

Media Watch...is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

There will never be enough palliative care specialists to meet all our patients' needs. It must be everybody's job to provide patients with relief from the symptoms and stress of serious illness.

'How COVID-19 is spotlighting the role of palliative medicine' (p.4), in *The ASCO Post*.

U.S.A.

Solomon Center for Health Law & Policy and the Center to Advance Palliative Care launch innovative palliative care policy-tracking database

YALE LAW SCHOOL | Online – 8 September 2021 – In recent years, state policy-makers have increasingly paid more attention to palliative care (PC), improving access and quality along the way. The importance of PC ... and the need for innovative policy-making to support it, has become clearer over the past year and a half. The COVID-19 pandemic increased the demand for PC and exacerbated many of the challenges it addresses, straining hospitals and communities across the country. But tracking developments in policies and regulations across states has been difficult. States maintain their own data on legislation and regulations, with no centralized platform bringing together information from across the country. The Solomon Center for Health Law & Policy and the Center to Advance Palliative Care aim to fill the gap with an innovative new initiative – the Palliative Care Policy GPS – a publicly accessible and regularly updated database that tracks state policies on PC and related

services. The GPS tracks policies related to PC across the 50 states, Washington DC, the Indian Health Service, the Department of Veterans Affairs, and U.S. territories. By consolidating the landscape of state policy-making, the Palliative Care Policy GPS offers a new tool for healthcare professionals, policy-makers, PC champions, payers, and purchasers to search, compare, gain new ideas, and stay up-to-date on policy developments. <https://bit.ly/398JRCB>

Specialist Publications

'Guidance for timely and appropriate referral of patients with advanced heart failure: A scientific statement from the American Heart Association' (p.7), in *Circulation*.



Would this article be of interest to a colleague?

Hospices prepare for influx of dementia patients as World Health Organization predicts 40% rise

HOSPICE NEWS | Online – 7 September 2021 – The number of dementia patients is expected to rise by 40%, or 139 million people globally, by 2050, according to the World Health Organization (WHO).¹ Hospices have been caring for dementia patients in larger numbers in recent years and will have a significant role to play as rates of cognitive decline continue to rise. About 15.6% of hospice recipients during 2018 had some form of dementia as a primary diagnosis, according to the National Hospice & Palliative Organization. This amounts to more than 177,000 people nationwide. Rising dementia rates will take a massive human toll and could drive up global health care expenditures. “Dementia has significant social and economic implications in terms of direct

medical and social care costs, and the costs of informal care,” WHO reported. “In 2019, the estimated total global societal cost of dementia was \$1.3 trillion, and these costs are expected to surpass \$2.8 trillion by 2030 as both the number of people living with dementia and care costs increase.” <https://bit.ly/3BQo3Yv>

Specialist Publications

‘Improving end-of-life care for people with dementia in long-term care homes during the COVID-19 pandemic and beyond’ (p.7), in *Canadian Geriatrics Journal*.

1. ‘Dementia,’ World Health Organization, September 2021. <https://bit.ly/3jVl8b3>

N.B. Search back issues of Media Watch for additional articles on palliative and end-of-life care for people living with “dementia” at: <http://bit.ly/2ThijkC>

International

Every Story’s Ending – new report launched

U.K. (Scotland) | Scottish Partnership for Palliative Care – Accessed 10 September 2021 – ‘Every Story’s Ending’ is a new report that explores what can be done in Scotland to improve people’s experiences of serious illness, dying and bereavement. The report: 1) Sets out an ambition for what living with serious illness, dying and bereavement in Scotland could and should look like; 2) Explores what matters to people when they are seriously ill, dying or bereaved; 3) Explains why these issues are so important to so many people, and why change is needed; 4) Takes stock of recent progress, work underway and the current situation regarding living with serious illness, dying and bereavement; 5) Identifies key challenges; 6) Explores how to make change happen over the next 3-10 years; and, 7) Identifies priorities and recommends actions that will make a positive difference to experiences of living with serious illness, dying and bereavement in Scotland. **Download report at:** <https://bit.ly/38TFbjE>

N.B. Selected articles on palliative and end-of-life care in Scotland noted in Media Watch 16 august 2021 (#730, p.3).

Specialist Publications

‘Exploring health professionals’ experiences with a virtual learning and mentoring program on pediatric palliative care in South Asia’ (p.8), in *Global Pediatric Health*.

‘Using the Delphi technique to achieve consensus on bereavement care in palliative care in Europe: An European Association for Palliative Care White Paper’ (p.10), in *Palliative Medicine*.

‘Specialist palliative and end-of-life care for patients with cancer and SARS-CoV-2 infection: A European perspective’ (p.4), in *Therapeutic Advances in Medical Oncology*.

