

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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Hospital specialist palliative care teams often shifted from a responsive to a proactive model of care as patients with COVID-19 could deteriorate and die rapidly and some of those providing direct care lacked end-of-life care experience.

'Specialist palliative care service innovation and practice change in response to COVID-19... Results from a multinational survey...' (p.9), in *Palliative Medicine*.

U.S.A.

Palliative care works, so why is it rarely used? Follow the money

STAT | Online – 23 March 2021 – A decade ago, a team of researchers showed clearly that a new treatment for advanced lung cancer significantly improved patients' quality of life (QoL), reduced symptoms of depression, lowered the likelihood of being admitted to the hospital for a complication of their disease, and improved survival.¹ Subsequent research has found similar beneficial effects in other cancers and diseases. Flash forward to today: two-thirds of patients living with a serious illness who could benefit from this therapy don't get it,² and the majority of cancer physicians do not prescribe it despite endorsements from the American Cancer Society and the American Society of Clinical Oncology. The treatment is not a drug or a procedure. It is palliative care (PC): a team of specially trained doctors, nurses, social workers, and chaplains who focus on improving QoL and reducing the disease burden for seriously ill individuals and their families. This is different than hospice – care for those who are dying, which focuses on comfort. PC is provided alongside other treatments to people of any age

facing serious ailments. Once engaged, a palliative team can treat pain and other distressing symptoms, address family needs, coordinate care, and provide emotional and spiritual support. Study after study shows that the outcomes of PC for patients and families can be substantial.³ <http://bit.ly/397dcO4>

Specialist Publications

'A qualitative study describing pediatric palliative care in non-metropolitan areas of Illinois' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'Death education's "period of popularity": Lessons for contemporary P-12 schools in the U.S. during the COVID-19 pandemic' (p.8), in *Death Studies*.

'Indiana medical resident's knowledge of surrogate decision-making laws' (p.8), in *International Quarterly of Community Health Education*.

1. 'Early palliative care for patients with metastatic non-small-cell lung cancer,' *New England Journal of Medicine*, 2010;363(8):733-742. [Noted in Media Watch 23 August 2010 (#163, p.8)] **Full text:** <https://bit.ly/39ayxpU>

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2. 'Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey,' *Journal of Pain & Symptom Management*, 2019;58:1:39-47. [Noted in Media Watch 1 April 2019 (#608, p.12)] **Full text:** <http://bit.ly/2JCTteG>
3. 'Association between palliative care and patient and caregiver outcomes: A systematic review and meta-analysis,' *Journal of the American Medical Association*, 2016;316(20):2104-2114. [Noted in Media Watch 28 November 2016 (#489, p.1)] **Full text:** <http://bit.ly/3d0jK1T>

International

Most health professionals feel unprepared to give palliative care, survey finds

SINGAPORE | *The Straits Times* – 26 March 2021 – Most healthcare professionals feel unprepared to provide palliative care (PC) for patients with life-threatening illnesses, a recent survey shows. But more are becoming aware of the importance of this field, which focuses on relieving pain and improving quality of life for the seriously ill or dying. The Singapore Hospice Council survey of 2,326 healthcare professionals revealed that only about four in 10 received training in PC either at medical school, at nursing school or while studying social work. Of those who had been trained, 58% of doctors, 45% of nurses and 60% of allied health professionals felt it was not enough to prepare them to support patients with life-threatening illnesses. Around six in 10 doctors and nurses who took part in the online survey between ... said they were aware of hospice and PC... <https://bit.ly/3tRbhVE>

Specialist Publications

'End-of-life care for people with advanced dementia and pain: A qualitative study in Swedish nursing homes' (p.4), in *BMC Nursing*.

'Quality indicators in pediatric palliative care: Considerations for Latin America' (p.7), in *Children*.

'The doctrine of double effect and potential criminal liability of medical practitioners in Australia' (p.8), in *Journal of Law & Medicine*.

'British laypeople's attitudes towards gradual sedation, sedation to unconsciousness and euthanasia at the end of life' (p.11), in *Plos One*.

Scottish Council for Voluntary Organisations

£16.9 million emergency hospice funding agreed

U.K. (Scotland) | *Third Force News* (Edinburgh) – 24 March 2021 – Emergency funding for all hospices in Scotland has been agreed by the Scottish Government, amounting to £16.9 million. As charitable organisations, hospices have been badly impacted by the COVID-19 pandemic, which has greatly affected their ability to fundraise vital income. In 2020, Hospice UK negotiated emergency funding for all hospices in the U.K., including the devolved nations. However, as the effects of the pandemic are expected to continue into 2021-2022, hospices are continuing to work with the Scottish Government to discuss the pressures on hospice care. Each year, hospices support more than 22,400 people through delivering care to people in their own homes, as well as inpatient, outpatient and day services. Hospices have demonstrated significant innovations over the past year to continue fundraising in virtual ways. However, the external landscape continues to have a major impact on hospices' ability to raise funds. With a significant deficit expected in fundraising income in the coming year, the confirmation of this emergency funding provides a level of reassurance for forward planning of care services. <https://bit.ly/3rgSD7Z>

