

End of Life Care Current Awareness Bulletin

August 2021

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Title: The Role of Hospice Palliative Care Volunteers With Respect to Conversations About Medical Assistance in Dying (MAiD)

Citation: Journal of Palliative Care; Jul 2021; vol. 36 (no. 3); p. 143

Author(s): Claxton-Oldfield, Stephen

Title: Moral Injury: An Increasingly Recognized and Widespread Syndrome.

Citation: Journal of religion and health; Jul 2021

Author(s): Koenig, Harold G; Al Zaben, Faten

Abstract: Moral injury (MI), originally discussed in relationship to transgressing moral beliefs and values during wartime among military personnel, has expanded beyond this context to include similar emotions experienced by healthcare professionals, first responders, and others experiencing moral emotions resulting from actions taken or observations made during traumatic events or circumstances. In this article, we review the history, definition, measurement, prevalence, distinctiveness, psychological consequences, manifestations (in and outside of military settings), and correlates of MI in different settings. We also review secular psychological treatments, spiritually integrated therapies, and pastoral care approaches (specific for clergy and chaplains) used to treat MI and the evidence documenting their efficacy. Finally, we examine directions for future research needed to fill the many gaps in our knowledge about MI, how it develops, and how to help those suffering from it.

Title: Psychological distress and moral injury to oncologists and their patients during COVID-19 pandemic.

Citation: Current psychology (New Brunswick, N.J.); Jul 2021 ; p. 1-6

Author(s): Rashid, Shazia; Reeder, Clare; Sahu, Satyajit; Rashid, Sabia

Abstract: The impact of the COVID-19 pandemic on healthcare systems has been unprecedented, and the psychological effects on cancer patients and health care professionals are likely to be significant and long-lasting. The traditional methods of face-to-face health care interactions have been replaced by virtual consultations to reduce exposure to COVID-19 infection. This has put the healthcare professional under tremendous psychological pressure and led to considerable anxiety and distress among cancer patients. Treatment decisions have had to be adjusted to account for a healthcare system that has been temporarily consumed by the care of people with COVID-19, and this has put cancer patients at risk of inferior outcomes. This has had the potential to cause moral injury and psychological distress to health care professionals as well as patients, who have had to deal with a range of stressors due to the uncertainty, sense of loss of control, reduced accessibility to medications and social support, changes to personal circumstances (e.g. financial pressures) and fear of death due to COVID-19 infection. Long term consequences also include post-traumatic responses and complex grief reactions. Cancer services in particular should gear themselves to recognize and monitor these effects and allocate adequate resources to combat them in the months and years to come.

Title: Understanding and mitigating moral injury in nurses.

Citation: Nursing standard (Royal College of Nursing (Great Britain) : 1987); Jul 2021

Author(s): Rowlands, Sacha Leanne

Abstract: Moral injury may be experienced when a person perpetrates, witnesses or fails to prevent an act that conflicts with their moral values and beliefs. The concept of moral injury has its origins in the context of military personnel encountering ethically challenging decisions during armed conflict. The term has been applied to healthcare and moral injury is increasingly acknowledged to be a challenge for healthcare professionals. Nurses across all specialties and settings are frequently required to make or witness ethically challenging decisions about patient care. The coronavirus disease 2019 (COVID-19) pandemic has increased nurses' risk of sustaining moral injury. This article discusses the manifestations of moral injury and its associated risk factors, including the effects of the COVID-19 pandemic. It also outlines various strategies that can be used to mitigate and/or prevent moral injury in nurses.

Title: Understanding and addressing challenges for advance care planning in the COVID-19 pandemic: An analysis of the UK CovPall survey data from specialist palliative care services

Citation: Palliative Medicine; Jul 2021; vol. 35 (no. 7); p. 1225

Author(s): Bradshaw, Andy; Dunleavy, Lesley; Walshe, Catherine; Preston, Nancy; Cripps, Rachel L; Hocaoglu Mevhibe; Bajwah Sabrina; Maddocks, Matthew; Oluyase, Adejoke O; Sleeman, Katherine; Higginson, Irene J; Fraser, Lorna; Murtagh Fliss

Background: Specialist palliative care services play an important role in conducting advance care planning during COVID-19. Little is known about the challenges to advance care planning in this context, or the changes services made to adapt.

Aim: Describe the challenges that UK specialist palliative care services experienced regarding advance care planning during COVID-19 and changes made to support timely conversations.

Design: Online survey of UK palliative/hospice services' response to COVID-19. Closed-ended responses are reported descriptively. Open-ended responses were analysed using a thematic Framework approach using the Social Ecological Model to understand challenges.

Respondents: Two hundred and seventy-seven services.

Results: More direct advance care planning was provided by 38% of services, and 59% provided more support to others. Some challenges to advance care planning pre-dated the pandemic, whilst others were specific to/exacerbated by COVID-19. Challenges are demonstrated through six themes: complex decision making in the face of a new infectious disease; maintaining a personalised approach; COVID-19-specific communication difficulties; workload and pressure; sharing information; and national context of fear and uncertainty. Two themes demonstrate changes made to support: adapting local processes and adapting local structures.

Conclusions: Professionals and healthcare providers need to ensure advance care planning is individualised by tailoring it to the values, priorities, and ethnic/cultural/religious context of each person. Policymakers need to consider how high-quality advance care planning can be resourced as a part of standard healthcare ahead of future pandemic

waves. In facilitating this, we provide questions to consider at each level of the Social Ecological Model.

Title: Learning to care for the spirit of dying patients: the impact of spiritual care training in a hospice-setting.

Citation: BMC Palliative Care; Jul 2021; vol. 20 (no. 1); p. 1-12

Author(s): Chahrour ; Hvidt, Niels Christian; Hvidt, Elisabeth Assing; Viftrup, Dorte Toudal

Background: Patients approaching the end of their life do not experience their existential and spiritual needs being sufficiently met by the healthcare professionals responsible for their care. Research suggest that this is partly due to a lack of insight about spiritual care among healthcare professionals. By developing, implementing, and evaluating a research-based educational course on spiritual care targeting hospice staff, we aimed to explore the perceived barriers for providing spiritual care within a hospice setting and to evaluate the post-course impact among staff members.

Methods: Course development and evaluation was based on primary exploratory action research and followed the UK Medical Research Council's framework for complex intervention research. The course was implemented at two Danish hospices and comprised thematic days that included lectures, reflective exercises and improvised participatory theatre. We investigated the course impact using a questionnaire and focus group interviews. The questionnaire data were summarized in bar charts and analysis of the transcribed interviews was performed based on Interpretative Phenomenological Analysis.

Results: 85 staff members participated in the course. Of these, 57 answered the evaluative questionnaire and 15 participated in 5 focus group interviews. The course elements that the participants reported to be the most relevant were improvised theatre unfolding existential themes and reflexive group activities. 98% of participants found the course relevant, answering either "relevant" or "very relevant". 73,1% of participants answered "to a considerable extent" or "to a great extent" when asked to what extent they assessed the content of the course to influence their work in hospice. The focus group data resulted in 3 overall themes regarding perceived barriers for providing spiritual care: 1. Diverse approaches is beneficial for spiritual care, but the lack of a shared and adequate spiritual language is a communicative barrier, 2. Existential conversation is complicated by patients' overlapping physical and existential needs, as well as miscommunication, and 3. Providing spiritual care requires spiritual self-reflection, self-awareness, introspection, and vulnerability.

Conclusions: This study provides insights into the barriers facing spiritual care in a hospice setting. Furthermore, the course evaluations demonstrate the valuable impact of spiritual care training for health care professionals. Further course work development is warranted to enhance the "science" of spiritual care for the dying.

Title: An integrative review to identify how nurses practicing in inpatient specialist palliative care units uphold the values of nursing.