Bereaved children: Calls for mandatory training for teachers to support pupils who have lost loved ones

U.K. | Sky News (London) – 4 September 2021 – Education leaders are calling for U.K. teachers to receive mandatory bereavement training following the staggering number of COVID-19 victims. Training to support children who have lost loved ones is currently voluntary and only a small number of teachers benefit from it during their initial training or once they are enrolled in schools. The charity Child Bereavement UK said this is despite 86% of teachers saying they have experienced a death in the school community, and nearly three quarters reporting teaching students affected by the death of someone significant.¹ Bereavement training for teachers is being driven by the Centre For The Art Of Dying Well at St. Mary's University in west London.² The university, which trains more than a thousand new teachers each year for primary and secondary roles, has made the sessions compulsory for new starters on their courses. The course leader and director of the Institute of Education at St Mary's, Anna Lise Gordon, said they aim to normalise conversations around death for children. <https://bit.ly/2WYaGqq>



The Crossroads of Grief:
Understanding Grief & Diversity
<http://bit.ly/2OB4Y6C>

N.B. Scroll down to 'Grieving or Bereaved Children: Literature Review 2015-2018' and 'In the classroom' (beginning on p.37)

1. 'Improving Bereavement Support in Schools,' Child Bereavement UK, September 2019. **Download at:** <https://bit.ly/3jMCyGF>
2. 'Grief in the classroom – why training in bereavement care is so important,' Centre For The Art Of Dying Well, St. Mary's University: <https://bit.ly/38HL2Zq>

Noted in Media Watch 23 August 2021 (#731, p.4):

- *BMJ OPEN* | Online – 16 August 2021 – '**Experiences of preparing children for a death of an important adult during the COVID-19 pandemic: A mixed methods study.**' Three themes were identified: 1) Obstacles to telling children a significant adult is going to die; 2) Professionals' role in helping families to prepare children for the death of a significant adult during the pandemic; and, 3) How families prepare children for the death of a significant adult. Professionals need to: provide clear and honest communication about a poor prognosis; start a conversation with families about the dying patient's significant relationships with children; and, reassure families that telling children someone close to them is dying is beneficial for their longer term psychological adjustment. **Full text:** <https://bit.ly/3iYGELA>

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.**' Conversations about death are often associated with fear, anxiety, avoidance and misunderstandings. Many adults feel these discussions are inappropriate and confusing for young people. In this project, two fourth-year 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. **Abstracts:** <https://bit.ly/37KQaN7>



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Specialist Publications

How COVID-19 is spotlighting the role of palliative medicine

THE ASCO POST | Online – 7 September 2021 – The COVID-19 pandemic has exposed the tragedy of patients dying in isolation, separated from family and friends to limit infection in hospital settings. The process has altered the experience of serious illness for patients and their loved ones, including their ability to grieve, share important words and feelings, and provide comfort. The ongoing pandemic has been a reminder of the importance of having human connection and support at any time, but especially when faced with serious illness, and the essential contribution palliative care (PC) makes in supporting human connection while reducing patients' physical, emotional, and spiritual suffering. Recently, *The ASCO Post* talked with Diane E. Meier, Director Emerita and Strategic Medical Advisor, Center to Advance Palliative Care ... about some of the most concerning issues confronting the field of oncology, including the impact of the ongoing COVID-19 pandemic on palliative medicine; racial inequities in the receipt of PC; and, the controversy surrounding physician-assisted suicide.

Full text: <https://bit.ly/3A0C3OR>

Related:

- *THERAPEUTIC ADVANCES IN MEDICAL ONCOLOGY* | Online – 2 September 2021 – ‘**Specialist palliative and end-of-life care for patients with cancer and SARS-CoV-2 infection: A European perspective.**’ This is the first observational study investigating specialist palliative care (PC) outcomes in this patient population, where guidance on clinical management rests on expert opinions rather than direct evidence. This is particularly important when considering the potentially increased reliance on hospital-based services in providing psychosocial and supportive care... The relative contribution of PC in the context of a highly lethal and often rapidly fatal diagnosis such as COVID-19 has remained relatively unaddressed in patients with cancer. Full text: <https://bit.ly/3k0I3l8>

Documenting plans for care: Advance care directives and the 7-step pathway in the acute care context