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

- U.K. (Scotland) | *The Times* (Glasgow) – 8 March 2021 – ‘**Struggling hospices are left waiting for millions.**’ Scotland’s health secretary has been branded “a disgrace” after it emerged that at least £14 million of emergency funding has been withheld from hospices – more than half the amount allocated by the U.K. Treasury. Jeane Freeman pledged in April that £19 million would be channelled into hospices across the country as “consequentialists” of a £200 million emergency grant to the sector in England made by Rishi Sunak, the chancellor. Along with a further winter payment from Sunak, a total of £24 million has been made available to the Scottish government as a consequence of the Barnett formula. However, only £10 million has been passed on. <http://bit.ly/3rynrSQ>

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

Tŷ Gobaith children’s hospice joins calls for new sustainable “Lifeline Fund”

U.K. (Wales) | *The Leader* (Mold, Flintshire) – 20 March 2021 – In the run up to elections in Wales this May, Wales’ two children’s hospices have joined forces to call for a new sustainable “Lifeline Fund” and funding parity with the rest of the U.K. to ensure that all children with life-limiting conditions and their families can receive the support they desperately need. Between them, South Wales based Tŷ Hafan and North Wales based Tŷ Gobaith provide respite and palliative care for more than 400 families with children with life-limiting conditions, but currently the two hospices receive less than 10% of their annual funding from the Welsh Government. Across the border, children’s hospices in England receive 21% of their funding from the U.K. Government – more than double the amount of government funding received by children’s hospices in Wales. Meanwhile government funding for children’s hospices in Northern Ireland and Scotland runs at 25% and 50% respectively, making children’s hospices in Wales the poor relation of those elsewhere in the U.K. <http://bit.ly/3r8jT8L>

Noted in Media Watch 23 November 2020 (#693, p.6):

- U.K. (Wales) | BBC News (Cardiff) – 17 November 2020 – ‘**Families “let down” by children’s hospices funding.**’ Families with children who have life-limiting conditions “urgently need more access to respite care,” a report has found.¹ More than 130 families across Wales’ seven health boards who use children’s hospices contributed to the critical Family Voices report. They want better access and more money for Wales’ two hospices. The Welsh Government said it was working with hospices “to understand their future funding requirements.” Tŷ Hafan, near Cardiff, and Tŷ Gobaith, near Conwy, provide specialist one-to-one care and outreach services to children and their families, including end-of-life and crisis care, plus respite help to full-time carers. <https://bbc.in/3IEgnRx>

1. ‘Our lifeline,’ Family Voices, November 2020. Download/view at: <https://bit.ly/38XHZgK>

Noted in Media Watch 9 March 2020 (#656, p.4):

- U.K. (Wales) | BBC News (Cardiff) – 4 March 2020 – ‘**Welsh children’s respite care cut due to hospice funding “crisis.”**’ Funding for Wales’ children’s hospices is reaching “crisis point” amid calls for more public funding to stop them cutting respite care for sick children. They get on average less than 10% of funding from the Welsh Government, lower than for other U.K. countries. The Welsh Government said it was discussing funding needs with hospices. Children’s hospices in Scotland get more than half of their funding from the Scottish government while England’s children’s hospices get 21% of their cash from the public purse. The two children’s hospices in Wales, Ty Hafan near Cardiff and Ty Gobaith near Conwy, rely on public donations to survive. <https://bbc.in/39rARH2>

N.B. 22 March 2021, the Welsh Government published ‘National clinical framework: A learning health and care system.’ End-of-life care is discussed (see p.21), but there is no mention of pediatric palliative care or of childrens’ hospice care. Download/view at: <http://bit.ly/3f7OTmY>

Specialist Publications

U.S. Alzheimer's Association report

2021 Alzheimer's disease facts and figures

ALZHEIMER'S & DEMENTIA | Online – 23 March 2021 – This article describes the public health impact of Alzheimer's disease (AD), including incidence and prevalence, mortality and morbidity, use and costs of care, and the overall impact on caregivers and society. The authors discuss the challenges of providing equitable healthcare for people with dementia in the U.S. An estimated 6.2 million Americans age 65 and older are living with Alzheimer's dementia today. This number could grow to 13.8 million by 2060 barring the development of medical breakthroughs to prevent, slow or cure AD. Official death certificates recorded 121,499 deaths from AD in 2019, the latest year for which data are available, making Alzheimer's the sixth-leading cause of death in the U.S. and the fifth-leading cause of death among Americans age 65 and older. Between 2000 and 2019, deaths from stroke, heart disease and HIV decreased, whereas reported deaths from AD increased more than 145%. This trajectory of deaths from AD was likely exacerbated in 2020 by the COVID-19 pandemic. More than 11 million family members and other unpaid caregivers provided an estimated 15.3 billion hours of care to people with Alzheimer's or other dementias in 2020. These figures reflect a decline in the number of caregivers compared with a decade earlier, as well as an increase in the amount of care provided by each remaining caregiver. Unpaid dementia caregiving was valued at \$256.7 billion in 2020. Despite years of efforts to make healthcare more equitable in the U.S., racial and ethnic disparities remain – both in terms of health disparities, which involve differences in the burden of illness, and healthcare disparities, which involve differences in the ability to use healthcare services. **Full text:** <https://bit.ly/3tUF0gD>

