

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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In this review, oncologists and haematologists have drawn symbolic inferences about palliative care (PC) referral. They felt that PC referral symbolised the loss of hope, abandonment, break in the therapeutic relationship, and role conflict.

'How views of oncologists and haematologists impacts palliative care referral: A systematic review' (p.7), in *BMC Palliative Care*.

Canada

Expand palliative care for the homeless

HOSPICE NEWS | Online – 24 November 2020 – Naheed Dosani MD is a palliative care (PC) physician based in Toronto who cares for homeless and vulnerably housed individuals in his community. Dr. Dosani founded Palliative Education And Care for the Homeless (PEACH) program which has inspired similar models around the world, including the U.S. Through PEACH, interdisciplinary teams provide community-based hospice and PC to vulnerable individuals regardless of their housing status or factors such as poverty or substance abuse. PEACH brings housing, mental health, and healthcare providers together to plan an individual's care while recognizing that person's circumstances. Dosani also practices PC at William Osler Health System in Brampton,

Ontario, in a program that has garnered international attention for its innovations. His leadership also led to the development of Journey Home Hospice, Toronto's first hospice for people who experience homelessness. Dosani recently spoke with *Hospice News* about the PC needs of the homeless and how providers are moving toward addressing them. <https://bit.ly/361ZFGc>

Specialist Publications

'The Good Wishes Project: An end-of-life intervention for individuals experiencing homelessness' (p.13), in *Palliative Medicine Reports*.

N.B. Additional articles on PC for the homeless in Canada noted in Media Watch 16 November 2020 (#692, p.1).

National grief strategy needed to help Canadians cope with loss due to COVID-19, group says

CBC NEWS | Online – 23 November 2020 – An organization called the Canadian Grief Alliance has been pushing the federal government for a national strategy to help people cope with the increased loss society is facing – fearing it will have long-term mental health repercussions. Health Canada says the federal gov-

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ernment is investing \$240.5 million to support provinces and territories to develop, expand and launch virtual care tools, including supports for mental health. But the alliance says grief services specifically are falling through the cracks. Shelly Cory, executive director of Canadian Virtual Hospice and one of the founders of the Alliance, says the pandemic's impact on Canada and the number of people who are grieving is "astounding." "We're looking at grief as the hidden health crisis in this whole pandemic," she said. "One of the reasons we need a national grief strategy is to provide a coherent response to an urgent public health crisis." The alliance is calling for a national consultation to help them understand the impact the pandemic has had on grief services, so they can assess where the needs and gaps are. <https://bit.ly/3lWxrxz>

N.B. Additional articles on the Canadian Grief Alliance noted in Media Watch 25 May 2020 (#667, pp.1-2).

Noted in Media Watch 24 August 2020 (#680, p.6).

- *JOURNAL OF RELIGION & HEALTH* | Online – 20 August 2020 – '**The dead with no wake, grieving with no closure: illness and death in the days of Coronavirus in Spain.**' The pandemic caused by the spread of **COVID-19** is giving rise to an exceptional social situation because of the great speed of propagation of the illness and the high level of mortality it has occasioned in a very short time. Moreover, the lockdown measures decreed in Spain prohibit the holding of wakes to avoid contagion, and limit funerals to three people plus the officiant. Thus, coronavirus is robbing people of the opportunity of a final farewell, stripping the dead of their dignity and worsening the grief of the living. This article investigates the situation and the social and cultural impact it has provoked. **Full text:** <https://bit.ly/3j03j77>

N.B. Selected articles on grief and bereavement during the **COVID-19** pandemic noted in Media Watch 10 August 2020 (#678, pp.3-4).

U.S.A.

Cultural training, community outreach bridges gaps in hospice service

HOSPICE NEWS | Online – 24 November 2020 – Providers have increasingly focused on closing racial and cultural gaps to equitable hospice care among historically underserved populations. Investing in culturally competent staff and local outreach could help break down barriers preventing many African American, Hispanic and Native American patients from accessing hospice. Racial disparities in utilization of hospice and palliative care persist, with data from the U.S. Agency for Healthcare Research & Quality showing that black and Hispanic populations are less likely to receive a referral than white patients.¹ Providers seeking to bridge racial divides have worked to better understand the root causes for these disparities and communicate the value of hospice care within underserved communities. Misconceptions about end-of-life care and a lack of trust in the healthcare system at large are among the frequently occurring barriers., even as hospice

providers seek to improve their outreach to underserved communities. <https://bit.ly/2HFskaY>

Specialist Publications

'**Surgical palliative care: Where are we in 2020?**' (p.5), in *The American Surgeon*.

'**Intensive care unit nurse: Could we call a palliative care consult? Intensive care unit provider: It's too early. Palliative care integration in the intensive care unit: The struggle to translate evidence into practice**' (p.8), in *Dimensions of Critical Care Nursing*.

'**Strengths and struggles for families involved in hospice care during the COVID-19 pandemic**' (p.10) in *Journal of Social Work in End-of-Life & Palliative Care*.

1. 'Trends and racial disparities of palliative care use among hospitalized patients with end-stage kidney disease on dialysis,' *Journal of the American Society of Nephrology*, published online 7 August 2019. [Noted in Media Watch 12 August 2019 (#626, p.8)] **Full text:** <http://bit.ly/2GT8oO1>

N.B. Additional articles on disparities in the provision and delivery of hospice and palliative care for racial/ethnic minorities in the U.S. noted in Media Watch 26 October 2020 (#689, p.10).

