

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

The power of evidence-based advocacy by palliative specialists should be strategically and consistently added to the chorus of patients, caregivers, and other healthcare professionals calling for a world free from serious health-related suffering.

'Top ten tips palliative clinicians should know about evidence-based advocacy' (p.6), in *Journal of Palliative Medicine*.

U.S.A.

The hidden curriculum of hospice: Die fast, not slow

HEALTH AFFAIRS, 2021;40(5):844-847. Hospice provides palliative care at the end of life, but the model fails when patients die more slowly than expected. **Access article at:** <https://bit.ly/3eg84tS>

Specialist Publications

'Acquisitions of hospice agencies by private equity firms and publicly traded corporations' (p.5), in *JAMA Internal Medicine*.

International

“Do not resuscitate” discussions: Can we do better?

U.K. (England) | Aljazeera – 30 April 2021 – In response to the growing concerns about Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions during the COVID-19 pandemic, the Care Quality Commission (CQC), England's independent regulator of health and social care, conducted a special review. In its report on the matter¹ ... the Commission said that while it found some examples of good practice, it has also heard from people “who were not properly involved in decisions, or were unaware that such an important decision about their care had been made.” The worrying findings of the CQC review added weight to existing concerns and triggered an important discussion about DNACPR decisions and how they should be handled – both during pandemics and normal times. Most people, who have only seen CPR attempts in movies and TV series, may believe the treatment's success rates to be reassuringly high, and side effects minimal. Thus, they might take the default position that health professionals should always attempt CPR, regardless of circumstances and the patient's overall condition. This, however, is a misconception. <https://bit.ly/3ehDxfb>

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>

Cont.

Noted in Media Watch 5 April 2021 (#711, p.11):

- *RESUSCITATION*, 2021;161(4):408-432. **‘European Resuscitation Council Guidelines 2021: Ethics of resuscitation and end-of-life decisions.’** These European Resuscitation Council Ethics guidelines provide evidence-based recommendations for the ethical, routine practice of resuscitation and end-of-life care (EoLC) of adults and children. The guidelines primarily focus on major ethical practice interventions, decision-making regarding resuscitation, education, and research. These areas are tightly related to the application of the principles of bioethics in the practice of resuscitation and EoLC. The Council’s ethics writing group provides sets of simple and clear recommendations supported by a wealth of systematic reviews, recent randomised controlled trials and non-randomised studies. **Full text:** <https://bit.ly/3IZ7oLM>

N.B. This issue of *Resuscitation* includes additional articles on the European Resuscitation Council Ethics guidelines. **Journal contents page:** <https://bit.ly/3dmggau>

Specialist Publications

Dying well in nursing homes during COVID-19 and beyond: The need for a relational and familial ethic

BIOETHICS | Online – 5 May 2021 – COVID-19 has brought to the forefront the inadequacies concerning end-of-life care (EoLC) and planning for older adults in nursing homes. The authors introduced a relational ethics framework for understanding some of the continued failings in EoLC for nursing home residents. Without a relational ethics lens, important insights are missed into the contextual considerations that make individuals’ lives rich and meaningful and the ways in which family members hold one another in identity. Joining this with the concept of appropriate death allows for the application of these relational insights through the process of dying. COVID-19 has shown us that the everyday particularities of our relationships – coffee with neighbors, dinner out with friends, visits with family – are what enrich our lives and help us fully realize and live out our identities. While lack of preparedness around

dying and death in nursing homes has been exacerbated by COVID-19, these concerns transcend the pandemic and require us to keep in mind the importance of relationships for living – and dying – well. **Full text:** <https://bit.ly/3b5E8yL>

Research Matters

‘Stakeholder-engaged process for refining the design of a clinical trial in home hospice’ (p.12), in *BMC Medical Research Methodology*.

Publishing Matters

‘How to write research articles that readers understand and cite’ (p.12), in *Journal of Marketing*.

Related:

- *NURSING STANDARD* | Online – 5 May 2021 – **‘Overcoming challenges in community end-of-life care during the COVID-19 pandemic.’** This article explores the challenges generated by the COVID-19 pandemic in relation to community end-of-life care (EoLC) in the U.K. and reflects on the psychological and emotional consequences for nurses, patients and families. It also discusses some of the fundamental aspects of EoLC in the community and explores how nursing interventions can be adapted to ensure that high standards of care are maintained. The pandemic may provide opportunities for transforming community EoLC and there is a need for further research into how health and social care services have adapted, which would inform future care planning and service provision. **Abstract:** <https://bit.ly/33n9EUy>



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Changing the eligibility criteria for welfare payments at the end of life: A budget impact analysis for England and Wales

