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NHS Foundation Trust

End of Life Care

Current Awareness Bulletin

September 2026

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New end of life care report

The Local Government and Social Care Ombudsman's new report, No second chances: what complaints teach us about end of life care, offers guidance to help councils and care providers deliver compassionate end of life care. It draws on learning from real cases and families' experiences. Our quality standard on end of life care for adults echoes this focus, highlighting advance care planning, coordinated care and family support as key to good practice.

Nurses warn pressures on time, staffing and care planning are affecting end of life care Marie Curie and Nursing Standard

More than 1,100 UK nurses have warned that pressures on staffing, time and care planning are putting end of life care at risk, leaving dying people facing distressing and undignified deaths.

End of life charity Marie Curie and Nursing Standard undertook a survey of frontline nurses working in the community and hospitals for their views on the biggest issues affecting the delivery of end of life care in the UK today. The findings make for harrowing reading, with

nurses describing a system under severe pressure and the stress and toll of caring for dying patients in corridors and other unsuitable or non-clinical settings.

The survey found:

More than 70% of nurses said staffing levels are a constraint or barrier to providing end of life care.

More than half said a lack of time is a constraint to giving people end of life care.

55% of nurses have treated patients in a corridor or non-designated clinical area.

Over 70% of nurses said patients being cared for in areas not designed for it compromised patient dignity and caused distress to relatives.

Nurses described care being affected by gaps in medical records, missing or inaccessible care plans.

In more positive findings, over 90% of respondents felt confident about initiating a conversation with a patient about their end of life care needs and wishes.

The findings point to widespread problems in care planning, leading to uncertainty around a patient's wishes at the end of their life. Nurses reported opportunities for such conversations are being missed or, where plans have been created, they aren't always accessible to the right people in the moment of crisis due to an over reliance on paper files, and care providers and the NHS using different electronic systems.

As a result, more than a third said they had witnessed a CPR decision in clinical practice they felt was inappropriate. One nurse shared it had happened twice in her career, and both times were horrendous, recalling a recent case of a terminal metastatic cancer patient: "We were never going to get her back. She died on the floor in the bathroom, undignified, family hysterical, staff all left traumatised."

Other accounts describe CPR being attempted on people whose wishes were known but not accessible in the moment because paperwork could not be found or a decision could not be verified over the phone. One nurse spoke of an older man carrying his paper care plan in his pocket at all times so that he wasn't subjected to intervention against his wishes.

Nurses cited a raft of reasons behind these experiences, but all led back to the lack of, or difficulty in accessing, Advance Care Plans. Over 40% of nurses surveyed said, in their experience, it was uncommon or very uncommon for patients approaching end of life to have an advance care plan in place.

Advance care planning is a way to record a person's wishes for their future care, especially if they have a terminal illness or are nearing the end of life. It helps care professionals and those close to them understand what matters most, including their care preferences, any medical treatments they may or may not want, and where they would prefer to be cared for.

In response, Marie Curie is calling on the UK Government to use the Health Bill, which returns to Parliament on September 7, to address gaps exposed by this survey.

The charity wants the Single Patient Record to be available to all palliative and end of life care providers, including social care, voluntary sector and private providers, so everyone involved in a person's care can see their wishes. It is also calling for everyone diagnosed with a terminal

illness to be offered a conversation about their holistic needs, wishes and end of life preferences.

Sarah Williamson, Marie Curie Director of Nursing and Quality, said: “These harrowing stories are incredibly difficult to read, but it's so important that we are aware of the stark reality facing nurses, clinical teams, families and patients every day.

“When someone has taken the time to think about how they want to die, that decision should follow them, wherever they are and to whoever is caring for them. The Health Bill is a chance to fix the systems behind these decisions, so that a person's wishes are recorded once and available to everyone involved in their care.

“We’re also looking at how we can help. Marie Curie is trialling new ways of working with the NHS in hospital emergency departments and GP practices, to identify people approaching the end of life earlier and put the right support in place, including Advance Care Plans.”

Flavia Munn, Editor of Nursing Standard, said: "Our survey shows the intense pressures nurses are facing as they try to provide compassionate care to people at the end of life. It is encouraging that so many nurses feel comfortable talking to patients about end of life, but they also described the impact of limited time, staffing pressures and care plans that are not always in place or accessible when needed. These are complex issues, but the findings point to the need for better support and systems so that patients, families and staff can have confidence that people's care is dignified and wishes are understood and respected."

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1. **Advancing Role-Specific Competency in Hospice and Palliative Nursing: Development of the Hospice and Palliative Nurses Association (Hpna) Homes Resources**

Publication Date: 2026

Journal: Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association 28(5), pp. 205–207

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2. **Regional Pediatric Education and Assistance Collaborative for Hospice Nurses (REACH): A Tele-Educational Intervention**

Authors: Aglio, Taylor;Bobelis, Alexa;Autrey, Ashley;Hills, Tracy;Superdock, Alexandra;Madni, Arshia;Bien, Kelly;Mali, Nidhi and Kaye, Erica C.

Publication Date: 2026

Journal: Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association 28(5), pp. 217–222

Abstract: Despite the well-known benefits of hospice care for seriously ill children and their families, pediatric hospice services remain difficult to access across community settings. The vast majority of hospice organizations utilize an adult-focused paradigm, in which adult-trained providers often lack the requisite pediatric-specific education to provide high-quality hospice

care for children and families. Hospice nurses self-report significant discomfort with pediatric care provision, resulting in hesitation by hospice agencies to accept pediatric patients, further exacerbating deficits in pediatric hospice access across the nation. Given the growing numbers of children with serious illness eligible for hospice in the community, innovative strategies are urgently needed. To address this gap, a multidisciplinary team comprising physicians, nurses, psychosocial clinicians, community members, and bereaved parents was convened to develop the Regional Pediatric Education and Assistance Collaborative for Hospice Nurses (REACH) initiative. Using a community-based participatory research approach, a stakeholder-driven tele-educational intervention was designed, refined, and implemented as a pilot for hospice nurses across Tennessee. Pilot data showed this hub-and-spoke model to be feasible, acceptable, and impactful, increasing hospice nurses' knowledge and comfort with provision of pediatric care in the community. Future work will focus on the expansion of REACH across Louisiana, followed by other states.