BMC PALLIATIVE CARE | Online – 9 September 2021 – This article represents an examination of advance care directives (ACDs) and an integrated care pathway (the 7-Step Pathway) as they intersect to guide end-of-life (EoL) care in an Australian hospital setting. The authors’ analysis suggests that ACDs are seen by healthcare professionals working in acute care as a potentially valuable means of promoting patient autonomy, but as rarely completed and poorly integrated into hospital systems. On the other hand, the process and documentation of the 7-Step Pathway was perceived as providing clarity for clinicians regarding their responsibilities for completion, storage, and implementation of an approved care plan, and as a well-understood resource that is fully integrated within hospital systems. Inherent in these accounts was the notion, identified elsewhere, that EoL documentation should ideally “strike a balance between patient advocacy and clear medical handover.” However, participants in this study appeared to emphasise the importance of patient autonomy “in principle,” while orienting to a need for relevant, clinically-informed directives “in practice.” Full text: <https://bit.ly/3yU5HEc>

Research Matters

‘Achieving *inclusive* research priority-setting: What do people with lived experience and the public think is essential?’ (p.12), in *BMC Medical Ethics*.

‘Assisted dying: We must prioritise research’ (p.12), in *British Medical Journal*.

‘Oscillations, boundaries and ethical care: Social work practitioner-researcher experiences with qualitative end-of-life care research’ (p.12), in *Qualitative Social Work*.

Publishing Matters

‘Predatory journals: The power of the predator vs. the integrity of the honest’ (p.13), in *Current Problems in Diagnostic Radiology*.

Cont.

Related:

- **PALLIATIVE MEDICINE** | Online – 6 September 2021 – ‘**Asian patients’ perspectives on advance care planning: A mixed-method systematic review and conceptual framework.**’ Because decision-making in Asia is primarily family-driven, advance care planning (ACP) should focus on achieving a shared understanding of patients’ values by encouraging open communications and establishing the connection between patients and their family. Findings may be relevant to the practice of ACP in Western countries when engaging patients or family members of Asian descent. Healthcare professionals who engage in ACP with patients of Asian origin should avoid stereotyping Asian collectivist culture and bear in mind that these patients may prefer active involvement in it. **Full text:** <https://bit.ly/3zQi2rK>
- **BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 6 September 2021 – ‘**Influence of individual, illness and environmental factors on place of death among people with neurodegenerative diseases: A retrospective, observational, comparative cohort study.**’ The authors demonstrate that professionals working in primary care are effective in recognising the final phase of a person’s life which counters some claims that prognosis is challenging and imprecise, particularly for those with non-malignant conditions. This has implications for facilitating discussions with people living with progressive neurological diseases and their families that potentially empower and enable them to make decisions about current and future care that maximise their quality of life. **Full text:** <https://bit.ly/2WRsV0I>

Burdens, resources, health and wellbeing of nurses working in general and specialised palliative care in Germany: Results of a nationwide cross-sectional survey study

BMC NURSING | Online – 6 September 2021 – This is the first nationwide study in Germany to compare the working situations of general palliative care (GPC) and specialist palliative care (SPC) nurses in various settings providing a large amount of information. Overall, the working situation of GPC and SPC nurses were different and the nurses reported burdens in several working areas. However, the study demonstrated that although nurses in SPC overall reported a higher level of burden than those in GPC, SPC nurses stated that they had a better health status and a lower intention to leave the profession than GPC nurses. Further, SPC nurses differed in the frequency of reported resources, which were helpful in dealing with the demands of their work to GPC nurses. The results of the present study may be used to develop individual concepts for improving health and wellbeing of nurses taking the differences between GPC and SPC into account. While SPC nurses for example often reported self-care as a resource, future interventions in the field of GPC could take self-care as a subject of discussion into account. In the future,

the demographic differences, further participants’ characteristics as well as the differences in the burdens and resources should be further analysed in order to examine which have the biggest impact on health status and intentions of leaving the profession. Additionally, future studies should review SPC as the best practice example for nursing care in Germany. <https://bit.ly/3l43SiT>

Extract from BMC Nursing article

The implementation of palliative care differs strongly around Europe and around the world. Future research is needed in order to find out to what degree the presented results can be transferred to other countries. Nevertheless, the results of the present study could have relevant implications for developing interventional studies, with the goal of improving the health status of nurses and enhancing job satisfaction. This includes first of all an improvement of working conditions like personal requirements, but simultaneously the strengthening of organisational, social and personal resources.

