

End of Life Care

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June 2026

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Factors affecting quality of life in older people with a cancer-related stoma: a scoping review.

Miyazaki A.

British Journal of Nursing 2026;35(6):S18-S28.

Older cancer survivors with a stoma often experience a decline in quality of life (QoL) due to multiple factors. This scoping review aimed to identify factors affecting QoL among older people with a cancer-related stoma.

Shaping opioid conversion education in the specialist palliative care setting: a pilot study of staff experiences.

Jacobs D.

British Journal of Nursing 2026;35(6):308-315.

An essential skill for working within specialist palliative care is an ability to convert opioid medications. The provision of education to support this skill is not consistent despite national guidance to seek specialist advice when converting opioids. The aim of this study was to explore the lived experiences of clinicians working within specialist palliative care who are involved in converting opioid medications and the education that supports them.

Hundreds helped by end of life support volunteers

BBC News

Nearly 1,000 patients and their families have been supported by a hospital's end-of-life volunteer service in its first year. A Friend In Need provides companionship to patients at the University Hospitals Sussex NHS Trust in their final days and hours.

Read online at <https://www.bbc.co.uk/news/articles/ckgwvx3g3j2o>

1. Comparison of End-of-Life Care Between Patients With Hematological Malignancies Versus Solid Tumors: A Retrospective Analysis

Authors: Almusaed, Salma; Sadler, Kim; Abdulmutaali, Walaa; Abudari, Gassan; Callaghan, Steven; Sroor, Mahmoud; Almutairi, Muneerah; AlGhamdi, Mohammed; Alshalwah, Muruf Zaid; Desai, Sameer; Abu Alsahm, Nessreen and Alzain, Khloud

Publication Date: 2026

Journal: Journal of Palliative Care 41(3), pp. 256–265

Abstract: Background: End-of-life care for cancer patients varies significantly based on the type of malignancy, with hematological malignancies (HMs) and solid tumors (STs) presenting unique challenges. While specialized palliative care (PC) is well-established for managing STs, its integration into HMs' care remains less common despite evidence of its benefits. Objective: To compare the quality of end-of-life care and PC involvement in patients with HMs versus those with STs using recognized quality indicators. Methods: A retrospective comparative study was conducted at a large tertiary care center in Riyadh, Saudi Arabia, covering the period from January 1, 2023, to December 31, 2023. Data were retrieved from medical records and included demographics, clinical information, and healthcare service use during the last 6 months before death. Results: The cohort consisted of 350 adult patients, of whom 86 (24.6%) had HMs and 264 (75.4%) had STs. Overall, HMs patients received more aggressive end-of-life care, including higher rates of Intensive Care Unit (ICU) admissions (81.4% vs 17.8%), intubation (36% vs 8.3%), disease-modifying treatments (23% vs 3.8%), as well as more enteral feeding, dialysis, blood transfusions, and antimicrobial use. Their resuscitation discussions occurred closer to death (3 vs 16 days; $p < .001$). Additionally, HMs patients had fewer referrals to PC services (43% vs 79.2%; $p < .001$), and most of them died in the ICU (59.3% vs 18.2%; $p = .0001$). Conclusions: These findings highlight the need for further research to understand the unique needs of HMs patients better and to adapt care models that improve their quality of life and end-of-life experience.