National Hospice & Palliative Care Organization Palliative Care Needs Survey Results: Summary

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 24 November 2020 – Palliative care (PC) services have grown rapidly in the hospital setting. As the seriously ill population grows exponentially, so does the need for community-based PC services. Hospice providers are ideally positioned to meet this need, and many are already engaged in providing PC services. While the focus of care is markedly different, the model of PC mirrors the hospice model: holistic care provided to the patient and family by an interdisciplinary team supporting symptom and medication management, goals of care discussions, advance care planning, and care coordination. **Download/view at:** <https://bit.ly/2Hunddo>

International

Hospice releases findings from its palliative care assessment report

U.K. (Isle of Man) | *IOM Today* (Douglas) – 28 November 2020 – The needs assessment ... was undertaken by Hospice's Scholl Academic Centre – established in 2019 to carry out academic research for the charity.¹ The needs assessment is the “evidence base” for the work outlined in the Hospice's five-year plan... Looking at how many people in the island could benefit from palliative and end-of-life care (EoLC), the assessment noted that the majority of people with cancer still die in hospice, and that most people with dementia or neurodegenerative disease die in their nursing home, often with hospice involvement. Researching what people want from palliative and EoLC, the assessment found that: “Most people, and the professionals who care for them, prefer that EoLC is delivered as far as possible at home.” As for potential improvements, the assessment concluded: “All staff involved in EoLC go ‘above and beyond’ in their attempts to deliver an integrated service but the extra work this involves is not sustainable. The current system is complex with navigation and coordination difficult for patients and families; they would benefit from a designated keyworker. Carers feel that the essential role they play in coordination of care is not

recognised by the services while, Third Sector groups also believe that their complementary role is not always acknowledged. Patients and carers face challenges, including off-Island care, and feel the need for more physical and emotional support.” <https://bit.ly/2JnBKYU>

Specialist Publications

‘Improving regional care in the last year of life by setting up a pragmatic evidence-based plan-do-study-act cycle: Results from a cross-sectional survey’ (p.7), in *BMJ Open*.

‘Humanize death in a time of sanitary crisis: Accompanied die, farewell and receive spiritual care’ (p.8), in *Cuadernos de Bioética*.

‘More proactive GPs, well timed, and less acute care: A clustered, partially controlled before-after study’ (p.10), in *Journal of Post-Acute & Long-Term Care Medicine*.

‘Effectiveness and cost-effectiveness of out-of-hours palliative care: A systematic review’ (p.11), in *Palliative Medicine*.

1. ‘Integrated Palliative and End of Life Care for the Isle of Man 2020,’ Hospice's Scholl Academic Centre, Isle of Man, November 2020. **Download/view at:** <https://bit.ly/2JhuSfZ>

Noted in Media Watch 29 October 2018 (#587, p.8):

- *INTERNATIONAL JOURNAL OF INTEGRATED CARE* | Online – 23 October 2018 – **‘Designing a population-based approach to integrated end-of-life care on a small island.’** The Isle of Man is a small island of 83,000 residents situated in the Irish Sea. The Island is a self-governing Crown Dependency of the U.K. Due to its geographic isolation, the Island provides a unique opportunity to re-design and co-create a model of care that incorporates private, public, third sector and community elements. The Island-wide strategy requires a population-based approach and methods to match patients and services based on needs. Early stakeholder engagement has identified the need for earlier identification of patients at the end of life in order to provide the most appropriate services. **Abstract:** <https://bit.ly/3ljxZ42>

Palliative care must be a priority for all governments

PALLIATIVE CARE AUSTRALIA | Online – 26 November 2020 – One of the greatest challenges for palliative care (PC) in aged care is the varying responsibilities across the Australian and state and territory governments. The level of PC funding and support varies across states and territories, with no clear national picture of what services are available. This can result in silos and system issues that impact aged care recipients and their ability to receive the PC services they need in aged care. It can also affect the transition between the primary health, hospital and aged care sectors and have a significant impact on emergencies. Making PC a priority for all governments will ensure greater oversight, national consistency and better relationships between the healthcare and aged care sectors. This could be further enhanced with the appointment of a National Palliative Care Commissioner to engage with the palliative sector and facilitating improved communication across jurisdictions by encouraging consistent approaches across all settings, including primary health, community health, tertiary health, aged care and disability. Currently, there are several National Commissioner roles that the Palliative Care Commissioner could be modelled on including National Rural Health Commissioner, National Data Commissioner, National Threatened Species Commissioner and National Skills Commissioner. It is not intended that the Palliative Care Commissioner would be a fund holding body or provide services; get involved in individual cases or advocate for individual people; or undertake dispute resolution, handle complaints or undertake investigations. <https://bit.ly/37e6Avx>

N.B. See 'Communications with the Public, Politicians, and the News Media,' *Oxford Textbook of Palliative Medicine*, 5th Edition (2015). **Synopsis:** <http://bit.ly/2rHlIEI>