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3. **Minimal Comfort Feeding in Advanced Dementia: Attitudes of Hospice and Palliative Care Professionals**

Authors: Becker, Clara;Wechkin, Hope;Bern-Klug, Mercedes;Pope, Thaddeus;Levine, Meredith;Shen, Megan J. and Loggers, Elizabeth

Publication Date: 2026

Journal: Journal of Pain and Symptom Management 72(4), pp. e327–e332

Abstract: Context Minimal Comfort Feeding (MCF) is a new approach to providing nutrition and hydration to persons with advanced dementia who have previously indicated (or whose surrogate believes) they would not want to live with advanced dementia. The acceptability of MCF has not been studied. Objectives To assess perceptions of hospice and palliative care (HPC) professionals toward MCF. Methods This cross-sectional exploratory survey study of a convenience sample was conducted at a national conference of HPC professionals in February 2025. During a presentation on MCF's definition and ethical basis, attendees engaged in audience response polling and an optional electronic survey. Descriptive results are presented. Results Fifty-one people attended the presentation. Forty-five attendees (88%) participated in audience polling, and 22 (43%) participated in both polling and the survey. The mean age of survey respondents was 50 (standard deviation 9.58), 19 (86%) identified as White, and 18 (82%) identified as women. Thirty-five of 42 respondents (83%) agreed or strongly agreed that MCF is an acceptable option for persons with advanced dementia (PWAD), and 93% (39/42) agreed or strongly agreed they would be comfortable discussing MCF with persons with early dementia or who are at risk for dementia as a potential future option. Sixty-nine percent (29/42) anticipated MCF would be somewhat or completely acceptable to families of PWAD, but respondents were divided regarding the ease of implementing MCF in clinical practice. Conclusion While MCF was highly acceptable in this study, the sample size was small and the risk of bias was high. Further research is needed.

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4. **Expanding End-of-Life Options for Incarcerated Individuals**

Authors: Bookbinder, Jack;Boaitey, Kwasi and Herington, Jonathan

Publication Date: 2026

Journal: The American Journal of Hospice & Palliative Care 43(10), pp. 1119–1125

Abstract: The aging prison population in the United States presents urgent challenges for providing appropriate end-of-life (EOL) care. Currently, there are two primary approaches to deliver this in a compassionate manner: medical release programs (MRPs) and prison-based end-of-life care programs (EOLCPs). Using New York State as a case study, we argue expanded MRPs represent the most ethical path forward, while acknowledging the continuing need for prison-based EOLCPs. Our analysis reveals significant barriers to accessing medical release, including lack of knowledge about the application processes, procedural inefficiencies, overreliance on prognostication, and social stigma. While prison-based programs offer some benefits, studies indicate they frequently fall short of community standards for EOL care, particularly regarding family involvement, pain management, and environment, including a shortage of beds and equipment. We argue for expanding MRPs based on three key considerations: (1) documented preferences of incarcerated individuals against dying in prison, (2) low recidivism rates among medically released individuals, (3) concerning variations in prison-based EOLCP implementation and oversight that likely leads to inconsistent care. While maintaining prison-based EOLCPs remains necessary for incarcerated people ineligible for medical release or those who prefer to remain in facility care, expanding MRPs may better protect patient autonomy and dignity. We recommend three policy changes: (1) training and requiring correctional staff to identify potential eligible individuals for medical release, (2) training community medical professionals on state medical release policies to facilitate applications during community care episodes, and (3) establishing independent physician panels for medical evaluations to expedite evaluations and reduce potential bias.

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5. **Predicting Complicated Grief in Caregivers of End-of-Life Cancer Patients**

Authors: Bovero, Andrea;Di Girolamo, Irene;Lamannis, Chiara;Cito, Alessandra Loreta;Borghetti, Patrizia;Bastita, Roberta;Pace, Fabrizio;Spatola, Melania;Perrini, Marzia;Bordino, Valentina;Battista, Manuela;Bruccheri, Selene;Savoca, Carmela;Iannopollo, Letizia and Oliva, Francesco

Publication Date: 2026

Journal: The American Journal of Hospice & Palliative Care 43(10), pp. 1049–1056

Abstract: ObjectivesPersistent Complex Bereavement Disorder (PCBD) is an independent clinical condition characterized by a severe grief reaction lasting more than twelve months after the loss of a loved one. This study aimed to assess the rate of PCBD among caregivers of end-of-life patients. The secondary aim was to explore the role of several risk factors for PCBD, including psychosocial characteristics of both patients and caregivers, patients' dignity-related distress, attachment style, and perceived social support as well as symptoms of depression, anxiety, and perceived stress of caregivers.MethodsThis was a prospective, multicenter and national study involving twelve Italian palliative care units. The sample consisted of 139 cancer patient-caregiver dyads. For each participant a set of rating scales was administered.ResultsIn line with the literature, only a minority of caregivers experienced PCBD (6.47%). Younger caregiver age and higher pre-loss depression levels significantly

predicted PCBD six months after the patient's death.

