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End of Life Care

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October 2025

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Challenges to timely access to out-of-hours end-of-life medications: a qualitative study in UK primary care

Okamoto I. *British Journal of General Practice* 2025

Timely, 24/7 access to medications in the community is essential for effective symptom management for people approaching the end of life. Little is known about current systems ensuring skilled & timely patient assessment, prescribing, & administration, & service gaps. We investigate out-of-hours access to end-of-life care medications in community settings, identifying gaps, challenges, & potential solutions. This is a qualitative study adressing out-of-hours community palliative care services.

Read it online at https://bjgp.org/content/75/759/e669

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1. **Preference for End-of-Life Care at Home and Attitudes Towards Death of Family Members Caring for Older Adults**

Authors: Abe, Koji

Publication Date: 2025

Journal: Psychogeriatrics : The Official Journal of the Japanese Psychogeriatric Society 25(6), pp. e70101

Abstract: Background: The issue of where to provide end-of-life care is an important concern for family members caring for older adults. Although many older adults would prefer to die at home, the preferences of family members and the psychosocial factors influencing these

preferences are not well understood. This study investigated the preferences of family caregivers for end-of-life care at home and examined the relationships between these preferences, death attitudes, and the disabilities of older adults.; Methods: We conducted a web-based screening survey of 6000 older persons, of which 339 respondents answered that they currently care for a family member who needs care at home due to dementia or ageing. Of these 339 respondents, data from 246 persons were analysed, excluding those who answered that they had no problems regarding the cognitive function and daily life functioning of the person requiring care.; Results: Multiple regression analysis revealed that in addition to the care recipients' activities of daily living (ADL), behavioural and psychological symptoms of dementia (BPSD) had affected family caregivers' preference for end-of-life care. Furthermore, among the psychosocial factors of family caregivers, attitudes towards death and memorial service awareness influenced family caregivers' preference for end-of-life care. Cluster analysis and ANOVA showed that the preference for caregiving at the end of life was significantly lower in a cluster where BPSD were present in older adults, even though their ADL was not declining.; Conclusions: This study showed that BPSD is an important consideration for families considering home-based end-of-life care. Additionally, memorial service awareness is a death attitude that influences preferences for end-of-life care. Traditional ancestor worship behaviours also affect the actions of families when older adults reach the end of their lives. (© 2025 Japanese Psychogeriatric Society.)

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2. **Balancing palliative care needs and medication appropriateness: Initiation and reinitiation of medications at the end of life**

Authors: Anlay, Degefaye Zelalem;Paque, Kristel;Brys, Astrid D. H.;Cohen, Joachim and Dilles, Tinne

Publication Date: 2025

Journal: Archives of Gerontology & Geriatrics 139, pp. N.PAG

Abstract: • Reinitiation of discontinued medications occurred in 17 % of nursing home residents. • Cancer, hospitalization, and polypharmacy increase the initiation and reinitiation rate. • Guidelines on medication appropriateness should explicitly address palliative care needs. • Findings are based on a cohort study of linked national healthcare data (N = 158,689). Medications deemed inappropriate and discontinued in the earlier stages of life-limiting disease may become relevant in palliative care context at the end of life. This study aims to determine the incidence of and factors associated with initiation and reinitiation of medications deemed inappropriate according to the STOPPFrail guideline. A retrospective cohort study using linked healthcare reimbursement data. We included nursing home residents aged ≥65 who died with a condition potentially amenable to palliative care between 2015 and 2019 in Belgium. Outcomes were: (1) reinitiation of previously discontinued STOPPFrail-listed medications; and (2) initiation of these medications, regardless of prior use, in the last three months. Log-binomial regression was used to estimate relative risks (RR) with 95 % confidence intervals (CI). Among 158,689 decedents, 29.7 % had at least one medication initiated, and 16.96 % reinitiated among those with at least one medication discontinued (n = 13,724). By medication type, initiation and reinitiation were significantly higher for symptomatic medications than preventive ones (initiation: 25.5 % symptomatic vs. 6.7 % preventive; reinitiation: 20.3 % symptomatic vs. 11 % preventive). The risk was higher among residents

with cancer, who were hospitalized, or taking ≥10 chronic medications. A significant proportion of residents undergo initiation or reinitiation of medications deemed inappropriate at the end of life per existing guidelines. Many were likely prescribed for palliative purposes. Thus, guidelines on medication appropriateness may need to more explicitly address palliative care contexts. A notable number also received preventive medications, suggesting inappropriate prescribing at the end of life that has received little attention.

