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End of Life Care

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June 2025

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Diverging paths: How other countries have designed and implemented assisted dying

Nuffield Trust

As the assisted dying Bill returns to the House of Commons next week, this analysis offers evidence from a wide range of contexts to further inform the debate. What can the UK learn from other countries that have legalised assisted dying? This long read explores assisted dying policies across 15 jurisdictions in 9 countries, highlighting practical and operational differences in implementation, and how these systems have evolved.

Read the analysis at https://www.nuffieldtrust.org.uk/news-item/diverging-paths-how-other-countries-have-designed-and-implemented-assisted-dying

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1. **Demoralization Syndrome in End-Of-Life Cancer Patients: A Qualitative Study**

Authors: Bovero, Andrea;Cito, Alessandra Loreta;Botto, Rossana;Pidinchedda, Alexa;Olivetti, Veronica;Tucci, Marcello and Geminiani, Giuliano Carlo

Publication Date: 2025

Journal: The American Journal of Hospice & Palliative Care 42(6), pp. 542–549

Abstract: Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; ObjectivesIn our previous study we analyzed the prevalence of demoralization in a sample of 235 end-of-life cancer patients using the Demoralization Scale (DS). The findings revealed that 50.2% of the participants reported experiencing a moderate level of demoralization. The main sub-dimensions observed from the original DS were Helplessness, Disheartenment, and Sense of Failure, which we have categorized as "Emotional Distress and Inability to Cope". The aim of this study was to qualitatively investigate the subjective experience of this factor among a group of terminal cancer patients.MethodA sample of 30 patients was interviewed using seven open-ended questions, divided into 3 categories: helplessness, disheartenment and sense of failure. Content analysis was performed.ResultsFaith and prayer, social support and preserving autonomy were the principal coping strategies used by the sample and have been classed as sources of hope. Sadness, anger, death anxiety, fear, and sickness were the most commonly expressed emotions. Faith, social support, autonomy, and fighting spirit were identified as the primary coping strategies.ConclusionsThis study allowed a better understanding of the patient's subjective experience of the demoralization sub-dimension. The deepening of the topic can increase personalized clinical interventions, according to the patient's needs.

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2. **Antibiotics at End of Life: Where Are We Now and Where Are We Going? A Narrative Review**

Authors: Crowley, Patrick D.;Whalen, Francis X.;Siegel, Leslie R. and Challener, Douglas W.

Publication Date: 2025

Journal: American Journal of Hospice & Palliative Medicine 42(8), pp. 792–800

Abstract: Background: Antibiotics are frequently prescribed at the end of life, though the benefits and harms are not well understood. Methods: We abstracted relevant findings from articles published in English in the past 25 years to answer questions generated by discussion among the authors and with stakeholders in Palliative Care and Infectious Diseases. Findings: Prescribing practices vary based on individual situation and geographic location. Patients with cancer and those hospitalized receive more antibiotics than those enrolled in outpatient hospice. Urinary tract infections and pulmonary infections are the most common conditions treated with antibiotics at the end of life -most often with penicillin derivatives and vancomycin in the hospital, fluoroquinolones in outpatient, and cephalosporins in both settings. When asked, patients most often prefer limiting antibiotics to symptom management at the end of life. Physicians' over-estimation of patient preference for antibiotics and the increased probability of misdiagnosis increases antibiotic prescription rates. Antibiotics can improve symptoms when used for specific diseases at the cost of drug reactions, resistant organisms, and delayed discharge. Antibiotic use has variable results on survival duration. Antimicrobial stewardship exists in hospital and long-term care facilities, but not outpatient hospice groups. Stewardship interventions could increase proper use of antibiotics, but more information is needed to apply these interventions to hospice groups. Conclusions: Antibiotics at the end of life are impactful and efforts to educate patients and providers will be invaluable in optimizing care.