U.K.'s COVID-19 bereaved suffer heightened grief, finds study

U.K. | *The Guardian* (London) – 26 November 2020 – COVID-19 grief is worse than other types of grief, according to the first findings of U.K.-wide research into how people have coped with the deaths of loved ones during the pandemic. Family and friends bereaved by coronavirus experienced “greatly increased negative experiences” and showed higher grief and support needs compared to people suffering the loss of loved ones from other illnesses, including cancer, researchers at Cardiff and Bristol universities found. Examining more than 500 deaths since mid-March, around half from COVID-19, they discovered that COVID-19-bereaved people were less likely to have been able to say goodbye to loved ones, less likely to have visited prior to death and less likely to have had contact with friends and family after their bereavement. There have been more than 70,000 excess deaths in the U.K. during the pandemic, adding to an estimated 450,000 which would have normally occurred over the nine months, the report's authors said. On the basis that a typical person dying leaves five people bereaved, they estimate 2.6 million people have been bereaved in the U.K. “at a time of profound disruption to our social support networks as well as intense pressure on health and social care.” <https://bit.ly/2V7WYgb>

N.B. Full study findings of the study will be analysed and published in a peer-review journal in the first quarter of 2021. 'Exceptional challenges of bereavement during the pandemic highlighted in interim findings,' University of Bristol press release: <https://bit.ly/37clU5y>

Framework to improve training for children's palliative care professionals launches in U.K.

U.K. | Children's Palliative Care Education and Training U.K. and Ireland Action Group (CPCET AG) – 25 November 2020 – A new educational framework and toolkit has launched in the U.K. and Ireland to improve training and guidance for those providing palliative and end-of-life care for children to establish a set of core principles of practice and standardise children's palliative care learning for practitioners. CPCET AG was formed in 2019 in response to recommendations by the U.K. All-Party Parliament Group on the need for standardisation and alignment of current approaches to children's PC.¹ The Action Group brings together experts from 26 organisations in the U.K. and Ireland including universities, hospital trusts, charities and hospices. The downloadable framework and self-assessment tool is not intended to regulate or limit education programmes but to provide a framework which it is hoped educationalists will use to coordinate and quality assure their programmes. <https://bit.ly/378SBab>

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1. 'End of life care: Strengthening choice,' An inquiry report by the All-Party Parliamentary Group for Children Who Need Palliative Care,' October 2018. [Noted in Media Watch 29 October 2018 (#587, p.4)] **Download/view at:** <https://bit.ly/39gFTJm>

Noted in Media Watch 1 October 2018 (#583, p.6):

- U.K. | Together for Short Lives – 25 September 2018 – '**New guide to commissioning and delivering children's palliative care.**' The national charity has launched its new guide to commissioning, planning and delivering children's palliative care (PC). 'A Guide to Children's Palliative Care' is widely recognised as the cornerstone of good PC for children in the U.K. and internationally and is endorsed by the National Institute for Health & Care Excellence (NICE), the Royal College of Paediatrics & Child Health, the International Children's Palliative Care Network, and the European Association for Palliative Care.¹ It aligns with the NICE guideline on end-of-life care for children.¹ It provides a "360-degree insight into children's PC: what it is, its principles, and its importance **Download/view at:** <https://bit.ly/365OAnS>
1. 'End-of-Life Care for Infants, Children & Young People,' National Institute for Health & Excellence, September 2017. [Draft issued during a consultation process noted in Media Watch 24 April 2017 (#509, p.14)] **Download/view at:** <https://bit.ly/3mbcRyg>

Specialist Publications

No impact of previous evidence advocating openness to talk to children about their imminent death

ACTA PAEDIATRICA | Online – 21 November 2020 – Communication is as important as the drug and the knife in medical care, particularly when patients are facing life-threatening conditions. However, the ability to communicate effectively has been commonly associated with strong emotional barriers among healthcare professionals and family members. Studies that have focused on paediatric oncology have showed that openness about the transition from curative to palliative care is frequently avoided. As long ago as the 1980s a paper in this journal reported that

children often wanted to share their thoughts and feelings towards the end of life, but that adults often failed to recognise that need.¹ **Abstract:** <https://bit.ly/36XiDNz>

Publishing Matters

'Meta-research: Journal policies and editors' opinions on peer review' (p.13), posted on *eLife* website.

1. 'Children talk about death,' *Acta Paediatrica*, 1981;70(2):179-182. **Abstract:** <https://bit.ly/35VFCJL>

N.B. See 'The Crossroads of Grief: Understanding Grief & Diversity,' Children & Youth Grief Network, Ontario, Canada, 2018. Scroll down to 'Complete Literature Review' for 'Children's Understanding of Dying & Death' (p.5). **Download/view at:** <http://bit.ly/2OB4Y6C>

Surgical palliative care: Where are we in 2020?

THE AMERICAN SURGEON | Online – 24 November 2020 – The practice of surgical palliative care (PC) is not new. Dr. Balfour M. M. Mount, a retired urologic surgeon is considered the father of North American PC and coined the term "palliative care" in 1975. 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' Dr. Mosenthal currently chairs the American College of Surgeons Committee on Surgical Palliative Care. This introductory article is a brief

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history about the origins of surgical PC and sheds light on the current landscape of surgeons integrating primary and specialty PC into surgical practice. The aim of this surgical PC symposium is to take everyday surgical problems and highlight the application and benefit of PC when treating surgical patients with serious illness. Integrating PC principles into standard clinical management is evidenced based patient-centered practice. **Abstract (w. list of references):** <https://bit.ly/2V0IGyZ>

Noted in Media Watch 29 June 2020 (#672, p.7):