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3. **Decision-making factors related to palliative care and hospice use in the community: a systematic review based on Andersen's behavioural model of health services use**

Authors: Choi, Subin;Kim, Minsung;Park, Jee-Eun;Kang, Juyeon and Woo, Kyungmi

Publication Date: 2025

Journal: BMC Palliative Care 24(1), pp. 1–17

Abstract: Background: Community-based palliative care and hospice is essential for meeting the preferences of terminally ill patients and reducing healthcare costs. However, systematic research on the decision-making factors concerning the patients and family caregivers remains limited. This study aimed to identify and categorise the factors related to the patients' and family caregivers' decision-making in the use of palliative care or hospice within the community. Methods: This systematic review (PROSPERO: CRD42024612049) was conducted using the CINAHL, Cochrane Library, EMBASE, and Medline databases. Studies focusing on the patients' and family caregivers' decisions regarding palliative care and hospice were included, excluding the studies focusing solely on healthcare professionals. Four authors independently assessed the eligible studies and resolved discrepancies through discussion. The quality of the included studies was assessed using the Mixed Methods Appraisal Tool 2018. The data were qualitatively synthesised using a narrative approach and a constant comparison model. Decision-making factors were categorised based on Andersen's behavioural model of health services use taking into consideration predisposing, enabling, and need factors. Results: Seven studies, four quantitative and three qualitative, were included. Sixteen factors, including five predisposing factors (age, education level, people in the household, experiences with institutional care, and death experience), four enabling factors (physician's disclosure, communication partner, communication context, and information about options), and seven need factors (acknowledgement of terminal status, knowledge, perception, end-of-life wishes, caregiver's commitment, preference for dying at home, and health condition), were identified. Conclusions: Patient and caregiver characteristics, personal experience, communication context, knowledge, preferences, and physical condition were the key factors related to the decision to use palliative care and hospice. This study highlights the importance of addressing these factors to support informed and patient-centred decision-making in end-of-life care.

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4. **Geographic variations in end-of-life hospitalisations for patients with mental illness: a population-based observational study in England, UK**

Authors: Chukwusa, Emeka;Wilson, Rebecca;Gaughran, Fiona and Gao, Wei

Publication Date: 2025

Journal: Discover Mental Health 5(1), pp. 147

Abstract: Competing Interests: Declarations. Ethics approval and consent to participate: The study used fully pseudonymised datasets and did not involve direct patient contact. Permission was granted by the King's College London Research Ethics Committee (reference number: LRS-17/18-6943) to allow the secondary analysis of HES-APC and ONS linked data. All methods were carried out in accordance with ethic guidelines and regulations. This study does not involve human participants. Only pseudonymised data was used in this study and therefore patient consent was not required. Consent for publication: Not applicable. Competing interests: The authors declare no competing interests.; Background: High rates of hospital admissions have been reported for patients with mental illness, but less is known about factors associated with multiple hospitalisations at the end-of-life in this group.; Aim: To describe the geographical variations in end-of-life hospitalisations and examine factors associated with multiple hospitalisations (≥ 2) in the last 90 days of life for people with mental illness.; Methods: A national population-based observational study in England UK using a linkage of Hospital Episode Statistics Admitted Patient Care (HES-APC) and the Office for National Statistics (ONS) death registry data. Our cohort comprised patients aged 18 and over, who died in England between 2018-04-01 and 2019-03-31 with HES-APC diagnoses of (1) Schizotypal, delusional disorders or schizophrenia, (2) schizoaffective or bipolar affective disorder, (3) substance use disorders; or (4) depressive episodes or recurrent depressive disorders. Geographic variations of end-of-life hospitalisations for each diagnostic group were described across National Health Services (NHS) regions. Modified Poisson regression models were used to estimate factors associated with multiple end-of-life hospitalisations in each diagnostic group.; Results: A total of 49,775 patients with mental illness died in the year 2018-2019, of whom 50.2% (n = 25,004) had multiple end-of-life hospitalisation in the last 90 days of life. Factors positively associated with multiple end-of-life hospitalisations included older age, being resident in an urban area, cancer related deaths, and, for patients with depressive disorders, higher socioeconomic deprivation.; Conclusion: Strengthening primary and community care services targeted at older adults with cancer could potentially reduce multiple end-of-life hospitalisations for patients with mental illness. (© 2025. The Author(s).)