BMC HEALTH SERVICES RESEARCH | Online – 4 May 2021 – A change to the special rules for the terminally ill (SRTI) scheme which expands eligibility to any person with terminal illness will lead to increased government expenditure on personal independence payments (PIP), and this increase is likely to be mirrored by similar increases in expenditure on other eligible benefits. However, the cost implications of a change to SRTI will be small compared to the overall cost of PIP. In the most plausible “low increase” and “medium increase” scenarios, the projected annual costs of PIP claims under the new SRTI scheme are around £1.1 billion and £1.9 billion, respectively. This compares to the projected cost of over £12 billion under non-SRTI. There are several ways that changes could be implemented, with varying consequences for eligibility and uptake. However, a range of scenarios were modelled, and the conclusions were robust even to extreme situations. Careful consideration should be given to how terminal illness is defined under any new SRTI scheme, as this is likely to have significant implications for eligibility and subsequently on expenditure. Finally, any increase to the overall cost is likely to be offset, at least to some extent, by wider economic benefits that are realised through improving financial support for people with terminal illness. **Full text:** <https://bit.ly/3uiTNIM>

Palliative care for homeless and vulnerably housed people: Scoping review and thematic synthesis

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 May 2021 – People who are homeless or vulnerably housed are subject to disproportionately high risks of physical and mental illness and are further disadvantaged by difficulties in access to services. Research has been conducted examining a wide range of issues in relation to end-of-life care (EoLC) for homeless and vulnerably housed people, however, a contemporary scoping review of this literature is lacking. Sixty-four studies, involving 2,117 homeless and vulnerably housed people were included, with wide variation in methodology, population and perspective. The thematic synthesis identified three themes around experience, beliefs and wishes, relationships, and EoLC. Discussion highlighted gaps in the evidence base, especially around people experiencing different types of homelessness. Existing evidence advocates for service providers to offer needs-based and non-judgmental care, for organisations to use existing assets in co-producing services, and for researchers to address gaps in the evidence base, and to work with providers in transforming existing knowledge into evaluable action. **Abstract:** <https://bit.ly/3eUkC9u>

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

Quality measures for end-of-life care for children with cancer: A modified Delphi approach

CANCER | Online – 31 March 2021 – The quality of adult end-of-life (EoL) cancer care has benefited from quality measures, but corresponding pediatric measures are lacking. Therefore, the authors used a validated expert panel method to recommend EoL quality measures for pediatric oncology. Panelists were selected on the basis of professional organization nominations and expert qualifications. Pediatric and adult oncology, pediatric palliative care (PC), social work, nursing, and hospice were represented. The authors provided the panel with a literature review on 20 proposed measures derived from adult measures and bereaved family interviews. The panel first scored the importance of each measure on a 9-point scale and then discussed the measures via a conference call. The panel then rescored the measures. The 16 endorsed measures included measures related to avoidance of medically intense care (e.g., intensive care unit death and intubation in the last 14 days of life), death location (e.g., death in the preferred location), hospital policies/programs (e.g., the removal of visitor restrictions at EoL and the presence of a bereavement program), and supportive care services (e.g., pediatric PC involvement and sibling needs assessment). Unendorsed measures included avoidance of chemotherapy at EoL and home death. The measures need validation with bereaved families and further refinement before they are ready for real-world application as a tool for standardizing EoL care in pediatric oncology. **Abstract:** <https://bit.ly/3upExnf>

Engaging people with lived experience in co-design of future palliative care services

INTERNATIONAL JOURNAL OF PUBLIC ADMINISTRATION | Online – 4 May 2021 – For people living with a life-limiting condition it is challenging to contribute to the design of future services due to limited research foregrounding meaningful engagement of “vulnerable groups” in co-design. The authors share findings and critical reflections on sensitively engaging people with lived experience of palliative care transitions, and making their lived experiences visible and legitimate in the co-design process. They present an asset-based approach for reframing “vulnerability,” and visual and narrative tools to facilitate participation. Sharing critical reflections on the design tools and methods, the authors discuss future considerations for engaging “invisible communities” in co-design of public services. **Abstract:** <https://bit.ly/3ezghcZ>

Integration of palliative care into all serious illness care as a human right

JAMA HEALTH FORUM | Online – 22 April 2021 – Deaths from COVID-19 are approaching 600,000 in the U.S. and 3 million worldwide. As ICUs have reached or exceeded capacity in many hospitals, concerns have grown about the ethical dimensions of rationed care. But many of these focused on who gets a ventilator, rather than how to provide palliative care (PC) to those who are seriously ill, including those treated with ventilators and those who may not want or cannot get a ventilator. Early on in the pandemic, clinical leaders at Mount Sinai Medical Center in New York City, New York, realized that although they had a PC team, they did not have enough clinicians prepared to lead the crucial conversations with patients and families about end-of-life decision-making and symptom management. There is always a consistent need for the deep expertise of PC teams, but COVID-19 has highlighted that every clinician needs knowledge and skills in the fundamentals of PC. Access to PC is a human right. Our inability to deliver it in the setting of COVID-19 and other serious illnesses is a human rights violation. Each of us is a stakeholder. Health systems and clinicians are charged with meeting the holistic needs of patients and family caregivers in the face of serious illness. Education, payment and health equity reforms are needed now to hold clinicians accountable to those we serve. **Full text:** <https://bit.ly/2RIX4lu>