End-of-life care for people with advanced dementia and pain: A qualitative study in Swedish nursing homes

BMC NURSING | Online – 20 March 2021 – This study shows that nurses face several demanding challenges when caring for persons with advanced dementia and pain at the end of life. One of the main issues was the difficulty in communicating with these persons, resulting in uncertain pain assessment. This results in difficulties in separating pain from anxiety and balancing the benefits and risks of morphine administration. Relatives can significantly influence the assessment and management of pain, both as interpreters of

Research Matters

'A spiritual care intervention for chaplains in home-based palliative care: Design of a mixed-methods study investigating effects on patients' spiritual wellbeing' (p.12), in *Journal of Health Care Chaplaincy*.

'Opportunities for public involvement in big data research in palliative and end-of-life care' (p.13), in *Palliative Medicine*.

Extract from *Alzheimer's & Dementia* article

Based on data from the National Hospice Survey for 2008 to 2011, nearly all (99%) hospices cared for individuals with dementia, although only 67% of hospices had residents with a primary diagnosis of dementia. Fifty-two percent of individuals in for-profit hospices had either a primary or comorbid diagnosis of dementia, while 41% of individuals in non-profit hospices had a diagnosis of dementia. More research is needed to understand the underlying reasons for the differences in the percentage of people with dementia in for-profit versus nonprofit hospices. Researchers have found similar reductions in hospitalizations at the end of life for individuals receiving palliative care (PC). For nursing home residents with moderate-to-severe dementia, those who received an initial PC consultation between one and six months before death had significantly fewer hospitalizations and emergency department visits in the last seven and 30 days of life, compared with those who did not receive PC. Patients with an initial PC consultation within one month of death also had significantly fewer hospitalizations in the last seven days of life compared with those who did not receive PC.

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pain behaviour and by questioning the care given. Factors facilitating good palliative care and pain management included having good relationships with the other healthcare personnel, having extensive relevant professional experience, and having enough time to care for the resident with advanced dementia and their relatives. The many challenges can affect the care of this growing and vulnerable group negatively and, therefore, it is crucial to promote more research in this area. Specifically trained specialist nurses are sorely needed at nursing homes in order to meet these challenges with the appropriate skills and knowledge. Additionally, there should be resources and strategies available for informing and involving family members in the care as they are often unfamiliar with the considerations involved in decisions (such as whether to administer morphine or not). **Full text:** <http://bit.ly/3r7R2RP>

Noted in Media Watch 1 March 2021 (#706, p.10):

- **PALLIATIVE MEDICINE** | Online – 23 February 2021 – ‘**Caring ahead: Mixed methods development of a questionnaire to measure caregiver preparedness for end of life with dementia.**’ New insight into indicators and core concepts of preparedness was gleaned through this study that helped to produce the ‘Caring Ahead’ questionnaire with current evidence for face and content validity. These findings should assist healthcare professionals and researchers to assess caregivers’ feelings of preparedness, identify caregivers in need of support, design and evaluate strategies aligned with a palliative approach. Future research is needed to evaluate questionnaire psychometrics (i.e., content, construct, predictive validity and reliability) in a larger sample and with different populations. **Full text:** <http://bit.ly/3qZfJR2>

N.B. Selected articles on end-of-life care for people living with dementia and other forms of cognitive impairment noted in Media Watch 18 January 2021 (#700, p.12) and 25 January 2021 (#701, pp.4-5).

Qualitative investigation of patient and carer experiences of everyday legal needs towards end of life

BMC PALLIATIVE CARE | Online – 23 March 2021 – Everyday legal needs commonly affect people living towards end of life (EoL), and their informal carers, and can create significant challenges. This study has shown that limited awareness of the issues and individual rights, together with lack of clear routes to support, generates frustration, variability in practice and unmet needs; resolution of legal needs results in practical and emotional benefit. Healthcare professionals hold key roles as “critical noticers.” trusted intermediaries and compassionate enablers, resolving legal needs directly, referring onto other agencies and facilitating difficult conversations around planning. Everyday legal needs must be included within holistic care towards EoL, integrating and utilising the full breadth of available services and expertise. **Full text:** <https://bit.ly/3cXOTmK>

Hospital-based acute care in the last 30 days of life among patients with chronic disease that received early, late or no specialist palliative care: A retrospective cohort study of eight chronic disease groups

BMJ OPEN | Online – 24 March 2021 – The reality for many jurisdictions is very limited access to, or a continuing lack of, specialist palliative care (PC) providers. Given this, the importance of disease-specific specialists and primary care physicians in providing PC, particularly early PC, and early initiation of advance care planning discussions, cannot be overstated. An ongoing challenge is knowing precisely when and who to refer to specialist PC to best leverage these providers expertise, recognising that in many places this is a scarce resource. This is true particularly for patients without cancer chronic diseases where the disease trajectory is less predictable, and can be much longer. Addressing this challenge is important as evidence shows that the addition of PC benefits outcomes for patients with and without cancer. Future work examining differing patient needs and preferences by chronic disease is needed, and could inform referral to specialist PC services, which in turn would impact timing of PC referrals. Development of disease-specific quality of end-of-life (EoL) care indicators would help ensure that the right outcomes are focused on by all providers. Within specialist PC, questions remain on the role that location and model of delivery play in improving patient quality of life (QoL) and optimising healthcare resource use near the EoL. For example,

