

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

A strict visitation policy that prohibits all visits to COVID-19 patients, including in end-of-life situations, might save hospital personal protection equipment supply and increase safety to some degree, but it can wear down medical staff's emotional resilience, increase their already heavy workloads with the painful task of facilitating remote goodbyes, and cause harm to patients and families, who report feeling deeply helpless and like they have no sense of closure.

'Not dying alone: The need to democratize hospital visitation policies during COVID-19' (p.9), in *Medical Law Review*.

U.S.A.

Pitt researchers study new approach to expand palliative care access for cancer patients

PENNSYLVANIA | University of Pittsburgh – 13 September 2021 – With the goal of developing a low-cost and widely available model of palliative care (PC), Yael Schenker, a professor of medicine and the director of the Palliative Care Center at the university, and her team worked ... to train oncology infusion nurses to provide this care in addition to their usual duties of administering chemotherapy, blood products and other treatments. "We chose infusion nurses because they are in every oncology practice, and they have existing relationships with patients and oncologists," said Schenker. "We wanted to leverage those relationships and the strength of existing oncology teams." To investigate whether PC led by infusion nurses would improve patient well-being, the researchers set up a clinical trial with 672 advanced-stage cancer patients ... located in communities of western Pennsylvania. Half of the patients received standard oncology care, and the

other half received up to three PC sessions in addition to standard treatments. During monthly PC sessions, nurses focused on symptom assessment, emotional support, coordination of care and planning for future care. After three months, the researchers found that both patient groups had similar scores for quality of life, physical symptoms, anxiety and depression, an unexpected finding that they report in *JAMA Internal Medicine*.¹ <https://bit.ly/3C6j1aq>

Specialist Publications

'Evaluation of the LIGHT curriculum: An African American church-based curriculum for training lay health workers to support advance care planning, end-of-life decision-making, and care' (p.8), in *Journal of Palliative Medicine*.

1. 'Effect of an oncology nurse-led primary palliative care intervention on patients with advanced cancer: The CONNECT cluster randomized clinical trial,' *JAMA Internal Medicine*, published online 13 September 2021. Full text: <https://bit.ly/3kaajBV>

International

U.K. COVID policies may have disproportionately impacted ethnic minorities at the end of life

U.K. | About Manchester – 15 September 2021 – Visiting restrictions may have had a disproportionate adverse impact in those ethnic minority groups that would traditionally have large numbers of family members involved in providing care, support and/or decision-making, and where it was important for the wider community to visit and support in times of illness, according to a new study.¹ Visiting restrictions may have not only removed patients' psychosocial support and advocates, but also their personal and professional translators; for many, their only means of communication while COVID-related policies prohibiting physical contact with loved ones after death, may have particularly impacted ethnic minority groups who are more likely to conduct compulsory after death rituals such as prayer in large groups with touching and washing of the body. Professor Catherine Walshe, from the International Observatory on End-of-Life Care, Lancaster University, and co-author said: "This important research has made it clear that one size really does not fit all when it comes to the provision of palliative and end-of-life care. Whilst those involved in providing care were working hard to be equitable in their approach, it is important to recognise that such approaches can impact in different ways and create inequity where none were intended" COVID-19 has disproportionately affected ethnic minority groups and these latest findings suggest "one size fits all" policies introduced during the COVID-19 pandemic may have adversely impacted these groups disproportionately, causing distress that services struggled to manage. <https://bit.ly/2VMvpNt>



1. 'Specialist palliative care services response to ethnic minority groups with COVID-19 – equal but inequitable: An observational study,' *BMJ Supportive & Palliative Care*, published online 12 September 2021. Full text: <https://bit.ly/3nt6Ss7>

During the pandemic two thirds of bereaved people report experiencing social isolation and loneliness

U.K. (England) | University of Bristol – 14 September 2021 – New research shows impact of grief during the pandemic as two thirds of bereaved people report experiencing social isolation and loneliness.¹ Those bereaved due to COVID-19 were also less likely to be involved in care decisions and be well supported by healthcare professionals after the death of their loved one. The research which has been carried out by the University of Bristol and Cardiff University's Marie Curie Palliative Care Research Centre found that participants reported high levels of challenges relating to bereavement during the pandemic with the three most common being restricted funeral arrangements (93%), limited contact with other close relatives or friends (81%) and experiencing social isolation and loneliness (67%). When deaths were unexpected rather than expected, such as many COVID-19 deaths, the bereaved person was less likely to be involved in care decisions. Almost half (48%) of participants reported that a healthcare or other care professional had not provided information about bereavement support services, even though this would have been relevant to them. <https://bit.ly/3hz51yd>

Specialist Publications

'Who needs, receives and misses out on palliative and end-of-life care? A population-based study to identify needs and gaps in a regional health service' (p.5), in *Australian Health Review*.

'Palliative care integration indicators: An European regional analysis' (p.7), in *BMJ Supportive & Palliative Care*.

"I am dying a slow death of White guilt": Spiritual carers in a South African hospice navigate issues of race and cultural diversity' (p.7), in *Culture, Medicine & Psychiatry*.

'Twelve years of postgraduate palliative medicine training in Finland: How international guidelines are implemented' (p.11), in *Palliative Medicine Reports*.