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5. **Impact of digital health interventions on pain and symptom management in home hospice patients: A systematic review and meta-analysis protocol**

Authors: Dos Santos, Thiago Oliveira;Dos Passos Da Rosa, Fábila Fernanda;Medeiros, Kleyton Santos and Tourinho, Francis Solange Vieira

Publication Date: 2025

Journal: PloS One 20(10), pp. e0333513

Abstract: Competing Interests: The authors have declared that no competing interests exist.; Background: The growing global demand for palliative care, particularly in low- and middle-income countries, underscores the urgent need for innovative strategies to ensure symptom control and quality of life for patients with advanced illnesses. Among these strategies, digital health interventions (DHIs) have emerged as promising tools to support pain and symptom management in home hospice settings, especially for cancer patients.; Objective: This protocol outlines a systematic review and meta-analysis designed to evaluate the effectiveness of

digital health interventions in managing pain and other symptoms among cancer patients receiving palliative care at home.; Methods: This review will include randomized clinical trials and quasi-randomized clinical trials that assess the impact of digital health interventions on pain and symptom control in adult cancer patients under palliative care at home. Studies will be identified through searches in major bibliographic databases, following PRISMA-P guidelines and the Cochrane Handbook. Only peer-reviewed publications will be considered. Interventions must align with the World Health Organization's definition of DHIs. The primary outcome is the effectiveness of these interventions in pain management compared to traditional in-person care.; Expected Results: This review is expected to identify and synthesize evidence on the effectiveness of DHIs in improving pain and symptom control, as well as overall patient well-being in palliative home care settings.; Conclusion: The findings will provide a comprehensive understanding of the role of digital technologies in enhancing palliative care delivery, guiding clinical practices and policy decisions aimed at optimizing end-of-life care through remote support. This protocol is registered in the International Prospective Register of Systematic Reviews (PROSPERO): CRD420250572413.

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6. **Healthcare Professionals' Perspective on Supporting Patients and Family Caregivers in End-Of-Life Care Decision-Making: A Qualitative Study in Specialist Palliative Care**

Authors: Featherstone, Hannah J.;McQuillan, Regina and Foley, Geraldine

Publication Date: 2025

Journal: American Journal of Hospice & Palliative Medicine 42(10), pp. 1005–1011

Abstract: Background: Healthcare professionals in specialist palliative care have a key role in conducting end-of-life care discussions with patients and their family caregivers. We aimed to identify key barriers and facilitators for healthcare professionals in specialist palliative care to support patients and their family caregivers in decision-making for patient end-of-life care. Methods: Twenty-two healthcare professionals from different healthcare professions were recruited from a large regional specialist palliative care service in Ireland comprising 2 hospice sites. Five focus groups were conducted with participants. Data were member checked and analyzed using thematic analysis. Results: Open communication and trusting relationships with patients and family caregivers combined with sufficient time for early and phased exploration of the patient's preferences for end-of-life care, were key facilitators for participants. Family caregivers keeping information from the patient, family misunderstanding about who is responsible for decision-making, and a lack of involvement of other specialties in end-of-life care discussions were perceived by participants as key barriers. Although participants indicated they had sufficient expertise to support patients in end-of-life care decision-making, they felt that end-of-life care discussions were not solely the responsibility of specialist palliative care services. Conclusion: Open communication with patients in end-of-life care decision-making can be of central importance for healthcare professionals in specialist palliative care. Further research is needed to understand the role of healthcare professionals outside of specialist palliative care in end-of-life care discussions and decision-making.