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3. **Palliative Care Nurse Specialists' Perspectives on Spiritual Care at End of Life-A Scoping Review**

Authors: Dunning, Bronagh;Connolly, Michael and Timmins, Fiona

Publication Date: 2025

Journal: Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association 27(3), pp. 113–125

Abstract: Competing Interests: The authors have no conflicts of interest to disclose.; The purpose of this scoping review was to explore and to summarize the published literature on palliative care nurse specialist's perspectives of spiritual care at end of life. The Preferred Reporting Items for Systematic reviews and Meta-Analyses Extension for Scoping Reviews Checklist was followed. Searches were conducted in 6 online databases (PubMed, MEDLINE, CINAHL, PsycINFO, Cochrane, HSELibrary). Following a rigorous review process, 15 studies met the inclusion criteria. Data were extracted using a template analyzing aims, population, mean age, setting, year of study, methodology, and key findings. The findings were organized into 4 categories: communication, education and experience, religion, and nurse-patient relationship. The research demonstrates that specialist palliative care nurses perceive spiritual care as an important element of holistic care at end of life; however, these nurses also agree that spiritual care is lacking. This deficiency results from a lack of education in spirituality; experience of the nurse; the nurses' own spiritual and religious beliefs and values, fears, and difficulties in communication; and the nurse-patient relationship. The findings demonstrate the necessity to increase the level of spiritual care education in nurse programs, educating nurses on the provision of spiritual care, and how to deal with conflicts in spiritual and religious beliefs. (Copyright © 2025 by The Hospice and Palliative Nurses Association. All rights reserved.)

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4. **Reducing Racial Disparities at End-of-life: Using Narratives to Build Trust and Promote advance Care Planning**

Authors: Ewy, Donna

Publication Date: 2025

Journal: The American Journal of Hospice & Palliative Care 42(6), pp. 532–537

Abstract: Competing Interests: Declaration of conflicting interestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; Black Americans are less likely than White Americans to have advance directives, die while receiving hospice services, or have their end-of life wishes honored. The root causes of disparities include imbalance of resources, lack of trust in health care institutions, lack of adequate education regarding end-of-life options, communication differences of health care providers with black vs white patients, variable access to hospice services in different communities, and poorer pain management for Black patients compared to White patients. Because root causes are numerous, comprehensive solutions are required. When advance care planning is in place, people are more likely to choose care focused on priorities and comfort than on seeking aggressive, sometimes futile, interventions in the last weeks of life. One important component of the solution should include listening to narrative stories of Black people as they encounter life-limiting diagnoses. Gathering the stories about life events and how strength was found through adversities can be a tool for growing trusting relationships and engaging in shared decision-making. Health care professionals should invite Black patients with serious illnesses to explore the sources of their strengths and identify their core values to work toward developing directives for the nature and place of their end-of-life and help to mitigate disparities in high quality end-of-life care.

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5. **"Qualitative study on nursing students' perspective on ethical conflicts at the end of life: "We are not prepared"**

Authors: González-Pérez, Marta;Sánchez-Romero, Sheila;Ruiz-Fernández, María Dolores;Ibañez-Masero, Olivia;Ventura-Miranda, Mar and Ortega-Galán, Ángela María

Publication Date: 2025

Journal: Nurse Education Today 149, pp. 106671

Abstract: Competing Interests: Declaration of competing interest No conflict of interest declared.; Background: Nursing care for people at the end of life is a crucial aspect of health care that involves challenges and responsibilities. In this scenario, ethical conflicts often arise resulting in situations of great suffering and high-level emotional impact, for which nursing students do not feel sufficiently prepared.; Objective: The aim of this study was to find out how nursing students perceive the ethical conflicts present at the end of life and their reflective and deliberative capacity in the face of these conflicts.; Design: Descriptive qualitative study.; Setting and Participants: Between February and March 2023 with nursing students at the University of Huelva in Spain.; Methods: Sixteen in-depth interviews were conducted. The data analysis was carried out using Giorgi's method and Atlas.ti 22 software as a support.; Results: The students reported that they had encountered ethical conflicts in the end-of-life phase during their internship care period. The main causes they mention are: the management of ethical conflicts, the position on euthanasia and conscientious objection, and the influence of values and beliefs about care. They highlight the lack of training in coping and emotion management in end-of-life care.; Conclusion: Nursing students feel unprepared to deal with the suffering and ethical conflicts involved in end-of-life care, as well as the management of their own internal conflicts. There is therefore a need for the implementation of high-fidelity simulation-based training that generates the learning of the necessary competencies in bioethics and defensive palliative care through appropriate competencies. (Copyright © 2025 Elsevier Ltd. All rights reserved.)