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6. **Noticing and responding to end-of-life suffering in the PICU: A co-designed conceptual framework for nursing practice**

Authors: Broden Arciprete, Elizabeth,G.;Michelson, Kelly N.;Feder, Shelli L.;Marr, Jerris W.;Al-Roub, Nora;Gouda, Suzanne R.;Jones, Aubrey Mckenzie;Schopen, Ashleigh B.;Tapper, Alexandra K.;Pasek, Tracy A.;Kelly, Reena J.;Morris, Liz R.;Olszewski, Aleksandra E.;Gallagher, Christine;Taylor, J. A.;McCarthy, Sarah Brand;Snaman, Jennifer M. and Ananth, Prasanna

Publication Date: 2026

Journal: Intensive & Critical Care Nursing 96, pp. 104498

Abstract: Objectives Pediatric intensive care unit (PICU) nurses spend the most time with patients and families during a critical illness. However, nurses, families, and other clinicians conceptualize suffering differently, leaving some types of suffering when a child is nearing the end-of-life (EOL) unaddressed. PICU nurses are thus well-positioned but underequipped to address suffering during EOL. We aimed to 1) characterize distinctive features that indicate the presence and/or absence of suffering; and 2) identify nursing care responses that help attend to EOL suffering. Methods Using qualitative interpretive description, we collaborated with a purposive sample of bereaved parents and interdisciplinary health professionals, including nurses, to develop a conceptual model to better equip nurses to notice and respond to EOL suffering. The sample participated in 3 focus group discussions. Two coders generated descriptive codes from each focus group, which were revised with participants at subsequent sessions and then arranged into overarching categories. Categories and sub-categories were then co-designed into a conceptual model that was iteratively refined by participants and the research team. Results Participants (N = 25) included 8 parents, 6 PICU nurses, 3 PICU physicians/advanced practice providers (APPs), 3 palliative care physicians/APPs, and 5 allied health professionals. Together with the research team, participants co-designed A Conceptual Framework to Guide Bedside Nursing Care to Address EOL Suffering, which relates four overlapping categories: 1) Noticeable Indicators for Acknowledgement and Validation, 2) Responsive Indicators for In-the-Moment Interventions, 3) Collaborative Responses, and 4) Dynamic Contextual Factors. Participants described that some indicators of suffering may be acknowledged and/or validated (such as shattered assumptive world) but not always eased. Whereas other indicators (such as physical and emotional expressions) may be responsive to in-the-moment interventions (such as facilitating opportunities for connection). Collaborative Responses included nurse strategies to address suffering such as partnering with parents, promoting connection and comfort, and connecting with resources. Dynamic Contextual Factors included external influences beyond the patient, family, and nurse, that shaped how nurses notice and respond to suffering, such as uncertainty. Conclusions This study helped operationalize indicators of and nurse-led responses to EOL suffering using a parent and clinician collaborative approach. The conceptual model can inform nurse-led, parent-partnered interventions to acknowledge and ease suffering among children nearing EOL and their families. Implications for Clinical Practice Some manifestations of suffering during EOL in the PICU may be readily addressable through nursing care while others may be witnessed and validated by nurses. Partnership between parents and nurses is a cornerstone of holistically

addressing suffering.

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7. **Exploring communication between people with intellectual disabilities and hospice staff: A conversation analysis pilot study**

Authors: Bruun, Andrea and Tuffrey-Wijne, Irene

Publication Date: 2026

Journal: Palliative Medicine , pp. 2692163261482008

Abstract: Background Communication challenges are key barriers for people with intellectual disabilities in accessing palliative care. However, no studies to date have closely analysed the communication between people with intellectual disabilities and palliative care staff. Aim To assess feasibility and acceptability of conducting a Conversation Analysis study with people with intellectual disabilities and hospice staff. Design A small-scale Conversation Analysis pilot study was conducted. Hospice consultations between people with intellectual disabilities and staff were recorded, transcribed, and analysed. Setting/participants Three consultations with three people with intellectual disabilities, one paid carer, three hospice nurses, and one welfare officer were video-recorded in a UK hospice between April and May 2025. Results Study procedures were deemed feasible and acceptable, enabling data collection. Most hospice patients with intellectual disabilities lacked capacity to consent and/or received in-home hospice care. This hindered recruitment due to data collection being restricted to hospice premises, and the Research Ethics Committee disallowing people who lack capacity to participate. Pain assessment was identified as a phenomenon of interest. Analysis showed an assessment involving multiple questions aimed at assessing frequency, severity, and management of the person's pain. The analysis displayed communicative challenges around brief patient answers with limited elaboration and how these were navigated by staff. Conclusion The Conversation Analysis pilot study was deemed feasible and acceptable. Analyses of pain assessments provided in-depth detail of the communication challenges and strategies employed to navigate them. This type of study and evidence can inform future communication and assessment guidelines.

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8. **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.

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9. **Policy priorities in palliative and end-of-life care: An exploration of issues reflected in public strategy**

Authors: Collins, Anna;Coghlan, Rachel;Agar, Meera R.;Greenland, Rohan;Hofmeyer, Christine;Boughey, Mark and Philip, Jennifer

Publication Date: 2026

Journal: Health Policy (Amsterdam, Netherlands) 172, pp. 105685

Abstract: Objectives To map the issues and priorities reflected in palliative and end-of-life care policy in Australia. Methods A qualitative documentary policy analysis examined the content of national and state-based policies and strategies on palliative and end-of-life care that were published in Australia and identified during July-September 2020. Summative content analysis was used to quantify policy characteristics, key domains and depth of coverage across strategy documents and to identify emergent themes. Results Nine policies comprising a total of 304 pages published from 2005-2019 and covering all jurisdictions of Australia were included. Whilst there was breadth of coverage of key palliative care domains across policies, the depth to which they were covered varied. Use of research evidence to guide policy outcomes was infrequent. Aspirational narratives were commonly used to convey shared principles of person-centred, high quality, integrated, coordinated and accessible care for the person and their family carer. The conceptual framing and definitions of palliative care and end-of-life care were inconsistent and varied, and there was a disconnect between this framing and the target audiences, the actions to achieve priority areas, and the intended outcomes. Conclusions This study documented the key priorities articulated in palliative care and end-of-life care policy in Australia, revealing possibilities for a re-imagined best-practice evidence-to-policy cycle.

