bit.ly/2lxH54o>

Promoting evidence-based practice in clinical education at a hospice designated education unit

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 31 March 2021 – Integration of palliative care principles into undergraduate nursing curriculum is essential to prepare students to provide supportive care services across the continuum of care for individuals with serious illness. Baccalaureate nursing curricula emphasize development and application of evidence-based practice (EBP); however, development of nursing skills often overshadows teaching students how to deliver care or facilitate practice changes based on evidence in clinical education. Problems revealed in clinical practice are a valuable tool for improving student use and appreciation of EBP in clinical settings. The EBP project presented in this article provides a process to promote palliative and end-of-life EBP in clinical education. This project highlights the proposed American Association of Colleges of Nursing hospice/palliative/supportive care sphere of care in a hospice dedicated education unit following The Seven Steps of EBP. Students participating in the project developed core skills to search, appraise, and translate evidence and the ability to lead EBP projects guided by the dedicated education unit model. Dedicated education units serve as ideal clinical education sites to develop student EBP competencies and support transition to practice through collaboration with practice partner stakeholders. **Abstract:** <https://bit.ly/3mkWslg>

Continuous deep sedation until death: First national survey in France after the 2016 law promulgating it

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 2 April 2021 – The French parliament passed a groundbreaking law in 2016, opening a right for patients to access continuous and deep sedation until death (CDS) at the end of life (EoL), under conditions. Parliamentarians' goal was to consolidate patients' rights whilst avoiding legislating on medical aid in dying. Early 2018, an online survey was sent to all French hospitals, nursing homes, hospital at homes services and general practitioners (GPs). Respondents generally approve the law on CDS as it sets a legal framework; nonetheless, there is a persistent controversy about CDS vs. euthanasia for some physicians in all settings. In hospital settings in particular, differentiating CDS from other sedation practices is uneasy. This study highlights the wide range of elements of language used by patients at the EoL, as understood by respondent physicians to mean a request for CDS and underscores the polymorphous meaning of CDS. **Abstract (w. references):** <https://bit.ly/3rVrLus>

N.B. Additional articles on patient rights and the doctor obligations under France's Claeys-Leonetti Law noted in Media Watch 24 February 2020 (#654, p.12).

Harnessing the chaplain's capacity to identify unmet palliative needs of vulnerable older adults in the emergency department

JOURNAL OF PALLIATIVE CARE | Online – 5 April 2021 – A palliative chaplain-fellow conducted a retrospective chart review evaluating 580 emergency department (ED) patients using the Palliative Care & Rapid Emergency Screening (P-CaRES) tool. An emergency medicine physician and chaplain-fellow screened 10% of these charts to provide a clinical assessment. One year post-study, charts were re-examined to identify which patients received a palliative care (PC) consultation or died, providing an objective metric for comparing predicted needs with services received. Within one year of ED presentation, 31% of the patient sub-sample received a PC consultation; 17% died. Forty percent of deceased patients did not receive a PC consultation. Of this 40%, chaplain screening for P-CaRES eligibility correctly identified 75% of the deceased as needing a PC consultation. Establishing chaplain-led PC screenings as standard practice in the ED setting may improve end-of-life care for older patients. **Abstract (w. references):** <https://bit.ly/3msbE6D>



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

“If we turned our backs, they would ignore our wishes”: Bereaved family perceptions of concordance of care at the end of life

JOURNAL OF PALLIATIVE MEDICINE | Online – 6 April 2021 – Interviews were conducted with 51 next of kin... In-depth interviews focused on aspects of care at the end of life (EoL) that were not consistent with the decedent's wishes. Approximately 10% of next of kin who reported ... that the decedent had specific wishes for medical care at the EoL also reported that the decedent received care that went against their wishes in the last month of life. The main theme of the in-depth interviews with next of ... was that discordant care was inconsistent with wishes for comfort-focused care and a lack of symptom palliation. Despite decades of work to improve quality of EoL care, poor pain and symptom management that result in lack of comfort remain the main reason next of kin state wishes were not honored. **Abstract:** <https://bit.ly/39RfvF6>