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6. **Family Caregiver's Depression, Confidence, Satisfaction, and Burden Regarding End-of-Life Home Care for People With End-Stage Dementia**

Authors: Green, Gizell;Halevi Hochwald, Inbal;Radomyslsky, Zorian and Nissanholtz-Gannot, Rachel

Publication Date: 2025

Journal: Omega 91(2), pp. 1041–1057

Abstract: Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; To detect differences between two care services units: regarding family-caregiver (FC) depression, perceived-burden and confidence in the provision of care to people with end-stage dementia (PWESD); examine predictors such as FC age, depression, confidence in the provision of care to PWESD and satisfaction with the community-home-care service to burden; and explore a mediation model.The participants were 139 FC, caring for PWESD living at home. The questionnaire was composed of FC background characteristics, perceived-burden, satisfaction with the community-home-care services, depression, and confidence in the provision of care to the PWESD. HCUs' FC felt significantly more burdened than HHUs' FC. Furthermore, satisfaction with the community-home-care services mediated the relationship between FC confidence in the provision of care to the PWESD and FC burden. The study results may affect the development of end-of-life care policies and services which meet the needs of PWESD and their FC.

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7. **Longitudinal Analysis of Cancer Family Caregiver Perception of Sleep Difficulty During Home Hospice**

Authors: Hull, William;Donaldson, Gary;Cloyes, Kristin G.;Ellington, Lee;Lee, Kathryn and Mooney, Kathleen

Publication Date: 2025

Journal: The American Journal of Hospice & Palliative Care 42(6), pp. 602–609

Abstract: Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; BackgroundSleep difficulty in caregivers is associated with poor physical and psychological outcomes. The purpose of this study was to describe family caregivers' perception of sleep difficulty through the hospice trajectory after a cancer diagnosis as predicted by age, sex, self-report of anxiety or depression, and cohabitation.MethodsWe conducted a secondary analysis of longitudinal data using multilevel modeling with nested model comparisons. Beginning with an unconditional growth model, predictors were added to nested models to test differential impact.ResultsCaregivers (n = 164) were predominately white (n = 160; 97%) and female (n = 113, 69%). We hypothesized that age, sex, history of anxiety or depression, and cohabitation would predict sleep difficulty. The cohabitation predictor model was a statistically significant model for caregiver perception of sleep difficulty that worsened throughout hospice caregiving (b = .184, INLINEMATH2 = 7.199, P = 0.027) but age, sex, and history of depression or anxiety did not improve model fit.ConclusionOur findings indicate that family caregivers who cohabitate exhibit increased perception of sleep difficulty over the course of hospice. Future studies and interventions for hospice family caregivers' sleep should consider cohabitation between the patient and the caregiver as a significant predictor of sleep difficulty to observe and potentially mediate the negative outcomes associated with caregiver sleep difficulty. Further, determining the underlying reasons for sleep difficulty in cohabitation (e.g., patient symptoms or treatments) should be explored.

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8. **Antibiotic Use at the End of Life: Current Practice and Ways to Optimize**

Authors: Kang, Minji;Wang, Winnie S. and Chang, Zieanna

Publication Date: 2025

Journal: The American Journal of Hospice & Palliative Care 42(6), pp. 610–615

Abstract: Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; Infections are common complications in end of life (EOL). However, clinicians have minimal guidance regarding antibiotic decision-making in EOL care, leading to the overuse of antibiotics. While symptom relief is frequently cited as a major reason for antibiotic use in EOL, antibiotics have not been shown to provide significant improvement in symptoms outside of urinary tract infections. In addition, when prognosis is expected to be in the range of days to weeks, antibiotics have not been shown to provide significant survival benefit. Antibiotics can be beneficial in EOL care in appropriate scenarios, but the current widespread use of antibiotics in EOL requires reevaluation. There needs to be broader efforts to think about antibiotics like other invasive medical procedures in which benefits and risks are weighed, recognizing that not all patients in EOL who receive antibiotics will benefit. In addition, during care planning process, discussing and documenting antibiotic preferences will be beneficial. Non-antibiotic symptom management should be incorporated to plan of care when infection is suspected. Ultimately, the use of antibiotics at EOL should be for the clear benefit for the recipient and should be guided by the type of infection and its clinical course, patients' primary disease and its prognosis, and the preferences of patients or surrogate decision makers.