Cont.

1. 'Place, cause and expectedness of death and relationship to the deceased are associated with poorer experiences of end-of-life care and challenges in early bereavement: Risk factors from an online survey of people bereaved during the COVID-19 pandemic,' medRxiv, posted online 14 September 2021. **Full text:** <https://bit.ly/3nxqg7d>

N.B. This is a preprint, so it is a preliminary piece of research that has not yet been through peer review and has not been published in a scientific journal – so this is early data.

Noted in Media Watch 5 July 2021 (#724, p.4):

- U.K. | Marie Curie Palliative Care Research Centre – 15 June 2021 – '**New research shows U.K. faces post-pandemic bereavement crisis and lasting legacy of grief.**' New research has highlighted the difficulties and distress people experienced when trying to get support after the death of a loved one during the pandemic, with more than half of people (51%) experiencing high or severe vulnerability in their grief and those seeking support facing long waiting lists or being told they are ineligible. The survey found that of bereaved people demonstrating high or severe levels of vulnerability, three quarters (74%) were not accessing formal bereavement services or mental health support. People also reported discomfort asking for help and were unsure how to access services. <https://bit.ly/3xg3Ppe>

One in four think they only have days to live if their doctor talked to them about palliative care: Survey

IRELAND | *The Independent* (Dublin) – 13 September 2021 – Four in five people living with a serious illness would like their doctor to talk to them about palliative care (PC) if it could help them. The finding was from a new survey of the public's perceptions of PC commissioned by the All-Ireland Institute of Hospice & Palliative Care. The survey of 1,000 people also highlighted some of the misconceptions that exist about PC. One in four people would think they only have days to live if their doctor or healthcare professional talked to them about PC, whereas PC may be appropriate for several years, not just for weeks and days at a person's end of life. And one in four would feel their doctor is giving up on them if they talked to them about PC. It showed over 60% don't mind where they receive PC as long as they have a good quality of life and their physical and emotional pain is managed, and they are comfortable. <https://bit.ly/3nuagTA>



Noted in Media Watch 10 February 2020 (#652, p.7):

- **HRB OPEN RESEARCH** | Online – 3 December 2019 – '**Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046?**' The number of people in Ireland dying from a disease associated with palliative care (PC) need is estimated to increase 68% between 2016 and 2046 if levels of need stay constant. Under assumptions of changing need, increases are estimated in the range 78-84% depending on projection method employed. The equivalent estimates for England & Wales between 2015 and 2040 are 25% with constant needs and up to 47% with changing needs.¹ The number of people living with a disease associated with PC need outnumber those in the last year of life with a relevant diagnosis. **Full text:** <http://bit.ly/2OzrhJJ>

1. 'How many people will need palliative care in 2040? Past trends, future projections and implications for services,' *BMC Medicine*, published online 18 May 2017. [Noted in Media Watch 22 May 2017 (#513, p.11)] **Full text:** <http://bit.ly/2IHcYCI>



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>

Specialist Publications

Is comfort care the same as do not resuscitate? How misinterpreting code status may lead to potential patient harm

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 September 2021 – Several research studies have shown that code status documentation is misinterpreted or incorrectly defined by a significant number of medical professionals. This misinterpretation among the medical team (i.e., equating do not resuscitate with comfort care measures only) may lead to false reporting, poor symptom management, and potentially adverse clinical outcomes. Most hospice and palliative care (PC) providers are aware of these distinctions, however a shortage (and continued foreseen shortage) of hospice and PC providers may mean these conversations and distinctions will fall to non-subspecialists, or

providers of other medical specialties or degrees. The literature has demonstrated that these shortfalls and misinterpretations are present and constitute potential harm to patients. **Abstract (w. references):** <https://bit.ly/2VMDp0W>

Research Matters

'Performance status and trial site-level factors are associated with missing data in palliative care trials: An individual participant-level data analysis of 10 phase 3 trials' (p.13), in *Palliative Medicine*.

Healthcare professionals' knowledge, skills, and role in offering and facilitating memory-making during end-of-life care in the adult intensive care unit

AUSTRALIAN CRITICAL CARE | Online – 13 September 2021 – An activity to provide a tangible keepsake following the death of a loved one is termed "memory-making." However, limited evidence is available related to professionals' education and support to provide memory-making opportunities in the adult intensive care unit (ICU). Having a greater understanding of healthcare professionals' experiences can inform future patient/family care and support for professionals in end-of-life (EoL) care. Participants in this study reported memory-making to include the creation of tangible keepsakes as well as non-tangible activities. Overall, participants reported high agreement scores that the responsibility for initiating memory-making predominately belonged to the nurse. Participants reported skills most needed involved the ability to interact with the family, being open to the concept, and integrating memory-making into their standard of care. Having developed a rapport with families was considered an enabler, whereas lack of knowledge and clinical workload were reported as inhibitors to offering memory-making. Nurses are more likely to perceive professional responsibility for offering memory-making, likely due to their increased time at the bedside and higher prominence and leadership in other EoL practices. To support professionals, education should include conceptual knowledge, procedural knowledge of keepsake creations, communication techniques using reflective practices, and organisational support to facilitate time requirements. **Abstract:** <https://bit.ly/3lrU9Dr>