7. **Palliative care experts' relative importance of end-of-life care quality indicators: Findings from a discrete choice experiment**

Authors: Finkelstein, Eric Andrew and Gonzalez Sepulveda, Juan Marcos

Publication Date: 2025

Journal: Palliative Medicine , pp. 2692163251366092

Abstract: Background: End-of-life care delivery is shaped by subject matter experts who influence treatment decisions, policies, and programs and set guidelines that inform end-of-life care practices. However, little is known about what these experts view as most important when delivering high quality end-of-life care.; Aim: To quantify the relative value that experts place on 13 key indicators of care quality at end-of-life and to assess whether preferences vary across high- and low/middle income countries.; Design: Cross-sectional survey using a discrete choice experiment that asks respondents to trade-off between three hypothetical care providers with varying ratings across indicators, based on a five-star rating system. Mixed logit regression analysis was used to estimate the relative importance for each indicator, such that the sum across indicators totals 100%.; Participants: A total of 193 experts from 121 countries.; Results: Experts placed greatest relative importance on managing pain and discomfort (19.0%), quality of life extending treatments (10.0%), treating patients kindly (9.1%), and ensuring costs are not a barrier to treatment (8.7%). They placed least emphasis on non-medical concerns (3.7%) and spiritual needs (2.2%). No differences were found between respondents from high- and low/middle income countries.; Conclusion: These results reinforce the importance of pain management as the most important indicator of end-of-life quality. Results further suggest that excessive emphasis on life extension may not be the best use of scarce resources and greater value may be achieved by focusing on other aspects of end-of-life care quality. These results hold for both high- and low/middle income countries.

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8. **Trends in hospice and palliative care consults initiated in the emergency department: An eight-year utilization analysis**

Authors: Gunaga, Satheesh;Al-Hage, Abe;Buchheister, Alyssa;Neelam, Harish;Corcoran, Jessica;Welchans, Michael;Swan, Kirby;Awada, Mahmoud;Miller, Joseph and Mowbray, Fabrice

Publication Date: 2025

Journal: American Journal of Emergency Medicine 97, pp. 237–243

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9. **End-of-Life Outcomes and Staff Visits for Hospice Recipients Residing in Assisted Living**

Authors: Guo, Wenhan;Cai, Shubing;Li, Yue;McGarry, Brian E.;Caprio, Thomas V. and Temkin-Greener, Helena

Publication Date: 2025

Journal: Journal of the American Medical Directors Association 26(12), pp. 105887

Abstract: Competing Interests: Disclosure The authors declare no conflicts of interest. A version of our study findings was presented at the AcademyHealth 2025 Annual Research Meeting in Minneapolis, MN, on June 7, 2025.; Objectives: To examine (1) whether hospice staff visits are associated with end-of-life (EOL) transitions, place of death (POD), and live discharges among assisted living (AL) residents, and (2) whether state AL regulations on staffing and medication administration influence these outcomes. We hypothesized that more frequent staff visits and specific regulatory provisions would be associated with improved EOL outcomes.; Design: Retrospective cohort study using Medicare claims data from 2018-2019. Sensitivity analyses used logistic regression models to assess robustness.; Setting and Participants: National, population-based study of Medicare decedents residing in licensed AL communities across the United States. The main analytic sample included 42,466 AL residents who received hospice and died during enrollment. A separate sample of 61,851 was used to assess live discharges. Participants were identified by linking 9-digit ZIP codes of 10,452 licensed ALs to Medicare enrollment files. Individuals younger than 55 years, not enrolled in hospice, or enrolled in Medicare Advantage were excluded.; Methods: Key exposures included the frequency of hospice staff visits (clinical vs nonclinical) and the presence of state AL regulations related to staffing and medication delegation. Outcomes included EOL transitions within the last 7 days of life, POD in AL vs other settings, and live discharges from hospice.; Results: More frequent clinical staff visits were associated with lower rates of EOL transitions -12 percentage points (pp)], reduced live discharges (-4 pp), and increased likelihood of dying in place (+4 pp; all P < .001). Nonclinical visits showed modest but consistent associations with improved outcomes. State regulations requiring on-site staffing and permitting medication delegation were associated with fewer transitions and higher rates of in-place death.; Conclusions and Implications: Hospice staffing intensity, especially clinical visits, appears to be associated with EOL outcomes for AL residents. AL state regulations are also associated with hospice quality. These findings underscore the role of both organizational practices and regulatory policy in shaping hospice experiences in AL settings.