- *JOURNAL OF THE AMERICAN COLLEGE OF SURGEONS*, 2020;231(1):185-186. ‘**Understanding the core principles of primary and specialty surgical palliative care.**’ Although the current literature has established the benefits of specialty consultations in the overall processes of palliative care (PC), the common reliance ... on the presence or absence of the “palliative consult” as an outcome measure is problematic because it does not substantially enhance understanding of what elements of PC are most important to the individual patient. Other than calling for the assistance of specialists, reports unfortunately offer limited insight into the strengths or deficiencies of care. The ability to provide meaningful progressive research and education in this important arena has remained limited. **Abstract:** <https://bit.ly/3fLAPN2>

Noted in Media Watch 27 April 2020 (#663, p.9):

- *JOURNAL OF AMERICAN THE AMERICAN COLLEGE OF SURGEONS* | Online – 17 April 2020 – ‘**Identifying core principles of palliative care consultation in surgical patients and potential knowledge gaps for surgeons.**’ Previous studies demonstrated that surgeons tend to underuse palliative care (PC) in comparison with medical services. Furthermore, little is known about the specific use of PC services among surgical oncology practices. The authors evaluated the use of PC in cancer patients undergoing major oncologic surgery. Surgical patients were less likely to undergo PC consultation for assistance with symptom management and more likely to undergo consultation for assistance with end-of-life discussions than were medical oncology patients. **Abstract:** <https://bit.ly/3cBMNgM>

Duration of palliative care before death in international routine practice: A systematic review and meta-analysis

BMC MEDICINE | Online – 26 November – This review suggests that duration of palliative care (PC) before death for patients with life-limiting illness is much shorter than is supported by research evidence and widely advocated in healthcare policy. This study also highlights wide variation at the level of country, across disease types and settings to which patients are referred. This review draws attention to the increasing extent to which PC research is capturing the duration and interaction provided to patients and their families. However, to better understand the timing of PC provision internationally, there is need for more consistent terminology and methodology, and routine assessment of duration of PC from all countries, to allow benchmarking, service evaluation and quality improvement. This could lead to a greater understanding of the duration of PC and associated factors. However, the authors acknowledge that further research is required across all countries to understand the mechanisms influencing differences in the duration of PC received, across the levels of patients, caregivers, health professionals, policymakers and the public, and the settings in which care is provided. In particular, there is a need for greater reporting in less developed settings where there is a dearth of related literature and likely to be the greatest need in future. Reducing barriers to accessing PC and promoting earlier integration alongside active treatment would maximise benefits to patients before they die and reduce costs to the wider healthcare service. **Full text:** <https://bit.ly/3mfMdo8>



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>

How views of oncologists and haematologists impacts palliative care referral: A systematic review

BMC PALLIATIVE CARE | Online – 23 November 2020 – The findings of this review suggest that some oncologists and haematologists liked to control and coordinate the care of their patients at all stages of illness trajectories and determine the timing of referral. They considered palliative care (PC) referral as abandonment, a break in the therapeutic relationship and loss of hope. They also expressed concerns regarding the professional competency of the PC providers and felt that they had the self-efficacy to manage the PC needs. Although illness-related factors acted as triggers for PC referral, the stigma associated with PC, patient and family attitudes, organisational challenges, lack of referral guidelines and limited PC resources made referral a daunting task. The findings of this review suggest that the majority of oncologists appreciated the pain and symptom management and psychosocial support role of PC. Lesser-known roles of PC were seldom elucidated. Some oncologists and haematologists felt that PC referral comes with a cost due to incongruencies in communication and curtailment of care. They felt that an integrated model of care,

changing the name of PC and augmenting PC resources might facilitate a referral. There is a need for PC trainees to have training in oncology, and likewise, there is a need for oncology trainees to have PC training. PC providers regularly joining the multidisciplinary team meetings might provide an excellent opportunity for both the teams to bond and build confidence, which could better inter-team communication. Moreover, to facilitate integration, a rebranding strategy is probably required. **Full text:** <https://bit.ly/3m042HD>

Making a palliative care referral: A daunting task

Data from this review suggests that oncologists and haematologists perceive the task of making a PC referral as daunting. They had to deal with the stigma associated with PC, navigate illness and treatment associated factors, address patient and family attitudes, and overcome organisational challenges. Moreover, a lack of referral criteria and limited PC resources made the referral process even more challenging.

Related:

- *SUPPORTIVE CARE IN CANCER* | Online – 20 November 2020 – ‘**Palliative care in onco-hematology: A perspective.**’ This is a commentary about palliative care (PC) applied to hematologic patients. Onco-hematology (OH) patients need more specialized care for symptomatic control since diagnosis, which cannot be solely accomplished by hematologist with no specialization in PC or PC physicians without some knowledge in hematology. There is a need for higher cooperation between PC and hematology, more health professionals specialized in both areas working together, more educational programs on this issue, and higher governmental investment in infrastructures to manage these patients. PC should also be integrated earlier in the care of OH patients. **Full text:** <https://bit.ly/3pZM22c>

Improving regional care in the last year of life by setting up a pragmatic evidence-based plan-do-study-act cycle: Results from a cross-sectional survey

BMJ OPEN | Online – 24 November 2020 – This study is the first to the authors’ knowledge to set up a pragmatic plan-do-study-act (PDSA) cycle to improve regional care in the last year of life. Embedded in a regional health services research and development structure, they comprehensively analysed patient experiences with care in the last year of life from the bereaved relatives’ perspectives. For symptom control, both home as well as acute hospital setting was rated the most poorly. Hospitals were reported as the main player for diagnosing a progressive condition, for being involved in most transitions during the last year of life, and being the most frequent place of death despite all home palliative and hospice services available in Cologne, Germany. Yet, satisfaction was lowest with care provided in an acute hospital setting, which was determined by the feeling of not being treated with respect and dignity and the impression that hospitals did not work well together with other services. Based on this first step of the PDSA cycle, two interventions were developed to continue the cycle. **Full text:** <https://bit.ly/3kZiJt2>