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World Hospice and Palliative Care Day | **9 OCTOBER 2021**

www.thewhpc.org/world-hospice-and-palliative-care-day

Who needs, receives and misses out on palliative and end-of-life care? A population-based study to identify needs and gaps in a regional health service

AUSTRALIAN HEALTH REVIEW | Online – 16 September 2021 – There is a small but expanding literature on estimating the need for palliative care (PC) at a population level. There is a lack of data, however, regarding access to palliative and other end-of-life care (EoLC) across multiple settings (e.g., home, specialist PC unit, hospital) and patient groups (e.g., defined by socio-demographics and diagnostics). This study builds on previously used methods for estimating the need for PC, with some refinements, including the addition of “other clinical indications” and the use of weights to derive more realistic estimates. The estimates of need are consistent with recent estimates from Australia and overseas, whereas the estimates of access are similar to a recent Australian estimate, but higher than estimates from overseas. The gaps in access are highest among those with the major types of chronic organ failure... The study demonstrates how routinely collected data at a regional level can be used to estimate need and access to palliative and EoLC, in the hospital and in the community. These methods of estimating need and unmet need can be used to inform the planning and development of services, as well as to monitor progress with implementation of changes in service provision. **Abstract (w. references):** <https://bit.ly/3zldomR>

Implementing welfare technology in palliative homecare for patients with cancer: A qualitative study of health-care professionals’ experiences

BMC PALLIATIVE CARE | Online – 17 September 2021 – This study of municipal healthcare professionals’ experiences with the use of a welfare technology application for providing palliative homecare to patients with cancer in Norway indicates that a shift from a disease-focused approach to a person-centered approach enables healthcare professionals (HCPs) to remotely assess elements that are priorities for patients. Concurrently, lack of sufficient knowledge, experience, fear, and uncertainty among HCPs concerning serious illness and death proved to be a great challenge with the potential to inhibit palliative care assessments and professional care. Providing networks where difficult issues can be discussed was found to represent an important resource that facilitated the implementation of remote home care (RHC) in palliative homecare for patients with cancer. Finally, our study suggests that welfare technology applications, such as RHC, cannot function satisfactorily until digital infrastructure is fully established throughout society. Until appropriate systems for the transfer of patient information and documentation across the several organizational structures of the healthcare systems are in place, it will remain nearly impossible for HCPs to offer a full-fledged service in which patients’ interests are fulfilled. This fact should be considered in future research projects in which new technologies are to be implemented and explored. **Full text:** <https://bit.ly/3Ey5BG8>

Related:

- *INTERNATIONAL JOURNAL OF LAW, POLICY & THE FAMILY* | Online – 9 September 2021 – ‘**Funeral wills and the autonomy of a dying person: Experiences of older people in palliative care and their carers.**’ In the capital area of Finland (Uusimaa), the number of ageing customers in home care has increased over 40% in the past few years, while the number of care workers and care visits has decreased. The data in this article comprises anecdotal evidence from older people in palliative care, their carers and bereaved persons concerning funeral wills and the autonomy of a dying person. These narratives included both clearly expressed funeral plans and interpretations of the presumed wishes of a deceased person concerning their funeral. **Full text:** <https://bit.ly/3hrEIKd>
- *PLOS ONE* | Online – 14 September 2021 – ‘**Dying within dyads: Stress, sense of security and support during palliative home care.**’ This study provides new insights about the dyads of patients in palliative care and their closest relative. It shows how they, within the dyads, experience similar and dissimilar pattern of stress, self-efficacy, dimensions of sense of security and perceived support and in what way these patterns are associated with aspects such as family caregiver gender, relationship, patient age, attachment styles and health-related quality of life. Previous research supports these findings and has shown that patient-family caregiver dyads often agree well in their ratings of the perceived reality of quality of care and stress. **Full text:** <https://bit.ly/3kcuBuz>



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Evaluating satisfaction with the quality and provision of end-of-life care for patients from diverse ethnocultural backgrounds

BMC PALLIATIVE CARE | Online – 17 September 2021 – Recently immigrated and ethnic minority patients in Ontario, Canada, are more likely to receive aggressive life-prolonging treatment at the end of life (EoL) in comparison to other patients. To explore this finding further, this survey-based observational study aimed to evaluate satisfaction with the quality of EoL care for patients from diverse ethnocultural backgrounds. Satisfaction with the quality of EoL care was higher among patients dying in ICU compared to other hospital units and lower among Muslim patients or when there were language/communication barriers between patients, families and the healthcare team. These findings underscore the need to identify and remedy potential disparities in care delivery and/or ethnocultural expectations for care that may contribute to lower satisfaction at the EoL. Complementary qualitative research designs should seek to capture – more explicitly – the experiences of patients and families from specific ethnocultural backgrounds. More insight to the patient care experience and decision-making process at the EoL will further understanding of factors that constitute quality care and culturally unique gaps that exist along the EoL trajectory. **Full text:** <https://bit.ly/3zmmRuf>