10. **Relationship between Antibiotic Prescription and Survival in Hospice**

Authors: Crowley, Patrick D.;Siegel, Leslie R.;Dickinson, Drew T.;Lahr, Brian D.;Whalen, Francis X. and Challener, Douglas W.

Publication Date: 2026

Journal: Clinical Infectious Diseases : An Official Publication of the Infectious Diseases Society of America

Abstract: Background At hospice enrollment, patients are asked preferences regarding antibiotic use. Limited evidence on how these medications impact survival makes it difficult for clinicians to offer clear guidance. To support decision-making and antimicrobial stewardship, we assessed the association between antibiotic use and survival in outpatient hospice patients. Methods The association between antibiotic use and survival was evaluated using a time-dependent Cox proportional hazards model, adjusted for age, sex, Charlson Comorbidity Index, and hospice-qualifying conditions (HQCs). The cohort included patients enrolled in a large health system's outpatient hospice program between June 20, 2017, and January 1, 2023. Results Among 6169 patients with an HQC, 1233 received at least one antimicrobial prescription during the study period. The median time from hospice enrollment to first prescription was 16 days (IQR 3-83). Antimicrobial prescribing patterns varied by HQC category. In time-dependent Cox models, antibiotic use was associated with increased hazard of death (aHR 1.47; 95% confidence interval CI], 1.37-1.57).Stratified analyses showed the strongest association with increased mortality in patients with cancer HQCs (aHR 1.67; 95% CI, 1.50-1.87) and a survival benefit in those with infectious HQCs (aHR 0.60; 95% CI, 0.40-0.89). Discussion Physicians, patients, and families often overestimate the benefits of antibiotics near the end of life. The observed increase in mortality shortly after antibiotic initiation suggests that symptoms prompting antibiotic use may reflect the dying process rather than treatable infection. Knowledge of the limited role of antibiotics in prolonging life in hospice settings may improve decision-making and enhance the quality of end-of-life care.

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11. **The Role of Advance Care Planning in Hospital Transfer From Aged Care Facilities at the End-of-Life: A Scoping Review**

Authors: Gillan, Pauline Catherine;Podham, Maryanne;Hanson, Melissa and Parker, Christina

Publication Date: 2026

Journal: Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association 28(5), pp. E217–E224

Abstract: Approximately 70% of aged care residents are transferred to a hospital during the last few months of life. Many factors contribute to hospital transfer at the end-of-life; however, little is known about the role of advance care planning on hospital transfer decision-making. A scoping review using Arksey and O'Malley's framework and the Joanna Briggs Institute Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews was conducted to reveal the available research on hospital transfers of aged care residents at the end-of-life and the role of advance care planning. Seven databases were

searched. One hundred and ninety-seven potential papers were identified from screening. After applying the population concept context inclusion and exclusion criteria, 23 research papers were identified; most were quantitative (n = 15), n = 7 were qualitative, and 1 was mixed methods. Studies were from 9 different countries and published between 2004 and 2024. Advance care plans or advance care directives that included instructions to not resuscitate or not hospitalize resulted in fewer hospital transfers than those that did not. Reasons for hospital transfer were classified as age, acuity, vulnerability, and family-related. Of concern were reports of hospital transfers against resident's wishes as documented on advance care plans and advance care directives.

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12. **Effective Palliative Care for Hospice Transitions**

Authors: Hua, May;Cid, Miguel;Barshied, Claire;Shelton, Rachel C.;Hu, Grace;Stekl, Natasha;Brill, Carrie;Carey, Elise C. and Morrison, R. S.

Publication Date: 2026

Journal: JAMA Internal Medicine

Abstract: Importance Variation in hospice use for patients with cancer exists between palliative care programs, but factors underlying this heterogeneity are unknown. Objective To identify hospital and palliative care program factors that may impact the ability of palliative care teams to affect hospice use in cancer. Design, Setting, and Participants This multicenter qualitative study included 6 palliative care programs in the United States. Using a cohort of patients with metastatic cancer who received specialist palliative care, a positive-negative deviance approach was used to select 3 programs with high and 3 programs with low performance on hospice use. In-depth site visits were conducted and included semistructured interviews with palliative care and oncology clinicians and patients as well as in-person observation. Interviews were conducted from February 2025 to January 2026. Site visits were conducted from May 2025 to January 2026. Main Outcomes and Measures Program-specific practices and their potential effect on hospice use for patients with cancer. Results A total of 93 interviews and 424 hours of in-person observation were conducted across 6 palliative care programs in the Midwest, Upper South, and Deep South regions of the United States. Interview participants had a median (IQR) age of 43 (37-47) years; 68 (73.1%) were female; clinicians had a median (IQR) of 11 (5-16) years of experience. There were notable differences in the relationships between palliative care and oncology teams between high- and low-performing programs. At high-performing programs, the relationship was characterized by mutual trust and respect, warmth and familiarity, and empathy for each other, whereas at low-performing programs, the relationship was characterized by a lack of trust and familiarity and negative regard for each other. Factors observed in programs with positive relationships included intentionality in relationship building, physical presence and proximity between teams, use of real-time communication, and the palliative care team having a service-oriented mentality and a reputation for reliable service. At high-performing programs, observable differences in care included collaborative care delivery, increased access and timeliness of palliative care, and earlier introduction of hospice by oncology clinicians. Conclusions and Relevance In this multicenter qualitative study, differences in the relationship between palliative care and oncology teams were identified that may mechanistically affect end-of-life patient outcomes. These findings are important to ensure the delivery of high-quality care for

all patients with cancer.