2. Family resistance to end-of-life prognosis in hospice care: A conversation analytic single case analysis

Authors: Anderson-Kittow, Rebecca and Bloch, Steven

Publication Date: 2026

Journal: Patient Education and Counseling 149, pp. 109660

Abstract: Objectives: Some clinicians lack confidence providing prognostic information to families, particularly when they do not accept a short prognosis. This paper aims to understand the communication practices used when the family of a dying patient resist the provision and acceptance of prognostic information, and how a doctor responds to this.; Methods: Naturally occurring conversations between senior hospice clinicians and families of patients at the end of life were audio-recorded. We present a single-case of a consultation between a doctor and the family of an imminently dying patient. Using conversation analysis, we examine the ways in which prognostic information is resisted by the family and pursued by the doctor. Our analysis contrasts this with practices identified in previously analysed cases where prognostic information was accepted.; Results: Three practices for resisting prognosis were identified: passive resistance (minimal acknowledgement of prognostic statements), questioning the clinician's account for the prognosis and their certainty, and providing disaligning responses that do not engage with the prognostic statement. We demonstrate how in response, the doctor pursued prognostic talk, making increasingly explicit prognostic statements. The clinician balanced expressions of certainty that the patient was dying, with honesty about their uncertainty regarding timing. The doctor's statements more clearly resembled 'bad news delivery' than other cases in the dataset.; Conclusions: The analysis demonstrates how families can resist the provision and acceptance of prognostic information at the end of life. It shows an obligation for doctors to disclose this information and possible strategies to respond to resistance.; Practice Implications: When delivering prognostic information at the end of life, doctors can look for signs of resistance from the family and use strategies to respond, such as expressing certainty where possible while acknowledging uncertainty. These insights may be particularly valuable in acute settings, where prognostic awareness among families may be limited. (Copyright © 2026 The Authors. Published by Elsevier B.V. All rights reserved.)

3. Understanding end-of-life injectable medication patient safety origin incidents in the community: a mixed-methods analysis of national incident-reporting data

Authors: Bowers, Ben;Gwyn, Sioned;McFadzean, Isobel Joy;Hellard, Stuart;Yardley, Sarah;Clarkson, P. J.;Pollock, Kristian;Barclay, Stephen and Carson-Stevens, Andrew

Publication Date: 2026

Journal: International Journal of Nursing Studies 180, pp. 105544

Abstract: Background: The use of injectable end-of-life symptom control medications is complex and a risk-prone healthcare activity in the community. Attention is often directed towards the immediate causes of medication-related incidents; however, valuable learning can be gained by examining 'origin incidents', the first adverse event occurring in incident chains that resulted in patient harm or the potential for harm. Understanding these origin incidents can underpin improvements in system resilience to ensure the provision of timely, effective and safe symptom management. System resilience arises from capacities at individual, team and structural levels that enable a complex system to adapt practices and maintain essential functions under varying conditions.; Objective: To understand the nature of reported origin incidents involving injectable end-of-life symptom control medication in the community and to identify how system resilience can be improved.; Design: Retrospective observational study

and mixed-methods analysis of nationally reported community injectable medication patient safety incidents, sourced via the National Reporting and Learning System database.; Setting(s): Community-based care in England and Wales.; Participants: A stratified random sample of 2150 incidents was screened for eligibility: 317 incident reports were included. Incident reports involving injectable end-of-life symptom control medications were included. These related to adult patients (aged 18+) receiving end-of-life care in the community, between 2017 and 2022.; Methods: Eligible incidents involved reported chains of incidents (events) influenced by an origin incident. Incident narratives were coded to classify incident types, contributory factors, patient impact and harm severity. Data analysis utilised a mixed methods approach. An initial quantitative descriptive analysis informed subsequent qualitative thematic analysis lines of inquiry.; Results: Ineffective and unsafe symptom control care is influenced by injectable medication origin incidents occurring across the full range of medication management processes. 67.5% (214/317) of reports described actual harm to patients. System resilience was impeded by ineffective transfers of care, difficulties sourcing timely symptom management input from clinical teams, and medication stock and supplies issues. Chains of negative incidents were often exacerbated by discontinuity of care, inadequate communication between in-hours and out-of-hours care providers, mistakes and omissions, failure to follow protocols and insufficient staffing capacity.; Conclusions: Examining upstream origin incidents generated valuable system-wide insights, as these initial events influence subsequent actions and system resilience. Enhancing system resilience to support timely and safe symptom management requires improved coordination during transfers of care, reliable access to equipment and valid permission to administer charts, and adequate staffing to provide responsive, cross-organisational care. (Copyright © 2026 The Author(s). Published by Elsevier Ltd.. All rights reserved.)