Citation: BMC Palliative Care; Jul 2021; vol. 20 (no. 1); p. 1-16

Author(s): Moran ; Bailey, Maria; Doody, Owen

Background: Caring for individuals and their families with a life-limiting, symptomatic illness and those who are dying has long been an integral role of palliative care nurses. Yet, over

the last two decades, the specialty of palliative care has undergone significant changes in technology and medical treatments which have altered both the disease trajectory and the delivery of palliative care. To date, there is little evidence as to the impact of these medical and nursing advancements on the role of nurses working in palliative care and how in clinical practice these nurses continue to uphold their nursing values and the philosophy of palliative care.

Methods: An integrative review was conducted searching seven academic databases from the time period of January 2010 – December 2019 for studies identifying research relating to the role of the palliative care nurse working in specialist palliative care units and hospices. Research articles identified were screened against the inclusion criteria. Data extraction was completed on all included studies and the Crowe Critical Appraisal Tool was utilized to appraise the methodological quality and thematic analysis was performed guided by Braun and Clarke's framework. The review was conducted and reported in lines with PRISMA guidelines.

Results: The search yielded 22,828 articles of which 7 were included for appraisal and review. Four themes were identified: (1) enhancing patient-centred care (2) being there (3) exposure to suffering and death (4) nursing values seen but not heard. The findings highlight that while palliative care nurses do not articulate their nurse values, their actions and behaviors evident within the literature demonstrate care, compassion, and commitment.

Conclusion: These findings suggest that there is a need for nurses working in specialist palliative care units to articulate, document, and audit how they incorporate the values of nursing into their practice. This is pivotal not only for the future of palliative nursing within hospice and specialist palliative care units but also to the future of palliative care itself. To make visible the values of nursing further practice-based education and research is required.

Title: Caring for Dying Infants: A Systematic Review of Healthcare Providers' Perspectives of Neonatal Palliative Care.

Citation: American Journal of Hospice & Palliative Medicine; Aug 2021; vol. 38 (no. 8); p. 1013-1027

Author(s): Beltran ; Hamel, Marie Nicole

Objectives: The palliative and hospice care movement has expanded significantly in the United States since the 1960s. Neonatal end of life care, in particular, is a developing area of practice requiring healthcare providers to support terminally ill newborns and their families, to minimize suffering at the end of the neonate's life. This paper seeks to systematically summarize healthcare providers' perspectives related to end of life, in order to identify needs and inform future directions.

Methods: Informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines, we systematically reviewed the literature discussing healthcare provider perspectives of neonatal end of life care ranging from year 2009 to 2020. To be included in the review, articles had to explicitly focus on perspectives of healthcare providers toward neonatal end of life care, be published in academic peer-reviewed sources, and focus on care in the United States.

Results: Thirty-three articles were identified meeting all inclusion criteria. The literature covers, broadly, provider personal attitudes, experiences delivering care, practice approaches and barriers, and education and training needs. The experiences of physicians, physician assistants, nurse practitioners, and nurses are highlighted, while less is discussed of other providers involved with this work (e.g., social work, physical therapy).

Conclusion: Future research should focus on developing and testing interventions aimed at training and supporting healthcare providers working with neonates at end of life, as well as addressing barriers to the development and implementation of neonatal palliative teams and guidelines across institutions.

Title: End-of-Life Nutrition Considerations: Attitudes, Beliefs, and Outcomes.

Citation: American Journal of Hospice & Palliative Medicine; Aug 2021; vol. 38 (no. 8); p. 1028-1041

Author(s): Loofs ; Haubrick, Kevin

Objective: To assess the physiological outcomes and interpersonal influences that should be considered when making the decision to provide artificial nutrition and hydration (AN&H) for patients in hospice/palliative programs.

Methods: A systematic review was conducted using items from the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols 2015 checklist. Distinct search strategies were employed to find primary research articles that addressed: General health outcomes of artificial nutrition and hydration interventions and nutrition therapy interventions (n = 16), nutrition-related symptoms in end-of-life care (n = 8), and the attitudes of patients and providers toward artificial nutrition and hydration (n = 21).

Results: The effect of AN&H on health outcomes, quality-of-life measures and nutrition-related symptoms is limited and may vary by patient setting and diagnosis. In the absence of consistent evidence for specific health outcomes, decisions regarding AN&H should be made in context of the desires and beliefs of a patient, their family, and their medical providers. These beliefs may not be consistent with likely outcomes or may be inconsistent between individuals involved in the decision-making process, and individuals of different cultures or geographic regions may approach AN&H decisions from different perspectives. To help navigate the intersection of nutrition-related health outcomes and patient/provider beliefs, palliative care teams may employ a variety of strategies for approaching the decision-making process, and may benefit from specific involvement of a Registered Dietitian to help contribute to or lead these discussions.

Title: Actual and Missed Opportunities for End-of-Life Care Discussions With Oncology Patients: A Qualitative Study.

Citation: JAMA Network Open; Jun 2021; vol. 4 (no. 6)

Author(s): Knutzen ; Sacks, Olivia A.; Brody-Bizar, Olivia C.; Murray, Genevra F.; Jain, Raina H.; Holdcroft, Lindsay A.; Alam, Shama S.; Liu, Matthew A.; Pollak, Kathryn I.; Tulskey, James A.; Barnato, Amber E.

Key points: Question: How do oncologists successfully navigate and miss opportunities for discussions about end of life (EOL), including advance care planning, palliative care, discontinuation of disease-directed treatment, hospice care, and after-death wishes, with outpatients with advanced cancer?

Findings: In this secondary qualitative analysis of 423 outpatient encounters, only 21 encounters (5%) included EOL discussions, whereas a random sample of 93 encounters revealed that 35 encounters (38%) included missed opportunities for EOL discussions. Oncologists missed opportunities for these discussions when they responded inadequately

to patient concerns about disease progression or dying, used optimistic future talk to address patient concerns, or expressed concern over treatment discontinuation.

Meaning: Opportunities for EOL discussions were rarely realized, and missed opportunities for these discussions were common, a trend that seemed to mirror oncologists' treatment style. This qualitative study describes successful navigation and missed opportunities for end-of-life discussions, including advance care planning, palliative care, discontinuation of disease-directed treatment, hospice care, and after-death wishes, between oncologists and outpatients with advanced cancer.

Importance: Early discussion of end-of-life (EOL) care preferences improves clinical outcomes and goal-concordant care. However, most EOL discussions occur approximately 1 month before death, despite most patients desiring information earlier.

Objective: To describe successful navigation and missed opportunities for EOL discussions (eg, advance care planning, palliative care, discontinuation of disease-directed treatment, hospice care, and after-death wishes) between oncologists and outpatients with advanced cancer.

Design, setting, and participants: This study is a secondary qualitative analysis of outpatient visits audio-recorded between November 2010 and September 2014 for the Studying Communication in Oncologist-Patient Encounters randomized clinical trial. The study was conducted at 2 US academic medical centers. Participants included medical, gynecological, and radiation oncologists and patients with stage IV malignant neoplasm, whom oncologists characterized as being ones whom they "...would not be surprised if they were admitted to an intensive care unit or died within one year." Data were analyzed between January 2018 and August 2020.

Exposures: The parent study randomized participants to oncologist- and patient-directed interventions to facilitate discussion of emotions. Encounters were sampled across preintervention and postintervention periods and all 4 treatment conditions.

Main outcomes and measures: Secondary qualitative analysis was done of patient-oncologist dyads with 3 consecutive visits for EOL discussions, and a random sample of 7 to 8 dyads from 4 trial groups was analyzed for missed opportunities.