Lack of racial diversity within the palliative medicine workforce: Does it affect our patients?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 September 2021 – A palliative medicine (PM) workforce that reflects the diverse population that it serves will understand their needs through lived experience and be better equipped to meet those needs. By addressing inequalities within our own workforce and understanding a range of perspectives, we can begin to tackle the health inequalities that exist in PC and in society. More research is needed and justified to understand the association between diversity among clinicians, and access to palliative care (PC) and diversity among patients. Diversity in the PC workforce should be a societal goal in itself, even in the absence of documented patient benefit. Collectively, we have an obligation to create a diverse medical workforce that represents the diverse communities it serves. **Full text:** <https://bit.ly/2XnPGcw>

Community palliative care services on addressing physical and psychosocial needs in people with advanced illness: A prospective cohort study

BMC PALLIATIVE CARE | Online – 15 September 2021 – The findings of this study has several implications for future practice and research. First, health and social care for community palliative care (PC) should be enhanced by involving multiple health disciplines to address the escalating care needs as the patients' health condition deteriorates. For example, general practitioners and family physicians may adjust the medication for better symptom control, other allied health professionals may provide advices on dietary or physical exercise to maintain nutritional status or muscle strength. The wider scope of services might optimize the patients' quality of life in the last phase of life. Second, professional education should be strengthened for generalists to enhance their awareness and sensitivity toward the PC needs of patients, irrespective of diagnoses. Third, additional research is warranted to examine the effects of community PC support on a larger and diverse group and the effects in the later phase of illnesses. **Full text:** <https://bit.ly/3lxTFLU>

Related:

- *INDIAN JOURNAL OF PALLIATIVE CARE* | Online – 9 September 2021 – '**Psychosocial challenges in palliative care: Bridging the gaps using digital health.**' Psychosocial challenges continue to impact health and well-being among palliative care (PC) patients, informal caregivers and healthcare providers. Despite a growing body of evidence on psychosocial burden across PC populations, little efforts are made to address such problems. Evidence-based digital interventions are being used for improving healthcare services and multiple health outcomes in PC settings. Critical challenges may affect the widespread adoption of such interventions, especially in low-resource contexts. Future research should explore individual and population-based barriers and facilitators... **Full text:** <https://bit.ly/2YWFwXq>

Palliative care integration indicators: An European regional analysis

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 September 2021 – There is limited availability of information regarding palliative care (PC) integration into identified domains of health systems and what there is varies greatly between countries. Although PC integration appears to be progressing in paediatric, primary and oncological care, progress is slower for cardiology, the volunteer sector and long-term care (LTC) settings. These results, obtained by exploring six different domains where European Association for Palliative Care expert groups were available, provide credible preliminary data to measure achievements in PC integration across the health systems of European countries. Only 4 out of 51 European countries consistently indicated a high level of integration across specific populations (children), at the generalist level (primary care), for different diseases (cancer and heart failure), by different providers (volunteers) and in other care settings (e.g., LTC). Representing 7% of the countries studied, the overall results demonstrate that the majority of health systems are unprepared to manage population-level PC needs beyond selected specialised provision. Moreover, preparedness is uneven across sub-regions, with small residual samples of Central and Eastern European countries showing reasonable levels of PC integration (e.g., Czech Republic, Poland and Kyrgyz Republic). By contrast, countries located in the Western region, mostly high-income ones, had the highest average Integration Capacity score (e.g., The Netherlands, U.K., Germany and Switzerland). These findings support previous publications reporting the absence of and uneven PC integration into the majority of health systems. **Full text:** <https://bit.ly/3tDQx4V>

Noted in Media Watch 1 March 2021 (#706, p.5):

- *BMC PALLIATIVE CARE* | Online – 24 February 2021 – ‘**Evaluating the integration of palliative care in national health systems: An indicator rating process with European Association for Palliative Care Task Force members to measure advanced palliative care development.**’ A process composed of a desk literature review, consultation and semi-structured interviews with Association task force members and a rating process was performed to create a list of indicators for the assessment of palliative care (PC) integration into pediatrics, long-term care facilities, primary care, cardiology, and volunteering. The new indicators were mapped onto the 4 domains of the WHO Public Health Strategy. Thirty-four indicators were identified for national-level monitoring of PC integration. **Full text:** <http://bit.ly/3pORcgt>

“I am dying a slow death of White guilt”: Spiritual carers in a South African hospice navigate issues of race and cultural diversity

CULTURE, MEDICINE & PSYCHIATRY | Online – 12 September 2021 – Culturally appropriate spiritual care is increasingly recognised as a crucial component of spiritual care. As part of a larger study, the authors were interested in cultural and racial issues as experienced by spiritual carers in a hospice in Cape Town, South Africa. They conducted one-on-one interviews and focus group discussions with a cohort of spiritual care workers, who, being volunteers and relatively privileged South Africans, discussed their sensitivity to cultural issues, but also mentioned a host of political, racial and identity issues which profoundly affect their work. The data suggest that the concept of culturally appropriate care must be understood and acted on contextually. The authors note that the work of transformation of care cannot be separated from broader questions of social inequality and change. **Full text:** <https://bit.ly/3CjxNe0>