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Humanize death in a time of sanitary crisis: Accompanied die, farewell and receive spiritual care

CUADERNOS DE BIOÉTICA, 2020;31(102):203-222. The crisis in the health system caused by **COVID-19** has left some important humanitarian deficits on how to care for the sick in their last days of life. The humanization of the dying process has been affected in three fundamental aspects, each of which constitutes a medical and ethical duty necessary. In this study, the author analyzes why dying accompanied, with the possibility of saying goodbye and receiving spiritual assistance, constitutes a specific triad of care and natural obligations that should not be overlooked – even in times of health crisis – if we do not want to see human dignity violated and violated some fundamental rights derived from it. **Full text (via Europe PMC):** <https://bit.ly/39acmRI>

Intensive care unit nurse: Could we call a palliative care consult? Intensive care unit provider: It's too early. Palliative care integration in the intensive care unit: The struggle to translate evidence into practice

DIMENSIONS OF CRITICAL CARE NURSING, 2021;40(1):51-58. Despite evidence regarding the value of palliative care (PC), there remains a translation-to-practice gap in the intensive care setting. The purpose of this article is to describe challenges and propose solutions to PC integration through the presentation and discussion of a critical care patient scenario. The authors present recommendations for a collaborative PC practice framework that holds the potential to improve quality of life for patients and families. Collaborative PC is characterized by close working relationships with families, interprofessional intensive care unit healthcare teams, and PC specialists. The shortage of PC specialists has become a pressing policy and practice issue and highlights the importance of increasing primary PC delivery by the intensive care team. Underexplored aspects of collaborative PC delivery include the interprofessional communication required, identification of key skills, and expected outcomes. Increased recognition of intensive care unit PC as a process of engagement among nurses, providers, patients, and their family members heralds a vital culture shift toward collaborative PC. The interprofessional palliative specialist team has the expertise to support intensive care teams in developing their primary palliative skills and recognizing when specialist PC support is required. **Abstract:** <https://bit.ly/3l1Fdte>

Noted in Media Watch 31 August 2020 (#681, p.7):

- *CRITICAL CARE* | Online – 25 August 2020 – ‘Assessing physicians’ and nurses’ experience of dying and death in the ICU: Development of the CAESAR-P and the CAESAR-N instruments.’ As an increasing number of deaths occur in the intensive care unit (ICU), studies have sought to describe, understand, and improve end-of-life (EoL) care in this setting. Most of these studies are centered on the patient’s and/or the relatives’ experience. This study aimed to develop an instrument designed to assess the experience of physicians and nurses of patients who died in the ICU, using a mixed methodology and validated in a prospective multicenter study. The authors described and validated two new instruments for assessing nurses’ and physicians’ experience of EoL in the ICU. **Full text:** <https://bit.ly/3hwhKzx>

N.B. Selected articles on PC in the ICU noted in Media Watch 17 August 2020 (#679, pp.7-8).

Care workers of people with intellectual and developmental disabilities feel the need for soft skills training to accomplish better palliative care deliverance

EVIDENCE-BASED NURSING | Online – 17 November 2020 – Direct care workers (DCWs) dealing with people with intellectual and developmental disabilities (PWIDD) are increasingly required to provide basic palliative care (PC) assistance. Being an active part of the patient’s care team, they should be informed about the care plan and advance directives for the patient and trained to assist in these matters. DCWs of PWIDD need more training regarding effective communication, spiritual, social and emotional needs, cultural competence to support people from diverse cultural backgrounds, as well post-death logistics and legal matters. In this article, recommendations are provided to prepare training programs for DCWs of PWIDD. **Overview:** <https://bit.ly/395biOE>

N.B. Selected articles on PC for people living with intellectual and developmental disabilities noted in Media Watch 9 November 2020 (#691, p.10).

**A new kind of paternalism in surrogate decision-making?
The case of *Barnsley Hospitals NHS Foundation Trust v MSP***

JOURNAL OF MEDICAL ETHICS | Online – 23 November 2020 – The modern legal and ethical movement against traditional welfare paternalism in medical decision-making extends to how decisions are made for patients lacking decisional capacity, prioritising surrogates' judgment about what patients would have decided over even their best interests. In England & Wales, the Mental Capacity Act 2005 follows this trend of prioritising the patient's prior wishes, values and beliefs but the dominant interpretation in life-sustaining treatment cases does so by in effect calling those values the "best interests" of the patient and focusing nearly exclusively on the "subjective" viewpoint of the patient. In this article, we examine the recent Court of Protection judgment in *Barnsley Hospitals NHS Foundation Trust v MSP [2020] EWCOP 26*, which adhered closely to this approach, to suggest that it could have unexpected negative consequences. These include insufficient information gathering about and attention to patients' objective medical interests, inadequacy of the evidentiary standard used for the substituted decision-making and, in some cases, even prioritising a surrogate's current substituted judgment over the potential for an actual judgment by the patient. **Abstract:** <https://bit.ly/2J8qsOO>

"Invisible voices": A critical incident study of family caregivers' experience of nursing homes after their elder relative's death