Results: The full sample included 141 patients (54 women [38.3%]) and 39 oncologists (8 women [19.5%]) (mean [SD] age for both patients and oncologists, 56.3 [10.0] years). Of 423 encounters, only 21 (5%) included EOL discussions. Oncologists reevaluated treatment options in response to patients' concerns, honored patients as experts on their goals, or used anticipatory guidance to frame treatment reevaluation. In the random sample of 31 dyads and 93 encounters, 35 (38%) included at least 1 missed opportunity. Oncologists responded inadequately to patient concerns over disease progression or dying, used optimistic future talk to address patient concerns, or expressed concern over treatment discontinuation. Only 4 of 23 oncologists (17.4%) had both an EOL discussion and a missed opportunity.

Conclusions and relevance: Opportunities for EOL discussions were rarely realized, whereas missed opportunities were more common, a trend that mirrored oncologists' treatment style. There remains a need to address oncologists' sensitivity to EOL discussions, to avoid unnecessary EOL treatment.

Title: Socio-Economic Deprivation and Symptom Burden in UK Hospice Patients with Advanced Cancer—Findings from a Longitudinal Study.

Citation: Cancers; Jun 2021; vol. 13 (no. 11); p. 2537-2537

Author(s): Lloyd-Williams ; Shiels, Christopher; Dowrick, Christopher; Kissane, David

Simple summary: We know that socio-economic factors influence delay in presentation and diagnosis of cancer and that patients living in areas of greater socio-economic deprivation are less likely to be referred to palliative care services including hospice. However, very little is known regarding the impact of socio-economic deprivation on symptom burden in advanced cancer patients. Our study found that patients experiencing greater socio-economic deprivation were more likely to report depression and pain and greater global symptom burden than patients from less socio-economically deprived areas. We also found that reporting a lack of information at time of diagnosis was significantly associated with socio-economic deprivation. Although more than one-third of patients recruited into this study were diagnosed with cancer within the preceding 12 months, this was not associated with socio-economic factors and socio-economic factors did not appear to influence survival in our study. The impact of socio-economic factors on symptom burden and information needs should be acknowledged within palliative care settings. Socio-economic deprivation is known to impact on cancer diagnosis, treatment and access to services, but little is known of the impact of socio-economic deprivation on symptom burden in patients with advanced cancer. Patients with advanced cancer attending hospice day services were recruited into a 24 week longitudinal study. An area-based index of social deprivation was collected along with depression and symptom burden at baseline, 8, 16 and 24 weeks. Of the 595 patients included, with an age range of 33–89 years and a mean age of 68 years, 67% were female, and 37% were diagnosed with cancer in the last 12 months. Twenty nine percent lived in one of the most deprived 20% of neighbourhoods. Patients living in the most socio-economically deprived areas were significantly likely to report receiving insufficient information regarding their cancer at diagnosis ($p = 0.007$), greater pain ($p = 0.02$), moderate to severe depression ($p = 0.04$) and higher global symptom burden ($p = 0.04$). This study is the first to report that patients with advanced cancer attending hospice services, living in the most deprived neighbourhoods experience significantly greater symptom burden, notably depression and pain. We recommend using patient outcome measures in order to provide targeted support and thereby reduce the increased symptom burden that socio-economically disadvantaged patients experience at the end of life.

Title: Survival in hospice patients with dementia: the effect of home hospice and nurse visits.

Citation: Journal of the American Geriatrics Society; Jun 2021; vol. 69 (no. 6); p. 1529-1538

Author(s): Luth ; Russell, David J.; Xu, Jiehui Cici; Lauder, Bonnie; Ryvicker, Miriam B.; Dignam, Ritchell R.; Baughn, Rosemary; Bowles, Kathryn H.; Prigerson, Holly G.

Background: Hospice patients with dementia are at increased risk for live discharge and long lengths of stay (>180 days), causing patient and family caregiver stress and burden. The location and timing of clinician visits are important factors influencing whether someone dies as expected, in hospice, or experiences a live discharge or long length of stay.

Objective: Examine how home hospice and nurse visit frequency relate to dying in hospice within the Medicare-intended 6-month period.

Design: Retrospective cohort study. Setting: Non-profit hospice agency. Participants: Three thousand eight hundred and thirty seven patients with dementia who received hospice services from 2013 to 2017.

Methods: Multivariable survival analyses examined the effects of receiving home hospice (vs. nursing home) and timing of nurse visits on death within 6 months of hospice enrollment, compared to live discharge or long length of stay. Models adjust for relevant demographic and clinical factors.

Results: Thirty-nine percent (39%) of patients experienced live discharge or long length of stay. Home hospice patients were more likely to experience live discharge or long length of stays (HR for death: 0.77, 95%CI: 0.69–0.86, $p < 0.001$). Frequency of nurse visits was inversely associated with live discharge and long lengths of stay (HR for death: 2.87, 95%CI: 2.47–3.33, $p < 0.001$).

Conclusion: Nearly 40% of patients with dementia in our study experienced live discharge or a long length of stay. Additional research is needed to understand why home hospice may result in live discharge or a long length of stay for patients with dementia. Nurse visits were associated with death, suggesting their responsiveness to deteriorating patient health. Hospice guidelines may need to permit longer stays so community-dwelling patients with dementia, a growing segment of hospice patients, can remain continuously enrolled in hospice and avoid burden and costs associated with live discharge. See related editorial by Hunt et al. in this issue.

Title: Disparities in access to palliative care facilities for patients with and without cancer: A retrospective review.

Citation: Palliative Medicine; Jun 2021; vol. 35 (no. 6); p. 1191-1201

Author(s): Lau ; Meaney, Christopher; Morgan, Matthew; Cook, Rose; Zimmermann, Camilla; Wentlandt, Kirsten

Background: To date, little is known about the characteristics of patients who are admitted to a palliative care bed for end-of-life care. Previous data suggest that there are disparities in access to palliative care services based on age, sex, diagnosis, and socioeconomic status, but it is unclear whether these differences impact access to a palliative care bed.

Aim: To better identify patient factors associated with the likelihood/rate of admission to a palliative care bed.

Design: A retrospective chart review of all initiated palliative care bed applications through an electronic referral program was conducted over a 24-month period. Setting/participants: Patients who apply and are admitted to a palliative care bed in a Canadian metropolitan city.

Results: A total of 2743 patients made a total of 5202 bed applications to 9 hospice/palliative care units in 2015–2016. Referred and admitted cancer patients were younger, male, and more functional than compared to non-cancer patients (all $p < 0.001$). Referred and admitted patients without cancer were more advanced in their illness trajectory, with an anticipated prognosis <1 month and Palliative Performance Status of 10%–20% (all $p < 0.001$). On multivariate analysis, a diagnosis of cancer and a prognosis of <3 months were associated with increased likelihood and/or rate of admission to a bed, whereas the presence of care needs, a longer prognosis and a PPS of 30%–40% were associated with decreased rates and/or likelihood of admission.

Conclusion: Patients without cancer have reduced access to palliative care facilities at end-of-life compared to patients with cancer; at the time of their application and admission, they are "sicker" with very low performance status and poorer prognoses. Further studies investigating disease-specific clinical variables and support requirements may provide more insights into these observed disparities.

Title: Health-Care Professionals Perceived Barriers to Effective Cancer Pain Management in the Home Hospice Setting: Is Dying at Home Really Best?