Holding hope for patients with serious illness

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 16 September 2021 – Clinicians often struggle with imparting hope in providing patient care, especially for patients with serious illness. Although clinicians intuitively appreciate the potential therapeutic benefit of hope, concern about taking away hope is a common reason for delaying conversations about poor prognosis. Conversely, clinicians may be concerned when patients have unrealistic hopes for cure or a longer life; they may perceive a need to correct their patients’ hopes to enable more informed decision-making. This tension presents a dilemma: How can clinicians help patients hold onto hope? Should hope be protected, even when being hopeful is unrealistic? Or should clinicians risk a loss of hope to ensure that patients understand their prognosis? These may be the wrong questions. **Full text:** <https://bit.ly/3zi5yL4>

Palliative care in rural aboriginal communities: Conversations around experiences and needs

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 9 September 2021 – The aim of this study was to investigate the experiences and needs



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of aboriginal community members with regard to rural community-based palliative care (PC). Conversations with aboriginal elders were conducted. (In this aboriginal community, elders was not confined to older age. It referred to community leaders and includes younger, emerging leaders.) The results were analyzed using descriptive analysis. The findings of this study showed that there was a general lack of understanding of PC as distinct from curative care and limited awareness of services available. There was a strong need for clear information and on-call and practical support. Some concerns were expressed regarding limited awareness among healthcare providers of specific cultural needs. However, the home-based nature of PC was not, in itself, perceived as a barrier, provided that appropriate respect was displayed. The authors conclude that the current lack of understanding and awareness of services still impedes access to, and utilization of, care. More attention is needed for specific cultural needs. Adoption of a cultural humility approach for the promotion and delivery of PC seems to best fit the expressed needs and experiences of the participants. **Abstract:** <https://bit.ly/2Xaw7EC>

Noted in Media Watch 12 July 2021 (#725, p.12):

- *RURAL & REMOTE HEALTH* | Online – 5 July 2021 – ‘Remote area nurses’ perceptions of the enablers and barriers for delivering end-of-life care in remote Australia to aboriginal people who choose to pass away on their traditional lands.’ This research shows that communication and acknowledgement of each party’s requirements, needs, wants, expectations and limitations, and brainstorming both formally and informally about these needs, could lead to fewer barriers. Overall, it seems that when those involved from the community and the remote area nurses came together, they were able to deliver what they considered a successful service to patients, families, communities and themselves, enabling end-of-life care to occur on traditional homelands. **Full text:** <https://bit.ly/3jGkeiV>

Noted in Media Watch 2 December 2019 (#642, p.15):

- *RURAL & REMOTE HEALTH* | Online – 30 November 2019 – ‘Passing on wisdom: Exploring the end-of-life wishes of aboriginal people from the Midwest of Western Australia.’ Indigenous patients with life-limiting conditions have complex needs, experience reduced access to and uptake of treatment, and have lower utilisation of palliative care (PC) services than the general population. Lack of understanding of the role of PC and poor availability of culturally safe specialist PC services impact on Indigenous people’s end-of-life (EoL) decision-making. Aboriginal people were engaged to talk frankly about their wishes and concerns around EoL. The community consultations raised considerable discussion about wills, where to die, burial versus cremation, and the cost of funerals. **Full text:** <http://bit.ly/37RtZ5g>

Evaluation of the LIGHT curriculum: An African American church-based curriculum for training lay health workers to support advance care planning, end-of-life decision-making, and care

JOURNAL OF PALLIATIVE MEDICINE | Online – 9 September 2021 – Lay health workers (LHWs) engaging African Americans in conversations about advance care planning (ACP) often have felt unprepared for the challenges of communicating with patients as they approach the end of life (EoL). The authors developed a church-based training curriculum, LIGHT (Listening, Identifying, Guiding, Helping, Translating), in response to this need. They evaluated the LIGHT Curriculum by assessing its impact on knowledge, beliefs and attitudes, and self-efficacy of the learners; describing their assessment of the classroom component of the training; and describing their visit activities, and perceptions derived during client visits. LHWs, trained using the LIGHT Curriculum, can acquire the knowledge and self-efficacy necessary to support African American clients with ACP, EoL decision-making, and EoL care. **Abstract:** <https://bit.ly/3ntJPNJ>

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Noted in Media Watch 14 June 2021 (#721, p.4):

- *HEALTHY EQUITY* | Online – Accessed 8 June 2021 – ‘**LIGHT: A church-based curriculum for training African American lay health workers to support advance care planning and end-of-life decision-making.**’ A partnership of academia with the African American Church can create a curriculum for training lay health workers (LHWs) for the principal role of enhancing and facilitating communications about end-of-life (EoL) decision-making. Health inequities of African Americans at the EoL require new interventions and approaches to care. Funders and health systems are increasingly deploying LHWs to meet this need. Communications of LHWs with African Americans about ... EoL decision-making should be buttressed by community-centered discussions and education. **Full text:** <https://bit.ly/3pvhJAK>

Noted in Media Watch 17 December 2018 (#594, p.9):

- *JOURNAL OF PALLIATIVE CARE* | Online – 12 December 2018 – ‘**Engaging the African American church to improve communication about palliative care and hospice: Lessons from a multi-level approach.**’ The authors’ primary goal was to encourage churches to embrace palliative care (PC) and hospice as acceptable alternatives for end-of-life care by creating venues to improve communications about PC and hospice. This article compares their experience in five churches in the Philadelphia region of Pennsylvania, revealing lessons learned and the challenges of engaging, implementing, and maintaining a multilevel approach in the churches, and the authors’ strategies in response to those challenges. **Abstract (w. list of references):** <https://goo.gl/Y1ebhk>