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how do the different specialist PC services (e.g., palliative home care, palliative consult team) compare in their impact on QoL and EoL resource use outcomes, and does it differ by chronic disease (underlying cause of death). At the level of individual specialist PC services, is there a difference in timing for each? For many patients, specialist PC is a complex, multifaceted intervention, and determining what aspect of the care have the greatest impact on outcomes could help in determining how to deliver the highest quality and highest value EoL care. **Full text:** <https://bit.ly/3d4m8EZ>

Breaking bad news: Tackling cultural dilemmas

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 24 March 2021 – Requesting that serious diagnoses be concealed from patients, a widespread phenomenon in many cultures, presents a professional dilemma. Practical and sensitive communication strategies are needed. The authors use analysis of the existing literature to develop a communication tool for practitioners facing requests for diagnostic non-disclosure. Their approach builds on existing strategies, in providing a mnemonic communication tool, permitting more than one outcome, and focusing on the need for mutual understanding and cooperation. Existing work on this dilemma highlights the need to appreciate the family's standpoint, affirm their benevolent intentions and correct misperceptions. To this end, the authors have developed a mnemonic tool, 'ARCHES.' to be used in situations where the family has requested diagnostic non-disclosure. The model has six stages: 1) Acknowledge the request for non-disclosure; 2) Build the relationship; 3) Find common ground; 4) Honour the patient's preferences and outline the harm of non-disclosure; 5) Provide emotional support; and, 6) Devise a supportive solution. Facing requests for diagnostic non-disclosure is a challenge of communication. **Abstract:** <https://bit.ly/3d7xTdH>

Improving do not attempt cardiopulmonary resuscitation discussions, decisions and documentation

BRITISH MEDICAL JOURNAL | Online – 24 March 2021 – The Care Quality Commission (CQC) published a report on the quality of decision-making, discussion with patients and families, and documentation on DNACPR (do not attempt cardiopulmonary resuscitation) decisions in the COVID-19 pandemic.¹ The report was commissioned by the government in response to news stories, complaints, and campaigns about perceived failings. It acknowledged that the extreme demands of the pandemic response had increased pressure on clinical and care staff and services, which may have hampered decisions and communication. The CQC said that DNACPR decisions don't exist in isolation but are part of a broader spectrum of care planning for long term conditions, advance care planning for end-of-life decisions, and emergency treatment escalation plans. Ensuring that people in nursing and residential homes have a clearly structured emergency care and treatment escalation plan can help reduce unnecessary acute admissions. In hospitals, this planning can stop excessive medicalised intervention that may worsen distress, ignore a patient's own priorities, or add little value. It can also guide critical care outreach, resuscitation, or on-call medical teams as to necessary levels of intervention for deteriorating patients. As for DNACPR itself, we need more discussions, not fewer. If these don't happen until patients present in an acute crisis we need to discuss and make decisions there and then, although "upstream" planning is preferable. The CQC highlighted examples of good practice in all of these areas – but also failings that we shouldn't seek to play down. It found a big gap between accepted, law compliant best practice and reality. **Full text:** <https://bit.ly/3lNYyk0>

1. 'Protect, respect, connect – decisions about living and dying well during COVID-19,' Care Quality Commission, March 2021.[Noted in Media Watch 22 March 2021 (#709, pp.3-4)] <http://bit.ly/3eMn6ly>

Related:

- *GERONTOLOGY & GERIATRIC MEDICINE* | Online – 20 March 2021 – **'Moving from “do not resuscitate” orders to standardized resuscitation plans and shared-decision making in hospital inpatients.'** The process of documenting No-CPR orders and now resuscitation plans has evolved in response to a complex interaction of previous systemic failures and advancing medical knowledge, with a renewed emphasis on shared decision-making and respect for a patient's right to refuse treatment. These developments in resuscitation planning have also been facilitated by a changing hospital culture, which has allowed for an increasingly robust, transparent and de-stigmatized debate about how resuscitation decisions are made. **Full text:** <https://bit.ly/3sgTVkE>

Quality indicators in pediatric palliative care: Considerations for Latin America

CHILDREN | Online – 23 March 2021 – Pediatric palliative care (PC) is a growing field in which the currently available resources are still insufficient to meet the PC needs of children worldwide. Specifically, in Latin America, pediatric PC services have emerged unevenly and are still considered underdeveloped when compared to other regions of the world. A crucial step in developing pediatric (PC) programs is delineating quality indicators; however, no consensus has been reached on the outcomes or how to measure the impact of pediatric PC. Additionally, Latin America has unique socio-cultural characteristics that impact the perception, acceptance, enrollment and implementation of PC services. To date, no defined set of quality indicators has been proposed for the region. This article explores the limitations of current available quality indicators and describes the Latin American context and how it affects pediatric PC development. This information can help guide the creation of standards of care and quality indicators that meet local pediatric PC needs while considering the socio-cultural landscape of Latin America and its population. **Full text:** <https://bit.ly/3rkvJwm>