Citation: Omega: Journal of Death & Dying; Aug 2021; vol. 83 (no. 3); p. 587-600

Author(s): Johnson ; Bell, Cynthia J.; Ridner, Sheila; Murphy, Barbara

Abstract: Hospice health-care professionals (HCP) evaluate and manage cancer pain in patient homes. This study explores HCP's perceptions of barriers that affect pain management for home hospice cancer patients. A convenience sample of 20 experienced hospice HCP were recruited from a regional hospice agency. Data were collected through two focus groups using semistructured interviews and analyzed using a constant comparative approach to generate themes. An unexpected finding revealed patient's religious and cultural beliefs about suffering and family caregiver's beliefs that patients deserve to suffer due to past actions are barriers to pain management in home hospice. Hospice HCP can identify patients at risk for suffering at the end of life. Interventions targeting spiritual suffering and needs are needed. Home hospice HCP have an ethical obligation to address undue suffering through family's withholding of necessary pain medications and should consider alternative placement when home is not suitable for a peaceful death.

Title: Reducing Hospital Visit Rates in Hospice Patients Using Telemedicine.

Citation: Computers, informatics, nursing : CIN; Jun 2021

Author(s): Teter, Clara Michelle; Whitted, Kelli; Vardaman, Shellye A

Abstract: The purpose of this project was to examine the impact of accessibility to a provider via telemedicine on emergency department visit rates in adults, 35 years and older, on home hospice and palliative care. Utilizing a quasi-experimental design, 44 adults 35 years and older were educated on Doxy.me telemedicine usage as an intervention. Measures included gender, diagnosis, age, the reason for contact, and outcome (intervention group only); the number of emergency department visits, the number of 911 calls, and the number of discharges/transfers (control and intervention) in the 8 weeks after the evidence-based telemedicine intervention. Statistical analyses were performed to examine the number of emergency department visits and 911 calls preintervention and postintervention among all participants. A total of eight teletechnology calls were documented from a patient or patient caregiver. Among the intervention group, the number of emergency department visits and the number of 911 calls decreased from 12 (54.5%) to one (4.5%) postintervention. Paired-samples t tests show there were statistically significant differences in the number of emergency department visits and 911 calls between the two points in time. In conclusion, a telemedicine hospice care application may benefit a palliative and hospice organization by enhancing patient clinical outcomes and decreasing emergency department visit rates.

Title: "We are taking every precaution to do our part...": a comparative analysis of nursing, palliative and hospice care facilities' websites during the COVID-19 pandemic.

Citation: BMC health services research; Jun 2021; vol. 21 (no. 1); p. 579

Author(s): Ölcer, Sabahat; Idris, Mohamed; Yilmaz-Aslan, Yüce; Brzoska, Patrick

Background: The COVID-19 pandemic has a significant impact on health care processes. Precautions such as restrictions imposed on visitors and social distancing have led to multiple challenges, particularly in terms of communication. Using the case of nursing, palliative and hospice care facilities in Germany and drawing on agenda-setting theory, the present study aims to shed light on how health care facilities use their websites to inform (potential) health care users about changes in regulations, new protective measures implemented and about recommendations in the context of the COVID-19 pandemic.

Methods: The websites of nursing, palliative and hospice care facilities in Germany were examined using qualitative document analysis and qualitative content analysis. A total of 138 websites was analysed in the study. The data gathered includes all information about COVID-19 on these websites published from the beginning of March until August 15, 2020.

Results: Facilities show similarities in adhering to the measures taken by the authorities to restrict the spread of SARS-CoV-2 and to protect vulnerable patients and employees. All facilities urged the public to avoid paying visits to patients in facilities unless there was an emergency; however, visiting procedures in practice varied by types of facilities. For optimal communication, telephone and especially video calls were the options preferred by health care providers and health care users. Facilities made great efforts to prevent emotional stress and to strengthen resilience among all stakeholders. Transparency was adopted by many facilities in order to build the public's trust.

Conclusions: The agenda of health care facilities has been seriously affected by the COVID-19 pandemic. The study sheds light on the strategies developed by facilities, their efforts to increase emotional resilience among health care staff and health care users, the ethical guidelines they have adopted regarding privacy policies as well as how these themes are communicated via the facilities' websites. The results can inform other health care facilities about how websites can be used as essential communication tools in times of public health crises.

Title: Perceptions That Influence Acupuncture Use in Hospice Settings: Results of a State-Wide Survey Study.

Citation: Journal of alternative and complementary medicine (New York, N.Y.); Jun 2021

Author(s): Luh, Colin; Eckstrom, Elizabeth

Background: Acupuncture is an effective and low-risk therapy for a wide spectrum of medical conditions. In the hospice setting, where comfort is the top priority, acupuncture could play a vital role in reducing symptom burden at the end of life.

Objective: This state-wide survey study explored perceived barriers to acupuncture use in the hospice setting from acupuncturist and hospice staff perspectives. Specific barriers addressed included insurance coverage/funding for acupuncture, lack of knowledge of acupuncture as a therapeutic modality, and perceived insufficient evidence base for acupuncture.

Materials and methods: Acupuncturists and hospice staff in Oregon were recruited by e-mail and/or telephone to complete their survey.

Results: Among acupuncturists, a response rate of 50% was obtained. The response rate of hospice staff could not be obtained. There were a total of 270 providers and hospice staff (102 acupuncturists, 16 hospice doctors, 14 hospice directors, 93 hospice nurses, 30 hospice social workers, and 15 hospice chaplains). The majority of acupuncturists (76% and 89%, respectively) and hospice staff (59% and 82%, respectively) strongly agreed or somewhat agreed that insurance coverage/funding for acupuncture and lack of knowledge of acupuncture as a therapeutic modality are important barriers. With respect to the perceived

evidence base for acupuncture, the majority of acupuncturists (91%) and hospice staff (69%) strongly agreed or somewhat agreed that acupuncture can help provide a higher quality of life for hospice patients, although knowledge of specific conditions amenable to acupuncture among acupuncturists and hospice staff varied.

Conclusions: From the acupuncturist and hospice staff perspectives, insurance coverage/funding for acupuncture, lack of knowledge of acupuncture as a therapeutic modality, and perceived insufficient evidence base for acupuncture are primary barriers to the use of acupuncture in hospice care. Increased awareness/education about acupuncture in the hospice setting, as well as improved funding structures, is critical.

Title: Evidence on the economic value of end-of-life and palliative care interventions: a narrative review of reviews.

Citation: BMC palliative care; Jun 2021; vol. 20 (no. 1); p. 89

Author(s): Luta, Xhyljeta; Ottino, Baptiste; Hall, Peter; Bowden, Joanna; Wee, Bee; Droney, Joanne; Riley, Julia; Marti, Joachim

Background: As the demand for palliative care increases, more information is needed on how efficient different types of palliative care models are for providing care to dying patients and their caregivers. Evidence on the economic value of treatments and interventions is key to informing resource allocation and ultimately improving the quality and efficiency of healthcare delivery. We assessed the available evidence on the economic value of palliative and end-of-life care interventions across various settings.

Methods: Reviews published between 2000 and 2019 were included. We included reviews that focused on cost-effectiveness, intervention costs and/or healthcare resource use. Two reviewers extracted data independently and in duplicate from the included studies. Data on the key characteristics of the studies were extracted, including the aim of the study, design, population, type of intervention and comparator, (cost-) effectiveness resource use, main findings and conclusions.

Results: A total of 43 reviews were included in the analysis. Overall, most evidence on cost-effectiveness relates to home-based interventions and suggests that they offer substantial savings to the health system, including a decrease in total healthcare costs, resource use and improvement in patient and caregivers' outcomes. The evidence of interventions delivered across other settings was generally inconsistent.

Conclusions: Some palliative care models may contribute to dual improvement in quality of care via lower rates of aggressive medicalization in the last phase of life accompanied by a reduction in costs. Hospital-based palliative care interventions may improve patient outcomes, healthcare utilization and costs. There is a need for greater consistency in reporting outcome measures, the informal costs of caring, and costs associated with hospice.

Title: Earlier initiation of palliative care in the disease trajectory of people living with dementia: a scoping review protocol.