Not dying alone: The need to democratize hospital visitation policies during COVID-19

MEDICAL LAW REVIEW | Online – 13 September 2021 – Of the many adverse outcomes that may result from the spread of ... COVID-19, one stands out as particularly vile: the experience of dying alone. Many healthcare facilities in the U.S. and elsewhere adopted ‘No-Visitor Rules’ in an effort to contain the virus, but these rules mean that the countless people in nursing homes and hospital wards were isolated during their final hours of life. There is no epidemiological or U.S. federal or state requirement to prohibit visitation to (and thereby isolate) dying patients – even those with COVID-19. Instead, constructing pandemic-specific visitation policies is usually left to the discretion of hospitals and healthcare providers. Such policies aim to limit the risk of exposure, but fail to account for the individual and social costs associated with dying alone for patients, families, and frontline healthcare workers. As a result, the policies may be overly restrictive and actively cause harm. This article argues that U.S. hospital visitation policies need to be democratized to include the perspectives of community members and patients. By drawing on existing patient rights frameworks, this article outlines several legal strategies to reconceptualise hospital visitation policies as a civil rights issue. **Full text:** <https://bit.ly/3AboL2j>

Dying like a dog: The convergence of concepts of a good death in human and veterinary medicine

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 15 September 2021 – Standard views of good death in human and veterinary medicine considerably differ from one another. Whereas the good death ideal in palliative medicine emphasizes the positive aspects of non-induced dying, veterinarians typically promote a quick and painless killing with the aim to end suffering. Recent developments suggest a convergence of both professions and professional attitudes, however. Palliative physicians are confronted with patients wishing to be “put to sleep,” while veterinarians have begun to integrate principles and practices from hospice care. The authors argue that the discourses on good human and animal deaths are not distinct, but that they interact and influence each other. On the one hand, veterinary medicine adapts techniques like chemotherapy or sedation from palliative end-of-life care (EoLC). On the other hand, philosophers, veterinarians, pet owners, patients and the general public alike make certain assumptions about the (dis)analogy of human and animal dying or killing. Unfortunately, these interactions have only scarcely been reflected normatively, especially on the part of human medicine. Conflicts and misattributions with potential serious negative consequences for the (animal and human) patients’ wellbeing are provoked. For these reasons, palliative physicians and veterinarians are invited to engage in the debate around human and animal EoLC. **Full text:** <https://bit.ly/3tLTGj1>

N.B. Additional articles on the parallels to be drawn between palliative and veterinary medicine noted in Media Watch 4 February 2019 (#600, p.13) and 6 May 2019 (#613, p.14).

Impact of augmented intelligence on utilization of palliative care services in a real-world oncology setting

ONCOLOGY PRACTICE | Online – 10 September 2021 – Although several studies have evaluated machine learning (ML) tools to predict mortality in patients with cancer, to the authors' knowledge, thus far, only one has been shown to influence clinical practice, by increasing the number of serious illness conversations. However, the intervention in this trial combined the ML insights ... with behavioral nudges, using text message reminders, and performance reports and data on peer comparisons for serious illness conversations. The combined intervention makes it difficult to tease out the specific contribution of the ML insights to driving behavioral change. By contrast, this study provided the ML insights and recommendations within the electronic health record without any additional prompts directing clinicians toward specific actions, allowing for their own interpretation and decision-making with respect to clinical care for the patient. This retrospective cohort study found that incorporation of a novel augmented intelligence (AI) solution into the workflow at a large oncology practice in the U.S. was feasible. The 30-day mortality insights generated by the AI were effective in prompting clinical practice changes, resulting in increases in both palliative care consults and hospice referrals. This study provides early evidence that AI can assist with and improve decision-making in the management of patients with cancer at end of life identified as high or medium risk for short-term mortality. **Full text:** <https://bit.ly/3lesy8M>

The impact of poverty and deprivation at the end of life: A critical review

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 12 September 2021 – This critical review interrogates what we know about how poverty and deprivation impact people at the end of life (EoL) and what more we need to uncover. While we know that people in economically resource-rich countries who experience poverty and deprivation over the life course are likely to die younger, with increased co-morbidities, palliative care (PC) researchers are beginning to establish a full picture of the disproportionate impact of poverty on how, when and where we die. This is something the COVID-19 pandemic has further illustrated. The authors use a critical social science lens to investigate an eclectic range of literature addressing health inequities and is focused on poverty and deprivation at the EoL. The authors' aim was to see if we could shed new light on the myriad ways in which experiences of poverty shape the end of people's lives. They start by exploring the definitions and language of poverty while acknowledging the multiple intersecting identities that produce privilege ... [and] ... discuss poverty and deprivation as a context for the nature of PC need and overall EoL circumstances. In particular, the authors explore: total pain; choice at the EoL; access to PC; and, family caregiving. Overall, they argue that in addressing

the effects of poverty and deprivation on EoL experiences, there is a need to recognise not just socio-economic injustice but also cultural and symbolic injustice. Too often, a deficit-based approach is adopted which both "others" those living with poverty and renders invisible the strategies and resilience they develop to support themselves, their families and communities. The authors conclude with recommendations for future research, highlighting in particular the need to amplify the voices of people with lived experience of poverty regarding palliative and EoL care. **Full text:** <https://bit.ly/3Aa3E02>