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13. **Inpatient Hospice Access in the United Kingdom: A Spatial Provision Analysis**

Authors: Jayaprakasan, Akshithanand Kuzhikkat;Doughty Herrera-Carrasco, Kristiam;White, Nicola;Sallnow, Libby;Pinzón-Calderón, Sofía;Vélez-Restrepo, Laura;Santana, Isabelle;Sharma, Parth and Correa-Morales, Juan

Publication Date: 2026

Journal: Journal of Palliative Care 41(4), pp. 359–368

Abstract: ObjectiveTo evaluate spatial access to inpatient hospice units across the UK by analysing travel times and population coverage at national and subnational levels.MethodsA population-based spatial analysis using UK-wide data. Hospice locations were mapped, and motorised travel times to the nearest unit were estimated. Access population coverage was calculated for the following time thresholds: 30, 60, and 120 min. All 199 adult inpatient hospice units operating within the UK were included. High-resolution population data (1 km^2) from the WorldPop dataset and administrative boundaries from the UK Office for National Statistics were used to estimate access for the total population.ResultsMedian travel times varied widely: 16.4 min in England, 25.5 in Wales, 40.3 in Northern Ireland, and 70.4 in Scotland. Within a 30-min threshold, 97.6% of England's population had access compared with 78.5% in Wales, 70.3% in Scotland, and 68.5% in Northern Ireland. Even with a 60-min threshold, 15.4% of Scotland's population and 6.4% of Northern Ireland's remained without access.ConclusionsThis study provides the first national spatial analysis of hospice inpatient access in the UK, highlighting persistent regional inequities. Geographic accessibility analysis offers valuable insights to guide equitable service planning and should inform future policy and research.

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14. **End-of-Life Trajectories Among Hospitalized Muslim Patients: Evolving from Aggressive to Comfort-Focused Care Across ICU, Post-ICU, and Ward Settings**

Authors: Khalid, Imran;Imran, Manahil;Imran, Raafey;Akhtar, Muhammad Ali;Imran, Maryam;Alshehri, Basel Ghurm;Imran, Ibrahim M.;Salman, Anam;Khalid, Tabindeh Jabeen;Muhammad, Saqib;Khateeb, Faisal and Ali, Syed S.

Publication Date: 2026

Journal: The American Journal of Hospice & Palliative Care 43(10), pp. 1098–1106

Abstract: BackgroundMuslim patients have historically received aggressive end-of-life care, though palliative acceptance is growing. The factors that influence ICU (aggressive) vs ward (comfort-focused) deaths remain unclear, limiting value-concordant care.PurposeTo examine end-of-life care patterns and predictors of ICU vs ward death among Muslim patients, to guide culturally sensitive care.MethodsRetrospective cohort of adult Muslim decedents (2021-2024) at tertiary hospital in Muslim-majority country, stratified by death location: ward, ICU, and post-ICU ward. Multivariable logistic regression identified predictors of ward deaths.ResultsFrom fifty-thousand admissions, 1859 Muslim decedents were analyzed: ward (53%, *n* = 981), ICU

(39%, *n* = 722), and post-ICU ward (8%, *n* = 156). Ward deaths involved older, comorbid patients, often with cancer (63%); ICU deaths were predominantly male with acute illnesses (29% sepsis). Post-ICU deaths showed intermediate profiles but highest tracheostomy rate (22%) and longest stays (48 days). ICU deaths had greatest life-sustaining interventions (82% mechanical ventilation), while ward deaths had highest palliative-care involvement (66%). Do-Not-Attempt-Resuscitation (DNAR) status rose from 20% on admission to 88% at death, with earliest transitions in ward deaths (median 3 days vs ICU: 15; post-ICU: 18). Ward deaths were independently associated with palliative care (aOR 15.11), code status discussion documentation (aOR 4.56), pre-existing terminal disease (aOR 2.98), cancer (aOR 1.61), and comorbidity burden (aOR 1.29), all *P* < .05.ConclusionMuslim ward deaths were associated with palliative involvement, prior terminal diagnoses, and earlier DNAR; while ICU/post-ICU deaths reflected aggressive care with delayed transitions. DNAR adoption was high (88%) but late, underscoring the need for earlier, culturally aligned goals-of-care discussions.

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15. **Effect of Narrative-Based Palliative Care on Psychological Stress, Quality of Life, and End-of-Life Acceptance in Elderly Terminal Cancer Patients and Their Families**

Authors: Li, Junhua;Zhou, Linlin and Sun, Lijie

Publication Date: 2026

Journal: The American Surgeon 92(10), pp. 2652–2660

Abstract: ObjectiveThis study aimed to preliminarily evaluate the impacts of narrative-based palliative care on psychological stress, end-of-life acceptance, and quality of life in elderly terminally ill cancer patients and their family caregivers.MethodsThis single-center, small-sample randomized controlled study enrolled 50 elderly terminal cancer patients. Patients were randomly assigned to either the observation group or the control group (n = 25 each). The observation group received narrative-based palliative care, while the control group received routine standard care. Family psychological stress was assessed using the Relative Stress Scale (RSS), and patients' perceived stress was evaluated with the Perceived Stress Scale-10 (PSS-10). Caregiver satisfaction was measured using a hospital-developed questionnaire. Patients' quality of life was evaluated using the SF-36, Chinese Version of the Death Attitude Profile (DAP-C), and Pittsburgh Sleep Quality Index (PSQI), respectively.ResultsBaseline characteristics did not differ significantly between the two groups (*P* > .05). Post-intervention, the observation group demonstrated significantly lower psychological stress among family members and higher caregiver satisfaction (*P P* < .05).ConclusionAs a small-sample, single-center study, these findings offer preliminary evidence that narrative-based palliative care may reduce psychological stress in elderly terminal cancer patients and caregivers while enhancing patients' quality of life, sleep quality, and acceptance of death. However, the limited sample size, single-site design, and narrow inclusion criteria restrict generalizability. Larger multicenter trials are needed to confirm these results.