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9. **Palliative prognostic tools in surgical patients at the end of life: a systematic review**

Authors: Lee, Chuan-Whei;Wong, Aaron B.;Lazarakis, Smaro;Lim, Wen Kwang and Darvall, Jai

Publication Date: 2025

Journal: British Journal of Anaesthesia 134(6), pp. 1648–1660

Abstract: Competing Interests: Declaration of interest The authors disclose there are no conflicts of interest.; Background: Identifying surgical patients at the end of life (EOL) is the first step in integrating palliative and perioperative practices. Palliative prognostic tools (PPTs) are established frameworks from palliative care that assess patients at risk of early death. We conducted a systematic review investigating PPTs in adult surgical populations, their role in surgical decision-making, and their association with perioperative outcomes.; Methods: A prospectively registered systematic review was performed (PROSPERO registration: CRD42023411303). Ovid MEDLINE, Ovid EMBASE, and Cochrane CENTRAL (Wiley) databases were searched for studies investigating PPTs in surgical patients. The primary outcome was the decision to proceed to surgery; secondary outcomes included mortality, quality of life, palliative care consultation, and EOL documentation completion. Abstract screening, full-text review, and study quality appraisal were performed by two authors independently. Results were synthesised narratively owing to study heterogeneity.; Results: Seven studies assessing four different PPTs were included in the review. Studies identified that 12-61% of surgical patients were at the EOL. Patients identified as being at the EOL by a PPT using an illness phase, trajectory approach, or both had an increased in-hospital and 12-month mortality. The impact on decisions to proceed to surgery was uncertain because of conflicting results. Palliative care referral and EOL document completion occurred in <15% of surgical patients at the EOL. No studies described patient-reported outcomes.; Conclusions:

Palliative prognostic tools have significant potential for incorporation into preoperative assessment. Future research should focus on preoperative end of life assessments and patient-reported outcomes such as quality of life, decision satisfaction, and disability-free survival. (Copyright © 2025 British Journal of Anaesthesia. Published by Elsevier Ltd. All rights reserved.)

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10. **Potentially Inappropriate Prescriptions in End-of-Life Cancer Patients in Home-Based Hospice Care**

Authors: Lee, Junyong;Lee, Chung-woo;Kim, Hwa Sun;Kim, Hak Ryeong;Lim, Soo Yun and Kim, Jung Ran

Publication Date: 2025

Journal: Journal of Pain & Symptom Management 70(1), pp. 22–29

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11. **Advance Care Planning Among Adult Patients and Their End-of-Life Care Preferences**

Authors: Liu, Chia-Jen;Yang, Chun-Yi;Hsieh, Ming-Hsuan;Liu, Chih-Kuang;Chen, Ming-Chih;Huang, Sheng-Jean and Yeh, Te-Chun

Publication Date: 2025

Journal: Omega 91(2), pp. 837–850

Abstract: Competing Interests: Declaration of Conflicting InterestThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article; To explore people's intentions to opt for a good death when planning for their end-of-life care, this study examined the type of end-of-life care preferred by patients receiving advance care planning (ACP) consulting services for five specified clinical and disability conditions and possible factors affecting their decision-making. This cross-sectional study analyzed 1303 hospital patients and 1032 nonhospital patients who attended a clinic providing ACP consulting services. This study revealed the following two results. First, patients who were older, were female, did not have an appointed surrogate decision-maker, and were nonhospital patients had a higher intention of not receiving life-sustaining treatments (LST) or artificial nutrition and hydration (ANH) under the five specified clinical and disability conditions. Second, people who were the least willing to receive LST or ANH under the following conditions (in descending order): permanent vegetative state, severe dementia, irreversible coma, other disease conditions recognized by the central competent authority, and end-of-life stage.