4. Between reality and meaning: a qualitative study on virtual reality as a compassionate technology in end-of-life care

Authors: Chatchumni, Manaporn;Phibunnithikasem, Petpailin;Thatsiriniratkul, Ravinan;Prasertsri, Thongdech;Chotikunnan, Rawiphon and Chotikunnan, Phichitphon

Publication Date: 2026

Journal: International Journal of Qualitative Studies on Health and Well-Being 21(1), pp. 2669695

Abstract: Background: Virtual reality (VR) is increasingly recognized as a supportive tool in palliative care due to its potential to promote relaxation, emotional comfort, and spiritual reflection. In Thailand, where end-of-life care is shaped by family relationships, Buddhist beliefs, and the value of a peaceful death, little is known about how VR is perceived in this context.; Aim: To explore perceptions, emotional and spiritual needs, and anticipated acceptability of VR in end-of-life care among terminally ill patients, family caregivers, and palliative care professionals in Thailand.; Method: A qualitative descriptive study was conducted using semi-structured interviews with 15 purposively selected participants, including five terminally ill patients, five family caregivers, and five healthcare professionals. The study focused on anticipated rather than directly experienced use of VR. Interviews were conducted in Thai, audio-recorded, transcribed verbatim, and analyzed using inductive content analysis. Rigor was enhanced through investigator triangulation, reflexive memo writing, peer debriefing,

and an audit trail.; Results: Four interrelated themes were developed: (1) emotional and existential needs, including longing for home, peace, and unresolved concerns; (2) spirituality and meaning, where VR was perceived as a medium for reflection and religious connection; (3) facilitators and barriers, including perceived benefits alongside concerns about usability, emotional impact, and staff workload; and (4) compassionate innovation, reflecting the potential of VR to support dignity, comfort, and meaning at the end of life. Participants viewed VR not merely as a distraction tool, but as a means of symbolic connection and emotional support.; Conclusion: In this Thai palliative care context, VR was perceived as a potentially compassionate and culturally meaningful technology that may support emotional, existential, and spiritual well-being when tailored to patient readiness, cultural values, and clinical feasibility. As findings reflect anticipated perceptions, further research is needed to evaluate its practical, emotional, and ethical impacts in clinical settings.

5. Mindfulness-Based Interventions for End-of-Life Professionals

Authors: Corpuz, Jeff Clyde G.

Publication Date: 2026

Journal: Journal of Palliative Care 41(3), pp. 247–248

Abstract: In a recently published paper in this journal, Covington et al explored the potential advantages of mindfulness-based interventions (MBIs) for healthcare staff burnout and associated problems. In the demanding and emotionally charged field of end-of-life (EOL) care, healthcare professionals play a pivotal role in supporting patients and their families during their most vulnerable moments. However, as a recent systematic review reveals, the empirical research on MBIs in the context of EOL care is still in its nascent stages. This correspondence contributes to the research gap on mental health and self-care of EOL for professionals.

6. Effect of end-of-life care video simulation versus written unfolding case study on nursing students' knowledge, communication attitude, and clinical judgment: A quasi-experimental study

Authors: Fearon-Lynch, Jennifer and Galloway, Sharon

Publication Date: 2026

Journal: Nurse Education Today 163, pp. 107084

Abstract: Background: End-of-life care is a core concept foundational to nursing education. A plethora of evidence shows that undergraduate nursing students are ill prepared to provide care at the end-of-life. Active learning strategies including classroom simulation, unfolding case study, and flipped classroom have shown to positively impact learning, yet these strategies are used sparingly to support end-of-life care instruction.; Aim: Our aim was to determine if using flipped classroom video simulation versus written unfolding case study as part of classroom instruction improved sophomore baccalaureate nursing students' end-of-life care knowledge, communication attitude, and clinical judgment.; Design: A two-group, pretest

posttest quasi-experimental design was used.; Settings: The study was conducted at a college in the northeastern USA.; Participants: Sophomore nursing students N = 151 consented to participate. Participants N = 130 completed all surveys (comparison group (CG) n = 68 and intervention group (IG) n = 62).; Methods: The CG had flipped classroom end-of-life care instruction including a written unfolding case study, while the IG received the same instruction plus a video simulation of the same unfolding case study. End-of-life care knowledge, communication attitude, and clinical judgment were assessed. Data analysis used descriptive statistics, t-tests, and Analysis of Variance.; Results: Although there was a significant increase (p = .000) in all three measures for both groups over time, no statistically significant difference was found between groups. The clinical judgment measure had a mean difference in favor of the IG (15.51 vs 11.47), indicating the video simulation had substantial impact on clinical judgment. Scores for the other two measures were also better for the IG.; Conclusions: Integration of video simulation unfolding case study within flipped classroom may enhance students' end-of-life care knowledge, communication attitude, and clinical judgment to better care for the dying patient. The combined strategies may better address students diverse learning needs. (Published by Elsevier Ltd.)