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10. **End-of-Life Discussions From the Perspective of Social Care and Healthcare Professionals in Palliative Care**

Authors: Kuusisto, Anne;Saranto, Kaija;Korhonen, Päivi and Haavisto, Elina

Publication Date: 2025

Journal: Omega: Journal of Death & Dying 92(1), pp. 448–470

Abstract: This study describes the state of end-of-life discussions in Finland. A qualitative descriptive study with thematic interviews was conducted. Data were gathered from palliative care unit nurses, physicians and social workers. Inductive content analysis was used. According to interviewees (n = 33), the state of end-of-life discussion included three main categories. First, optimal end-of-life discussion time included early end-of-life discussion, end-of-life discussion at different phases of severe illness, and flexibility and challenges in scheduling end-of-life discussion. Second, end-of-life discussion initiators included both healthcare professionals and non-healthcare professionals. Third, social care and healthcare

professionals' experiences of end-of-life discussion consisted of the importance and challenge of end-of-life discussion, end-of-life communication skills development in multiprofessional care context, and end-of-life communication in multi-cultural care context. The results can be used to justify the need of a national strategy and systematic implementation on Advance Care Planning (ACP), considering the multiprofessional, multicultural and internationalizing operating environment.

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11. **Patient cues about end-of-life matters: An observational study of palliative care consultations using conversation analysis**

Authors: Land, Victoria and Pino, Marco

Publication Date: 2025

Journal: Patient Education and Counseling 139, pp. 109243

Abstract: Competing Interests: Declaration of Competing Interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.; Objective: This article examines instances of patients making allusive or ambiguous potential reference to death and dying (cues) and analyses how they are built and received in consultations.; Methods: Conversation analysis of video and audio recorded interactions in a large UK hospice. These consultations occurred between patients and companions and a variety of healthcare professionals (HCPs), comprising six palliative medicine consultants, five occupational therapists, and three physiotherapists.; Results: Patients may foreground the end-of-life (EoL) aspect of a cue by, for example, producing it while launching a topic or making a pronouncement/report. This exerts sequential pressure for HCPs to address the EoL implication (unmarked case), but HCPs may avoid engaging with it (marked case). Sometimes, patients allusively or ambiguously refer to death and dying in the course of another interactional activity, thereby backgrounding the EoL implication. The unmarked case involves the HCP attending to the ongoing activity, which maintains the backgrounding. However, HCPs can target the EoL implications in cues produced in the service of other activities or in cases in which the patient has unpacked with a non-EoL concern.; Conclusion: Although not determinative, the sequential environment in which the cue is deployed shapes how HCPs respond to it. This is important because it permits HCPs avenues for engaging in EoL discussion.; Practice Implications: HCPs can better understand the interactional work done with cue like utterances if there are contextualised in the ongoing sequence of interaction. For patients reticent to talk about EoL issues, stepwise engagement with the topic, even when EoL has been backgrounded may provide an opportunity for discussing difficult but essential topics.

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12. **South Asian Experiences of Palliative and End-of-Life Care Provision in the UK: A Systematic Literature Review and Thematic Synthesis**

Authors: Pardi, Jane;Nuzum, Eleanor;Judickaite, Ugne;Stott, Joshua;Charlesworth, Georgina and Desai, Roopal

Publication Date: 2025

Journal: Journal of Palliative Care , pp. 8258597251343932

Abstract: Objective: South Asian communities represent one of the largest ethnic minority groups in the UK. Within this group the number of adults requiring palliative and end-of-life care is growing. However, there are often barriers to engagement and underutilization of palliative care services. We aimed to understand the experiences of South Asian patients and/or carers of palliative and end of life care services in the UK. Methods: We conducted a systematic literature review of qualitative data. The review was prospectively registered on PROSPERO (CRD42023442603). Three databases were searched to August 2023. Studies were included if they reported qualitative data on the experiences of South Asian patients, their carers or the perspective of health care staff involved in palliative or end of life care. Quality of studies was assessed using the Critical Appraisal Skills Programme Checklist. Data were analyzed using a thematic meta-synthesis framework. Results: Sixteen studies comprising 407 patients, carers, and healthcare staff were included. The themes identified were: barriers and facilitators to discussing and preparing for end of life; the impact of identity and culture on end-of-life practices and rituals; family roles and expectations regarding palliative care, and navigating challenges across care settings and healthcare interactions. Identified themes highlighted challenges, including language barriers, lack of awareness, and cultural insensitivity. Conclusions: Addressing these gaps through training and culturally appropriate services could significantly enhance the quality and inclusivity of palliative care services for South Asian communities.