Related:

- *JAMA NETWORK OPEN* | Online – 6 April 2021 – ‘**Redefining healthcare utilization as a quality measure for goal concordance at the end of life.**’ Despite most patients expressing wishes to die at home and with less aggressive care, many patients spend their final days in the hospital, and nearly 60% die in acute-care settings. Goal concordance is often used as a quality measure to evaluate the delivery of end-of-life care for patients with serious illness. Family members and surrogate decision-makers can provide important insight on whether healthcare was concordant with patient wishes in the last stages of life. However, the extent to which older patients with serious illness are being provided with goal-concordant care has seldom been explored. **Full text:** <https://bit.ly/3q0EAl8>
- *JAMA NETWORK OPEN* | Online – 6 April 2021 – ‘**Concordance of end-of-life care with end-of-life wishes in an integrated healthcare system.**’ This quality improvement study found positive results in the three areas often described as challenges. First, the study found that approximately 80% to 90% of decedents discussed preferences with next of kin, filled out an advance directive, or gave real thought to the care they desired. Moreover, 65.0% had discussed their treatment preferences with physicians or other medical staff members. Second, the study found that approximately 85% to 95% of decedents gave positive scores on receiving the care they wanted. Third, most decedents thought they got the right amount of care (82.5%). **Full text:** <https://bit.ly/3rW00IB>

N.B. Search back issues of Media Watch for additional articles on “concordance”/“discordance” in medical decision-making at: <http://bit.ly/2ThijkC>

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 5 April 2021 – ‘**Effects of dignity therapy on palliative patients’ family members: A systematic review.**’ The evidence suggests that family members generally believe that dignity therapy (DT) will better prepare patients for end of life (EoL) and overcome the bereavement phase. The results of this systematic review are encouraging, but still reveal many aspects that need to be investigated further so that DT can be used in the most appropriate and beneficial way possible. Further studies are also needed to evaluate the effects of DT on family members. They should preferably be methodologically more uniform: not only in relation to the patient samples but also to the measures used to quantify the benefit of this therapy... **Full text:** <https://bit.ly/3dz8lq7>

Nephrology and palliative care collaboration in the care of patients with advanced kidney disease: Results of a clinician survey

KIDNEY MEDICINE | Online – 31 March – 2021 – Respondents reported being comfortable caring for patients near end-of-life and endorsed advance care planning and collaboration between nephrology and palliative care (PC) teams. Yet, both rarely happen. Fragmentation, or poor coordination of care was perceived to be the main barrier to collaboration. Perceptions regarding collaboration facilitation differed; nephrology clinicians identified patient/family education as the most important facilitator while PC clinicians identified clinician education as most important. Top clinical priorities differed. PC clinicians reported pain/symptom management as taking priority while nephrology clinicians identified caregiver/family support. Developing interventions to support treatment-related decision-making was the top research priority. **Full text:** <https://bit.ly/3mvdGmv>

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Noted in Media Watch 16 November 2020 (#692, p.4):

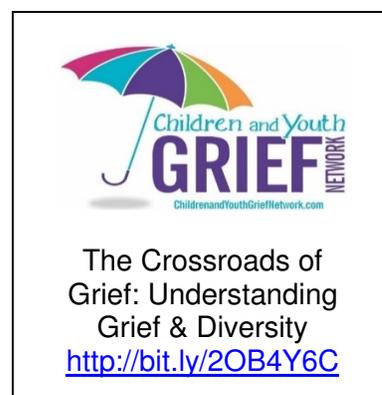
- *AMERICAN JOURNAL OF KIDNEY DISEASES* | Online – 8 November 2020 – ‘**Advancing palliative care in patients with chronic kidney disease: From ideas to practice.**’ During the last 15 years, an engaged community of kidney care professionals, patients and researchers has embarked on a series of activities to adopt an integrated palliative approach to routine care in patients with chronic kidney disease. Although the provincial renal network operates in a publicly funded healthcare system, where coordination across multiple healthcare organizations may be readily facilitated, the authors believe many activities described in this report are broadly applicable to many other settings, including single health maintenance organizations or for-profit systems. **Full text (click on pdf icon):** <https://bit.ly/36yoYyL>