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12. **Mental Health Service Integration in Hospice Organizations: A National Survey of Hospice Clinicians and Medical Leadership**

Authors: Lowenthal, Catherine;Ekwebelem, Maureen;Callahan, Mary E.;Pike, Katherine;Weisblatt, Samuel;Silva, Milagros;Novas, Angela L.;Tucci, Amy S.;Reid, M. C. and

Shalev, Daniel

Publication Date: 2025

Journal: American Journal of Hospice & Palliative Medicine 42(7), pp. 665–671

Abstract: Background: Unmet mental health needs are associated with a range of negative consequences for individuals at the end of life. Despite the high prevalence of mental health needs among individuals enrolled in hospice, there is a paucity of data describing mental health service integration in hospices in the United States. Objectives: 1. To identify patterns of mental health service integration in hospice organizations nationally; 2. To characterize gaps in mental health service delivery in hospice settings as perceived by hospice clinicians and medical leadership. Methods: A cross-sectional survey querying hospice clinicians and hospice medical leadership nationally. Results: A total of 279 surveys were included. Clinically significant mental health symptoms were common among hospice patients; the most frequently encountered symptom groups were depression, anxiety, dementia, and delirium. A minority of hospices maintained relationships with psychiatrists (23%, n = 60), psychiatric nurse practitioners (22%, n = 56), or psychologists (19%, n = 49). Only 38% (n = 99) of respondents were satisfied with their patients' access to services and only 45% (n = 118) were satisfied with the quality of these services. Common limitations to providing adequate mental health services included lack of specialist services, short length of stay for patients, and reluctance of patients to engage in these services. Conclusions: Significant mental health symptoms are common among hospice patients, and hospice organizations perceive these needs are not being met. Further research is needed to better understand the current treatment landscape and design interventions to address these needs.

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13. **Caring at the end of life: Bereaved family members' experiences of preparedness, readiness, and anticipation fatigue**

Authors: MacArthur, Nathan D.;Kirby, Emma and Mowll, Jane

Publication Date: 2025

Journal: Social Science & Medicine 380, pp. N.PAG

Abstract: Ensuring patient and family members' preparedness for dying is a key focus for palliative care. This article draws on the retrospective accounts of bereaved adult family members' experiences of anticipation and preparedness following a death in palliative or residential aged care. Participants completed in-depth interviews (n = 36). A constructivist grounded theory approach guided data collection and analysis, through which the complexities of engaging in preparedness whilst navigating questions of how to care well emerged. We propose the concept of anticipation fatigue as a means by which to understand the impacts of holding multiple, sometimes contradictory, positions in the pursuit of 'good' care at end of life. These results deepen our understandings of the impacts of caring-in-anticipation and offer insights for improving support to families receiving palliative care. • Ensuring preparedness for dying and bereavement is a key focus for palliative care. • Preparedness is thought to facilitate 'good dying' and mitigate bereavement risk. • Retrospective accounts reveal the relational complexities of caring-in-anticipation. • Anticipation fatigue draws attention to the pressures of preparedness at end of life. • Diverse, holistic support is needed to sustain wellbeing when caring for the dying.

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14. **Death and Dying in the Emergency Department: A New Model for End-of-Life Care**

Authors: McCallum, Kay;Jackson, Debra;Walthall, Helen and Aveyard, Helen

Publication Date: 2025

Journal: Journal of Advanced Nursing (John Wiley & Sons, Inc.) 81(7), pp. 4000–4009

Abstract: Background: Death and dying remain taboo subjects in society today and therefore people may come to the end of their life without having thought about what death and dying might be like and what it is to have a good death. The purpose of this qualitative study was to understand the experience of death and dying in a hospital emergency department. Culturally, some individuals are unprepared for death, and when death occurs in an emergency setting it can be particularly shocking. Methods: A phenomenological study was undertaken, based on the existential phenomenology of Merleau-Ponty; and framed by the nurse theorist Hildegard Peplau. Bereaved relatives and registered nurses gave in-depth interviews describing their experiences and the interviews were analysed using an adaptation of the work of Thomas and Pollio (2002) and Hycner (1985), consistent with Merleau-Ponty's theories. Results: The study brings new understanding of what it is like to die in an emergency setting through new understanding of what the accompanying relatives/friends of the deceased person experience, aided by new understanding of the experiences of emergency nurses. Conclusions: A nursing model based both on the work of Peplau (Parse et al. 2000) and on the work of the nurse theorists Ruland and Moore (1998) and Zaccara et al. (2017) was devised for use in the emergency department when death occurs. It is hoped that this model will help nurses improve the care given to this group of patients and their loved ones.