Citation: BMJ open; Jun 2021; vol. 11 (no. 6); p. e044502

Author(s): Gilissen, Joni; Hunt, Lauren; Van den Block, Lieve; van der Steen, Jenny; Tahir, Peggy; Ritchie, Christine

Introduction: While the need for palliative care for people living with dementia has widely been recognised, they continue to be a disadvantaged group when it comes to timely initiation, and controversies remain regarding appropriate timing, or what elements constitute high quality palliative care early in the disease trajectory. To date, no literature review has summarised this debate or offered insights. The aim of this scoping review is to provide a general overview of research regarding palliative care in mild or moderate dementia, to identify existing controversies, and to examine what are key components of palliative care in dementia, specifically when initiated earlier in the disease trajectory.

Methods and analysis: Consistent with recent guidelines and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews, we carried out a search for academic literature in PubMed, CINAHL, EMBASE, Cochrane Library, PsycINFO, Web of Science; on 5 November 2019 and an updated search on 2 February 2021. We will include studies with different study designs published in English over the last decade that focused on palliative care in early stages of dementia. We will include models targeting at least one outcome domain of palliative care (physical, psychological, social or spiritual) and advance care planning, and will exclude hospice models with limited prognosis similar to the requirements in the USA. We will report study characteristics and quality. We aim to apply narrative synthesis techniques to develop a theoretical model of how, for whom and why palliative care can be relevant in early stages of dementia, and what are facilitators and barriers. We anticipate to also describe if and how the concept of (early) palliative care in dementia changed across time and studies.

Ethics and dissemination: No ethical review required. Results will identify research gaps and lay out basic principles for conceptualising palliative care in early stages of dementia.

Title: Virtual reality in hospice: improved patient well-being.

Citation: BMJ supportive & palliative care; Jul 2021

Author(s): Lloyd, Anna; Haraldsdottir, Erna

Background: Virtual reality (VR) technology as a therapeutic intervention has been gaining attention in healthcare settings in recent years. Studies suggest that using the technology can help alleviate symptoms such as pain and anxiety and induce positive emotions for people in hospital. Managing symptoms and promoting emotional and psychological well-being are core palliative care goals of relieving suffering of people with life-limiting illness. Accordingly, VR may be highly beneficial for use in hospice care yet remains underdeveloped in such settings. This qualitative study aimed to trial the technology and consider what benefits may emerge for hospice in patients.

Methods: A one-off VR session was offered to patients at a hospice in Scotland. Sessions were observed by a researcher and followed by qualitative semi-structured interviews to discuss the experience with those who took part. Interviews were audio recorded, transcribed and thematically analysed.

Results: Nineteen hospice patients successfully tried an immersive VR experience. VR sessions were acceptable for people within the hospice environment. The majority of participants enjoyed the experience. Many expressed joy and delight at the process. VR holds possibilities for relieving symptoms such as pain and anxiety frequently experienced by people in hospices. Furthermore, the technology offers the capacity to reconnect with a previous sense of self and to allow respite through the capacity to transcend current reality and connect with another meaningful reality. This exploratory study offers a starting point for larger studies to investigate the utility of VR for hospice patients.

Title: Hospital Readmissions in Hospice Patients: Evaluation of Medication-Related Causes for Readmission.

Citation: The American journal of hospice & palliative care; Jul 2021; vol. 38 (no. 7); p. 745-749

Author(s): DeAngelis, Joanna; Lowry, Maria Felton

Context: Hospital readmissions, frequent medication changes, and polypharmacy are common issues for hospice patients. It is important to consider if close monitoring of medications by pharmacists could help these patients avoid hospital readmissions.

Objective: The objectives of this study were to determine the incidence and types of medication-related problems that contributed to hospital readmissions from hospice settings.

Methods: A retrospective chart review was conducted from October 1, 2018 to January 31, 2020. Patients admitted from hospice settings (i.e. Home, ALF, LTCF) and who were seen by the palliative care teams at 9 Maryland and Washington DC MedStar hospitals were included. Demographic information was collected: age, gender, race, primary hospice diagnosis, prognosis determined by provider prior to hospice disposition, reason for readmission, and medication list at readmission. The primary outcomes were the incidence and types of medication-related problems. Secondary outcomes included patient characteristics associated with readmission, and classes/number of medications changed before readmission. Descriptive statistics were used to analyze data.

Results: Seventy-five hospice patients were readmitted and seen by palliative care during the study period. Forty-three patients (57%) were found to have medication-related problems at readmission. The most common problem identified was needing additional drug therapy. Dose too low, dose too high, incorrect drugs, adverse drug reactions, and non-adherence were also identified. Additional reasons for readmission were: unanticipated new medical issue (n = 46, 61%) and uncontrolled symptoms (n = 34, 34%).

Conclusions: These findings suggest that deprescribing practices possibly contribute to readmissions from hospice settings.

Title: Incorporating Early Palliative Medicine Consultation Into Daily Morning Huddle in the ICU.

Citation: Critical care explorations; Jul 2021; vol. 3 (no. 7); p. e0459

Author(s): Babar, Arslan; Eilenfeld, Katherine; Alqaisi, Sura; MohamedElfadil, Mahmoud; Al-Jaghbeer, Mohammed J

Objectives: Early palliative medicine consult in the ICU can significantly improve outcomes in high-risk patients. We describe a pilot study of including a recommendation for palliative medicine consult in the ICU morning huddle.

Design: A prospective, observational, quality improvement study.

Patients and setting: Adult patients (age above 18 yr) admitted with cardiac arrest, stage IV cancer, admission from a long-term acute care facility, and circulatory shock on mechanical ventilation to the medical ICU.

Interventions: We aim to assess the effect of an early palliative medicine consultation in selected high-risk patients on change in code status, referral to hospice, tracheostomy, and or percutaneous gastrostomy tube placement.

Measurements and main results: There were 83 patients who triggered an early palliative medicine consult. Palliative medicine consultation occurred in 44 patients (53%); 23 patients (28%) had a palliative medicine consult within the first 48 hours, 21 (25%) had a palliative medicine consult afterwards. There was a significantly higher number of patients who de-escalated their code status in the palliative medicine consult group compared with the no palliative medicine consult group (63.6% vs 7.7%); however, the number was higher in the late palliative medicine consult group (71.4% vs 56.5%). There were more patients referred to hospice in the palliative medicine consult group. No difference in length of stay was observed.

Conclusions: Early palliative medicine consultation in the daily ICU morning huddle is achievable, can produce a palliative medicine consultation in most cases, and results in a significant change in code status toward less aggressive measures.

Title: Social acceptance of death and its implication for end-of-life care

Citation: Journal of Advanced Nursing; Jul 2021; vol. 77 (no. 7); p. 3132

Author(s): María Dolores Ruíz-Fernández; Isabel María Fernández-Medina; José Granero-Molina; José Manuel Hernández-Padilla; Matías Correa-Casado; Cayetano Fernández-Sola

Aims: To understand how the social patterns about death influence end-of-life care from the perspective of healthcare professionals.

Design: A qualitative study according to the theory of Glaser and Strauss.

Methods: A purposeful sample of 47 participants with different roles (nurses, physicians and clinical psychologists) were involved in four focus groups and 17 interviews in 2017–2019. Responses were audio-recorded, transcribed verbatim and analysed using computer-assisted qualitative data.

Results: A core category ‘the theory of social patterns about death’ emerged, which is explained by three categories: the culture of concealment and stubbornness towards death, the effort and internal work to make death a part of existence, and the influence of the social patterns of coping with death on end-of life care and healthcare professionals. Our results suggest that social coping with death is affected by a network of concealment and obstinacy towards death.

Conclusion: Recognizing death as part of life and thinking about death itself are social coping strategies. Although healthcare professionals occupy a privileged place in this process, the culture of concealment of death influences end-of-life care.