Related:

- **AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE** | Online – 24 March 2021 – ‘**A qualitative study describing pediatric palliative care in non-metropolitan areas of Illinois.**’ Themes related to pediatric palliative care (PC) perceptions, availability and use of local resources and, challenges associated with travel, care coordination and finances. Participants described benefits of and limits ... including pediatric-specific issues such as attending to siblings, creating child peer-support activities, providing school guidance, and financing for pediatric PC. Recommendations included suggestions to enhance care coordination, use existing resources, improve community and provider education, develop community networks, and minimize financial challenges. **Abstract (w. references):** <https://bit.ly/3da0izS>
- **JOURNAL OF PAIN & SYMPTOM MANAGEMENT** | Online – 25 March 2021 – ‘**Stuck moments and silver-Linings: The spectrum of adaptation among non-bereaved and bereaved parents of adolescents and young adults with advanced cancer.**’ Adaptation to a child’s serious illness and death likely occurs on a dynamic spectrum and parents may oscillate both cognitively and emotionally. This has important implications for how clinicians and communities support parents. Greater comfort with and normalization of the adaptation process may enable parents to more openly share both the unimaginable hardships and unexpected silver-linings that are part of their parenting experiences during their child’s illness and death. **Abstract (w. references):** <https://bit.ly/3w70cBE>
- **PAEDIATRICS & CHILD HEALTH** | Online – 24 March 2021 – ‘**End-of-life issues in the paediatric intensive care unit.**’ A child’s death will always be a tragic and challenging experience, but the way it is managed can influence the impact it has on everyone involved. This article provides a review of the issues surrounding the end-of-life (EoL) process for patients in paediatric intensive care units and explores the challenges and considerations involved in decision-making to withhold or withdraw life-sustaining therapy. The authors discuss the practicalities of managing and optimising EoL care within and beyond the paediatric intensive care unit and the different aspects that healthcare teams need to address before and after a child’s death. **Abstract:** <https://bit.ly/31ISvt>
- **PALLIATIVE MEDICINE** | Online – 26 March 2021 – “**Living in parallel worlds**” – bereaved parents’ experience of family life when a parent with dependent children is at end of life from cancer: A qualitative study. Parents often live in “parallel worlds” throughout the end of life period. In one world, “living in the moment,” cherishing the ordinariness of family life, remaining hopeful treatment will prolong life, whilst adapting as the illness unfolds. The other world presents as “intermittent glimpses that death is approaching,” shadowed with painful emotional concerns surrounding their children and the future. At the end, death rapidly approaches, characterised as suddenly “falling off the cliff”; placing significant demands on the well-parent. **Full Text:** <https://bit.ly/3spzXo7>
- **PALLIATIVE MEDICINE** | Online – 26 March 2021 – ‘**Hearing the voices of children diagnosed with a life-threatening or life-limiting illness and their parents’ accounts in a palliative care setting: A qualitative study.**’ Interview data demonstrated that there was a gap in the child’s experience and understanding of their condition compared to their parents. The data produced six major themes: 1) Awareness of the illness; 2) Death and dying; 3) The spiritual response to illness; 4) The emotional response to illness; 5) Striving for normality and independence; and, 6) Coping strategies. The study showed that children can read subtle cues or they may talk with other children to learn about their illness when information is not openly available to them. **Abstract (w. references):** <https://bit.ly/3rpxecL>

Death education's "period of popularity"

Lessons for contemporary P-12 schools in the U.S. during the COVID-19 pandemic

DEATH STUDIES | Online – 24 March 2021 – As students gradually 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 is no longer a formal component of the American curriculum, death education took on a prominent role in the curriculum during its “Period of Popularity” from 1968-1977. Lessons from this period can help guide educators in bringing back needed components of death education to P-12 classrooms today. **Abstract:** <https://bit.ly/3d3TDHr>

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).

Indiana medical resident's knowledge of surrogate decision-making laws

INTERNATIONAL QUARTERLY OF COMMUNITY HEALTH EDUCATION | Online – 22 March 2021 – Only 22.9% of medical residents [i.e., survey respondents] knew the default state law in Indiana did not have a hierarchy for settling disputes among surrogates. They correctly identified which family members could participate in medical decisions 86% of the time. Under the U.S. Veterans Affairs surrogate law, medical residents correctly identified appropriate family members or friends 50% of the time and incorrectly acknowledged the chief decision-makers during a dispute 30% of the time. All medical residents report only having little or some knowledge of surrogate decision-making laws with only 43% having remembered receiving surrogate decision-making training during their residency. These findings demonstrate that medical residents lack understanding of surrogate decision-making laws. In order to ensure medical decisions are made by the appropriate surrogates and patient autonomy is upheld, an educational intervention is required to train medical residents about surrogate decision-making laws and how they are used in clinical practice.