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16. **Considerations of equity in the development of tools that identify and respond to end-of-life carer support needs: a scoping review**

Authors: Long, Hannah A.;Rowland, Christine;Higgerson, James;Hall, Alex;Urwin, Sean and

Brooks, Joanna

Publication Date: 2026

Journal: BMJ Open 16(9), pp. e121897

Abstract: Objectives To (1) systematically identify tools developed to assess and address the support needs of informal carers in palliative or end-of-life care and (2) examine the extent to which socially stratifying sample characteristics have been reported following tool use. Design A systematic scoping review was conducted. Methods Medline, CINAHL, PsycINFO, ASSIA, ProQuest Central and Web of Science databases were searched from inception to May 2024 and again in May 2025. Primary studies using any methodology reporting the development and/or use of tools to assess informal carer support needs in end-of-life care were included. Consistent with scoping review methodology, we did not conduct a quality appraisal of included studies. We extracted tool characteristics, frequency of use and sample characteristics according to PROGRESS+. Results A total of 74 articles were included. From these, 24 unique tools were identified. Nine tools were used in ≥2 articles, while 15 were used only once. The most commonly used tools were the Carer Support Needs Assessment Tool (35 articles), the Family Inventory of Needs (6 articles), the Carer Alert Thermometer (5 articles) and the Spiritual Needs Inventory (4 articles). There was limited evaluation of tools beyond psychometric validation. There were substantial gaps in equity-informed caregiver sample reporting. While gender, age and country of participants were commonly reported, most other PROGRESS+characteristics were inconsistently or minimally reported. Conclusions While numerous tools exist to assess and address informal caregiver support needs, there is considerable variation in tool uptake, evaluation and the extent to which tools consider equity factors. There is a need for equity-informed tool development and clearer conceptualisation of caregiver needs, alongside efforts to evaluate tool implementation, impact and sustainability in palliative care settings.

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17. **The effect of palliative care involvement in vascular patients at the end of life**

Authors: McCarthy, Angela;Wrana, Kristy;Triantafyllou, Emma;Li, Ya-Huei;Strycharz, Carol;Lynch, Lindsay and Gifford, Edward D.

Publication Date: 2026

Journal: Journal of Vascular Surgery 84(4), pp. 1045–1052

Abstract: Background Vascular surgeons frequently manage critically ill patients and support complex end-of-life decision-making. Despite well-documented benefits of palliative care in serious illness, prior studies report that only 25% of patients receiving vascular surgery services near the end of life received such support. We evaluated the integration of palliative care for patients receiving vascular surgery services at the end of life, examining both utilization rates and its impact on care trajectories. Methods Adult patients hospitalized at a tertiary academic medical center between January 1, 2017, and December 31, 2022, who received vascular surgery consultation or intervention and were determined to be near the end of life, defined as in-hospital death or discharge to inpatient or home hospice, were included. Patient demographics, comorbidities, admission problem, vascular intervention (consultation

vs surgical intervention), intensive care unit stay, overall length of hospital stay, palliative consultation ordered, and discharge dispositions (such as hospital death without hospice, hospital death with hospice, and nonhospital death with hospice) were compared by palliative consultation utilization. The code status and goal of care before vs after palliative consultation among patients who received palliative consultation were compared. Results Of the 329 end-of-life patients, 196 (60.7%) received a palliative care consultation. Patients who received and those who did not receive palliative care were similar in terms of gender, race, ethnicity, and comorbidities. Although palliative care consultation did not affect whether a patient received vascular surgery, it did influence their care trajectory. Those without a palliative consultation were more likely to undergo a code (18.0% vs 6.6%; P = .001). After palliative consultation, the proportion of patients with a code status of do-not-resuscitate increased from 50.0% to 77.4%, and the proportion with a full code designation decreased from 50% to 22.6% (P < .001). Patients with the goal of care to allow natural death increased to more than half of the patients from 18.4% after the palliative consultation (P < .001). On multivariate analysis, patients admitted with a primary vascular diagnosis were more likely to receive palliative care consultation (odds ratio, 6.4; 95% confidence interval, 3.3-12.2; P < .001). An extended hospital stay (odds ratio, 1.1; P < .001) was associated with a higher likelihood of a palliative consultation order. Conclusions Palliative care consultation was associated with significant changes in code status and goals-of-care decisions among patients receiving vascular surgery services at the end of life. These findings highlight an opportunity for vascular surgeons to proactively integrate palliative care, improving alignment between clinical interventions and patient preferences.

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18. **Beyond Treatment Disagreement: Ethical Conflict, Surrogate Decision-Making, and Nonbeneficial Treatment at the End of Life**

Authors: McCullough, Joshua

Publication Date: 2026

Journal: Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association 28(5), pp. 243–244

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19. **Hospice family caregivers' preparedness to provide care during the death vigil**

Authors: Oliver, Debra Parker;Becker, Todd D.;Helmkamp, Joanna;Benson, Jacquelyn J.;Daniels, Justin D.;Demiris, George;White, Patrick and Washington, Karla T.

Publication Date: 2026

Journal: Patient Education and Counseling 152, pp. 109771

Abstract: Family caregivers of hospice patients face numerous demands during their family member's final days of life, including escalating symptom management needs, physical strain, and intense emotional challenges. Informed by preparedness theory and the National Cancer Institute framework for patient-centered communication (adapted for family caregivers), this qualitative descriptive study explored the knowledge, skills, and presence family caregivers required to fulfill their role as their family member was actively dying, as well as their

perceptions of their communication with hospice teams during this particularly stressful time. Data for this secondary analysis were drawn from individual interviews with a convenience and snowball sample of 50 bereaved caregivers who had participated in a broader cross-sectional study of hospice death vigils, defined as gatherings of family members and friends around a person who is in the final week of life. Interview transcripts were analyzed using an abductive content analysis approach, combining artificial intelligence (AI)-assisted coding with investigator review. Findings indicated that, caregivers received information, identified ways to provide comfort, and recognized the importance of being present as their family member was dying however, their actions were often reactive rather than proactive, reflecting a potential gaps in preparedness. Caregivers highlighted supportive communication with hospice providers and identified opportunities for improving communication to support their preparedness to provide adequate care and maintain their own well-being during their family member's final days.