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15. **A Qualitative Exploration of Healthcare Workers' Experiences of End of Life Care for People With an Intellectual Disability**

Authors: McCarron, Mary;Burke, Eilish;Callion, Philip Mc and Timmins, Fiona

Publication Date: 2025

Journal: Journal of Advanced Nursing (John Wiley & Sons, Inc.) 81(7), pp. 3972–3986

Abstract: Aim: To explore healthcare workers' experiences of end of life care for people with an intellectual disability. Design: A descriptive qualitative study. Method: Semi-structured interviews were conducted with 28 healthcare workers who cared for older people with an intellectual disability at their end of life. Data were analysed using thematic analysis and reported according to the COREQ guidelines. Results: Three major themes emerged: not joining up the dots, living the life desired in one's last days and dealing with death and beyond. Conclusion: Gaps emerged in the care of the person with intellectual disability. Pain assessment and pain management were particular challenges. End of life care was not always effectively planned, and earlier intervention, including end of life conversations, were needed.

More needs to be done in terms of education for healthcare workers, and especially those in the acute care setting and palliative care services who may be unfamiliar with the needs of this cohort. Implications for the Profession and/or Patient Care: There is little consensus or understanding about the palliative care needs of those with intellectual disability. There are often specific challenges around providing palliative care particularly in relation to healthcare staffs' knowledge and confidence in understanding palliative care needs of this group and indeed communicating and assessing particular needs. Staff require educational preparation and training in palliative care to address the particular needs of this cohort. Impact: This study revealed that there are gaps emerging in the care of the person with intellectual disability at the end of life. Pain assessment and pain management are particular challenges that require urgent attention. Patient or Public Contribution: There was no patient or publication contribution in this specific study, although IDS-TILDA has a client representative and advisory committee that advise on all aspects of project design and management.

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16. **Factors Influencing Discharges to Hospice for Patients With Late-Stage Huntington's Disease**

Authors: Ogilvie, Amy C.;Carnahan, Ryan M.;Mendizabal, Adys;Gilbertson-White, Stephanie;Seaman, Aaron;Chrischilles, Elizabeth and Schultz, Jordan L.

Publication Date: 2025

Journal: American Journal of Hospice & Palliative Medicine 42(7), pp. 644–652

Abstract: Background: Hospice services for patients with Huntington's disease (HD) are likely beneficial in relieving significant burdens and minimizing costly hospitalizations at the end of life, though there has been little study or clinical guidance on hospice enrollment for patients with HD. Objectives: The primary objective of this study was to identify clinical, sociodemographic, and system-level factors associated with discharges to hospice compared to other dispositions for hospitalized patients with late-stage HD. Methods: These analyses used data from the Nationwide Inpatient Sample between the years 2007 and 2011. Weighted logistic regression with a forward selection approach was performed to identify factors associated with discharge to hospice compared to discharge to home, facility, other locations, and death in hospital. Results: These analyses included 6544 hospitalizations of patients with late-stage HD. There was a significant increasing trend in discharges to hospice over the study period ($P < 0.001$). After adjustment, multiple clinical, sociodemographic, and system-level variables were identified as being associated with discharges to hospice. Patients with aspiration pneumonia and non-aspiration pneumonias had lower odds of being discharged to hospice compared to dying in the hospital. When comparing to discharges to facilities and home, weight loss and palliative care consultation were associated with greater odds of discharge to hospice. Conclusions: Our findings serve as a foundation for future studies on these factors, and thus help clinician decision-making on when to start advance care planning or end-of-life care for patients with HD. These results also support studies developing hospice referral criteria specific to patients with HD.