Extract from *Palliative Care & Social Practice* article

Death exposes in high relief the layers of inequities, in race and income, care and opportunity, that shape life down to its final hours. It is a truth the pandemic has only underscored – one hard to see, because it is so much easier to look away.¹

1. 'Is death the great equalizer?' *The Boston Globe*, 25 September 2020. [Noted in Media Watch 5 October 2020 (#686, p.2). <https://bit.ly/3mY2xdB>]

Identifying older adults with frailty approaching end-of-life: A systematic review

PALLIATIVE MEDICINE | Online – 13 September 2021 – Clear implications for end-of-life (EoL) policy and practice are hindered by the lack of evidence that relates to older adults explicitly identified as frail. Frailty trajectories, measures of physical fitness and assessment of malnutrition may all be helpful to indicate entry into the EoL phase, but the evidence is limited. There is also a paucity of evidence for appropriate interventions. Future research could helpfully adopt explicit measurement and reporting of frailty among study populations. In view of the challenges to identification of frailty and EoL, a focus on models of care that incorporate a palliative care approach within frailty is critical. **Full text:** <https://bit.ly/398p0yZ>

Twelve years of postgraduate palliative medicine training in Finland: How international guidelines are implemented

PALLIATIVE MEDICINE REPORTS | Online – 17 September 2021 – In Finland, two years of postgraduate training in palliative medicine (PM) is provided by the Finnish Society for Palliative Medicine. After the training, the Finnish Medical Association qualifies the doctor with a special competence in PM. In this study, Finnish physicians evaluated that the Finnish curriculum covers most of the content of the European Association for Palliative Care (EAPC) curriculum well. Most of the training deals with palliative oncology and the dying process, but administrative issues, research, and spiritual support are covered less. Additional education tailored for different specialties must be obtained by the specialist physicians themselves. The educational content of the Finnish courses has changed during the observational period of 12 years along with changes in medical care. According to their self-evaluation, all the trained doctors reported that they had received sufficient skills to work as a palliative consultant in all but academic capabilities. However, there is a lack of multidisciplinary education and an obvious need to modernize the pedagogic methods of the teaching. The authors have provided an audit of a national PM postgraduate program. The current audit was based on: 1) Comprehensive examination of teaching programs and exams; 2) Analysis of documentation in the pedagogic archives of the education provider and personal interviews; 3) Evaluations by previous and currently attending students; 4) Comparison of the national and EAPC curricula; and, 5) Assessment of the learning outcomes. In this study, for the first time, not only experts but also physicians who had attended the training compared the experienced education with the European standard. **Full text:** <https://bit.ly/3tPCGZn>

How can we know what we don't know? An exploration of professionals' engagement with complicated grief

PATIENT EDUCATION & COUNSELING | Online – 13 September 2021 – Research has shown that complicated grief has the potential to adversely affect bereaved individuals, and in this context, understanding how mental health professionals engage with it in practice is of relevance. Gaining an understanding of professionals' knowledge, attitudes, skills and training in relation to complicated grief could provide insights that will inform their training and professional development. The aim of this study was to consider professionals' engagement with complicated grief, as represented by self-reported knowledge, attitudes, skills and training. Analysis yielded 15 integrated findings across three phases [i.e., systematic review, qualitative interviews, and a quantitative survey], which were grouped into two clusters: the first highlighted tension between professionals' reported confidence and competence and the second explored the parameters and contribution of research and training in this area. Professionals' perception of their competence to work with complicated grief seems overstated and research and professional practice are not aligned. These findings are positioned to inform empirically supported training that addresses identified deficits in professionals' knowledge, attitudes and skills. It is important therefore that training is reflective of the needs of different professional groups. **Abstract:** <https://bit.ly/3tF26sp>

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Would the *Patient Education & Counseling* article be of interest to a colleague?

Related:

- *DEATH STUDIES* | Online – 14 September 2021 – ‘**The relational landscape of bereavement after anticipated death: An interpretive model.**’ To complement existing literature and capture the diversity of factors influencing grief a more interpersonal understanding is required. The authors used the relational landscape’s concept and empirical investigation to clarify the roles of individuals surrounding the bereaved. Interviews with bereaved individuals ... were analyzed using “interpretive description.” The authors present a model describing 5 types of actors in the environment of the bereaved and their ways of “being with” or giving space. They include 4 lived landscapes in their model with the purpose of describing how bereavement can be experienced within the social environment. **Abstract:** <https://bit.ly/2Z15nas>