Abstract (w. references): <http://bit.ly/3cb56FR>

The doctrine of double effect and potential criminal liability of medical practitioners in Australia

JOURNAL OF LAW & MEDICINE, 2021;28(2):503-520. Recent parliamentary inquiries into end-of-life (EoL) choices identify the need to provide legal certainty for health practitioners working in EoL care. A concern identified is the lack of clarity surrounding the operation, status and application of the doctrine of double effect. This discussion clarifies these concerns. Although the doctrine is judicially recognised in several overseas jurisdictions, in Australia the doctrine of precedent means that it does not form part of the common law. In most jurisdictions, the fault element for murder includes recklessness, and application of the doctrine does not avoid criminal liability being established against orthodox criminal law principles. Although the prosecution of a medical practitioner who incidentally causes death in the proper course of medical treatment is a rare event, it remains a live issue. Legislative protection of medical practitioners, as has occurred in Queensland, South Australia and Western Australia, is the means to achieve the certainty sought. **Abstract (via PubMed):** <https://bit.ly/3tYPpla>

Prognostic assessments

Conflicting goals influence physicians' expressed beliefs to patients and colleagues

MEDICAL DECISION MAKING | Online – 25 March 2021 – An online panel of 398 specialists in internal medicine who completed their medical degrees and practiced in the U.S. provided their estimated diagnostic accuracy and prognostic assessments for a randomly assigned case. In addition, they reported the diagnostic and prognostic assessments they would report to patients and colleagues more generally. Physicians answered questions about how and why their own beliefs differed from their expressed beliefs to patients and colleagues in the specific case and more generally in their practice. When discussing beliefs about prognoses to patients and colleagues, most physicians expressed beliefs that differed from their own beliefs. Physicians were more likely to express greater optimism when talking to patients about poor prognoses than good prognoses. Physicians were also more likely to express greater uncertainty to patients when prognoses were poor than when they were good. The most common reasons for the differences between physicians' own beliefs and their expressed beliefs were preserving hope and acknowledging the inherent uncertainty of medicine. **Abstract (w. references):** <https://bit.ly/3sp2hXr>

"Necessity is the mother of invention"

Specialist palliative care service innovation and practice change in response to COVID-19. Results from a multinational survey...

PALLIATIVE MEDICINE | Online – 23 March 2021 – In this study, services had to rely on a “quick fix,” “making do,” being flexible and thinking in a frugal way. So called “frugal” or “jugaad” innovation can challenge standard definitions of innovation. The aim is to provide low cost solutions to problems in environments that have resource constraints, and has been used in healthcare in economically disadvantaged communities, including in the context of palliative care. Changes seen do not reflect the standard literature on the diffusion of innovations. Standard forms of innovation require planning and funding, often impossible when responding to an unforeseen event like the COVID-19 pandemic. The term improvisation rather than innovation has been used in crisis management, as organisations are required to be creative by using, adjusting and recombining existing resources, structures and processes to manage the impact of a crisis. In these circumstances, resistance to change is limited as there is an acceptance that “normal” rules no longer apply and a collective

identity develops, as seen in this study, with clinicians no longer working in professional silos and previously resisted technology being used. Whilst used in a different context, such limited resistance to change resonates with Klein's concept of the “shock doctrine” in which extreme crises (such as COVID-19) pertain the power to “shock” systems and, in doing so, shake up socio-cultural norms to the extent that new changes – that may have been previously resisted – can be made quicker and easier than usual. **Full text:** <http://bit.ly/3f6rsu8>

Extract from *Palliative Medicine* article

Specialist palliative care services are part of a whole healthcare system response to COVID-19 which involves services working collaboratively with each other and with other external healthcare organisations in response to the pandemic. Services need to make practice changes in response to the global pandemic.

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

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 5 February 2021 – ‘**The challenges of caring for people dying from COVID-19: A multinational, observational study (CovPall).**’ Palliative care (PC) services responded actively but most felt ignored by national health systems during the COVID-19 pandemic, despite supporting patients who were dying or had severe symptoms, supporting their families/carers and supporting other professionals to deliver care. Services provided expertise in symptom management and holistic care while facing shortages of equipment, staff and medicines. The crucial role of PC during pandemics must be better recognised and integrated. This is particularly the case for charity managed services and those providing care in people's homes. **Full text:** <https://bit.ly/3rnwKnY>

Futility and terminal mental illness: The conceptual clarification continues

PERSPECTIVES IN BIOLOGY & MEDICINE, 2021;64(1):44-55. Conceptual parity posits that both medical and mental illness are both simply illness, and thus should be considered as fundamentally the same, especially in health services and policy. Recent controversy over medical assistance in dying (MAiD) highlights both the unequal treatment of physical and mental illnesses in end-of-life care and the need for more conceptual clarification of terminal mental illness. This article presents an argument for the necessary elements in terminal mental illness, the value of qualitative assessments, and important areas that require further research and clarity in order for terminal mental illness to be appropriately identified. Given current conceptual limitations, palliative psychiatry, and not MAiD, is recommended in severely treatment-resistant cases of mental illness. First page view: <http://bit.ly/3tJfNWj>