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13. **Understanding challenges and barriers to quality end-of-life care for patients with hematologic malignancies: a GIMEMA survey**

Authors: Potenza, Leonardo;Efficace, Fabio;Borelli, Eleonora;Fazi, Paola;Baldi, Thomas;Tartaglia, Francesca;Sparano, Francesco;Cartoni, Claudio;Niscola, Pasquale;Mucciarini, Claudia;Odejide, Oreofe;Bruera, Eduardo;Zimmermann, Camilla;Vignetti, Marco;Luppi, Mario and Bandieri, Elena

Publication Date: 2025

Journal: Annals of Hematology

Abstract: Competing Interests: Declarations. Competing interests: FE has received consultancy fees from AbbVie, Incyte, Novartis, and Jazz Pharmaceuticals, and research funding (institution) from Daiichi Sankyo, all unrelated to the submitted work. ML has participated in advisory boards and meetings with honoraria from AbbVie, Gilead Sciences, Jazz Pharmaceuticals, Novartis, MSD, Grifols, Sanofi, Daiichi-Sankyo, Incyte, Roche, and Istituto Gentili, also unrelated to the submitted work. EBa has served on the advisory board for Sandoz, unrelated to the submitted work. All other authors declared no potential conflicts of interest concerning the research, authorship, and/or publication of this article.; Patients with hematologic malignancies often receive aggressive end-of-life (EOL) care, which may be partly related to hematologists' discomfort with discontinuing aggressive treatments at EOL. It is therefore important to investigate how hematologists perceive EOL care and how this affects their clinical practice. We assessed a cohort of Italian hematological oncologists through a GIMEMA online survey to explore their attitudes toward standard measures of quality EOL care, their opinions on barriers to providing this care, and potential interventions. EOL quality

measures were defined acceptable to hematologist if at least 55% of respondents agreed with their suitability. One-hundred eight-six hematologists completed the survey. Hematologists rated 8 of 13 EOL quality measures as highly acceptable, including no new chemotherapy, no intensive care unit admission, no intubation/cardiopulmonary resuscitation in the last 30 days of life, and hospice admission > 7 days before death. Major barriers to quality EOL care included unrealistic patient expectations, clinician concerns about taking away hope, and uncertainty about what to say. Moreover, 73% admitted to being unfamiliar with discussing goals of care (GOC) or advance care planning (ACP). Suggested interventions for improvement included increasing the availability and timely integration of palliative care, and access to home care services. In conclusion, Italian hematologists find most standard EOL quality measures acceptable, they identify barriers to quality care, and are open to interventions, including early integration of palliative care, to improve patients' EOL care. However, they lack familiarity with GOC and ACP discussions, highlighting the need for communication skills training. (© 2025. The Author(s).)

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14. **Palliative and end-of-life care research funding: an analysis of current UK health research spending**

Authors: Sheridan, Bethan and Murtagh, Fliss

Publication Date: 2025

Journal: BMJ Supportive & Palliative Care

Abstract: Competing Interests: Competing interests: FM is a National Institute for Health and Care Research (NIHR) Senior Investigator. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care.; Objectives: Despite increasing demand for palliative and end-of-life care, the funding for research in this area has historically been low. Previous UK analyses in 2016 found that less than 0.3% of the funding for cancer research was directed towards palliative care research; current expenditure on palliative and end-of-life care research is unknown. We therefore sought to determine current UK expenditure on palliative and end-of-life care research.; Methods: Secondary analysis of publicly available research funding data-UK Health Research Analysis 2022, from the UK Clinical Research Classification System Health Research Classification System. This dataset details UK health research funding from all public sectors (including the governments of the four nations of the UK), charities, societies and professional bodies for the year 2022.; Results: Out of 18 023 research funding awards in total in 2022, we identified 136 relating to palliative and end-of-life care research. The total funding for palliative and end-of-life care research was £10.9 million, representing just 0.26% of the total £4.2 billion awarded.; Conclusions: Palliative and end-of-life care research continues to be one of the lowest-funded areas of healthcare research in the UK. More investment into palliative and end-of-life care research is urgently needed to advance evidence to meet the rising demand for palliative care. (© Author(s) (or their employer(s)) 2025. No commercial re-use. See rights and permissions. Published by BMJ Group.)