17. **Culturally appropriate and respectful end-of-life care for patients and their families in the intensive care unit: A mixed-method study**

Authors: O'Neill, Kylie;Brooks, Laura;Manias, Elizabeth and Bloomer, Melissa J.

Publication Date: 2025

Journal: Australian Critical Care 38(4), pp. N.PAG

Abstract: Australia is culturally and linguistically diverse. Yet little is known about perceived barriers to the provision of end-of-life care tailored to diverse cultural needs and preferences. The aim of this study was to measure critical care nurses' cultural intelligence, comfort, and capabilities in providing end-of-life care and explore the perceived barriers to providing end-of-life care for culturally diverse patients and their families. An explanatory mixed-method approach was undertaken utilising surveys and interviews. A national survey was distributed in February 2024, collecting data about critical care nurses' capability, comfort, and cultural intelligence when providing end-of-life care. Individual interviews were conducted with nurses between March and April 2024. Quantitative data were analysed using descriptive and inferential statistics, and open-ended survey and interview responses were analysed using inductive content analysis. From the sample of 89 survey responses, the median number of years nurses worked in the intensive care unit was 15 (interquartile range = 7.0–21.5). Respondents came from 14 different countries, 20.2% (n = 18) spoke a second language, and 50.6% (n = 45) were affiliated with a religion. One-third had completed end-of-life care training (34.8%, n = 31), whilst 31.5% (n = 28) had completed training in cultural diversity. Respondents who completed end-of-life care training had significantly higher comfort and capability scores regarding end-of-life care provision (Mdn = 91.0) than those with no training (Mdn = 80.5, U = 1301.0, $p < 0.001$). Interview participants acknowledged some discomfort with diversity, and the importance of prioritising comfort and dignity, and understanding and interpreting cultural preferences. Communication challenges associated with professional interpreter access were also identified. Critical care nurses' comfort and capabilities with end-of-life care and perceptions of the barriers are critical to understand because end-of-life care is about more than clinical care. Supporting nurses to build their understanding and comfort with providing care that aligns with cultural and religious needs and preferences, and optimising access to professional interpreters, is imperative.

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18. **Exploring older people's end-of-life care preferences over time: A scoping review**

Authors: Robinson, Lucy;Dewhurst, Felicity;Huggin, Amy;Stow, Daniel;Stenson, Charlotte;Westhead, Elizabeth;Frew, Katie;Hanratty, Barbara and Paes, Paul

Publication Date: 2025

Journal: Palliative Medicine 39(6), pp. 665–677

Abstract: Competing Interests: Declaration of conflicting interestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.; Background: Understanding the evolution of end-of-life preferences over time is important for dynamic, person-centred palliative care. This is particularly relevant for older

people whose preferences can be incompletely expressed and subject to change.; Aim: To summarise the nature of the current evidence about how and why the end-of-life preferences of older people change over time.; Design: A scoping review was performed, using a predefined protocol and following the JBI manual for evidence synthesis.; Data Sources: Final searches of Medline, Embase, PsycINFO and Web of Science were carried out in October 2023. Reference lists were also reviewed. Eligibility criteria included studies recruiting people over the age of 60 that explored how or why end-of-life preferences developed over time.; Results: Screening identified 52 articles, reporting on 40 studies. A majority were longitudinal studies collecting quantitative data about treatment preferences. Other preference categories included euthanasia, balancing quality and length of life, goals of care, preferred place of death, decision-making and spiritual preferences. Studies explored a variety of factors that may influence preference change or stability. There was a lack of research with ethnic minority groups and people aged over 80.; Conclusions: Existing research has focused on preferences about specific therapies, at the expense of understanding what matters most to older people. Synthesis of the available evidence about why preferences change will guide reviews of patients' advance care plans. To inform dynamic, person-centred end-of-life care we need studies prospectively exploring how older people construct a broader range of preferences, and negotiate these over time.