Denied the right to comfort: Racial inequities in palliative care provision

eCLINICAL MEDICINE | Online – 14 April 2021 – People who are racialized often exist in the margins of our health systems. Inequitable healthcare is experienced from the moment of birth and continues throughout life, extending into end of life and palliative care (PC). This occurs even though the United Nations acknowledges PC as a human right, and the World Health Organization mandates that all states provide it. As we strive for health systems where all people are treated equitably, PC must be included. To begin, it is important to collate what is known, and then to chart a way forward. This commentary focuses on PC in the U.S. and Canada, but similar concepts may apply more broadly. PC in many countries has its roots in policies, beliefs and practices that were determined by its almost unanimously White founders. It is time to critically examine PC provision through a lens grounded in anti-racism and the protection of human rights. We, as a PC community, must move from a system of exclusion and marginalization to one of inclusion and empowerment. We must use our collective power to build up a society where all individuals can receive high quality PC that acknowledges their individual worth and dignity. The time for action is now. **Full text:** <https://bit.ly/3tqEXZn>

Related:

- *BRITISH JOURNAL OF SOCIAL WORK* | Online – 3 May 2021 – ‘**Social work as a human rights profession: An action framework.**’ Human rights are foundational to social work ... leading many to consider social work a human rights profession. Although human rights has become an important compass for social work, comprehensive frameworks for understanding the “practice” of human rights in social work are still limited. Only recently attempts have been made to fill this gap. This article seeks to continue these efforts and contribute to a better understanding of how social work constructs, deconstructs and reconstructs ideas of human rights in daily practice. The authors investigated the question: “How do social workers “act” when using human rights as a framework for practice?” **Abstract:** <https://bit.ly/3b0ZPzX>

Acquisitions of hospice agencies by private equity firms and publicly traded corporations

JAMA INTERNAL MEDICINE | Online – 3 May 2021 – Over the past three decades, the U.S. hospice industry has transitioned from a mostly not-for-profit sector to one where nearly two-thirds of all agencies operate on a for-profit basis. A substantial driver of this trend has been the growth of large for-profit hospice chains, many of which are part of publicly traded corporations (PTCs). In general, for-profit hospice agencies have been associated with higher rates of live discharge, lower levels of skilled staffing, and provision of a narrower range of clinical services than nonprofit agencies. An understudied and less visible factor is the more recent entry of private equity (PE) investment into the sector. Facilitated by relatively easy market entry and the prospect of stable Medicare payments, PE firms and PTCs have made strategic hospice investments in recent years, raising quality concerns among some policymakers and patient advocates. In this study, the authors measure the prevalence of hospice agency acquisitions by PE firms and PTCs over the period from 2011 to 2019. **Abstract:** <https://bit.ly/3vFifhn>

N.B. See ‘Hospice tax status and ownership matters for patients and families,’ a commentary on ‘Acquisitions of hospice agencies...’ **Abstract:** <https://bit.ly/3eQEESi>

Palliative medicine specialization in Latin America: A comparative analysis

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 April 2021 – Formal recognition of palliative medicine as a specialty has been one of the main drivers in the development of palliative care. The authors conducted a comparative study of 19 Latin American countries. Key informants and persons in charge of the specialization training programs were identified and interviewed. The authors collected data on general recognition as specialty (title, process of certification) and on training program characteristics (title, start year, requirements, training length and type full time or part time). Eight of 19 countries (42%) Argentina, Brazil, Colombia, Costa Rica, Ecuador, Mexico, Paraguay and Venezuela reported palliative medicine as medical specialty. Thirty-five (sub)specialization training programs in palliative medicine were identified in the region (8 as a specialty and 27 as a subspecialty), the majority in Colombia (43.5%) and Brazil (33.7%). 20% of the programs have yet to graduate their first cohort. Length of clinical training as specialty varied from two to four years, and from 520 hours to three years for a subspecialty. Despite long-standing efforts to improve quality of care, and significant achievements to date, most Latin American countries have yet to develop palliative medicine as medical specialty. Specialty and sub-specialty training programs remain scarce in relation to regional needs, and the programs that do exist vary widely in duration, structure, and content. **Abstract (w. references):** <https://bit.ly/3tbna89>

Noted in Media Watch 29 March 2021 (#710, p.7):