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions for older medical inpatients: A cohort study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 7 September 2021 – Older patients admitted to acute medical wards are at high risk of cardiorespiratory arrest, but are unlikely to have a good outcome from CPR. The authors found that only a minority of patients had a documented DNACPR decision at the time of acute admission to hospital. As a result, many DNACPR decisions had to be made in hospital, often

Cont.

when the patient was severely ill and close to death. Changes in priorities will be required if we are to address this repeatedly documented failure to achieve timely DNACPR decisions. In an increasingly busy clinical environment, discussions about DNACPR are often left to another time or to another clinician. As a result, the conversation and decision happen all too often during an emergency admission, with a clinician caring for an extremely ill patient. It would be a positive step if all clinicians caring for patients with multimorbidity in non-acute settings seized the opportunity to address this issue with their patients. This change in practice is only likely to come about by education of doctors and by education of the public so that all concerned understand the reality of CPR and the need to discuss its role well before it is needed. Palliative care professionals have a particularly important role in education about the need for earlier discussions about CPR and end-of-life care as well as in the education, training and support recently called for by the English [sic] Care Quality Commission.¹ **Full text:** <https://bit.ly/3hcJ0Ff>

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>

Out-of-hours services and end-of-life hospital admissions: A complex intervention systematic review and narrative synthesis

BRITISH JOURNAL OF GENERAL PRACTICE | Online – 6 September 2021 – This review provides evidence as to why issues experienced during out-of-hours (OoH) may lead to end-of-life (EoL) hospital admissions (circumstances), how such admissions occur (processes), and by whom they are instigated (mechanisms). Importantly, although the findings may be unsurprising to many clinicians and EoL care researchers, this review highlights significant gaps in the evidence. Knowledge on how the identified factors interact with each other (for example, how circumstances may affect processes or how different mechanisms may respond to different circumstances) is currently lacking. Also lacking is evidence of effective interventions to improve care to prevent potentially avoidable EoL hospital admissions. The issues highlighted are pertinent to EoL care provision at all times of the day and night, although they seem to be particularly acute when they occur OoH. What this review suggests is that, although OoH EoL care can often be readily resolved by hospital admissions, it comes with multiple challenges that appear to be widespread and systemic. Some of these challenges might be prevented by action in-hours or better management of unscheduled care episodes within the community leading to reduced hospital admissions, which is what most recent empirical evidence seems to suggest. Bearing in mind, however, that the OoH periods comprise the majority of the week, service managers, commissioners, and policymakers need to continue to strive for integrated and comprehensive approaches to EoL care, 24/7. **Full text:** <https://bit.ly/38UkGDi>

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

- *PALLIATIVE MEDICINE* | Online – 21 November 2020 – '**Effectiveness and cost-effectiveness of out-of-hours palliative care: A systematic review.**' While out-of-hours 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. Consistent with other areas of palliative and end-of-life care research, this agenda will have to be flexible and pragmatic in matching methodological approaches to specific problems. **Full text:** <https://bit.ly/3nNIU7P>

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

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

Improving end-of-life care for people with dementia in long-term care homes during the COVID-19 pandemic and beyond

CANADIAN GERIATRICS JOURNAL | Online – 1 September 2021 – COVID-19 pandemic has resulted in a significant increase in deaths in long-term care (LTC) homes. People with dementia living in LTC homes represent one of the most frail and marginalized populations in Canada. The surge of COVID-19 cases in LTC homes and rationing of healthcare resources during the pandemic have amplified the pre-existing need for improvements in palliative and end-of-life care (EoLC) in LTC homes. This position statement, created by a task force commissioned by the Alzheimer Society of Canada, provides recommendations for a multipronged coordinated approach to improving palliative and EoLC of people with dementia living in LTC homes during the COVID-19 pandemic and beyond. **Full text:** <https://bit.ly/3kXJU9M>



N.B. Search back issues of Media Watch for additional articles on EoLC for people living with “dementia” at: <http://bit.ly/2ThijkC>

Guidance for timely and appropriate referral of patients with advanced heart failure: A scientific statement from the American Heart Association

CIRCULATION | Online – 10 September 2021 – Among the estimated 6.2 million Americans living with heart failure (HF), ≈5%/y may progress to advanced, or stage D, disease. Advanced HF has a high morbidity and mortality, such that early recognition of this condition is important to optimize care. Delayed referral or lack of referral in patients who are likely to derive benefit from an advanced HF evaluation can have important adverse consequences for patients and their families. A 2-step process can be used by practitioners when considering referral of a patient with advanced HF for consideration of advanced therapies, focused on recognizing the clinical clues associated with stage D HF and assessing potential benefits of referral to an advanced HF center. Although patients are often referred to an advanced HF center to undergo evaluation for advanced therapies such as heart transplantation or implantation of a left ventricular assist device, there are other reasons to refer, including access to the infrastructure and multidisciplinary team of the advanced HF center that offers a broad range of expertise. The intent of this statement is to provide a framework for practitioners and health systems

to help identify and refer patients with HF who are most likely to derive benefit from referral to an advanced HF center. **Full text (click on pdf icon):** <https://bit.ly/3hDSjOT>