Noted in Media Watch 22 March 2021 (#709, p.13):

- *PROGRESS IN PALLIATIVE CARE* | Online – 19 March 2021 – ‘**Lean in, don’t step back: The views and experiences of patients and carers with severe mental illness and incurable physical conditions on palliative and end-of-life care.**’ People with severe mental illness (SMI) have a life expectancy of up to twenty years less than the general population and many live with incurable physical health conditions. Yet, they continue to experience barriers when trying to access palliative and end-of-life care. Little research has been carried out which includes the views and experiences of people with SMI, and this study presents first findings which include people with both SMI and an incurable condition and their carers. **Abstract:** <https://bit.ly/30XohwA>

Noted in Media Watch 24 August 2020 (#680, p.8):

- *JOURNAL OF PALLIATIVE CARE* | Online – 18 August 2020 – ‘**Working at the intersection of palliative end-of-life and mental healthcare: Provider perspectives.**’ The most prominent issues pertained to assessment of patients and differential diagnosis of chronic and persistent mental illness, and preparedness of caregivers to deliver mental health interventions, given the isolation of palliative care from other agencies. Among the assets mentioned, informal relationships with frontline caregivers were seen as the main support structure, rather than the formal policies and procedures of the practice settings. Strategies to improve mental healthcare in palliative and end-of-life care centered on holistic roles and interventions benefiting the entire palliative population... **Abstract (w. references):** <https://bit.ly/31fr7hr>

Noted in Media Watch 20 January 2020 (#649, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 January 2020 – ‘**Mental healthcare and palliative care: Barriers.**’ Psychological symptoms are common among palliative care (PC) patients with advanced illness, and their effect on quality of life can be as significant as physical illness. The demand to address these issues in PC is evident, yet barriers exist to adequately meet patients’ psychological needs. This article provides an overview of mental health issues encountered in PC, highlights the ways psychologists and psychiatrists care for these issues, describes current approaches to mental health services in PC, and reviews barriers and facilitators to psychology and psychiatry services in PC, along with recommendations to overcome barriers. **Abstract:** <http://bit.ly/35YIN1e>



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>

British laypeople's attitudes towards gradual sedation, sedation to unconsciousness and euthanasia at the end of life

PLOS ONE | Online – 26 March 2021 – The authors' survey findings cannot, in themselves, yield normative conclusions about what end of life (EoL) policy ought to be. However, the views of the general public do provide valuable insights into the ethical intuitions of the community, which can be compared to ethical arguments. This data is therefore valuable for public and medical discussion and may contribute significantly to a dynamic process of reflective equilibrium. The survey indicates community support for euthanasia in dying patients. This support appears to be relatively stable over several decades, though assisted dying remains illegal in the U.K. The survey also demonstrated support and desire for the option of rapid, deep sedation or anaesthesia at the EoL. Recent studies have indeed described the use of anaesthetic agents for patients receiving EoL care in whom other forms of palliation have not been effective. Relevant for public debate, "terminal anaesthesia" (TA) was supported by a majority of those who supported and those who opposed euthanasia and was supported by a majority of both religious and non-religious members of the community. Neither TA nor withholding food and fluids at the EoL are illegal, though euthanasia is. EoL care raises many complex ethical questions and is frequently controversial. However, two uncontroversial values endorsed by palliative care organisations and national guidelines in the U.K. are the importance of relief of suffering and respecting patient wishes at the EoL. This study indicates that a substantial proportion of the general community support a range of options at the EoL, including some that are not currently offered in the U.K. **Full text:** <https://bit.ly/3IUNIIV>

Public knowledge and attitudes concerning palliative care

SSRN (SOCIAL SCIENCE RESEARCH NETWORK) | Online – 20 March 2021 – In this national survey, less than half of participants who had high perceived knowledge of palliative care (PC) and believed they could explain PC to someone else had high actual knowledge of the World Health Organization (WHO) PC definition. Participants with high perceived knowledge about PC were more likely to associate it with care provided as a last resort at the end of life (EoL) and less likely to believe that PC offered patients hope. Conversely, those with high actual knowledge of the WHO definition of PC were less likely to associate it with EoL care, less likely to find the term PC fearful or depressing, and more likely to believe PC offered hope. These findings offer important insights for public education efforts about PC. Other studies have similarly reported on the public's misunderstanding that PC is associated only with terminal care. This study demonstrated that this misunderstanding was greatest in those with the highest perceived knowledge of PC. Further, these participants were not only less likely than those with low perceived knowledge to believe that PC offered hope to patients, but also more likely to have learned about PC from healthcare professionals (HCPs). In previous surveys and qualitative studies, physicians tended to associate PC with terminal care, and patients and caregivers recalled conversations with healthcare providers who had equated PC with EoL care. Together, these findings underline the importance of including HCPs as well as patients and the public in education initiatives about PC. **Full text (click on pdf icon):** <https://bit.ly/3w298Z4>

N.B. This preprint research paper has not been peer reviewed.