Impact: The social process that leads to the loneliness of the dying in our days has been theorized. However, social acceptance of death also influences healthcare professionals’ attitudes towards death. Thus, healthcare professionals’ own attitudes may affect the end-of-life care given to dying individuals and their families. The social patterns of death may contribute to the healthcare professionals’ negative attitudes towards death. The concept of dignified death has been linked to the notion of humanization of healthcare. Death should be approached from a more naturalistic perspective by healthcare professionals, healthcare and academic institutions.

Title: Health and social care professionals’ experiences of providing end of life care during the COVID-19 pandemic: A qualitative study

Citation: Palliative Medicine; Jul 2021; vol. 35 (no. 7); p. 1249

Author(s): Hanna, Jeffrey R; Rapa, Elizabeth; Dalton, Louise J; Hughes, Rosemary; Quarmby, Louise M; McGlinchey Tamsin; Donnellan, Warren J; Bennett, Kate M; Mayland, Catriona R; Mason, Stephen R

Background: Health and social care professionals' ability to address the needs of patients and their relatives at end of life is likely to have been impacted by the COVID-19 pandemic.

Aim: To explore health and social care professionals' experiences of providing end of life care during the COVID-19 pandemic to help inform current/future clinical practice and policy.

Design: A qualitative interview study. Data were analysed using thematic analysis.

Setting/participants: Sixteen health and social care professionals working across a range of clinical settings in supporting dying patients during the first wave (March–June 2020) of the COVID-19 pandemic in the United Kingdom.

Results: Participants reported emotional and practical challenges to providing end of life care during the pandemic, including increases in patient numbers, reduced staffing levels and relying on virtual platforms for sensitive, emotive conversations with relatives. Participants were central to promoting connections between patients and their families at end of life and creating opportunities for a final contact before the death. However, the provision of support varied as a consequence of the pressures of the pandemic. Results are discussed under two themes: (1) challenges and facilitators to providing end of life care, and (2) support needs of relatives when a family member was dying during the COVID-19 pandemic.

Conclusion: There is a need for flexible visiting arrangements at end of life during a pandemic. A systems-level approach is necessary to promote the wellbeing of health and social care professionals providing end of life care during and after a pandemic.

Title: Exploring the cost-effectiveness of advance care planning (by taking a family carer perspective): Findings of an economic modelling study

Citation: Health & Social Care in the Community; Jul 2021; vol. 29 (no. 4); p. 967

Author(s): Bauer, Annette; Dixon, Josie; Knapp, Martin; Wittenberg, Raphael

Abstract: Advance care planning is considered an important part of high-quality end-of-life care. Its cost-effectiveness is currently unknown. In this study, we explore the cost-effectiveness of a strategy, in which advance care planning is offered systematically to older people at the end-of-life compared with standard care. We conducted decision-analytic modelling. The perspective was health and social care and the time horizon was 1 year. Outcomes included were quality-adjusted life years as they referred to the surviving carers. Data sources included published studies, national statistics and expert views. Average total cost in the advance care planning versus standard care group was £3,739 versus £3,069. The quality-adjusted life year gain to carers was 0.03 for the intervention in comparison with the standard care group. Based on carer's health-related quality-of-life, the average cost per quality-adjusted life year was £18,965. The probability that the intervention was cost-effective was 55% (70%) at a cost per quality-adjusted life year threshold of £20,000 (£30,000). Conducting cost-effectiveness analysis for advance care planning is challenging due to uncertainties in practice and research, such as a lack of agreement on how advance care planning should be provided and by whom (which influences its costs), and about relevant beneficiary groups (which influences its outcomes). However, even when assuming relatively high costs for the delivery of advance care planning and only one beneficiary group, namely, family carers, our analysis showed that advance care planning was probably cost-effective.

Title: End-of-Life Nutrition Considerations: Attitudes, Beliefs, and Outcomes.

Citation: American Journal of Hospice & Palliative Medicine; Aug 2021; vol. 38 (no. 8); p. 1028-1041

Author(s): Loofs ; Haubrick, Kevin

Objective: To assess the physiological outcomes and interpersonal influences that should be considered when making the decision to provide artificial nutrition and hydration (AN&H) for patients in hospice/palliative programs.

Methods: A systematic review was conducted using items from the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols 2015 checklist. Distinct search strategies were employed to find primary research articles that addressed: General health outcomes of artificial nutrition and hydration interventions and nutrition therapy interventions (n = 16), nutrition-related symptoms in end-of-life care (n = 8), and the attitudes of patients and providers toward artificial nutrition and hydration (n = 21).

Results: The effect of AN&H on health outcomes, quality-of-life measures and nutrition-related symptoms is limited and may vary by patient setting and diagnosis. In the absence of consistent evidence for specific health outcomes, decisions regarding AN&H should be made in context of the desires and beliefs of a patient, their family, and their medical providers. These beliefs may not be consistent with likely outcomes or may be inconsistent between individuals involved in the decision-making process, and individuals of different cultures or geographic regions may approach AN&H decisions from different perspectives. To help navigate the intersection of nutrition-related health outcomes and patient/provider beliefs, palliative care teams may employ a variety of strategies for approaching the decision-making process, and may benefit from specific involvement of a Registered Dietitian to help contribute to or lead these discussions.

Title: The known unknowns of assisted hydration at the end of life.

Citation: British Journal of Community Nursing; Jun 2021; vol. 26 (no. 6); p. 284-285

Author(s): Kingdon ; Spathis, Anna; Bowers, Ben; Barclay, Stephen

Abstract: Much is unknown about assisted hydration at the end of life: why rates of usage vary so highly between institutions, cultures and countries, what beneficial or burdensome effects this treatment has, whether there is a place for subcutaneous hydration in the home setting, and how best to communicate about this difficult topic with dying people and their families. In light of a recently published systematic review concerning the impact of assisted hydration at the end of life, this article explores these questions and related issues, concluding that individualisation and shared decision-making are essential aspects of high-quality end-of-life care.

Title: End-of-life issues in the paediatric intensive care unit.

Citation: Paediatrics & Child Health; Jun 2021; vol. 31 (no. 6); p. 245-249

Author(s): Medani ; Brierley, Joe

Abstract: Recent changes in paediatrics with the growing provision of life-sustaining interventions in both complex and rare diseases have increased the prevalence of chronic

and life-limiting conditions in children. This has, in turn, led to changes in the population of children cared for and, consequently, the modes of death in paediatric intensive care units. In many countries, children with chronic conditions now constitute a large proportion of both admissions to paediatric intensive care units and the deaths occurring there. Managing end-of-life decisions and care is an integral part of practice and constitutes an imperative skill for all professionals working in paediatric intensive care. The process of end-of-life care involves many uncertainties and ethical, legal, religious, cultural and social considerations. A child's death will always be a tragic and challenging experience, but the way it is managed can influence the impact it has on everyone involved. This article provides a review of the issues surrounding the end-of-life process for patients in paediatric intensive care units and explores the challenges and considerations involved in decision-making to withhold or withdraw life-sustaining therapy. We discuss the practicalities of managing and optimising end-of-life care within and beyond the paediatric intensive care unit and the different aspects that healthcare teams need to address before and after a child's death.

Title: 'Traversing difficult terrain'. Advance care planning in residential aged care through multidisciplinary case conferences: A qualitative interview study exploring the experiences of families, staff and health professionals.

Citation: Palliative Medicine; Jun 2021; vol. 35 (no. 6); p. 1148-1157

Author(s): Rainsford ; Hall Dykgraaf, Sally; Kasim, Rosny; Phillips, Christine; Glasgow, Nicholas

Background: Advance care planning improves the quality of end-of-life care for older persons in residential aged care; however, its uptake is low. Case conferencing facilitates advance care planning.