Extract from Association’s scientific statement: The role of palliative care (p.e8)

Data suggest that practitioners often intuitively recognize the cues of advanced HF. Despite this, decisions about when to initiate end-of-life (EoL) discussions are often delayed, and the specialized services offered by palliative care (PC) consultants are underutilized. When patients were asked their perspectives and preferences on PC, they often confused PC with hospice care. Moreover, patients’ trust in their primary cardiology team and desire for continuity of care influenced some variability in their desire for PC specialty services. Thus, HF specialists at an advanced HF center can provide a comprehensive approach to clinical care by initiating PC and EoL conversations, explaining the differences between PC and hospice care, providing family and caregiver support, and understanding that some patients fear loss of continuity of care if they become disconnected from their HF clinician.

N.B. Selected articles on the role of PC in advanced heart failure noted in Media Watch 6 September 2021 (#733, pp.8-9).



Media Watch: Access Online – Updated 09.10.2021

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.

Project ECHO (Extension of Community Healthcare Outcomes)

Exploring health professionals' experiences with a virtual learning and mentoring program on pediatric palliative care in South Asia

GLOBAL PEDIATRIC HEALTH | Online – 31 August 2021 – This study identified the key benefits and barriers for healthcare providers participating in a technology-enabled learning program on pediatric palliative care (Project ECHO). Making the program's learning resources (video recordings, presentations, journal articles) available for sharing and use outside of the ECHO sessions is particularly important in low- and middle-income countries (LMICs). When developing ECHO programs, educators should pay close attention to the role of the facilitators, ensuring that these individuals are aware of their critical role in creating a supportive learning community for participants. Facilitators should also be encouraged to address the cultural and resource differences in medical care in LMICs, by making suggestions and stimulating discussion about how to adapt treatment plans from high income settings to local resource constraints. These considerations may allow educators to improve the quality of learning from Project ECHO for healthcare providers in resource-limited settings. **Full text:** <https://bit.ly/38K1x71>

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

- *JCO GLOBAL ONCOLOGY* | Online – 8 February 2021 – ‘**Using virtual learning to build pediatric palliative care capacity in South Asia: Experiences of implementing a teleteaching and mentorship program...**’ Project ECHO consists of biweekly videoconference sessions with didactic teaching and case-based discussions, engaging participants in meaningful learning by focusing on opportunities for participant interaction through teachings and case discussions. Key modifications to the model included course-specific leadership team, developing learning plans to address specific learning needs of participants, focusing on ensuring learner participation, and using social media and electronic resources to create opportunities for further learning outside of Project ECHO sessions. **Full text:** <http://bit.ly/3cVnSSt>

Interventions to improve prognostic understanding in advanced stages of life-limiting illness: A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 September 2021 – Among patients with advanced life-limiting illness, an inaccurate understanding of prognosis is common and associated with negative outcomes. Recent years have seen an emergence of new interventions tested for their potential to improve prognostic understanding. However, this literature has yet to be synthesized. Of the 2,354 initial articles, 12 were selected for final inclusion, representing 9 unique interventions. Intervention types included decision aids accompanying medical consults, palliative care consultations, communication training for patients and physicians, and targeted discussions regarding prognosis and treatment decision-making. Common components of interventions included provision of prognostic information, assistance with end-of-life care planning, and provision of decisional and emotional support during discussions. Most interventions were associated with some indication of improvement in prognostic understanding. However, even after intervention, inaccurate prognostic understanding was common, with 31–95% of patients in intervention groups exhibiting inaccurate perceptions of their prognosis. Prognostic understanding interventions hold the potential to improve patient understanding and thus informed decision-making, but limitations exist.

Abstract (w. references): <https://bit.ly/3hfMyqa>

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>



Enduring physical or mental suffering of people requesting medical assistance in dying

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 September 2021 – Medical assistance in dying (MAiD) is available in Canada for patients with grievous and irremediable medical conditions causing unbearable physical or mental suffering. It is not known how the “grievous and irremediable suffering” criteria is being interpreted and documented by physicians. The authors undertook a retrospective chart review of MAiD assessments from patients who submitted written MAiD requests to The Ottawa Hospital from 1 June 2016 to 18 September 2018. They identified 5 themes: 1) Patient’s context and history (e.g., past experiences, lack of disease modifying treatments); 2) Physical symptoms (e.g., chronic pain, fatigue); 3) Psychosocial symptoms (e.g., social isolation, or inability to communicate); 4) Sense of control; and, 5) Irreversibility. These themes were used to create a framework that describes the suffering of patients requesting MAiD. Patients who request MAiD describe how their disease causes suffering through physical symptoms, psychological symptoms and loss of control that is irreversible. These domains of suffering interact with their personal history and context leading to a reality that is unacceptable and irreversible. MAiD assessors’ working definition of ‘grievous and irremediable suffering’ as documented in their assessments is consistent with the body of literature on this topic. MAiD assessments could be enhanced with more information about existential aspects of suffering and the impact of illness on meaningful life roles.