JOURNAL OF NURSING SCHOLARSHIP | Online – 18 November 2020 – The literature provides few examples of family caregivers' retrospective evaluation of nursing home services. The results of this study suggested that positive long-term recollection of the nursing home was associated with different themes emerging from the interviews: medical reliability and expertise, active demonstrations of care that extend beyond the contract with the facility, individualized attention, responsiveness, openness to dialog with family members about routines, management of the first impression, and family engagement. Lack of professionals' expertise and medical failures, lack of care for patients' personal goods, lack of family involvement, lack of individualized attention, lack of responsiveness, poor patient surveillance, and structural limits of the facilities were the themes that were more frequently negatively associated with the nursing home experience. Focusing on the key dimensions connected to the quality of the experience of family members can enrich the quality of existing nursing home services and allow healthcare policymakers and managers to design better facilities for the patients. **Abstract:** <https://bit.ly/35Qio7J>

Applying the multiphase optimization strategy for the development of optimized interventions in palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 November 2020 – Recent systematic reviews and meta-analyses have reported positive benefit of multicomponent "bundled" palliative care (PC) interventions for patients and family caregivers while highlighting limitations in determining key elements and mechanisms of improvement. Traditional research approaches, such as the randomized controlled trial, typically treat interventions as "bundled" treatment packages, making it difficult to assess definitively which aspects of an intervention can be reduced or replaced or whether there are synergistic or antagonistic interactions between intervention components. Progressing towards PC interventions that are effective, efficient, and scalable will require new strategies and novel approaches. One such approach is the Multiphase Optimization Strategy (MOST), a framework informed by engineering principles, that uses a systematic process to empirically identify an intervention comprised of components that positively contribute to desired outcomes under real-life constraints. This article provides a brief overview and application of MOST and factorial trial design in PC research, including the authors' insights from conducting a pilot factorial trial of an early PC intervention to enhance the decision support skills of advanced cancer family caregivers... **Abstract:** <https://bit.ly/2HOwugl>



Palliative Care Network
Palliative Care for Everyone, Everywhere

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

Effects of an integrated palliative care pathway

More proactive GPs, well timed, and less acute care: A clustered, partially controlled before-after study

JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE | Online – 19 November 2020 – This study investigated three groups of possible effects of the implementation of an integrated, multidisciplinary palliative care (PC) pathway: GPs' experiences, experiences and satisfaction of relatives of patients, and healthcare utilization (primary care, hospital care, and medication). GPs reported not only that palliative patients die more often at home (their preferred place of death), but also that they now act more proactively toward palliative patients. More proactive attitude of GPs is seen in other studies, where the proactive assessment and palliative treatment were set as priorities. Relatives of deceased patients who were included into the pathway reported improved quality of dying (although not statistically significant) and more timely PC. Similar results have been reported elsewhere as a result of early identification and assessment of the palliative patient, and is thus strongly underpinned by current literature. The authors found mixed results for the pathway's effect on healthcare utilization. The findings of this study do not show a statistically significant decrease of hospital admissions, emergency room visits, and diagnostic, surgical, and other therapeutic activities in the hospital for patients in the pathway. An integrated PC pathway, however, improves a variety of clinical outcomes important to patients, their families, physicians, and the healthcare system. The integration of PC into multidisciplinary, proactive PC pathways, is therefore a desirable future development. **Full text:** <https://bit.ly/398Ms0g>

Strengths and struggles for families involved in hospice care during the COVID-19 pandemic

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 23 November 2020 – The COVID-19 pandemic presented unique health and social challenges for hospice patients, their families, and care providers. This qualitative study explored the impact of the pandemic on this population through the experiences and perceptions of social workers in hospice care. A survey was distributed through national and local listservs to social work practitioners throughout the U.S. between 15 May and 15 June 2020. The study was designed to learn the following: 1) Concerns patients experienced as a result of the pandemic; 2) Strengths/ resilience factors for patients during the COVID-19 pandemic; and, 3) The personal and professional impact of the pandemic on social workers. Themes uncovered in hospice care included isolation, barriers to communication, disruption of systems, issues related to grieving, family and community support, adaptation, and perspective. The authors provide recommendations for social work practice related to virtual communication, emergency planning, and evidence-based intervention for Persistent Complex Bereavement Disorder. Recommendations for policy include uniform essential worker status for social workers, telehealth reimbursement and expanded caregiver respite benefits. **Full text:** <https://bit.ly/3l71elU>

Development of a novel communication liaison program to support COVID-19 patients and their families

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 November 2020 – The authors present a model for rapidly deploying a broad range of providers to support families of the critically ill and provide relief to ICU teams working through severe and taxing conditions. This model is feasible in a variety of settings, easily scalable, and can be successful in supporting over-stretched palliative care and critical care teams. Clinicians with even minimal prior exposure to critical care or palliative medicine can quickly learn to perform such a liaison service skillfully and to great benefit. Liaisons exhibited a high degree of engagement with the program, evidenced by the high proportion of repeat volunteers and their magnanimous responses to scheduling disruptions, as well as by informal strongly positive feedback from many of the liaisons. Keys to success include strong logistical support, a team-based system with peer coaching, and "just-in-time" training with quick guides in wiki format to allow constant updates. As the nation faces new COVID-19-related ICU surges, expanded communication support remains a critical need in this pandemic. **Full text:** <https://bit.ly/372a5VL>

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Noted in Media Watch 16 November 2020 (#692, p.9):