Noted in Media Watch 9 November 2020 (#691, p.3):

- *ADVANCES IN CHRONIC KIDNEY DISEASE*, 2020;27(4):350-355. ‘**Palliative care in nephrology: The work and the workforce.**’ Kidney palliative care (PC), a growing subspecialty of clinical practice, education, and research in nephrology, is an essential aspect of care for patients across the continuum of advanced kidney disease (AKD) who have high symptom burden, multidimensional communication needs and limited life-expectancy. Training in kidney PC can occur in a variety of ways, from didactic curricula and clinical experiences embedded in nephrology fellowship training to the pursuit of additional dedicated fellowship training in PC. This article discusses opportunities and challenges in building a skilled workforce that will address the palliative needs of patients living with AKD. **Full text:** <https://bit.ly/3kPTv0N>

A group therapy program for parentally bereaved young adults with grief complications: Rationale, method and case examples

OMEGA – JOURNAL OF DEATH & DYING | Online – 4 April 2021 – Considerable effort has gone into studying bereavement in children, adults and the elderly, but few studies have investigated the effects of bereavement or grief interventions in young adults. Even fewer studies have reported on the effect of interventions for young adults with grief complications. The authors describe a Danish treatment program specially developed for young adults with complicated grief reactions. The dual process model of coping with bereavement, psychodynamic theory, and a narrative approach provide the foundation for the treatment. In addition, it utilizes an eclectic use of techniques and a group treatment modality that involves providing individual therapy within a group context. The core elements of the treatment are discussed and then exemplified in two case studies. **Abstract (w. references):** <https://bit.ly/3sRreeh>



Related:

- *CHILDREN* | Online – 4 April 2021 – ‘**Current grief support in pediatric palliative care**’ The authors provide a comprehensive overview of current grief support as it relates to pediatric palliative care. The following are addressed: 1) Anticipatory grief: the non-death losses that occur with a complex and chronic illness, as well as the time leading up to death; 2) Grief around the time of death: the intense and sacred experience of companionship with a dying child; 3) Grief after death: supporting bereavement and mourning through programing and other methods; and, 4) Innovative approaches: the future of grief support. The contents of this article are meant to support and educate programs currently providing grief services and those aiming to begin the meaningful work of grief support. **Full text:** <https://bit.ly/2QaXj2z>



Media Watch: Behind the Scenes
<http://bit.ly/2MwRRAU>

Dying in times of the coronavirus: An online survey among healthcare professionals about end-of-life care for patients dying with and without COVID-19 (the CO-LIVE study)

PALLIATIVE MEDICINE | Online – 7 April 2021 – Death due to COVID-19 occurs in all healthcare settings. During the peak of the COVID-19 outbreak, many measures were taken that may restrict possibilities of providing high quality care at the end of life (EoL), both for patients with and without COVID-19. Until now studies are lacking that give insight in how care at the EoL was given to patients with and without COVID-19 and how such care was affected by COVID-19 measures. The authors found that from the perspective of healthcare professionals [i.e., survey respondents] the COVID-19 pandemic generally does not seem to have led to substandard care at the EoL at a large scale, especially with regard to medical and nursing care, although the small group for which medical and nursing home care was insufficient should not be disregarded. Healthcare providers felt that care especially fell short in the emotional and existential domain. It is recommended that in future waves or pandemics attention is paid to timely identification of the EoL approaching, and giving personal attention to patients and their relatives, among others by having attention for their psychosocial and existential concerns and foremost by, where possible, being flexible in allowing relatives visiting patients in the last phase of life in order to be able to say goodbye properly. Palliative care services are particularly equipped to assist in achieving this. **Full text:** <https://bit.ly/3wumwpi>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 April 2021 – ‘**Scalable model for delivery of inpatient palliative care during a pandemic.**’ The authors developed an inpatient palliative care (PC) response to the COVID-19 pandemic that can be used by teams without an inpatient PC unit or where the number of patients with COVID-19 exceeds the capacity of the existing PC unit. The authors utilized data from other countries’ experiences with COVID-19 as well as data relating to previous pandemics to inform their response. While PC management approaches were mostly unchanged, new structures and strategies were developed to ensure patients’ needs were met. Other models of PC have also been successfully implemented during the COVID-19 pandemic. **Full text:** <https://bit.ly/3mpuOKI>
- *PALLIATIVE MEDICINE* | Online – 8 April 2021 – ‘**Home palliative care professionals perception of challenges during the Covid-19 outbreak: A qualitative study.**’ Three main themes were identified. The first showed both patient-related and practice-related challenges participants faced in their daily work, requiring the implementation of different communication methods and patient and family education on risk prevention. The second theme showed the perception of increased responsibility and being the only landmark for family played a decisive role in participants’ positive attitude. The third highlighted the participants’ perception of the critical role of a home care setting in this emergency situation. The first wave of the Covid-19 pandemic brought many challenges... **Abstract (w. references):** <https://bit.ly/3wRnplK>