Abstract (w. references): <https://bit.ly/2VyuPmo>

The meaning of together: Exploring transference and countertransference in palliative care settings

JOURNAL OF PALLIATIVE MEDICINE | Online – 2 September 2021 – Establishing an empathic clinical relationship is a cornerstone of high-quality palliative care (PC). More than simply approaching patients with a pleasant affect or “being nice,” the authors propose that skilled clinicians routinely employ distinct psychological elements when creating effective bonds with seriously ill patients and their families. PC involvement has been shown to improve a variety of outcomes for patients with serious cancer, and yet the components of this salutary effect are still becoming known in the literature. Many believe that a successful interpersonal relationship is the essential factor. In this article, the authors apply the psychological constructs of transference and countertransference to the unique arena of PC communication. Although most PC clinicians are not mental health clinicians and have not received training or certification in psychotherapeutic techniques, there are elements from these frameworks that may be advantageously applied. The authors draw on sources from psychology and psychiatry to explore the in-between spaces of clinical encounter. This article is the third installment of a series on the psychological elements of PC. **Abstract:** <https://bit.ly/3nb04iL>

Noted in Media Watch 6 September 2021 (#733, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2021;24(9):1274-1279. ‘Exploring the psychological aspects of palliative care: Lessons learned from an interdisciplinary seminar of experts.’ Palliative care (PC) has been shown to help patients live well with serious illness, but the specific psychological factors that contribute to this benefit remain investigational. Although support of patient coping has emerged as a likely factor, it is unclear how PC helps patients to cope with serious illness. The therapeutic relationship has been proposed as a key element in beneficial patient outcomes, possibly undergirding effective patient and family coping. Understanding the distress of patients with psychological depth requires the input of varied clinicians and thinkers. **Abstract:** <https://bit.ly/3kNMQfJ>

N.B. Search back issues of Media Watch for additional articles on the “psychological” aspects of PC at: <http://bit.ly/2ThijkC>

Palliative care needs, concerns, and affirmative strategies for the LGBTQ population

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 9 September 2021 – The provision and delivery of high-quality palliative, hospice, and end-of-life care starts with an understanding of the cultural framework that has shaped the life course of the lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) population and the minorities within minorities sub-groups. The long-standing prejudice, stigma, discrimination, and oppression have resulted in delays and avoidance in seeking medical care, disparate physical and mental health outcomes, and mistrust with the healthcare system as a whole. The barriers to comprehensive palliative care include gaps in competency training for providers, paucity in research studies, variable resource allocation, financial constraints, and non-protective regulatory policies and practices. There are key strategies to mitigate these barriers while providing affirmative and inclusive care toward sexual and gender minorities patients that can create a therapeutic alliance, improved patient and caregiver satisfaction, enhanced quality of life, and overall well-being. A holistic team-based approach coupled with empathic communication and non-judgmental mind-set are fundamental steps that offer an effective, successful, and trusting relationship to both patients and caregivers. **Full text:** <https://bit.ly/3tulo3C>

N.B. Search back issues of Media Watch for additional articles on the palliative and end-of-life care needs of the LGBTQ population at: <http://bit.ly/2ThijkC>

Unwelcome memento mori or best clinical practice? Community end-of-life anticipatory medication prescribing practice: A mixed methods observational study

PALLIATIVE MEDICINE | Online – 8 September 2021 – This study provides valuable insights into an important area of community end-of-life care (EoLC) practice. Standardised anticipatory medication pre-prescribing patterns suggest undue reliance on electronic EoLC templates and a lack of individualised prescribing as advocated in international policy. Marked variability in the timing of prescriptions, at times many months before death, underscores the challenge of prognostication and highlights the risks involved in putting medication in place too far in advance of possible need. The presence of anticipatory medications for long periods of time, or when situations are uncertain, may therefore compromise patient safety unless robust systems are in place to review their continued appropriateness and safe use. **Full text:** <https://bit.ly/3jRMrCQ>

N.B. Selected articles on anticipatory medication prescribing noted in Media Watch 15 March 2021 (#708, p.11).