- **PROFESSIONAL CASE MANAGEMENT** | Online – 10 November 2020 – ‘**Death and grieving for family caregivers of loved ones with life-limiting illnesses in the era of COVID-19: Considerations for case managers.**’ Family caregivers of a loved one with a life-limiting or terminal illness are often overwhelmed by – and underprepared for – their responsibilities. The authors provide ... recommendations on guiding caregivers/families through safety precautions when a loved one dies either because of a life-limiting illness or from COVID-19 during the pandemic... They present information about complicated grief and ways to support coping with death and suggest safe alternatives to traditional death-related rituals and funerals in a COVID-19 era. **Abstract:** <https://bit.ly/3ksAil8>

Supporting children and adolescents following parental bereavement: Guidance for healthcare professionals

THE LANCET CHILD & ADOLESCENT HEALTH, 2020;4(12):889-898. Death of a parent in childhood and adolescence is a distressing life event. Childhood grief reactions are distinct from those in adults, and are affected by developmental and contextual factors such as age of the child and changes in caregiving environments. Following parental bereavement, children and adolescents face unique emotional and behavioural challenges, and are susceptible to several adverse biopsychosocial outcomes. Empirically supported interventions can help young people to navigate the many grief-related challenges, and the core treatment components include grief psychoeducation, building emotion identification and regulation skills, cognitive coping and restructuring, grief and trauma processing, memorialising and continuing bonds, meaning making, involvement of caregivers in grief treatment, and future planning. Healthcare professionals often interact with children and adolescents following bereavement; therefore, it is important they have the foundational knowledge and skills to communicate effectively about the death, recognise and normalise different ways grief can manifest across development, and support surviving caregivers in facilitating adaptive grief in their children. **Summary:** <https://bit.ly/36R5Zzu>

N.B. Selected articles on supporting children and adolescents following parental bereavement noted in Media Watch 23 November 2020 (#693, p.13). See also ‘The Crossroads of Grief: Understanding Grief & Diversity,’ Children & Youth Grief Network, Ontario, Canada, 2018. Scroll down to ‘Complete Literature Review’ for ‘Parental Illness, Dying & Death’ (p.13) and ‘Death of a Parent’ (p.30). **Download/view at:** <http://bit.ly/2OB4Y6C>

Depression among children and adolescents in palliative care: Reflections between psychologists, child psychiatrists and mobile team of palliative care

MÉDECINE PALLIATIVE | Online – 21 November 2020 – If the topic of depression in pediatric palliative care (PC) is often evoked in the clinical setting, few studies have been published. The authors present a protocol of care ... to define, diagnose and manage depression among children in pediatric PC. A real interdisciplinary approach is essential so that each point of view can be expressed, heard and discussed in a respectful and open environment. There is a need to anticipate, identify and manage the clinical depression in a multidisciplinary manner, resisting the temptation to automatically medicalized the psychic suffering of the child, while calling upon the child psychiatrist, when and if necessary. It is crucial, while offering support to the child and the family, to be able to tolerate the adaptive depression and to resist to the utopian idea of a “beautiful death.” **Abstract:** <https://bit.ly/3kZojvv>

N.B. French language article.

Effectiveness and cost-effectiveness of out-of-hours palliative care: A systematic review

PALLIATIVE MEDICINE | Online – 21 November 2020 – This study illustrates that while out-of-hours palliative care is a recognised priority for patients and policymakers, no evidence base exists on which services are beneficial for patients and worthy of healthcare funding. The lack of evidence underscores the need for future studies to incorporate measurement of the effectiveness and/or cost-effectiveness of out-of-hours services. In principle there are two ways that such evaluations might be initiated. First, data are already

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collected by statutory bodies and other providers on existing out-of-hours services. Appropriate analyses of these data could produce the sort of evidence that this review hoped to identify, albeit statutory data tend to focus more on process than outcomes, which limits analytic scope. Second, original research must be conducted to collect data and evaluate out-of-hours care across its multitude of settings and practitioners. Consistent with other areas of palliative and end-of-life care research, this agenda will have to be flexible and pragmatic in matching methodological approaches to specific problems. **Full text (available on the HRB Open Research website):** <https://bit.ly/3nNIU7P>

N.B. The *Palliative Medicine* link (<https://bit.ly/35Sm8W5>) is to a list of references only.

Related:

- *BMJ OPEN* | Online – 24 November 2020 – ‘**Unscheduled and out-of-hours care for people in their last year of life: A retrospective cohort analysis of national datasets.**’ The extent of unscheduled care delivered to people in their last year of life is significantly greater and more varied than reported previously. People with diverse urgent care needs are accessing these services at high levels, particularly in their final month of life. More should be done to take account of underlying illness trajectories and social determinants of health, including better public understanding of how to access the right care in timely and effective ways. Systematic approaches to care planning with effective recording and sharing of key information ... is vital and should be recorded in routine healthcare datasets. **Full text:** <https://bit.ly/39bSKwn>

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

- IRELAND | Health Research Board (Dublin) – 21 August 2019 – ‘**Out-of-hours specialist and generalist palliative care service provision: An evidence review.**’ Ireland’s current position is typical among high-income countries with well-established services. That is, the importance of integrated, 24-hour care for people with serious and complex medical illness is widely acknowledged, but details on how to organise, provide, and evaluate out-of-hours services are scant. Barriers included insufficient resources, inadequate knowledge among practitioners and patients, a lack of guidance for non-specialists, inadequate communication between out-of-hours services and other parts of the healthcare system, and insufficient knowledge or confidence among unpaid caregivers. **Download/view at:** <http://bit.ly/2L4gPYh>