Aim: To explore the experience of participating in advance care planning discussions facilitated through multidisciplinary case conferences from the perspectives of families, staff and health professionals.

Design: A qualitative study (February–July 2019) using semi-structured interviews.

Setting: Two residential aged care facilities in one Australian rural town. Participants: Fifteen informants [family (n = 4), staff (n = 5), health professionals (n = 6)] who had participated in advance care planning discussions facilitated through multidisciplinary case conferences.

Results: Advance care planning was like navigating an emotional landscape while facing the looming loss of a loved one. This emotional burden was exacerbated for substitute decision-makers, but made easier if the resident had capacity to be involved or had previously made their wishes clearly known. The 'conversation' was not a simple task, and required preparation time. Multidisciplinary case conferences facilitated informed decision-making and shared responsibility. Opportunity to consider all care options provided families with clarity, control and a sense of comfort. This enabled multiple stakeholders to bond and connect around the resident.

Conclusion: While advance care planning is an important element of high quality care it involves significant emotional labour and burden for families, care staff and health professionals. It is not a simple administrative task to be completed, but a process that requires time and space for reflection and consensus-building to support well-considered decisions. Multidisciplinary case conferences support this process.

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

Citation: Palliative Medicine; Jun 2021; vol. 35 (no. 6); p. 1181-1190

Author(s): Jiao ; Chow, Amy YM; Wang, Juan; Chan, Iris IK

Background: Delivery of community-based end-of-life care for patients and family members has been recognized as an important public health care approach. Despite differences in different healthcare settings and the significance of a person-centered approach, little research has investigated facilitators of community-based end-of-life care from the perspective of service recipients. In particular, there has been limited exploration of strategies to ensure positive outcomes at an operational level.

Aim: To explore factors facilitating positive end-of-life care provision in community-based settings and how these are achieved in practice, from the perspectives of patients and family caregivers.

Design: A qualitative cross-sectional descriptive study was undertaken through semi-structured interviews with patients and family caregivers subjected to thematic analysis. Setting/participants: Ten patients and 16 family caregivers were recruited from an end-of-life community care program provided by four non-governmental organizations in Hong Kong.

Results: Seven core themes were identified: positive emotions about the relationship, positive appraisals of the relationship, care through inquiring about recipients' circumstances, instrumentality of care (i.e. information, coaching on care, practical help, psychological support, multiple activities), comprehensiveness of care (i.e. diversity, post-death care, family-level wellbeing), structure of care (i.e. timely follow-up, well-developed system), and qualities of workers.

Conclusions: 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.

Title: Priorities and opportunities for palliative and end of life care in United Kingdom health policies: a national documentary analysis.

Citation: BMC Palliative Care; Jul 2021; vol. 20 (no. 1); p. 1-10

Author(s): Sleeman ; Timms, Anna; Gillam, Juliet; Anderson, Janet E.; Harding, Richard; Sampson, Elizabeth L.; Evans, Catherine J.

Background: Access to high-quality palliative care is inadequate for most people living and dying with serious illness. Policies aimed at optimising delivery of palliative and end of life care are an important mechanism to improve quality of care for the dying. The extent to which palliative care is included in national health policies is unknown. We aimed to identify priorities and opportunities for palliative and end of life care in national health policies in the UK.

Methods: Documentary analysis consisting of 1) summative content analysis to describe the extent to which palliative and end of life care is referred to and/or prioritised in national health and social care policies, and 2) thematic analysis to explore health policy priorities that are opportunities to widen access to palliative and end of life care for people with serious illness. Relevant national policy documents were identified through web searches of

key government and other organisations, and through expert consultation. Documents included were UK-wide or devolved (i.e. England, Scotland, Northern Ireland, Wales), health and social care government strategies published from 2010 onwards.

Results: Fifteen policy documents were included in the final analysis. Twelve referred to palliative or end of life care, but details about what should improve, or mechanisms to achieve this, were sparse. Policy priorities that are opportunities to widen palliative and end of life care access comprised three inter-related themes: (1) integrated care – conceptualised as reorganisation of services as a way to enable improvement; (2) personalised care – conceptualised as allowing people to shape and manage their own care; and (3) support for unpaid carers – conceptualised as enabling unpaid carers to live a more independent lifestyle and balance caring with their own needs.

Conclusions: Although information on palliative and end of life care in UK health and social care policies was sparse, improving palliative care may provide an evidence-based approach to achieve the stated policy priorities of integrated care, personalised care, and support for unpaid carers. Aligning existing evidence of the benefits of palliative care with the three priorities identified may be an effective mechanism to both strengthen policy and improve care for people who are dying.

Title: Defining end of life in dementia: A systematic review.

Citation: Palliative medicine; Jun 2021 ; p. 2692163211025457

Author(s): Browne, Bria; Kupeli, Nuriye; Moore, Kirsten J; Sampson, Elizabeth L; Davies, Nathan

Background: Dementia is a life-limiting condition that affects 50 million people globally. Existing definitions of end of life do not account for the uncertain trajectory of dementia. People living with dementia may live in the advanced stage for several years, or even die before they reach the advanced stage of dementia.

Aim: To identify how end of life in people with dementia is measured and conceptualised, and to identify the factors that contribute towards identifying end of life in people with dementia.

Design: Systematic review and narrative synthesis.

Data sources: Electronic databases MEDLINE, EMBASE, PsychInfo and CINAHL, were searched in April 2020. Eligible studies included adults with any dementia diagnosis, family carers and healthcare professionals caring for people with dementia and a definition for end of life in dementia.

Results: Thirty-three studies met the inclusion criteria. Various cut-off scores from validated tools, estimated prognoses and descriptive definitions were used to define end of life. Most studies used single measure tools which focused on cognition or function. There was no pattern across care settings in how end of life was defined. Healthcare professionals and family carers had difficulty recognising when people with dementia were approaching the end of life.

Conclusion: End-of-life care and research that focuses only on cognitive and functional decline may fail to recognise the complexities and unmet needs relevant to dementia and end of life. Research and clinical practice should adopt a needs-based approach for people with dementia and not define end of life by stage of disease.

Title: Community end-of-life care during COVID-19: Findings of a UK primary care survey.

Citation: BJGP open; Jun 2021

Author(s): Mitchell, Sarah; Oliver, Phillip; Gardiner, Clare; Chapman, Helen; Khan, Dena; Boyd, Kirsty; Dale, Jeremy; Barclay, Stephen; Mayland, Catriona

Background: Thousands of people in the UK have required end-of-life care in the community during the COVID-19 pandemic. Primary healthcare teams (general practice and community nursing services) have provided the majority of this care, alongside specialist colleagues. There is a need to learn from this experience in order to inform future service delivery and planning.

Aim: To understand the views of general practitioners and community nurses providing end-of-life care during the first wave of the COVID-19 pandemic.

Design & setting: A web-based, UK-wide questionnaire survey circulated via professional general practice and community nursing networks during September and October 2020.

Method: Responses were analysed using descriptive statistics and an inductive thematic analysis.

Results: Valid responses were received from 559 individuals (387 community nurses, 156 General Practitioners (GPs) and 16 unspecified role), from all regions of the UK. The majority reported increased involvement in providing community end-of-life care. Contrasting and potentially conflicting roles emerged between GPs and community nurses. There was increased use of remote consultations, particularly by GPs. Community nurses took greater responsibility in most aspects of end-of-life care practice, particularly face-to-face care, but reported feeling isolated. For some GPs and community nurses, there has been considerable emotional distress.

Conclusion: Primary healthcare services are playing a critical role in meeting increased need for end-of-life care in the community during the COVID-19 pandemic. They have adapted rapidly, but the significant emotional impact, especially for community nurses, needs addressing alongside rebuilding trusting and supportive team dynamics.