7. Longing for continuity: A systematic review and thematic synthesis of qualitative research on the experience of older people living with chronic illness towards the end of life

Authors: Gobiet, Emma;Tripathi, Khyati;De Vleminck, Aline;Van den Block, Lieve and Pivodic, Lara

Publication Date: 2026

Journal: Social Science & Medicine (1982) 401, pp. 119220

Abstract: Many older people spend years living with chronic illness before death. However, we lack a comprehensive understanding of how they experience and make sense of this phase of life, as knowledge about this is fragmented across diagnoses, settings, and aspects of the illness experience. This systematic review thematically synthesises qualitative research on self-reported experiences of older people living with chronic illness towards the end of life. We included 31 articles based on primary qualitative research, or mixed-methods research with separate reporting of qualitative data, describing the illness experiences of 464 older people (aged ≥ 65 or mean age ≥ 70) living with any chronic illness and nearing the end of life. We developed nine themes spread over personal, relational, and behavioural dimensions of the experience of chronic illness. Older people long to preserve a continuous sense of self, seeking ways to connect their present reality with their past sense of self and the future they envisage. Three themes closely relate to this central notion of longing for continuity: longing for a continuous sense of self, needing familiarity in care, and striving for normalcy in daily activities. Six other themes capture experiences more distantly related to continuity: navigating losses, changing views of the future, feeling isolated, longing for independence while relying on others, preserving hope, and minimising the impact of illness. We conclude that sustaining continuity of self is central to older people's experience of illness at the end of life, emphasising the importance of a comprehensive understanding of their realities and needs. (Copyright © 2026 The Authors. Published by Elsevier Ltd.. All rights reserved.)

8. "They're exhausted": Hospice Staff Views on Caring for Patients and Families Impacted By Dementia

Authors: Hunt, Lauren J.;Growdon, Matthew E.;Smith, Alexander K.;Margalit, Noam and Harrison, Krista L.

Publication Date: 2026

Journal: Journal of Pain and Symptom Management 72(1), pp. 81

Abstract: Context: Medicare's Hospice Benefit was originally designed for cancer care, but now over half of hospice patients have dementia. To optimize hospice for people living with dementia (PLWD) and their caregivers, we must understand what hospice professionals view as the most important challenges and facilitators to caring for this population.; Objective: To assess hospice professionals' perspectives on hospice care for patients and families impacted by dementia.; Methods: Semi-structured interviews with multidisciplinary hospice professionals in 3 hospice agencies in California. We used inductive and deductive thematic analysis; deductive analyses were grounded in the socioecological model.; Results: 32 participants were included (9 nurses, 5 home health aides, 3 social workers, 3 chaplains, 2 NPs, 2 MDs, 9 leaders; 22% male, average age 45). Participants highlighted how challenges and facilitators spanned the socioecological domains, including hospice-specific issues as well as the broader context of the dementia experience. Challenges Individual-level: The prolonged decline of PLWD drained family's physical, emotional, and financial resources. Community/policy-level: Patient and family needs were unmet by local facility capacity and the clinical course of PLWD was a poor fit with hospice eligibility criteria. Facilitators Individual-level: Clinicians' positive attitudes emphasizing dignity of PLWD informed expert communication intended to develop connection and trust. Community/policy-level: Care coordination across systems supported patients along the continuum of decline.; Conclusion: Optimizing hospice for patients and families impacted by dementia requires addressing both hospice-specific practice and policy, as well as broader dementia care infrastructure. (Copyright © 2026 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.)