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20. **Palliative and End-of-Life Care Knowledge, Attitudes, and Representations Among Caregivers of Individuals With Major Neurocognitive Disorders and the General Population: A Cross-Sectional Study**

Authors: Pellerin, Roxane;Castonguay-Paradis, Sophie;Bravo, Gina;Plaisance, Ariane;Couture, Vincent;Downar, James;Dupéré, Sophie;Gagnon, Marie-Pierre;Roos, Pauline;Dumont, Isabelle and Tapp, Diane

Publication Date: 2026

Journal: Journal of Palliative Care , pp. 8258597261463917

Abstract: BackgroundCaregivers of individuals with major neurocognitive disorder are often required to participate in decision-making for their loved ones, including the initiation of palliative care and end-of-life care (PEoLC). Yet, it remains unclear whether caregivers are prepared to engage in such decision-making.ObjectivesThis study aims to assess the knowledge, attitudes, and representations of caregivers of individuals with major neurocognitive disorders regarding PEoLC practices, and to examine the extent to which sociodemographic variables influenced these outcomes compared to the general population.MethodA community-based cross-sectional questionnaire study was conducted in Quebec, Canada. A non-probability convenience sampling method was used to recruit 572 participants from the general population, who were then divided into two groups according to their experience as caregivers for a person with a neurocognitive disorder until their death.ResultsCaregivers demonstrated a higher level of knowledge, with mean scores of 10.1 versus 8.7 out of 14 (ranges 0-14, $P < .01$), as well as generally favorable and similar attitudes and representations toward PEoLC compared to the general population. Individuals' interpretations of ethical dilemmas at the end of life were also shaped by their religious beliefs. Results further indicate that 8% of caregivers reported having no experience with palliative care, although they all supported a person with a major neurocognitive disorder until their death.ConclusionThis study reaffirms the central role of family caregivers in end-of-life decision-making, while underscoring the influence of religiosity on their attitudes and representations. Further research is needed to understand how these factors interact in different cultural and legislative contexts, in order to better support caregivers, guide healthcare practice, and inform public policy, ultimately improving care for individuals with

major neurocognitive disorders and their families.

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21. **Advance care planning in the end-of-life phase: coordinating between social worlds**

Authors: Posthuma, Estella;Schuurmans, Jitse;Peeters, Hugo;Bal, Roland and Wallenburg, Iris

Publication Date: 2026

Journal: Social Science & Medicine (1982) 406, pp. 119669

Abstract: Advance care planning (ACP) for people in the last phase of life, living at home with complex care needs, is increasingly seen as a valuable practice to deliver patient-centred care and to prevent unnecessary hospitalizations and delay nursing home admissions. A notable difficulty of ACP is the coordination of ACP-practices over various domains involved in patient care (e.g. home care, GP care, hospital care). We draw on ethnographic data on ACP practices in home care, GP-care and hospital care in the Netherlands. We use social worlds theory to analyse the different information requirements of collaborating social worlds in end-of-life care (home care; GP care; hospital care) and show how actors succeed in coordinating ACP through three different coordinating practices: (1) via articulation work; (2) via boundary objects; and (3) via patients and their loved ones as boundary subjects. Furthermore, we articulate the conditions under which written ACP-agreements emerge as boundary objects to coordinate ACP practices in different domains of patient care. In the paper, we contribute to literature on coordination of care across domains by presenting a holistic account of care coordination practices in end-of-life care.

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22. **Hospice Use and Spiritual Support for Family and Friend Caregivers at the End of Life and During Bereavement**

Authors: Quigley, Denise D. and Kirkegaard, Allison

Publication Date: 2026

Journal: The American Journal of Hospice & Palliative Care 43(10), pp. 1064–1074

Abstract: ContextAs family and friend caregivers navigate care recipients' end of life and death, they may benefit from spiritual support. Hospice care typically includes access to chaplain care and grief support. However, this connection is underexplored.MethodsOur cross-sectional observational study examined bereaved caregivers' responses to a one-time survey module added during the 2023 wave of the Care Network Connections over Time study, a nationally representative longitudinal survey of family and friend caregivers helping adults 50 and older. We examined hospice use among care recipients and its relationship to spiritual support for caregivers.ResultsAmong the 315 caregiving dyads, 61% (*n* = 193) of care recipients were on hospice at time of death. Controlling for sociodemographic and contextual characteristics, caregivers of care recipients on hospice were more likely than those not on hospice to both want (OR = 2.66, *P* = .02) and receive (OR = 2.57*, P* = .04) spiritual support while caregiving. Caregivers belonging to a religious tradition were more likely to want and receive spiritual support than nonreligious caregivers. Evangelical Protestants wanted support

more often than other religious groups in bereavement and more than Catholic/Orthodox caregivers while caregiving. The type of spiritual support received varied by religious affiliation (eg, Catholic/Orthodox caregivers were more likely than others to receive support through rituals and sacraments). During bereavement, caregivers' desire for and receipt of spiritual support were not significantly associated with care recipients' hospice use.ConclusionHospice is an important determinant of caregivers' spiritual support. Hospice is a key resource for promoting wellbeing during end-of-life caregiving but not into bereavement.