Title: Before the 2020 Pandemic: an observational study exploring public knowledge, attitudes, plans, and preferences towards death and end of life care in Wales.

Citation: BMC palliative care; Jul 2021; vol. 20 (no. 1); p. 116

Author(s): Islam, Ishrat; Nelson, Annmarie; Longo, Mirella; Byrne, Anthony

Background: Understanding public attitudes towards death and dying is important to inform public policies around End of Life Care (EoLC). We studied the public attitudes towards death and dying in Wales.

Methods: An online survey was conducted in 2018. Social media and the HealthWiseWales platform were used to recruit participants. Data were analysed using descriptive statistics and thematic analysis.

Results: 2,210 people participated. Loss of independence (84%), manner of death, and leaving their beloved behind were the biggest fears around death and dying. In terms of EoLC, participants sought timely access to care (84%) and being surrounded by loved ones (62%). Being at home was less of a priority (24%). Only 50% were familiar with Advance Care Planning (ACP). A lack of standard procedures as well as of support for the execution

of plans and the ability to revisit those plans hindered uptake. The taboo around death conversations, the lack of opportunities and skills to initiate discussion, and personal fear and discomfort inhibited talking about death and dying. 72% felt that we do not talk enough about death and dying and advocated normalising talking by demystifying death with a positive approach. Health professionals could initiate and support this conversation, but this depended on communication skills and manageable workload pressure. Participants encouraged a public health approach and endorsed the use of: a) social media and other public platforms, b) formal education, c) formal and legal actions, and d) signposting and access to information.

Conclusions: People are ready to talk about death and dying and COVID-19 has increased awareness. A combination of top-down and bottom-up initiatives across levels and settings can increase awareness, knowledge, and service-utilisation-drivers to support health professionals and people towards shared decisions which align with people's end of life wishes and preferences.

Title: Healthcare professionals' experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life: A qualitative interview study.

Citation: Journal of pain and symptom management; Jul 2021

Author(s): Greenfield, Dr Katie; Carter, Bernie; Harrop, Dr Emily; Jassal, Dr Sabtir; Bayliss, Ms Julie; Renton, Dr Kate; Holley, Dr Simone; Howard, Dr Richard F; Johnson, Ms Margaret; Lioffi, Christina

Contexts: Inadequate pain management in community paediatric palliative care is common. Evidence to inform improved pain management in this population is limited.

Objectives: To explore the barriers and facilitators to paediatric community-based pain management for infants, children and young people at end-of-life as perceived by healthcare professionals.

Methods: A qualitative interview study was conducted. Semi-structured interviews were undertaken with 29 healthcare professionals; 12 nurses, five GPs, five consultants and registrar doctors, two pharmacists and five support therapists working in primary, secondary or tertiary care in the United Kingdom and involved in community end-of life care of 0-18-year-olds.

Results: The data corpus was analysed using an inductive thematic analysis and seven themes emerged: parents' abilities, beliefs and wellbeing; working relationships between families and healthcare professionals, and between healthcare teams; healthcare professionals' knowledge, education and experience; health services delivery; nature of pain treatment; and paediatric-specific factors. Across themes, the concepts of partnership working between families and healthcare professionals, and within healthcare teams, and sharing expertise were prevalent.

Conclusion: Partnership working and trust between healthcare professionals and parents, and within healthcare teams, is needed for effective at-home paediatric palliative pain management. Community healthcare professionals require more education from experienced multidisciplinary teams to effectively manage paediatric pain at end-of-life and prevent emergency hospice or hospital admissions, particularly during the COVID-19 pandemic.

Title: Why community specialist practitioner district nurses should promote tissue donation.

Citation: British Journal of Community Nursing; Jun 2021; vol. 26 (no. 6); p. 296-300

Author(s): Alker

Abstract: A high proportion of patients are being supported with end-of-life (EoL) care in the community, many of which are known to district nursing (DN) caseloads. Over time, community specialist practitioner district nursing (CSPDN) teams build therapeutic relationships with patients, and they are adept at providing EoL care. They are also now actively and routinely undertaking verification of death (VoD). Thus, they are in a prime position to promote and facilitate community tissue donation among patients and their families. The Government has recognised a need to promote organ and tissue donation, implementing the Organ Donation (Deemed Consent) Act (2019), whereby every person over the age of 18 years is now considered for organ and tissue donation with the anticipation of more recipients receiving life-changing tissue transplantation. DN teams seem to lack awareness of the change in law and, therefore, are not actively promoting this in practice. Further, there is no available community-focused guidance or training to support DNs to have these difficult and complex conversations enabling exploration of patients' wishes with regard to promote tissue donation. Therefore, guidance and education are needed in order to improve overall referrals, in the hope that they lead to an increase in donation.

Title: Developing local guidelines on deprescribing in end-of-life care.

Citation: Nursing Times; Jun 2021; vol. 117 (no. 6); p. 30-34

Author(s): O'Neill ; Matthews, Sam

Abstract: Deprescribing is the planned and supervised process of dose reduction or stopping medication that may no longer benefit a patient or may cause more harm than good, and may be particularly important in patients near the end of life. The practice is common in specialist palliative care yet it has not been studied to any great extent and there is a lack of formal guidelines. This article summarises a small audit we carried out to evaluate deprescribing practice in patients referred to the specialist palliative care team, before developing a local deprescribing guideline for patients in the last three months of life. Our aim was to improve quality of life by reducing treatment burden and adverse events, and to align care with patient goals, values and priorities.

Title: The benefits and challenges of embedding specialist palliative care teams within homeless hostels to enhance support and learning: Perspectives from palliative care teams and hostel staff.

Citation: Palliative Medicine; Jun 2021; vol. 35 (no. 6); p. 1202-1214

Author(s): Armstrong ; Shulman, Caroline; Hudson, Briony; Brophy, Niamh; Daley, Julian; Hewett, Nigel; Stone, Patrick

Background: People residing in UK homeless hostels experience extremely high rates of multi-morbidity, frailty and age-related conditions at a young age. However, they seldom receive palliative care with the burden of support falling to hostel staff.

Aim: To evaluate a model embedding palliative specialists, trained as 'homelessness champions', into hostels for two half-days a month to provide support to staff and residents and facilitate a multidisciplinary approach to care.

Design: An exploratory qualitative design.

Setting/participants: Four homeless hostels in London, UK, including nine hostel managers/support staff and seven palliative care specialists (five nurses and two social workers).

Results: Benefits to introducing the model included: developing partnership working between hostel staff and palliative care specialists, developing a holistic palliative ethos within the hostels and improving how hostel staff seek support and connect with local external services. Challenges to implementation included limited time and resources, and barriers related to primary care.

Conclusion: This is the first evaluation of embedding palliative care specialists within homeless hostels. Inequity in health and social care access was highlighted with evidence of benefit of this additional support for both hostel staff and residents. Considering COVID-19, future research should explore remote ways of working including providing in-reach support to homelessness services from a range of services and organisations.

Title: Symptom management of COVID-19 positive patients in an acute NHS trust: a specialist palliative care team perspective.

Citation: Clinical Medicine; Mar 2021; vol. 21 ; p. 15-16

Author(s): Renshaw ; Caulkin, Ruth; Cox, Sarah; Dave, Dijay; McAleny, Lisa

Abstract: The article presents a study of symptoms among COVID-19 patients in an acute National Health Service (NHS) trust in England in 2020. Topics discussed include the death of 84% of patients at follow-up, symptoms presented by those who died such as breathlessness, pyrexia and agitation, and the importance of early symptom control among patients with a rapid deterioration and symptomatic dying phase.

Sources Used:

The following databases are searched on a regular basis in the development of this bulletin:

British Nursing Index, Cinahl, Medline along with a number of other sources

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