9. Building a Career in a Hospice and Palliative Medicine Research: Advice for Early Investigators

Authors: Kaye, Erica C.;Cross, Sarah H.;Hunt, Lauren;Kotwal, Ashwin;Petrillo, Laura;Shalev, Daniel;Thammana, Rekha and Harrison, Krista L.

Publication Date: 2026

Journal: Journal of Pain and Symptom Management

Abstract: Growing the next generation of hospice and palliative medicine (HPM) researchers requires creative approaches to address shortages in available mentors, resources, and funding. In response to these challenges, the American Academy of Hospice and Palliative Medicine (AAHPM) Research Committee convened a multidisciplinary working group of HPM researchers to generate practical strategies to support early career investigators (ECIs) in growing and sustaining a career focused on serious illness research. This article presents

actionable advice for students, trainees, post-doctoral fellows, or early career faculty interested in HPM research, including information and encouragement to empower ECIs to pursue this career path. This paper offers specific guidance on ten steps important to creating and sustaining a HPM research career: 1) choosing to pursue research, 2) developing mentorship relationships, 3) establishing peer mentorship and community, 4) conceptualizing and developing an initial project, 5) establishing a research identity, 6) obtaining funding and protected time, 7) bridging identities between fields, 8) anticipating challenges, 9) maintaining perspective, and 10) becoming a mentor to others. Ultimately, ECIs are the future of HPM research, and their skills and passion are needed to help grow the field and advance science to improve outcomes for patients with serious illness and their families. Endorsed by the AAHPM Research Committee, this article provides a roadmap for ECIs to grow their careers with the long-term goal of promoting compassionate, holistic care for patients, caregivers, and communities navigating serious illness. (Copyright © 2026. Published by Elsevier Inc.)

10. The Impact of Early Palliative Care Decisions on Hospital Service Utilization and End-of-Life Care in Patients with Pancreatic Cancer-A Retrospective Study

Authors: Koivusalo, Sofia;Kitti, Pauliina;Nåhls, Nelli-Sofia;Carpen, Timo;Leskelä, Riikka-Leena;Saarto, Tiina and Akrén, Outi

Publication Date: 2026

Journal: Journal of Palliative Care 41(3), pp. 276–283

Abstract: Objectives Early palliative care (PC) is recommended in pancreatic cancer but remains underutilized. This study assessed whether the timing of the PC decision affected the hospital resource use and access to specialized PC services. The implementation of an integrated PC (IPC) was also evaluated. Methods This retrospective single-center cohort study included 440 deceased pancreatic cancer patients treated at the Comprehensive Cancer Center, Helsinki University Hospital (2017-2018). Patients were categorized by timing of the PC decision-defined as withholding or termination of life-prolonging treatment and transition to PC-into early (>30 days before death) or late/no (\leq 30 days before death) groups. Hospital resource utilization was obtained from electronic medical records. Results A PC decision was made for 87% of patients, median of 1.5 months before death. Chemotherapy was given to 8% during the last month. Compared to early decisions, late/no PC decisions were associated with anticancer treatment closer to death (43 days vs 115 days, $p < 0.001$), higher acute healthcare use, including double the emergency department visits (61% vs 27%, $p < 0.001$) and triple the hospitalizations (59% vs 20%, $p < 0.001$) in the final month. Early PC decision was associated with earlier and more frequent use of the outpatient PC unit (3.6 vs 1 month before death, $p < 0.001$; 84% vs 61%, $p < 0.001$). Only 36% received PC integrated with oncologic treatment. Conclusions Late or absent PC decisions were associated with increased end-of-life hospital interventions and reduced access to specialized PC services; both linked to impaired quality of EOL care and increased healthcare costs.

