NHS
Royal United Hospitals Bath
NHS Foundation Trust

End of Life Care

Current Awareness Bulletin

November 2025

Our Current Awareness Bulletins provide details of recently published articles in a given subject. They are a quick and easy way to keep up to date.

Please contact the Academy Library to request any articles:

✉ **ruh-tr.library@nhs.net**

☎ **01225 82 4897/4898**

Carry out basic searches using the Knowledge and Library Hub.

Sign up to NHS OpenAthens to access our subscriptions.

Contact us to receive our bulletins via email each month.

Get personalised alerts via our KnowledgeShare service.

ruh.nhs.uk/library

New training via MS Teams available from the Academy Library:

- **Bitesize searching databases for evidence: a quick guide to help you develop your literature searching skills**
  45 minutes. Learn how to transform a question into a search strategy, and how to find the best evidence in a database.
  Next sessions: 22nd January 2026 @ 2pm and 13th February 2026 @ 3pm

- **Simple and painless evidence into practice (BMJ Best Practice and the LKS Hub)**
  30 minutes. Learn about quick and hassle-free ways to seamlessly incorporate evidence into your daily work.
  Next sessions: 16th January 2026 @ 10am and 2nd February 2026 @ 11am

- **Quickfire health literacy: communicating with patients more effectively**
  30 minutes. Learn about the communication barriers patients may encounter, and ways to ensure they get the most from their care.
  Next sessions: 7th January 2026 @ 2pm and 19th February 2026 @ 3pm

Book a session today at https://forms.office.com/e/HyiSXfDaYV (these sessions will be held on a monthly basis)

New books available from the Academy Library

Somewhere towards the end / Diana Athill 2008

---

1. **Artificial intelligence-based models for clinical prognosis at the end of life in the ICU.**

Authors: Garces M.G.;Garcia J.V.;Montoya J.C.;Triana C.J. and Hernandez Rincon, E. H.

Publication Date: 2026

Journal: International Journal of Medical Informatics 206(pagination), pp. Article Number: 106156. Date of Publication: 01 Feb 2026

Abstract: Introduction: Artificial intelligence (AI) has emerged as a promising tool to enhance clinical prediction in critically ill patients near the end of life in the intensive care unit (ICU), overcoming the limitations of traditional prognostic scales.
Aim(s): To identify and describe artificial intelligence models implemented to support prognostic decisions at the end of life in the intensive care unit (ICU).
Method(s): A scoping review was conducted across three databases (PubMed, Scopus, and Web of Science), encompassing studies published between 2015 and 2025 that utilised AI algorithms to predict relevant clinical outcomes in critically ill patients near the end of life.
Result(s): Twenty-eight studies were included. The algorithms applied in the ICU showed good performance in terms of anticipating outcomes such as mortality, withdrawal of life support, or

clinical deterioration. There was variability in the type of algorithms used, data sources, and metrics reported, which limited comparisons between studies.
Conclusion(s): Artificial intelligence represents a promising tool for improving the clinical prognosis of critically ill patients at the end of life. However, greater methodological robustness and validation in real contexts are needed to strengthen its usefulness in clinical decision-making. Copyright © 2025 The Authors

---

2. **Psilocybin-assisted therapy for demoralisation in hospice patients: feasibility, safety and preliminary efficacy.**

Authors: Beaussant Y.;Sager Z.;Brennan C.;Kristan I.;Ljuslin M.;Mazzola E.;Macdonald D.;Murphy M.E.;Nigam K.;Rinaldi A.D.;Sanders J.;Schaefer K.G.;Sholevar R.;Summer L.;WalijiBanglawala A.;YudilevichEspinoza S. and Tulsky, J. A.

Publication Date: 2025

Journal: BMJ Supportive & Palliative Care (pagination), pp. Date of Publication: 03 Nov 2025

Abstract: OBJECTIVES: To assess the feasibility, safety and preliminary efficacy of psilocybin-assisted therapy (PAT) for demoralisation in terminally ill patients receiving home hospice care.
METHOD(S): In this open-label pilot trial, 4607 home hospice patients at a large community hospice were screened over 22 months; 66 were approached, 15 enrolled and 10 received psilocybin. Participants completed two home-based preparation sessions, a single 25 mg oral psilocybin session at an inpatient hospice facility, and two home-based integration sessions. Feasibility was assessed through recruitment, retention and acceptability. Safety was evaluated via adverse event monitoring, and preliminary efficacy was assessed using changes in demoralisation scores and other psychosocial measures.
RESULT(S): The intervention was well tolerated, with no serious adverse events attributed to psilocybin. At week 3, demoralisation scores significantly decreased (mean reduction: 8.8 points, p=0.0196), despite ongoing clinical decline. Grief- and peace-related themes were prominent during psilocybin sessions. While six participants rated the treatment favourably on the Reaction to Research Participation Questionnaire global evaluation factor, three rated neutral on one or more items, suggesting that the emotional intensity and demands of the intervention may influence acceptability.
CONCLUSION(S): This study provides initial evidence that PAT can be feasibly and safely integrated into hospice care for terminally ill patients. Further research is needed to optimise delivery and further assess therapeutic potential.
Copyright © Author(s) (or their employer(s)) 2025. No commercial re-use. See rights and permissions. Published by BMJ Group.