- *CHILDREN* | Online – 23 March 2021 – ‘**Quality indicators in pediatric palliative care: Considerations for Latin America.**’ Pediatric palliative care (PC) is a growing field in which the currently available resources are still insufficient to meet the PC needs of children worldwide. Specifically, in Latin America, pediatric PC services have emerged unevenly and are still considered underdeveloped when compared to other regions of the world. A crucial step in developing pediatric (PC) programs is delineating quality indicators; however, no consensus has been reached on the outcomes or how to measure the impact of pediatric PC. Additionally, Latin America has unique socio-cultural characteristics that impact the perception, acceptance, enrollment and implementation of PC services. **Full text:** <https://bit.ly/3rkvJwm>



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>

Perceptions of hematology among palliative care physicians: Results of a nationwide survey

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 April 2021 – Palliative care (PC) integration for patients with hematologic diseases has lagged behind solid-organ malignancies. Previous work has characterized hematologist perspectives, but less is known about PC physician views of this phenomenon. Respondents to a 44-item survey reported comfort managing symptoms in leukemia (84.0%), lymphoma (92.1%), multiple myeloma (92.9%), and following hematopoietic stem cell transplant (51.6%). Fewer expressed comfort with understanding disease trajectory ... and discussing prognosis... 97.6% of respondents disagreed that PC and hematology are incompatible. 50.6% felt that PC physicians' limited hematology-specific knowledge hinders collaboration. 89.4% felt that relapse should trigger referral. 80.0% felt that hospice referrals occurred late. In exploring perceptions of hematology-PC relationships, three themes were identified: misperceptions of PC, desire for integration, and lacking a shared model of understanding. These data inform efforts to integrate PC into hematologic care-at-large, echoing previous studies of hematologist perspectives. PC physicians express enthusiasm for caring for these patients, desire for improved understanding of PC, and ongoing opportunities to improve hematology-specific knowledge and skills. **Abstract (w. references):** <https://bit.ly/3tkL55m>

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

Diversity in representations and voices of terminally ill people in end-of-life documentaries

JOURNAL OF PALLIATIVE CARE | Online – 3 May 2021 – The 21st century has seen a proliferation of end-of-life (EoL) documentary films and television documentaries that contribute to building a public image of hospice and palliative care. The way in which terminally ill patients are represented in these documentaries creates impressions of who is welcomed to receive EoL care. These documentary representations have not been previously mapped. This study demonstrated racial biases in documentaries focusing on EoL care that are similar to biases found in other media representations. While white patients often appeared as central characters in the narratives presented, black, indigenous and people of color patients were more frequently marginalized and given much less opportunity to reflect on their experiences with terminal illness. As we build public awareness and continue to represent seriously ill patients across many forms of visual media, this study can serve as a foundation of knowledge for the current state of representation and help characterize the need for more inclusive representation of a diverse group of people facing serious illness. **Full text:** <https://bit.ly/33exB0o>

Top ten tips palliative clinicians should know about evidence-based advocacy

JOURNAL OF PALLIATIVE MEDICINE | Online – 30 April 2021 – The escalating global burden of serious health-related suffering makes the need for funded policies that integrate palliative care (PC) into the continuum of services more urgent than ever. Palliative specialists are uniquely positioned to merge their clinical expertise with empirical evidence to advocate for improved PC delivery. There is a vital feedback loop between advocacy and clinical practice that palliative specialists can leverage to influence key stakeholders and decision-makers and bridge PC policy deficits. Sustained interdisciplinary partnerships are critical to evidence-based PC advocacy that addresses resource gaps, social injustice, and unmet and disparate needs. Although PC advocacy may appear optional or even frivolous at times, it is an essential skill for any practitioner working to

improve care for seriously ill individuals and their families. This article highlights 10 pragmatic tips that palliative specialists can use to advocate for policy changes that enhance PC access and equity at institutional, local, national, and global levels. **Abstract:** <https://bit.ly/3ulPTZb>

*Oxford Textbook of
Palliative Medicine
(5th Edition)*

'Communications with the Public,
Politicians, and the News Media,'
Synopsis: <http://bit.ly/2rHIII1>

Dying as an issue of public concern: Cultural scripts on palliative care in Sweden

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 6 May 2021 – In Sweden, palliative care (PC) has, over the past decades, been subject to policies and guidelines with focus on how to achieve “good palliative care.” The aim of this study has been to analyse how experts make sense of the development and the current state of PC. Departing from this aim, focus has been on identifying how personal experiences of “the self” are intertwined with culturally available meta-level concepts and how experts contribute to construct new scripts on PC. Four scripts were identified after analysing the empirical material: 1) Script of paths towards working within PC; 2) Script of desirable and deterrent reference points; 3) Script of tensions between improvement and bureaucracy; and; 4) Script of low status and uncertain definitions. The findings of this study illustrate how experts in complex ways intertwine experiences of “the self” with meta-levels concepts in order to make sense of the field of PC. The participants in this study did not endorse one “right way” of “good” deaths. Instead, PC was considered to be located in a complex state where the historical development, consisting of both desirable ideals, death denials and lack of guidelines, and more recent developments of strives towards universal concepts, “improvement” and increased bureaucracy altogether played a significant role for how PC has developed and is organised and conducted today. **Full text:** <https://bit.ly/3bbM0yt>