Research Matters

The impact of international research collaborations on the citation metrics and the scientific potential of South American palliative care research: Bibliometric analysis

ANNALS OF GLOBAL HEALTH, 2021;87(1):32. 18.2% of the publications from South America investigators involved international research collaborations. Collaborations between South America countries are infrequent in the context of palliative care, representing only 2.8% of the publications. In contrast, international collaborations with countries outside South America are more frequent (17.2%) and have shown an increasing trend over the last decades. Studies with international research collaborations are cited more frequently and are greater scientific potential than those without international collaborations, as judged by having more complex methodologies (clinical trials and longitudinal studies), receiving external funding, and being published in journals with a higher scientific impact. The trend of economic and social globalization, as well as the ease of connections through the Internet, facilitate the establishment of research partnerships and international collaboration networks. International collaborations can have countless purposes, which may be distinct even for the collaborators within the same study. Multicenter studies have

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greater power of generalization and greater ability to obtain large sample sizes, sometimes necessary and unfeasible in single-center studies. Furthermore, research collaborations often occur as a function of the knowledge or skills demonstrated by specific researchers as well as the availability of equipment or resources that can implement specific advances in the study. In turn, research collaborations certainly have an educational impact when research centers with less expertise collaborate with large research centers that, consequently, provide capacity building so that the centers in development can attract new researchers and produce higher quality research. **Full text:** <https://bit.ly/31GqSLT>

Noted in Media Watch 27 January 2020 (#650, p.12):

- *PALLIATIVE MEDICINE* | Online – 23 January 2020 – ‘Do journals contribute to the international publication of research in their field? A bibliometric analysis of palliative care journal data.’ Research impacts on health service provision and patient benefit. Journals play an important dissemination role, but there may be geographical bias, potentially affecting access to evidence. The authors sought to understand if there is a relationship between the continent of journals and that of contributing authors. North American authors are more present in North American journals and European authors in European journals. This polarised approach, if replicated across readerships, may lead to research waste, duplication and be sub-optimal for healthcare development. **Abstract (w. references):** <http://bit.ly/3aCr8i5>

Factors affecting recruitment and participation of bereaved parents in research: A brief report

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 9 April 2021 – Inclusion of bereaved parents in survey-based research is essential to improving end-of-life care (EoLC) for children and their families. Compared to those who fully participated in this study, parents of non-white children were more likely to incompletely participate, while those with public insurance only were more likely to decline participation. Parents of children who had a documented limitation to resuscitation order were more likely to fully participate in the study (reference group) than incompletely participate, while parents of children who had sub-specialty palliative care involvement were less likely to decline participation in the study. To ensure optimal EoLC for children, all parental voices should be heard. Recruitment of racial/ethnic minorities in bereaved parent survey-based studies can be improved by focusing on specific factors that are associated with parental survey completion. **Abstract (w. references):** <https://bit.ly/2PldZ1w>

N.B. Additional articles on recruitment of children and parents in research noted in Media Watch 5 April 2021 (711, p.12).

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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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