Using the Delphi technique to achieve consensus on bereavement care in palliative care in Europe: An European Association for Palliative Care White Paper

PALLIATIVE MEDICINE | Online – 6 September 2021 – The World Health Organization definition of palliative care (PC) includes bereavement support as integral to PC, yet a previous survey of bereavement support in PC in Europe has shown a range of service responses to loss. A rigorous approach to agreeing and implementing a PC bereavement framework was required. The Delphi study was carried out by an expert panel among membership organisations of the European Association for Palliative Care. In total, 376 email requests to complete Delphi questionnaire were distributed with a response rate of 23% and a follow-up response-rate of 79%. Of the initial 54 statements in six dimensions, 52 statements were endorsed with 26 essential statements and 26 desirable statements. The six dimensions and 52 statements agreed through this Delphi study clarify a coherent direction for development of bereavement services in PC in Europe.

Abstract (w. references):

N.B. European Association for Palliative Care Bereavement Task Force: <https://bit.ly/38OfL76>



The effects of confronting one's own end of life on older individuals and those with a life-threatening disease: A systematic literature review

PALLIATIVE MEDICINE | Online – 6 September 2021 – Awareness of the impending end of one's life can pose profound existential challenges, thereby impairing wellbeing. Confronting one's own end of life (EoL) may be an approach to meet the psychological needs and consequently enhance overall wellbeing. Different approaches of confrontation have been evaluated positively using measures of psychosocial comfort. To date, there exists no systematic overview on the different ways of confrontation (e.g., psychosocial or individual coping approaches). Forty-nine studies reported on different approaches of confronting one's own EoL, including psychosocial interventions, meaning-enhancing approaches, educational programs, and learning from lived experiences. The results of this review suggest a clear trend toward beneficial effects on psychosocial comfort (e.g. anxiety, sense of meaning, wellbeing). **Abstract (w. references):** <https://bit.ly/3jPfzuM>

An exploration of palliative care undergraduate education at medical schools in Israel

PALLIATIVE & SUPPORTIVE CARE | Online – 10 September 2021 – Israel serves as a case study for understanding the importance of undergraduate palliative care (PC) education in implementing, developing, and enabling access to PC services. This article presents the findings collected from the five medical schools. Eleven expert interviews and five surveys demonstrate that PC is taught as a mandatory subject at only two out of the five Israeli universities. To enhance PC in Israel, it needs to become a mandatory subject for all undergraduate medical students. To teach communication, cultural safety, and other basic competencies, new interactive teaching forms need to be developed and adapted. In this regard, nationwide cooperation is proposed. An exchange between medical schools and university clinics is seen as beneficial. The new generation of students is open to PC philosophy and multidimensional care provision, but resources to support their growth as professionals and people remain limited. This study underlines the importance of teaching in PC at medical schools. Medical schools should cooperate, as the formation of expertise exchange across medical schools would automatically lead to better PC education. **Abstract (w. references):** <https://bit.ly/3nqgCU9>

Dying with disability: A disability and palliative care intersectoral partnership framework

RESEARCH & PRACTICE IN INTELLECTUAL & DEVELOPMENTAL DISABILITIES | Online – 9 September 2021 – People with intellectual disabilities have poor end-of-life (EoL) experiences compared with other community members. Few strategies are in place to ensure they receive EoL care tailored to their specific needs. More is known about “what” constitutes quality EoL care for people with intellectual disabilities, and the barriers to achieving these outcomes, than “how” to overcome these barriers. The expertise of both the palliative care (PC) and disability sectors are needed, at national, state, regional, and local levels, to address the causes that result in poor EoL experiences for people with intellectual disabilities, their families, and carers. This study developed an intersectoral disability and PC policy and practice partnership framework using a modified Delphi approach to integrate the key findings of two studies that provided guidance on what good EoL care looks like for people with intellectual disabilities: the ‘Disability Healthy End of Life Program’ service model with the ‘European Association of Palliative Care Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe.’¹ The intersectoral framework developed from this study is solution-focused and addresses the challenges of achieving quality practice. **Abstract:** <https://bit.ly/3tBJDwX>



1. ‘Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of Palliative Care,’ *Palliative Medicine*, 2016;30(5):446-455. [The Association’s White Paper was first published online and noted in Media Watch 17 August 2015 (#423, p.19)] **Full text:** <https://bit.ly/2YDOuIQ>

N.B. See commentary on ‘Dying with disability: A disability and palliative care intersectoral partnership framework’ at: <https://bit.ly/3yJOH3w>. Search back issues of Media Watch for additional articles on the palliative and EoL care needs of people living with “intellectual” or “developmental” disabilities: <http://bit.ly/2ThijkC>

Research Matters

Achieving *inclusive* research priority-setting: What do people with lived experience and the public think is essential?