Educational priorities for providing end-of-life care: Parent perspectives

PEDIATRICS | Online – 13 September 2021 – Partnership with parents is a tenet of pediatric medicine; however, initiatives to include parents in education and research have been limited. Through focus groups, we included parents at the beginning of curriculum development by asking them to identify the priorities, existing supports, and opportunities for improvement in their child’s end-of-life care (EoLC). Twenty-seven parents of 17 children participated... Four themes were identified as important to parents in their child’s EoLC: 1) Honoring the role of the parent; 2) Having confidence in the care team; 3) Receiving gestures of love and caring; and, 4) Navigating logistic challenges. Parents were asked to be partners in guiding priorities for healthcare education and professional development to improve pediatric EoLC. In addition to strengthening skills in communication, confidence in the team, and compassion, parents in this study identified a need for hospital staff to anticipate financial and social stressors and provide supportive resources more readily. Additionally, parents described clinical and non-clinical staff as providing support, suggesting that a multidisciplinary and interdisciplinary curriculum be developed to improve pediatric EoLC. **Abstract:** <https://bit.ly/3tDfkWJ>

Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 13 September 2021 – ‘**Trust in physicians, anxiety and depression, and decision-making preferences among parents of children with serious illness.**’ To the best of their knowledge, this is the first study in pediatrics to examine trust and decision-making preferences, and the first to look at how trust, anxiety, and depression might influence parent decision-making preferences. Parents who have lower levels of trust in physicians and report anxiety may prefer to make the medical decisions for their seriously ill child without help from physicians. Among parents with higher trust in physicians, anxiety was associated with greater preference for shared and delegated decision-making. **Full text:** <https://bit.ly/3CbIQWQ>

Bioethics, palliative care and liberation: A contribution to “dying well”

REVISTA BIOÉTICA, 2021;29(2):268-278. Our society has sought to institutionalize life and death, undertaking a search for longevity that almost denies the human condition. On the other hand, there are efforts to rescue the “good death” by respecting the patient’s autonomy and care practices that preserve the individual’s dignity and freedom. Reconciliation between these opposing poles will only be achieved through the education and critical reflection proposed by liberation. Thus, it is worth reflecting on the role of health education, since the achievement of liberation in current care and training practices depends on it. In this sense, patient-focused education is not only desirable, but also mandatory, to ensure that palliative care (PC), especially at the end of life, contributes to a good death, with autonomy and dignity. This article reflects on dying and the contributions that bioethics has made to the topic, either by the traditional principles of autonomy and dignity, or by the defense of a new category: liberation, proposed by intervention bioethics based on [Brazilian educator and philosopher] Paulo Freire. This qualitative research study, with a hermeneutic, reflective, socio-critical and analytical approach, aims to show that liberation can contribute to train more critical, committed and free professionals and patients, capable of facing a moment of such vulnerability as the moment of death is. The article argues that adopting the concept of liberation in the bioethical reflection on PC can contribute to the “dying well” process. **Download English, Portuguese or Spanish language versions of this article (click on pdf icon) at:** <https://bit.ly/3tBqsDv>



Universidade de Brasília

The impact of providing end-of-life care during a pandemic on the mental health and wellbeing of health and social care staff: Systematic review and meta-synthesis

SOCIAL SCIENCE & MEDICINE | Online – 13 September 2021 – Serious disease outbreaks and disasters can expose care staff to abnormally high levels of mortality and suffering. The authors aimed to: 1) Synthesise evidence describing the experiences of health and social care staff providing end-of-life care (EoLC) during a disease outbreak or humanitarian disaster; 2) Understand the impact on their mental health and wellbeing; and, 3) Identify means of support. The analysis generated two superordinate themes: 1) Individual experience; and, 2) Organisational responsibilities. Individual experience comprised four themes: 1) Dignity in death; 2) Positive experiences; 3) Negative experience; and, 4) Support for staff. Organisational responsibilities comprised four themes: 1) Preparation; 2) Adaption; 3) Resources; and, 4) Personal protective equipment. No studies quantitatively measured the impact of providing EoLC on staff mental health and wellbeing, however qualitative studies described experiences in varied settings. Health and social care systems need to proactively prepare for future events and enable peer support mechanisms that may help mitigate experiences of psychological distress in humanitarian crises. **Abstract:** <https://bit.ly/3EaL5LH>

Research Matters

Performance status and trial site-level factors are associated with missing data in palliative care trials: An individual participant-level data analysis of 10 phase 3 trials

PALLIATIVE MEDICINE | Online – 16 September 2021 – Missing data compromise the internal and external validity of trial findings, however there is limited evidence on how best to reduce missing data in palliative care (PC) trials. Participants with missing data at the previous time-point and poorer performance status were more likely to have missing data for the primary outcome and quality of life (QoL) outcomes, at the primary follow-up point and end of follow-up. At the end of follow-up, the number of site randomisations and number of study site personnel were significantly associated with missing data. Trial duration and the number of research personnel explained most of the variance at the trial and site-level respectively, except for the primary outcome where the amount of data requested was most important at the trial-level. Variance at the trial level was more substantial than at the site level across models and considerable variance remained unexplained for all models except QoL at the end of follow-up. Participants with a poorer performance status are at higher risk of missing data in PC trials and require additional support to provide complete data. Performance status is a potential auxiliary variable for missing data imputation models. Reducing trial variability should be prioritised and further factors need to be identified and explored to explain the residual variance. **Full text:** <https://bit.ly/3tLvZY9>

Media Watch: Editorial Practice

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

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International



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