11. 'They Need to Hear You Say It': Healthcare Professionals' Perspectives on Barriers and Enablers to End-of-Life Discussions With Adolescents and Young Adults With Cancer

Authors: Lee, Justine;Evans, Holly;Wakefield, Claire E.;Anazodo, Antoinette;Cohn, Richard J.;McGill, Brittany C.;Lobb, Elizabeth A.;Wiener, Lori;Juhrmann, Madeleine L. and Sansom-Daly, Ursula

Publication Date: 2026

Journal: Pediatric Blood & Cancer 73(7), pp. e70369

Abstract: End-of-life conversations with adolescents and young adults (AYAs) with cancer rarely occur without the guidance of healthcare professionals. As a part of the 'Difficult Discussions' study, focused on palliative care and advance care planning discussions with AYAs with cancer, we investigated the factors that healthcare professionals identify as barriers and facilitators to end-of-life conversations. Twenty-eight multidisciplinary healthcare professionals participated in semi-structured interviews exploring conversations focused on end-of-life care (29% oncologists/haematologists, 39% nurses and 32% allied health professionals). Data were analysed through qualitative content analysis using an inductive approach. The conversations were shaped by factors at the healthcare professionals' personal, interpersonal, teams and hospital system levels, as well as being influenced by cultural and societal influences. Barriers at each level included patients' and caregivers' emotional needs; patients' maturity levels; lack of relational trust between patient, caregiver and healthcare professional; and the social taboo of speaking about death with young people. Conversely, good communication between members of the multidisciplinary team was identified as a facilitator, as working effectively in a team was found to mitigate some of the emotional burden and logistical constraints of conducting end-of-life conversations. The results of this study offer new insights into how the interplay of these factors acts as facilitators and barriers to communication. Further research could explore the communication processes that facilitate trust between the AYA and healthcare team, factors associated with AYAs' readiness and the optimal time to conduct end-of-life conversations. (© 2026 The Author(s). Pediatric Blood & Cancer published by Wiley Periodicals LLC.)

12. Terminal Lucidity as a Health Promotion Challenge in End-of-Life Care

Authors: Perera, Sangeetha

Publication Date: 2026

Journal: Illness, Crisis & Loss 34(3), pp. 389–413

Abstract: This study examines terminal lucidity (TL) as a health promotion challenge in end-of-life care. It explores TL as a phenomenon, debates its classification as a natural or pathological occurrence, and investigates its emotional and social impacts on healthcare professionals, caregivers, and family members. A mixed-methods systematic review of 21 studies—spanning qualitative, quantitative, and mixed-method designs—was conducted using 10 academic databases. Studies were assessed for quality using the CASP, JBI checklist, and

mixed-methods appraisal tools. The findings were narratively synthesized to examine TL's nature, classification, and significance. TL was characterized as a sudden return of cognitive clarity near death, with conflicting perspectives on its classification. While some viewed it as a natural part of the dying process, others argued for further research into its neurological basis. Across all studies, TL was associated with significant emotional effects, including joy, grief, and confusion, underscoring its impact on stakeholders in end-of-life care. TL poses a substantial challenge in end-of-life care, requiring enhanced understanding and preparedness. Educational programs for caregivers and healthcare professionals are essential to address the phenomenon's complexities. Future research should focus on its neurobiological mechanisms, cultural implications, and role in care decision-making to improve end-of-life care practices.

13. The experiences of nursing and midwifery students with end-of-life care in Neonatal Intensive Care Units: A qualitative descriptive exploratory study

Authors: Vermeulen, Joeri;Fobelets, Maaïke;Van Heymbeeck, Isolde and Demedts, Dennis

Publication Date: 2026

Journal: Nurse Education Today 163, pp. N.PAG

14. Association between Advance Directives and Invasive Life Support Use at End of Life: A Retrospective Cohort Study

Authors: Wang, Zheng-Hui;Huang, Yan;Zhang, Tian-Feng;Wang, Yi-Ming;Sun, Shi-Huai and Tao, Ai-Bin