Noted in Media Watch 22 March 2021 (#709, p.5):

- **BMC PALLIATIVE CARE** | Online – 17 March 2021 – ‘**Examining public knowledge, attitudes and perceptions towards palliative care: A mixed method sequential study.**’ Whilst the findings indicate the public may claim to be aware of the term palliative care (PC), there is an inadequate understanding of the concept... The most common misconception about PC was that it is exclusively for people in the last 6 months of life. This is supported by previous literature internationally, which repeatedly reports a public perception of PC provided at the very end of life. Internationally, it is also reflected in health systems insurance policy, where PC is provided 6 months prior. Other common misconceptions included a tendency to associate PC for those diagnosed with cancer... **Full text:** <http://bit.ly/38Tl7hM>

Cont.

Noted in Media Watch 12 August 2019 (#626, p.1):

- CENTER TO ADVANCE PALLIATIVE CARE | Online – 8 August 2019 – ‘**Palliative care still relatively unknown among the general public: Shows education for consumers and physicians necessary to make a difference.**’ New opinion research confirms that once educated with the correct definition of palliative care (PC), understanding and favorability greatly increase among consumers and physicians. “All organizations and clinicians must proactively align themselves in defining PC correctly,” said Diane E. Meier, the Center’s director. “With an aging population increasing exponentially, it is more important than ever that both the field of PC and the referring clinicians evolve their rhetoric. The point must always be made that PC is based on need, not prognosis.” <http://bit.ly/2ZXaHXK>

Palliative medicine and end-of-life care in surgery

SURGERY | Online – 18 March 2021 – Surgeons are privileged to offer treatments that often cure disease. Optimizing comfort for those who cannot be cured is also a core part of every clinician’s duty: surveys repeatedly tell us that when death is approaching, people value quality of life above length of survival. Recognizing when someone is dying can be difficult. Tools exist to help; it is worth noting that emergency presentation with life-threatening symptoms can be a marker of poor prognosis. Clear, effective communication is crucial: understanding the patient’s perspective and expectations is vital before attempting to offer information that allows future care planning. Judicious use of surgery combined with careful prescribing will optimize comfort, allowing the patient to live as well as possible for as long as possible. Anticipatory prescribing includes opioid, anti-emetic, anti-secretory and sedative medication. Attention should also be given to care of the bereaved. Generalists should understand when to refer to specialist palliative care and remember that reflecting on care when someone has died can be beneficial for professional wellbeing. **Abstract:** <http://bit.ly/319k3ID>

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

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

N.B. Additional articles on palliative medicine and end-of-life care in surgery noted in this issue of Media Watch.

Research Matters

A spiritual care intervention for chaplains in home-based palliative care: Design of a mixed-methods study investigating effects on patients’ spiritual wellbeing

JOURNAL OF HEALTH CARE CHAPLAINCY | Online – 23 March 2021 – Recently, the call for chaplains to become “research literate” has been recognized by various scholars as well as by practitioners in the field. However, papers that present and discuss the study design and provide guidance on the methodology of chaplaincy research are scarce. The aim of this study is to present the design of a mixed-methods study that investigates the impact of a spiritual care intervention on patients’ spiritual wellbeing in palliative, home-based care. It reports on the steps needed to conduct such a study in chaplaincy care, and describes and discusses the study’s research design, intervention, participants, sampling strategy, patient and public involvement, procedure, ethical considerations, data collection, and analysis. Presenting and discussing such a design is not only useful for researchers before conducting their study, in order to create transparency, but also for chaplains to improve their knowledge on research methodology and research literacy. **Full text:** <https://bit.ly/3ssoc03>

Opportunities for public involvement in big data research in palliative and end-of-life care

PALLIATIVE MEDICINE | Online – 24 March 2021 – Public involvement – the process by which research is conducted in collaboration with patients, carers or members of the public – is increasingly considered a prerequisite for high-quality research. Evidence suggests that public involvement can benefit research by helping to identify and prioritise patient-focused research questions, aiding recruitment and retention, and helping to foster greater links between researchers and the wider community. Public involvement is encouraged across the research cycle and guidance has been developed to support researchers to involve the public at each stage. However, currently, such guidance is focused on studies which include primary data collection, and there is little guidance on how to meaningfully involve the public in big data research. Big data research takes many forms. In palliative care, this research often involves secondary analysis of routinely collected data (i.e., data initially collected for other purposes other than research, as part of a standard administrative or care process) such as death registry data and electronic health records. Differences in the reported presence of public involvement across studies have shown that involvement in big data research is significantly limited in comparison with other study designs. It has been suggested that this may be because common approaches to public involvement adopted in primary data research are not appropriate within big data analysis studies. While public members are commonly involved in primary research to review and develop patient information leaflets or other research materials, undertake interviews with research participants or even support recruitment for a clinical trial, these involvement opportunities are not applicable to big data research. In addition, the highly data driven discussions that underline this type of research can present a barrier to public involvement with “unfamiliar” and “scientific” language repeatedly being cited as an obstacle, across fields. **Full text:** <https://bit.ly/3dbpdTY>



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Something Missed or Overlooked?

IF YOU ARE AWARE OF A CURRENT REPORT, ARTICLE, ETC., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/38oM5gU>

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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTP://BIT.LY/3EPKUAC>

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