---

3. **Show and Tell: Photography and Storytelling to Better Understand the End-of-Life Experience of Families in the Intensive Care Unit**

Authors: Binette, Emilee;Elwell, Joy;Parekh de Campos, Amisha and Anderson, Robert V.

Publication Date: 2025

Journal: Omega 92(2), pp. 865–893

Abstract: Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; End-of-life in the Intensive Care Unit (ICU) is common, costly, and can contribute to negative health outcomes for bereaved family members. Insufficient understanding of the family experience results in poor quality, highly variable care riddled with deficiencies including effective identification and application of evidence-based clinical interventions. Successfully managing the multitude of transitions, for example changes in family role or personal identity requires creative practice guided by theory. This project supports the feasibility of using peri-mortem photographs captured by family members with story-telling and a standardized measurement of grief to explore the family experience of end-of-life in the ICU. Project findings reveal shared experiential themes and emphasize the value of photography and storytelling as meaning-making interventions for families. Further study to generalize findings and develop additional preventative and therapeutic interventions at and beyond end-of-life in the ICU is needed to better meet family needs and improve their health outcomes.

---

4. **A descriptive qualitative study exploring family dynamics in end-of-life care.**

Authors: Biney, Antoinette;Poku, Collins Atta;Dzansi, Gladys;Deegbe, David Atsu;Ohene, Lillian Akorfa;Sarfo, Jacob Owusu;Atibila, Fidelis;Nachinab, Gilbert Ti-Enkawol;Anaba, Emmanuel and Attafuah, Priscilla Yeye Adumoah

Publication Date: Oct 02 ,2025

Journal: International Journal of Palliative Nursing 31(10), pp. 484–498

Abstract: BACKGROUND: The extent of involvement of family caregivers in Ghana ranges from giving physical care and emotional support to making medical decisions and liaising with healthcare professionals. **METHODS**: This study used a descriptive exploratory qualitative methodology grounded in ethnographic theory. Data were collected through observations and interviews with 20 unpaid informal caregivers following a purposeful sampling recruitment. Semi-structured in-depth interviews, lasting 45 to 80 minutes, were conducted at home and on hospital premises, focusing on caregivers' involvement and the support services they received. Data were transcribed, translated and analysed using thematic analysis principles. **RESULTS**: The study found that caregivers were predominately female. Male caregivers were typically brothers, spouses or sons. Two primary themes emerged: the extent of caregiver involvement and the reasons for family involvement. Caregivers, despite their central roles in decision-making and extensive physical and emotional support, faced communication challenges with healthcare teams. These challenges, coupled with their moral and family obligations, underscore the complexity of their role. **CONCLUSION**: The findings highlight the critical role of family caregivers in the care of terminally ill patients and the diverse motivations behind their involvement. It is imperative that healthcare professionals, researchers and policymakers, recognise and support the vital contributions of family caregivers. This recognition and support are not only essential for improving palliative care outcomes, but also for ensuring the well-being of these caregivers.

5. **Association Between Systemic Anticancer Therapy Administration Near the End of Life With Health Care and Hospice Utilization in Older Adults: A SEER Medicare Analysis of End-of-Life Care Quality.**

Authors: Canavan, Maureen E.;Cheng, Lee;Xiang, Jenny Jing;Lin, John Kent;Hui, David;Zhao, Hui;Nortje, Nico;Ratan, Ravin;Cherny, Nathan;Pham, Trinh;Giordano, Sharon H.;Niu, Jiangong and Adelson, Kerin B.