15. **Disclosure Practices in Muslim Patients and the Impact on End-of-Life Care: A Narrative Review**

Authors: Tareen, Mona

Publication Date: 2025

Journal: American Journal of Hospice & Palliative Medicine 42(11), pp. 1196–1211

Abstract: Context: Non-disclosure practices hold significant weight in end-of-life care for Muslim communities, where cultural and religious beliefs are deeply intertwined with healthcare decision-making. This narrative review explores the complexities of medical decision-making and disclosure practices among terminally ill Muslim patients, examining how these factors shape palliative care delivery. Objectives: The primary objective of this review is to investigate the impact of non-disclosure practices on end-of-life care in Muslim populations, focusing on key themes that influence medical decision-making. Additionally, the review identifies ways in which Healthcare Provider (HCP) can navigate these culturally sensitive issues to enhance care. Methods: A comprehensive narrative review was conducted, utilizing articles from CINHAL, PsychINFO, Scopus, and PubMed databases published between 2009 and 2024. An initial search yielded 2025 articles. After applying inclusion and exclusion criteria, 12 studies were included for analysis. The SANRA guidelines for narrative reviews were followed, and the SPIDER framework was used for qualitative synthesis. Results: Of the 2041 articles initially retrieved, 2014 were excluded after screening, 8 were duplicates, and 7 full texts were excluded for not meeting the inclusion criteria. The final review included 12 studies. Three key themes emerged: (1) cultural, religious, and emotional factors driving requests for non-disclosure, (2) the prominent role of family in medical decision-making, and (3) healthcare provider communication challenges contributing to disparities in palliative care access. Conclusion: Non-disclosure practices present significant barriers to effective palliative care in Muslim communities. To improve care outcomes, culturally competent communication strategies and family-centered decision-making models are crucial.

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16. **Understanding Staff Needs for Improving End-Of-Life Care in Critical Care Units: A Qualitative Focus Group Analysis and Service Evaluation**

Authors: Tavabie, Simon;Pearson, Stephen;Balabanovic, Janet;Batho, Anna;Juj, Manoj;Kastande, Priscilla;Bennetts, Joanne;Collis, Emily and Bonnici, Tim

Publication Date: 2025

Journal: American Journal of Hospice & Palliative Medicine 42(11), pp. 1144–1150

Abstract: Objectives: Critical care is a place of frequent death, up to a quarter of those admitted die during admission. Caring for dying people provides many challenges, practically, professionally and personally. The aim of this study was to better understand the perspectives of staff caring for dying people in critical care and identify their priorities for improvement. Method: Three multidisciplinary focus groups of critical care staff at a large central London hospitals trust were facilitated with a semi structured format and digitally transcribed. Inductive thematic analysis was conducted to extract themes. Results: N = 34 (18 nursing, 7 allied

health professionals, 6 medical, 3 clerical/administrative). The five themes were structured as priority statements: "We need to recognise" included the subthemes of being "sick enough to die" and potential rapid deteriorations in this setting; "We need to understand" with subthemes of perspectives on dying and prioritising time for conversations; "We need to connect" with subthemes of therapeutic relationship and physical presence; "We need to collaborate" with subthemes of critical care working and empowerment, and cross teams working; "We need support" with themes of experiencing support and making time to support others. Conclusion: We present an approach to identifying critical care departmental priorities for an end-of-life care improvement programme. The themes extracted will be used to evaluate systems for dying in critical care, aiming to empower staff to provide excellent care every time they look after a dying person. Relevance to Practice: This service evaluation identifies key priorities among critical care staff regarding end-of-life care. The insights can guide service improvements, such as tailored training and enhanced support for staff, to ensure better communication, collaboration, and quality care for patients at the end of life.