Factors facilitating positive outcomes in community-based end-of-life care: A cross-sectional qualitative study of patients and family caregivers

PALLIATIVE MEDICINE | Online – 4 May 2021 – Delivery of community-based end-of-life care (EoLC) for patients and family members has been recognized as an important public healthcare approach. Despite differences in different healthcare settings and the significance of a person-centered approach, little research has investigated facilitators of community-based EoLC from the perspective of service recipients. In particular, there has been limited exploration of strategies to ensure positive outcomes at an operational level. This study identified seven core themes: 1) Positive emotions about the relationship; 2) Positive appraisals of the relationship; 3) Care through inquiring about recipients’ circumstances; 4) Instrumentality of care (i.e., information, coaching on care, practical help, psychological support, multiple activities); 5) Comprehensiveness of care (i.e., diversity, post-death care, family-level wellbeing); 6) Structure of care (i.e., timely follow-up, well-developed system); and, 7) Qualities of workers. Improvement in service quality might be achieved through alternating the perceptions or emotional reactions of care recipients toward care providers and increased use of sensitive inquiry. Comprehensive care and positive outcomes might be facilitated by addressing the dualities of care by providing diverse choices in pre-death and post-death care. **Abstract (w. references):** <https://bit.ly/3tjtYAz>

Related:

- *PUBLIC HEALTH*, 2021;194(5):167-169. ‘**Compassionate communities – What does this mean for roles such as a death doula in end-of-life care?**’ Compassionate communities calls for the mobilisation of informal care around the dying and their families. Formal health services as well, including palliative care, are already providing care as are death doulas. The death doula role is not yet fully articulated and has layers of complexity associated with a lack of formalised training and no registration. There is much to consider in the informal caregiving space at the end of life. Conversations are required for coherent, coordinated care delivery in what has become a complex arena. There are those who are in paid positions, volunteers, those who are negotiating fees as well as role overlap... **Abstract:** <https://bit.ly/3xNqyJZ>

N.B. Selected articles on the role of doulas in palliative care noted in Media Watch 8 March 2021 (#707, pp.1-2).



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

The importance of living well now and relationships: A qualitative study of the barriers and enablers to engaging frail elders with advance care planning

PALLIATIVE MEDICINE | Online – 3 May 2021 – The population of frail elders is growing, and due to their vulnerability to sudden deterioration, advance care planning (ACP) is particularly important. However, ACP is uncommon for multiple reasons, some of which are linked to the perceptions of frail elders and their families. Key barriers identified in this study were: ACP is unclear, in terms of meaning and the language used; lack of relevance, with frail elders preferring to focus on living well now; and, the Importance of family, relationships and home, and the influence of relationship on end-of-life decision-making. Engagement strategies included preparing the frail elder for ACP conversations and using a gentle, honest, individualised approach. Based on these findings, essential enablers for frail elders are understanding what ACP is and why it may be relevant to them. For professionals, essential enablers are recognising the emphasis many frail elders place on living well now and relational autonomy rather than autonomous future planning. The authors presents strategies for engagement suggested by participants. These included preparing the frail elder for ACP conversations and using a gentle, honest, individualised approach. To support this, early engagement and the conceptualisation of ACP as an ongoing process that in-

cludes current and future care is recommended. **Full text:** <https://bit.ly/3xDrlrz>

An unusual conversation about dying during the COVID-19 pandemic: A neurosurgery resident's experience

AJOB NEUROSCIENCE | Online – 29 April 2021 – A foreign-born patient who suffered a catastrophic brain bleed was facing the end of his life. This patient's wife, his surrogate decision-maker, was deaf-mute, and the only translator who signed in their native language was also deaf-mute. An urgent family meeting was arranged in order to help facilitate end-of-life (EoL) discussions. During the COVID-19 pandemic, EoL discussions have become ever so challenging. This unique patient encounter compounded those existing challenges, but through a concerted effort, necessary steps were made to consider this vulnerable patient and their families circumstances. The authors shed light on the importance of maintaining empathy and vital communication with patients and their families under circumstances that may erode empathy and seriously impede communication. They present key elements of communication used to help a vulnerable family make a vital decision, overcoming extraordinary obstacles of language and other impediments of this pandemic. **Abstract:** <https://bit.ly/3aXg8xt>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 May 2021 – **'Planning for end of life.'** Oncology provider discussions of treatment options, outcomes of treatment, and end-of-life (EoL) planning are essential to care for patients with advanced malignancies. Studies have shown that despite this, many patients do not have adequate care planning, including EoL planning. It is thought that the accessibility of information outside of clinical encounters and individual factors and/or beliefs may influence the patient's perception of disease. This survey of patients diagnosed with stage IV cancer shows that a significant number of patients had misunderstandings of the treatment and curability of their disease.. **Abstract (w. references):** <https://bit.ly/3eQAj1k>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 5 May 2021 – **'Informal caregivers and advance care planning: Systematic review with qualitative meta-synthesis.'** Knowledge about caregivers' needs might support implementation of advance care planning (ACP) interventions suitable to both care recipients and their caregivers. Healthcare professionals should carefully consider caregivers' conceptualisations ACP as well as the relationships within the family. They need to be skilled communicators, sensitive to individual needs and equipped with sufficient time resources to tailor ACP interventions to their clients' unique situation. Thus, they will support decision-making according to care recipients' wishes, caregivers' end-of-life experience and their life after bereavement. **Abstract:** <https://bit.ly/3ekntcB>