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19. **Impact of Palliative Care Referral on End-of-Life Outcomes for Patients With Hematologic Malignancy**

Authors: Seecof, Olivia M.;Jang, Charley and Abdul Hay, Maher

Publication Date: 2025

Journal: The American Journal of Hospice & Palliative Care 42(6), pp. 550–559

Abstract: Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; ContextCompared to patients with solid malignancies, less is known about the role of palliative care in patients with hematologic malignancies, leading to underutilization of palliative care.ObjectivesEvaluate the timing and impact of palliative care referrals on end-of-life outcomes over a 5-year period with intent to improve the utilization of palliative care in patients with advanced hematologic malignancies.MethodsA retrospective cohort of patients from an urban, NCI-designated comprehensive cancer center, aged 18 years and older with a diagnosis of an advanced hematologic malignancy were separated into groups of early, late, very late, or no specialty palliative care. Logistic regression models were constructed to examine variables associated with timing of palliative care referral. Groups were compared using the Kruskal Wallis test and Dunn's test with a Bonferroni correction method.Results222 patients with advanced hematologic malignancies who died between July 1, 20218 and June 30, 2023 were included. 50 (23%), 41 (18%), and 51 (23%) patients received an early, late, and very late palliative care referral, respectively and 80 (36%) patients did not receive a palliative care referral. There was a significantly high completion of ACP documentation among the palliative care cohorts. There was no significant difference among all cohorts in end-of-life outcomes in the last 14 or 30 days of life.ConclusionACP documentation improved with palliative care, however, end-of-life outcomes did not. These results are likely due to the majority of late, inpatient palliative care referrals. Future studies with targeted interventions are

needed to improve these outcomes.

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20. **Older Adults' Unmet Needs at the End of Life: A Cross-Country Comparison of the United States and England**

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Journal: Journal of Aging and Health 37(5-6), pp. 292–304

Abstract: Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; Objectives: This study aimed to compare the end-of-life (EOL) experiences in concentration with place of death, for older adults in the U.S. and England. Methods: Weighted comparative analysis was conducted using harmonized Health and Retirement Study and English Longitudinal Study of Ageing datasets covering the period of 2006-2012. Results: At the EOL, more older adults in the U.S. (64.14%) than in England (54.09%) had unmet needs (I/ADLs). Home was the main place of death in the U.S. (47.34%), while it was the hospital in England (58.01%). Gender, marital status, income, place of death, previous hospitalization, memory-related diseases, self-rated health, and chronic diseases were linked to unmet needs in both countries. Discussion: These findings challenge the existing assumptions about EOL experiences and place of death outcomes, emphasizing the significance of developing integrated care models to bolster support for essential daily activities of older adults at the EOL.

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21. **Understanding the Behavioral Health Needs of Hospice Patients and Their Family Caregivers: Perspectives of Hospice Medical Directors**

Authors: Tiwari, Abhay;Park, Taeyoung;Parillon, Brittney;Prather, Simone;Shalev, Daniel;Reid, Manney Cary;Czaja, Sara;Adelman, Ronald and Phongtankuel, Veerawat

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Abstract: Background: Behavioral health disorders are common among patients and caregivers in the hospice setting. Yet, limited data exist regarding what hospice providers perceive as the most common and challenging behavioral health disorders they encounter and how they manage these issues in practice. Objective: To characterize the perspectives of hospice medical directors (HMDs) on addressing the behavioral health challenges when caring for patients enrolled in home hospice care and their family caregivers. Methods: Semistructured interviews with seventeen certified HMDs were conducted. Data were analyzed using thematic analysis. Results: Many HMDs agreed that delivering high-quality behavioral health care is a tenet for good end-of-life (EoL) care. HMDs shared that depression and anxiety were the most common behavioral health challenges they encountered, while among caregivers, substance use disorder was the most challenging. Participants mentioned that nurses and social workers played a vital role in detecting and managing behavioral health problems. HMDs also stated that providing additional training for frontline staff and incorporating behavioral health experts are potential solutions to help address current challenges. Conclusion: HMDs emphasized the importance of addressing behavioral health challenges among patients and caregivers to provide effective end-of-life care. Future studies should examine the viewpoints of additional key stakeholder groups (e.g., hospice interdisciplinary team members, family caregivers) and confirm them in quantitative studies. Designing and implementing evidence-based assessments and interventions to improve behavioral health care by addressing anxiety, depression, and caregiver substance use disorders is essential to improving care and care outcomes in the hospice setting.

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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