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17. **Dexmedetomidine Versus Midazolam for End-of-Life Sedation: The DREAMS Non-Blinded Randomized Clinical Trial**

Authors: Thomas, Benjamin;Barclay, Gregory;Mansfield, Kylie;Mullan, Judy and Lo, Wing-Shan Angela

Publication Date: 2025

Journal: Journal of Pain and Symptom Management 70(5), pp. 459–469

Abstract: Context: End-of-life distress and delirium are common in palliative care inpatients, often requiring sedatives that diminish interaction. Current practices rely on clinical experience rather than evidence.; Objectives: To compare the sedative efficacy of subcutaneous dexmedetomidine versus midazolam in managing end-of-life distress while maintaining responsiveness, and to evaluate comparative effect on delirium in the terminal phase.; Methods: Single center randomized non-blinded clinical trial (ACTRN12621000052831) of palliative care inpatients in an Australian Local Health District admitted for end-of-life care. Patients received dexmedetomidine (0.5 μg/kg/h) or midazolam (0.25 mg/kg/day) via subcutaneous infusion for symptom management during the terminal phase. The primary outcome was responsiveness measured by mean Richmond Agitation Sedation Score-Palliative version (RASS-PAL) compared between treatment arms over the first 72 hours. Secondary outcomes included delirium severity (memorial delirium assessment score MDAS]) and patient comfort (Patient Comfort Assessment PCA]).; Results: Fifty two patients were randomized (median age 80 years IQR 72-88]; 63% male) and included in the primary analysis. Mean RASS-PAL scores showed no significant difference between arms (dexmedetomidine vs. midazolam: day 1: -2.33 vs. -1.90; day 2: -2.44 vs. -2.86; day 3: -2.95 vs. -2.53; all P > 0.05). Dexmedetomidine showed superior early delirium severity scores (day 1 MDAS: 6.5 vs. 8.8, P = 0.05) which did not persist. Protocol withdrawal occurred earlier in the midazolam arm (5 vs. 0 patients on day 1, P = 0.025). Patient comfort scores remained mild (PCA < 3) in both arms.; Conclusion: Dexmedetomidine and midazolam can achieve sedative equivalence with similar RASS-PAL scores. Dexmedetomidine patients experienced lower initial delirium severity scores and fewer early withdrawals in secondary analysis. Current dosing guideline for midazolam may need revising. (Crown Copyright © 2025.

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18. **End-of-life care among terminally ill patients in the emergency department: a best practice implementation project**

Authors: Yang, Piaoyu;Feng, Li;Zhou, Wanting;Zheng, Jili and Zhang, Yuxia

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Journal: JBI Evidence Implementation

Abstract: Competing Interests: The authors declare no conflicts of interest.; Introduction: The increasing number of older adults visiting emergency departments (EDs) near the end of life highlights the need for palliative and end-of-life care in this setting, despite the ED's focus on acute care.; Aim: This study implemented evidence-based end-of-life care for terminally ill adult patients in the ED in a medical center in Shanghai, China.; Methods: This project followed JBI Evidence Implementation Framework. A baseline audit was conducted to measure current practices against best practice recommendations. Barriers to evidence-based practices were identified, improvement strategies were implemented, and a follow-up audit was conducted to determine changes in compliance.; Results: The results showed significant improvement in adherence to best practice recommendations. For Criterion 1 (staff training), compliance rose from 77.5% to 100% and knowledge scores increased from 9.68±1.945 to 12.30±2.239 ($p<0.001$). For Criterion 2 (patients screened and/or assessed for palliative care needs), compliance increased from 50% to 100%. For Criterion 3 (ED protocol for end-of-life care), compliance rose from 0% to 100%. For Criterion 4 (palliative or end-of-life patients transitioned to the appropriate service), compliance increased from 0% to 30%. For Criterion 5 (strategies promoting a suitable environment), compliance increased from 70% to 90%.; Conclusions: This project resulted in positive changes, including the establishment of a formal end-of-life care protocol. Nursing team support and the range of end-of-life care interventions also improved. However, collaboration and referrals between hospitals and hospices remain challenging. Further audits are needed to assess improvements in care for end-of-life patients.; Spanish Abstract: http://links.lww.com/IJEBH/A395.

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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