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- **NEWS GP** (Royal Australian College of General Practitioners) | Online – 4 May 2021 – ‘**Majority of older Australians “sidestepping” end-of-life care.**’ 7 out of 10 Australians aged 65+ are missing the opportunity to control their end-of-life care, with men less likely to plan than women... A government-funded study¹ ... showed among the 30% of older Australians with advance care planning documents, only 14% are legally binding advance care directives (ACDs), which are considered the “gold standard.” ACDs can only be completed by a person with decision-making capacity. The majority of documents among older Australians are plans where preferences are reported by either family members or healthcare professionals. While these documents can be used to guide care, they are not legally binding. <https://bit.ly/2RIHfvh>
1. ‘Advance care directive prevalence among older Australians and associations with person-level predictors and quality indicators,’ *Health Expectations*, published online 1 May 2021. **Full text:** <https://bit.ly/3uk4qVg>

Population-based projections of place of death for Northern Ireland by 2040

PALLIATIVE MEDICINE & HOSPICE CARE | In print – Accessed 5 May 2021 – There are global challenges in relation to an increasingly older population, rising numbers of deaths and the resulting need for end-of-life care (EoLC). It is imperative for health and social care to examine where people die and forward plan. Deaths are projected to increase by 45.9%, from 15,922 in 2018 (of which 36.3% will be aged 85+ years) to 23,231 deaths in 2040 (39.8% aged 85+ years). Between 2004 and 2018, proportions of home and care home (defined as nursing and residential beds) deaths increased (24.5-27% and 16.3-19.4% respectively), while the proportion of hospital deaths declined (51.9-47.6%). If current trends continue, by 2040, deaths within the community (home and care home) will account for between 46.7-55.2% of all deaths. However, if care home capacity is limited at current levels (as of 2018), hospital deaths are projected to account for the largest proportion of deaths by 2040 (51.7%). Death at an increasing age has implications for EoLC provision. This study demonstrates an increasing need for EoLC over the next 20-years, particularly within community settings. Projections highlight the need for comprehensive planning to ensure service provision within the community meets the needs of the population. **Abstract:** <https://bit.ly/3enuHN3>

Dignity-conserving palliative care in a diverse population: A qualitative study of physicians’ perspective

PALLIATIVE & SUPPORTIVE CARE | Online – 6 May 2021 – Preserving personal dignity is an important aim of palliative care (PC). Little is known about how physicians perceive and preserve dignity of patients from non-western migration backgrounds. Insight in this is important given the increased demand for culturally sensitive PC. Dutch physicians, i.e., study participants, experienced dilemmas in preserving dignity of non-western patients in three situations: 1) Relief of suffering in the terminal phase; 2) Termination of interventions and treatment; and, 3) Disclosure of diagnosis. Physicians wanted to grant the needs of patients in the last phase of their lives, which was central to physicians’ view on dignity, but dilemmas arose when this conflicted with physicians’ other personal and professional values. To make the dilemmas manageable, physicians assessed whether needs of patients were authentic, but due to linguistic, cultural, and communication barriers, this was difficult with non-western patients. To find a way out of the dilemmas, physicians had three strategies: 1) Accept and go along with patient's wishes; 2) Convince or overrule the patient or family; or, 3) Seek solutions that were acceptable for all. Physicians encounter dilemmas providing PC for people from non-western backgrounds. **Abstract (w. references):** <https://bit.ly/33ngjhn>



Photo: Lori Waselchuk. Philadelphia, PA

Prison Hospice: Backgrounder: Updated 05.01.2021

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

Advance care planning in pediatric serious illness: Centering in the family experience