Publication Date: 2026

Journal: Journal of Pain and Symptom Management 72(1), pp. 75–80

Abstract: Context: Invasive life support is commonly administered at the end of life. However, decisions made in emergency situations often differ from the preferences of patients and their families.; Objectives: We investigated whether explicitly documented advance directives (ADs) were associated with the use of invasive life support, including endotracheal intubation and chest compressions.; Methods: We conducted a single-centre retrospective cohort study by analysing data from all patients who died in our cardiac care unit (CCU) between January 2015 and July 2025. After excluding those who died intraoperatively, of noncardiac causes, or within two hours of admission, 139 patients were included in the final analysis.; Results: Fifty-five patients (39.6%) had an AD. Patients with an AD had significantly lower odds of receiving endotracheal intubation and chest compressions ($P < 0.001$). Older age and a history of heart failure were also independently associated with reduced use of endotracheal intubation ($P < 0.001$ and $P = 0.003$, respectively). Among the 71 patients who died at night time, 40 (56.3%) received endotracheal intubation, compared with 25 of 68 (36.8%) who died during the daytime ($P = 0.008$).; Conclusions: Explicitly documented ADs were independently associated with reduced use of invasive life support. Night time death was an independent risk factor for receiving endotracheal intubation, revealing a systemic tendency towards default aggressive resuscitation. Therefore, implementing systematic and specific procedures for recording and accessing ADs is crucial to ensure that end-of-life medical interventions in the cardiac care unit

15. Understanding the "circle of support" for caregivers of adults with Alzheimer's disease and related dementias following a hospice live discharge

Authors: Wladkowski, Stephanie P.;Washington, Karla T.;Coccia, Kathryn W. and Wallace, Cara L.

Publication Date: 2026

Journal: Death Studies , pp. 1–15

Abstract: Hospice patients with Alzheimer's disease and related dementias (ARD) are more likely to experience a live discharge. This places increased burden on primary caregivers who may be unprepared for this transition and are more likely to be socially isolated. This study explored primary caregivers' "Circle of Support" (CoS) and how social context influences service utilization patterns, perceived support, and experiences of care transitions following a hospice live discharge. Semi-structured interviews were conducted with 32 caregivers and analyzed using thematic analysis. Caregivers described their CoS, how their CoS functioned (or failed to function) post-hospice, and key caregiver and network attributes affecting support use. Findings show that caregivers reporting no changes in their tasks after discharge described more absent CoS functions. Experiences were also influenced by patient location of care and resources availability, suggesting opportunities for targeted interventions to improve caregivers' experiences and outcomes.

16. Barriers and facilitators to home-based end-of-life care for people with dementia: A meta-ethnographic study

Authors: Yin, Guo;Sivaramakrishnan, Divya;Wang, Yajing;Chong, Huimin and Macaden, Leah

Publication Date: 2026

Journal: International Journal of Nursing Studies 179, pp. 105517

Abstract: Background: Achieving a "good death" at home for people with dementia remains an aspiration rather than a reality. Despite the preference for home-based end-of-life care among people with dementia and their families, institutional deaths continue to predominate.; Objectives: This review aims to systematically synthesize qualitative evidence to identify the barriers and facilitators influencing home-based end-of-life care for people with dementia and to develop a conceptual framework integrating these complex factors.; Methods: Qualitative evidence synthesis using a meta-ethnographic approach. A systematic search was conducted in PubMed, MEDLINE, Embase, CINAHL, PsycINFO, Web of Science, and the Cochrane Library in October 2024. Study quality was assessed using the CASP tool, and confidence in the review findings was assessed using GRADE-CERQual.; Results: Six core themes were identified through the synthesis of data from 17 studies. System-level factors included ambiguous and obstructed entry points for end-of-life care, strained supply, financial thresholds for care services, and unstable care support. Family-level factors involved

powerlessness in perceiving and seeking care and the limits of family capacity. Based on these findings, a conceptual framework was developed, which comprehensively presents the complexity of home-based end-of-life care for people with dementia.; Conclusions: Home-based end-of-life care for people with dementia remains a "long and challenging journey." Future research should pay greater attention to factors that enable and strengthen service provision and to feasible ways of implementing such care. Additionally, the existing evidence mainly comes from developed countries in the Global North and is largely based on the perspectives of family caregivers and healthcare professionals. Future research needs to incorporate the perspectives of people with dementia and pay attention to the context of low- and middle-income countries.; Registration: The review protocol was registered with PROSPERO (CRD42024578005). (Copyright © 2026 The Authors. Published by Elsevier Ltd.. All rights reserved.)

Sources Used:

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