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23. **Disparities in hospice enrollment timing and end-of-life care intensity across non-cancer diagnoses: a 10-year hospital-based cohort study**

Authors: Wang, Chun-Li;Lee, Lung-Chun;Hsu, Chiann-Yi and Lin, Chia-Yen

Publication Date: 2026

Journal: Annals of Medicine 58(1), pp. 2670058

Abstract: Introduction Non-cancer patients with advanced illnesses often experience delayed hospice referral and high-intensity care near the end of life, yet cross-diagnosis comparisons remain limited. This study examined diagnosis-specific patterns in hospice use and care intensity among non-cancer decedents. Materials and Methods We conducted a 10-year retrospective cohort study of adults with hospice-eligible non-cancer diagnoses who died or were discharged in a moribund condition between 2010 and 2019 at a tertiary referral hospital in Taiwan. Primary outcomes were place of death and an aggressive-care score (0-5) based on five EOL indicators in the last 28 days: hospitalisation >14 days, ≥1 intensive care unit (ICU) admission, ≥1 emergency department (ED) visit, cardiopulmonary resuscitation (CPR), and intubation with mechanical ventilation. Multivariable logistic regression identified factors associated with high aggressive-care scores (≥4). Results Among 5,127 non-cancer decedents, 7% received hospice care, with rates varying across diagnostic groups. Most hospice enrolments (60.2%) occurred within 7 days before death. Hospice recipients had lower median aggressive-care scores (2 vs. 3, $p < 0.001$) and lower ICU admissions (39.7% vs. 63.7%), ED visits (62.2% vs. 75.1%), CPR (1.7% vs. 10.1%), and mechanical ventilation (9.2% vs. 23.2%). Advanced heart disease (aOR 1.95) and end-stage renal disease (aOR 1.96) were associated with high aggressive-care scores, while hospice enrolment was associated with lower odds of such scores (aOR 0.46). Conclusion Hospice care among hospitalised non-cancer decedents was infrequent and often initiated in the final week across diagnoses. These findings highlight diagnostic differences in end-of-life care intensity and support referral strategies for earlier palliative care integration.

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24. **Deprescribing in Hospice and Palliative Care: A Rapid Review of Clinical Tools, Nursing Practice Considerations, and Nursing Policy Implications**

Authors: Wilson, JoAnn;Koplin, Andrea and Fasolino, Tracy K.

Publication Date: 2026

Journal: Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association 28(5), pp. E210–E216

Abstract: Adults with serious illnesses and limited life expectancy often continue medications with little meaningful benefit, contributing to polypharmacy, adverse drug events, patient distress, and caregiver burden. In hospice and palliative care, deprescribing is a systematic, patient-centered process used when medication-related harms outweigh potential benefits. This rapid review examined contemporary evidence on deprescribing practices for adults with serious illnesses, with emphasis on medication burden, deprescribing patterns, current tools and frameworks, and the nursing role in leading, coordinating, and communicating deprescribing decisions in hospice and palliative care. Systematic searches of PubMed, CINAHL, and Scopus were conducted for studies published from January 2020 through December 2025. Of 494 records identified, 37 studies met the inclusion criteria, including qualitative and observational studies, pharmacist-led interventions, systematic reviews, and evaluations of frameworks such as STOPPFrail and OncPal. Evidence indicates that long-term preventive medications near the end-of-life, including statins, antihypertensives, hypoglycemics, antithrombotic agents, and vitamins, often provide limited short-term benefit while increasing the risk of side effects and treatment burden. Despite this, deprescribing remains inconsistent and frequently reactive rather than proactive. Nurses play a central role in medication reconciliation, identifying potentially inappropriate medications, facilitating shared decision-making, and monitoring patient response after medication withdrawal. Deprescribing is an essential component of high-quality hospice and palliative nursing care. When implemented through structured, patient-centered, nurse-led approaches, deprescribing can reduce harm, align treatment with patient goals, and improve comfort and quality of life. Additional research is needed to strengthen communication strategies, operational models, and nursing education related to deprescribing.

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25. **Journey Mapping of the Patient Experience from Diagnosis to End of Life in Lung Cancer: A Qualitative Meta-Synthesis**

Authors: Zhang, Fanyun;Wang, Yuanqi;Xiao, Yalin;Li, Jinquan;Liu, Yi;Li, Han;Wang, Zhen and Li, Weihong

Publication Date: 2026

Journal: Seminars in Oncology Nursing 42(5), pp. 152260

Abstract: Objectives This study aimed to systematically synthesize the lived experiences and journey narratives of lung cancer patients across disease stages, and identify key tasks and pain points during the disease course through patient journey mapping, providing evidence for comprehensive disease management throughout the patient journey. Methods Ten databases, including PubMed, Embase, Web of Science, Scopus, PsycINFO, CINAHL, Cochrane Library, CNKI, Wanfang, and SinoMed, were systematically searched, with a search period from database inception to August 15, 2025. The JBI Critical Appraisal Tool for qualitative studies was used to evaluate the quality of studies, and the results were integrated using a meta-aggregative approach. Results Thirteen studies were included. Based on the patient journey mapping, the lung cancer patient journey comprises four potential stages: evaluation and diagnosis, initial treatment, maintenance therapy, and end-of-life. A total of 30 themes emerged within three dimensions: tasks, emotions, and pain points. Each dimension of each stage consists of 2-3 themes. Conclusion The journey of lung cancer patients is protracted and complex, characterized by stage-specific needs and challenges. Future management

strategies should be tailored to these distinct phases, providing precision supportive care to optimize treatment outcomes and enhance patients' quality of life. Implications for Nursing Practice This Patient Journey Map integrates routine clinical pathways with patients' lived experiences across each stage, revealing stage-specific challenges and providing targets for tailored nursing interventions. The framework promotes multidisciplinary, digitally enabled supportive care and indicates the importance of including patients' social circles to enhance patient-centered outcomes.

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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