PEDIATRICS | Online – 6 May 2021 – As advancements enable us to manage increasingly complex pediatric illness, we must be purposeful in ensuring that we meet patient and family goals. Thompson *et al* examine the impact of an advanced care planning intervention, the Family-Centered Advance Care Planning for Teens with Cancer (FACE-TC), on families' assessment of their experiences in caregiving and on familial distress.¹ The FACE-TC is a National Cancer Institute-recognized evidence-based intervention developed to foster goals-of-care discussions and completion of advanced directives between adolescent patients and their families. The authors conducted a multicentered randomized control trial with adolescents and young adults with cancer, along with their families, over 3 years. Patient-family dyads received either 3 weekly structured sessions through the FACE-TC intervention or treatment as usual. Participants in the FACE-TC intervention had a statistically significant increase in positive estimations of their caregiving, with no notable difference in distress. **Introduction:** <https://bit.ly/3vRoQpj>

1. 'Pediatric advance care planning and families' positive caregiving appraisals,' *Pediatrics*, published online 6 May 2021. **Abstract:** <https://bit.ly/3eVm0st>

Noted in Media Watch 29 March 2021 (#710, p.7):

- *PALLIATIVE MEDICINE* | Online – 26 March 2021 – '**Hearing the voices of children diagnosed with a life-threatening or life-limiting illness and their parents' accounts in a palliative care setting: A qualitative study.**' Interview data demonstrated that there was a gap in the child's experience and understanding of their condition compared to their parents. The data produced six major themes: 1) Awareness of the illness; 2) Death and dying; 3) The spiritual response to illness; 4) The emotional response to illness; 5) Striving for normality and independence; and, 6) Coping strategies. The study showed that children can read subtle cues or they may talk with other children to learn about their illness when information is not openly available to them. **Abstract (w. references):** <https://bit.ly/3rpxecl>

Noted in Media Watch 4 January 2021 (#698, p.14):

- *PALLIATIVE MEDICINE* | Online – 29 December 2020 – '**Factors associated with health professionals' decision to initiate paediatric advance care planning: A systematic integrative review.**' This review found a dearth of evidence specifically focusing on the initiation of paediatric advance care planning (ACP).¹ Overall evidence suggests that health professionals recognise early initiation to be the ideal, and they play a key role ensuring this. Yet ambiguity regarding prognosis, parents' reactions, who leads, and the skills needed to engage in such conversations act as deterrents in initiating paediatric ACP in clinical practice. Consequently, ACP conversation occur too late without time for the child and parent to reflect and enact their goals or wishes. **Full text:** <http://bit.ly/3mXA8mQ>

1. 'Paediatric advance care planning: Physician experience and education in initiating difficult discussions,' *Journal of Paediatrics & Child Health*, published online 21 December 2017. [Noted in Media Watch 1 January 2018 (#544, p.10)] **Abstract:** <https://bit.ly/2WWli4i>

N.B. Addition articles on ACP in pediatric serious illness noted in this issue of Media Watch.

"What is right for me, is not necessarily right for you": The endogenous factors influencing non-participation in medical assistance in dying

QUALITATIVE HEALTH RESEARCH | Online – 3 May 2021 – Access to medical assistance in dying (MAiD) [in Canada] is influenced by legislation, healthcare providers (HCPs), the number of patient requests, and the patients' locations. This research explored the factors that influenced HCPs' non-participation in formal MAiD processes and their needs to support this emerging practice area. Using an interpretive description

Extract from *Qualitative Health Research* article

Participants reflected on how MAiD fit within the spectrum of the existing end-of-life care (EoLC) options. Some HCPs articulated how MAiD did not align with their existing EoLC practices and approaches, while others discussed how MAiD was not encompassed within their vision of palliative care.

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methodology, the authors interviewed 17 physicians and 18 nurse practitioners who identified as non-participants in formal MAiD processes. Non-participation was influenced by their: 1) Previous personal and professional experiences; 2) Comfort with death; 3) Conceptualization of duty; 4) Preferred end-of-life care approaches; 5) Faith or spirituality beliefs; 6) Self-accountability; 7) Consideration of emotional labor; and, 8) future emotional impact. They identified a need for clear care pathways and safe passage. Two separate yet overlapping concepts were identified, conscientious objection to and non-participation in MAiD, and the authors discussed options to support the social contract of care between HCPs and patients. **Full text:** <https://bit.ly/3vD8f8l>

N.B. HCPs and hospice care provider perspectives (and clinicians' experience) with MAiD noted in Media Watch 19 April 2021 (#713, p.7).