BMC MEDICAL ETHICS | Online – 4 September 2021 – Robust ethical guidance for authentic engagement cannot be developed unless it is informed by the issues and concerns experienced by both researchers and their patient, public, and community partners. The findings of this study begin to identify the essential foundations for meaningful engagement in health research from the perspective of people with lived experience and members of the public. It builds an understanding of power sharing in health research from a non-academic researcher viewpoint. Although the findings reported in this paper speak to shared decision-making in health research generally, they offer insights as to what foundations are thought to be important to achieve it during health research priority-setting. It is particularly vital to develop ethical guidance on inclusive research priority-setting given that agenda-setting in health research is typically dominated by academic researchers and funders. Authentic engagement in health research begins with shared decision-making in priority-setting. Relational foundations such as forming connections and creating safe spaces will help people with lived experience and members of the public to share vulnerabilities, which provide key insights for identifying research topics and questions to explore. **Full text:** <https://bit.ly/3n1SGpO>

Assisted dying: We must prioritise research

BRITISH MEDICAL JOURNAL | Online 8 September 2021 – The case for legalisation is largely driven by polls that show around 80% of the U.K. public support assisted dying. However, similar polls from elsewhere have revealed poor understanding of what assisted dying legislation encompasses. Public views about legalisation of assisted dying are known to be significantly affected by their awareness of the relevant complexities. Opinion surveys that do not capture this complexity may not accurately reflect public attitudes. Deliberative democracy methods that allow in-depth exploration of potential trade-offs between individual freedom and societal safety could examine more complex scenarios, deepening our understanding of public opinion to help guide any legislative change. While there is increasing and strong evidence of the benefits of palliative care for people with terminal illnesses, the experiences of patients and families as they approach the end of life remain poorly understood. In addition, much more research is needed about the perspectives of patients and carers towards assisted dying. This is particularly important in areas of greatest clinical, legal, and ethical complexity, such as for people with dementia. **Full text:** <https://bit.ly/3jZT3PT>

Oscillations, boundaries and ethical care: Social work practitioner-researcher experiences with qualitative end-of-life care research

QUALITATIVE SOCIAL WORK | Online – 6 September 2021 – Policy and research acknowledge that the quality of end-of-life care (EoLC) in hospitals can be poor, with families reporting significant concerns regarding physical and psychosocial care. In order to design appropriate evidenced-based care approaches, the authors conducted qualitative research examining the perspectives of bereaved families of patients who received EoLC in their health network. This article reports on ethical dilemmas facing practitioner-researchers conducting interviews with bereaved families. Bereaved participants expressed grief, humour and anger regarding their experience, and several reported perceptions of negligent and harmful care. Irrespective of the protocols in place to mitigate distress, this posed an ethical dilemma for the practitioner-researcher as a member of the health network, who needed to balance clinical and research roles when responding to distress. The practitioner-researcher's own bias and assumptions emerged when analysing families' distressing recollections. More broadly, the issues discussed have clinical implications for models of hospital bereavement support. Participants' use of photos and mementos jointly served to include the presence of the deceased in the research interview, but also highlighted the potential to utilise visual methods to examine sensitive research issues. It helps every practitioner-researcher to distinguish between research-oriented goals and clinical responsibilities to care provision as they consider their human research ethics application before beginning any research. **Abstract (w. references):** <https://bit.ly/3nesPLI>

Publishing Matters

Predatory journals: The power of the predator vs. the integrity of the honest

CURRENT PROBLEMS IN DIAGNOSTIC RADIOLOGY | Online – 8 September 2021 – Over the last few decades, the authenticity and confidence of scientific work from around the world has been systematically corrupted by predatory journals and their affiliated publication houses. These journals predominantly prey on both aspiring and established academics and researchers from around the world, but primarily on individuals from developing countries, by aggressively soliciting manuscripts for a nominal publication fee without providing a robust editorial service or peer review system and ultimately promising fast track publication in a few days to weeks. Such journals may also diminish the opportunity for authors in developing countries from getting their original work published in legitimate journals. A majority of the work published in these pseudo journals aside from being incorrect and mundane, provide no advancement to science. But more importantly, the negative impact of these journals can have direct implications on patient health care and research. **Abstract:** <https://bit.ly/3BTzRcc>

Media Watch: Editorial Practice

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

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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.



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

Media Watch: Access on Online – Updated 09.10.2021

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3tw1eqa>

[Scroll down to 'Nursing"]

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

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

Asia



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

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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



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

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

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

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



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

[Scroll down to 'General Resources' and 'Media Watch']

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

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Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTPS://BIT.LY/3WVL5RW>

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

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

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