Improving the interdisciplinary clinical education of a palliative care program through quality improvement initiatives

PALLIATIVE MEDICINE REPORTS | Online – 19 November 2020 – This article describes an interprofessional team’s aim to develop an interactive, online curriculum in palliative care (PC), with an emphasis on interprofessional education. A new model was established with the themes of learning about “people,” learning the “job,” and learning “respect.” The team followed the plan-do-study-act model to guide their process. The newly developed interprofessional online curriculum was utilized by PC trainees from various disciplines and levels of education. Pre- and post-tests to measure the knowledge, behavior, attitudes, and skills needed for teamwork and core PC competencies were completed. Forty-three medical and nursing students, undergraduate and graduate, completed the pretest, and 32 students completed the post-test. Results indicate that learners are growing in interprofessional skills and attitudes, but not in formalized knowledge of PC as a result of their clinical experience. Results suggest that more formalized knowledge may need to be provided to learners who come to this clinical experience, which could be delivered through the online curriculum. The knowledge survey should also be re-evaluated for clarity and content. **Full text:** <https://bit.ly/2IYoDNM>



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.14.

The Good Wishes Project: An end-of-life intervention for individuals experiencing homelessness

PALLIATIVE MEDICINE REPORTS | Online – 18 November 2020 – Individuals experiencing homelessness face marginalization, dehumanization, and barriers to accessing quality palliative care (PC). Inspired by the 3 Wishes Project, the Good Wishes Project (GWP) facilitates granting wishes to individuals experiencing homelessness and receiving PC with a goal of enhancing comfort and personalizing the end-of-life experience. The GWP is a promising psychosocial intervention to improve the quality of PC for individuals experiencing homelessness, whose lives have largely been burdened with hardship and marginalization. In a population that often holds a mistrust in healthcare systems and providers, the project offers a way to establish trust with the care team and enhances authentic human connection. It also offered a way to acknowledge personhood, prioritize the clients' agendas, and celebrate them as individuals. The wishes showcase the scarcity

of resources this population has and offers a means to satisfy unmet basic needs. Although interventions like these are important to address gaps and provide equitable care to populations that face barriers in access to PC services, we must at the same time acknowledge and address the social, structural, and societal factors that create these inequities in the first place. **Full text:** <https://bit.ly/3740uNY>

The Good Wishes Project has been successfully replicated in more than 20 ICUs in North America. The project was created in Canada as a partnership between the Inner City Health Associates' Palliative Education & Care for the Homeless Program (PEACH) in Toronto, Ontario, and Haven Toronto, a drop-in center for elder homeless, marginally housed and socially isolated men.

N.B. Additional articles on PC for the homeless in Canada, the U.K., and the U.S., noted in Media Watch 3 August 2020 (#677, p.12).

Unsettling place(s) at the end of life

SOCIAL SCIENCES & MEDICINE | Online – 18 November 2020 – Critical considerations of space and place at the end of life (EoL) have been limited in the social science literature. To address this gap, the authors draw on empirical data from two interrelated but separate qualitative Australian data sets to critically examine dying in relation to considerations of space, place and affect. These studies share the primary aim to better understand and articulate EoL experiences, with one using video reflexive ethnography and the other semi-structured interviews with patients. Challenging the broader valorisation of particular places of dying and death (e.g., home, hospice, hospital), the authors critically explore the meanings and affects of space and place and how they are rooted in normative expectations. Drawing on participant accounts they interrogate simplistic concepts of home versus hospice, or hospital versus community, developing a critical social science of the intersections of space and place at the EoL. **Abstract:** <https://bit.ly/2HpwzHx>

Publishing Matters

Meta-research: Journal policies and editors' opinions on peer review

eLIFE | Online – 19 November 2020 – Peer review practices differ substantially between journals and disciplines. This study presents the results of a survey of 322 editors of journals in ecology, economics, medicine, physics and psychology. The authors found that 49% of the journals surveyed checked all manuscripts for plagiarism, that 61% allowed authors to recommend both for and against specific reviewers, and that less than 2% used a form of open peer review. Most journals did not have an official policy on altering reports from reviewers, but 91% of editors identified at least one situation in which it was appropriate for an editor to alter a report. Editors were also asked for their views on five issues related to publication ethics. A majority expressed support for co-reviewing, reviewers requesting access to data, reviewers recommending citations to their work, editors publishing in their own journals, and replication studies. Our results provide a window into what is largely an opaque aspect of the scientific process. The authors hope the findings will inform the debate about the role and transparency of peer review in scholarly publishing. **Abstract:** <https://bit.ly/39gmat0>

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3pmP1la>

[Scroll down to 'Media Watch']

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

PALLIMED: <http://bit.ly/2ResswM>

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

Asia



Asia Pacific
Hospice Palliative
Care Network

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

[Scroll down to 'Media Watch']

Australia

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

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

Canada



CSPCP
Canadian Society of
Palliative Care Physicians

SCMSP
Société canadienne des
médecins de soins palliatifs

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

[Scroll down to 'Are you aware of Media Watch?']

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

Europe



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

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

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

South America

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

Media Watch: Editorial Practice

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

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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3. Links often remain active, however, for only a limited period of time.
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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

[Something Missed or Overlooked?](#)

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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