Willingness to pay for quality and length of life gains in end of life patients of different ages

SOCIAL SCIENCE & MEDICINE | Online – 4 May 2021 – Health gains are increasingly weighted in economic evaluations of new health technologies to guide resource-allocation decisions in healthcare. In Norway and The Netherlands weights are, for example, based on the disease severity of patients. In England and Wales, a higher weight is attached to quality-adjusted life-years (QALYs) gained from life-extending end-of-life (EoL) treatments. Societal preferences for QALY gains in EoL patients are increasingly examined. Although the available evidence suggests that gains in health-related quality of life (QoL) may be preferred to gains in life expectancy (LE), little is known about the influence of EoL patients' age on these preferences. The authors examine the willingness to pay (WTP) for QoL and LE gains in EoL patients of different ages in a sample of the general public in The Netherlands. They found that WTP was relatively higher for QoL and LE gains in younger EoL patients. The authors further found indications suggesting that WTP may be relatively higher for QoL gains at the EoL, except for patients aged 20 for whom we observed a higher WTP for LE gains. Results of this study may inform discussions on attaching differential weights to QoL and LE gains in EoL patients of different ages with the objective to better align resource-allocation decisions with societal preferences. **Full text:** <https://bit.ly/3unXPJC>

10 years of end-of-life criteria in the U.K.

VALUE IN HEALTH, 2021;24(5):691-698. In January 2009, the National Institute for Health & Care Excellence introduced supplementary guidance for end-of-life (EoL) treatments, which allowed treatments with an incremental cost-effectiveness ratio over the regular threshold (£20,000-£30,000) to be recommended, if they satisfied the EoL criteria. The aims of this study were to systematically review 10 years of EoL supplementary guidance implementation and explore how it could be improved, and to create a framework for incorporating the uncertainty relating to EoL criteria satisfaction into model-based cost-effectiveness analyses for decision-making. An EoL discussion was identified in 35% of appraisals, 57% of which led to a positive EoL decision. Only 5.7% of technologies with positive EoL decisions were not recommended, versus 43.8% of technologies with negative EoL decisions. EoL criteria assessment was often reported insufficiently and evaluated inconsistently and non-transparently. A total of 54.9% of EoL decisions were made while at least one criterion was surrounded by considerable uncertainty. By applying the proposed quantitative method, this EoL criteria satisfaction uncertainty was accounted for in decision-making. The stylized example demonstrated that the impact of EoL criteria satisfaction uncertainty can be substantial enough to reverse the reimbursement decision. To improve consistency/transparency and correct reimbursement decisions' likelihood, new guidelines on the implementation of the EoL criteria are needed. **Full text:** <https://bit.ly/338PMUS>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.13.

Research Matters

Stakeholder-engaged process for refining the design of a clinical trial in home hospice

BMC MEDICAL RESEARCH METHODOLOGY | Online – 30 April 2021 – Clinical trials in home hospice settings are important to build the evidence base for practice, but balancing the burden and benefit of clinical trial conduct for clinicians, patients, and family caregivers is challenging. A stakeholder-engaged process can help inform and refine key aspects of home hospice clinical trials. The aim of this study was to describe a stakeholder-engaged process to refine, design, and implement aspects of an educational intervention trial in home hospice, including recommendations for refining intervention content and delivery, recruitment and enrollment strategies, and content and frequency of outcome measurement. Five initial biweekly teleconferences with a panel of interprofessional and two family caregiver stakeholders resulted in recommendations for recruitment strategy, enrollment process, measurement frequency, patient inclusion, and primary care physician notification of the patient's trial involvement. The panel continues to participate in quarterly teleconferences to review progress and unexpected questions and concerns. Panelist reflections reveal personal and professional benefit from participation. **Full text:** <https://bit.ly/33gwgWA>

Publishing Matters

How to write research articles that readers understand and cite

JOURNAL OF MARKETING | Online – 7 May 2021 – Academia is a marketplace of ideas. Just as firms market their products with packaging and advertising, scholars market their ideas with writing. Even the best ideas will make an impact only if others understand and build on them. Why, then, is academic writing often difficult to understand? In two experiments and a text analysis of 1,640 articles in premier marketing journals, this research shows that scholars write unclearly in part because they forget that they know more about their research than readers, a phenomenon called “the curse of knowledge.” Knowledge, or familiarity with one's own research, exacerbates three practices that make academic writing difficult to understand: abstraction, technical language, and passive writing. When marketing scholars know more about a research project, they use more abstract, technical, and passive writing to describe it. Articles with more abstract, technical, and passive writing are harder for readers to understand and are less likely to be cited. The authors call for scholars to overcome the curse of knowledge and provide two tools... to help them recognize and repair unclear writing so they can write articles that are more likely to make an impact. **Abstract (w. references):** <https://bit.ly/3f018CY>

N.B. A related issue: See ‘A Journalist's Guide to Writing Health Stories,’ *American Medical Writers Association Journal*, 1999;14(1):32-42. **Full text (click on pdf icon):** <https://bit.ly/33psDxA>

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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Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/2RsCRKZ>

[Scroll down to 'Media Watch']

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

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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
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 SCMSP
Canadian Society of
Palliative Care Physicians
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 | 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>

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

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Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): [HTTP://BIT.LY/3EPKUAC](http://bit.ly/3EPKUAC)

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

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>

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