Publication Date: Nov ,2025

Journal: Journal of Clinical Oncology 43(31), pp. 3391–3402

Abstract: PURPOSE: Use of cytotoxic chemotherapy at end-of-life (EOL) is associated with adverse quality of life, increased health care utilization, and lower hospice rates. Although EOL cytotoxic chemotherapy use has declined in recent years, EOL novel (immunotherapy and targeted therapy) use has increased. The association between use of novel therapies at EOL and health care utilization has not been widely studied. **METHODS**: We identified patients within SEER-Medicare who had part D coverage (excluding those with Medicare Advantage) age 66 years and older, and breast, colorectal, lung, prostate, bladder, cervical, kidney, liver, ovarian, pancreatic, melanoma, or uterine cancer. Patients were diagnosed between 2005 and 2019 and died between 2015 and 2020. We analyzed associations between EOL systemic anticancer therapy (SACT) use (overall and by subtype), and health care utilization in the last 30 days of life (emergency department [ED], hospitalization, intensive care unit [ICU], and inpatient death), and hospice with multivariable regression, controlling for sociodemographic and cancer covariates. **RESULTS**: Of 315,089 beneficiaries, 23,970 (7.6%) received SACT within 30 days of death. The breakdown by type was cytotoxic therapy 50.6%, immunotherapy 20.8%, targeted therapy 18%, and combination therapies 10.6%. After adjusting for covariates, any SACT use at EOL was associated with higher ED use (odds ratio [OR], 3.05 [95% CI, 2.95 to 3.15]), hospital admissions (OR, 2.64 [95% CI, 2.56 to 2.72]), ICU admission (OR, 1.78 [95% CI, 1.72 to 1.83]), hospital death (OR, 2.02 [95% CI, 1.96 to 2.08]), and lower hospice use (OR, 0.51 [95% CI, 0.50 to 0.53]) compared with no SACT. All subtypes of SACT were individually associated with higher health care utilization and lower hospice use (*P* **CONCLUSION**: All subtypes of SACT use were associated with markers of worse-quality EOL care. These data can inform decisions for current care guidelines and efforts to reduce overutilization.

---

6. **Creating an e-learning resource to improve clinical induction within hospices.**

Authors: Cassidy M.;Longwell S. and Khanche, S.

Publication Date: 2025

Journal: Journal of Pain and Symptom Management (pagination), pp. Date of Publication: 31 Oct 2025

Abstract: OBJECTIVES: Clinical induction for resident doctors rotating into new posts is vital for patient safety. Hospices provide repeated induction sessions to individual rotating doctors with limited resources. We proposed that a shared online learning resource could improve

efficiency. METHOD(S): We created a re-usable online learning resource on Moodle© and piloted at Marie Curie Hospice, Bradford. standardising the teaching, offering knowledge check quizzes and record of learning. We surveyed UK Marie Curie Hospices on their induction practices and with our digital education team developed a higher quality resource, hosted on the Marie Curie Virtual Learning Environment (VLE). RESULT(S): 6 of 9 hospices surveyed responded; the majority reported clinical induction is resource intensive and were interested in an online resource. 22 resident doctors completed the pilot resource. 50% completed a feedback survey; 100% respondents rated the resource good or excellent and 100% agreed it met their learning needs. 102 users have now accessed the resource; knowledge check quiz scores are 74-86%, with at least 20% improvement in confidence scores post resource completion. CONCLUSION(S): We have successfully developed a re-usable online learning resource for more efficient clinical induction within Marie Curie hospices. We propose that this could be adopted by other hospices. Copyright © 2025. Published by Elsevier Inc.

---

7. **Impact of consultation-based hospice palliative care team on self-determination respect rates.**

Authors: Choi H.L.;Kim J.A.;Seo M.H.;Lee E.J.;Heo Y.J.;Kim K.W.;Lee Y.;Cho I.Y.;Yoon S.E. and Shin, D. W.

Publication Date: 2025

Journal: Palliative & Supportive Care 23, pp. e197

Abstract: OBJECTIVES: Despite the increasing implementation of consultation-based hospice palliative care teams in tertiary hospitals of Korea, there is limited research on their impact on self-determination respect rates. Understanding this impact is crucial for improving end-of-life care practices and respecting patient autonomy. The aim of this study is to assess the trends in self-determination respect rates regarding advance care planning before and after the introduction of a consultation-based hospice palliative care team in a tertiary hospital.
METHOD(S): A retrospective observational study was conducted using medical records from a tertiary hospital in Korea from March 2018 to December 2023. The study included all patients aged 19 years and older with medical records at a tertiary hospital during the specified period. We examined the characteristics of patients referred to the palliative care team, the effects of the consultation-based hospice palliative care team on the completion rates of advanced care planning, and changes in self-determination respect rates.
RESULT(S): Following the introduction of the consultation-based hospice palliative care team, 411 patients were referred. The proportion of patients with completed advance care planning increased from 27.0% to 60.6% ($p < 0.001$). The overall number of advanced care planning completions and the self-determination respect rate also showed a marked increase, particularly from 2021 to 2022, when the respect rate spiked from 27.6% to 43.2%.
SIGNIFICANCE OF RESULTS: Introduction of a consultation-based hospice palliative care team improved the respect for patient self-determination in end-of-life care decisions. These findings support the integration of hospice care teams in tertiary hospitals to enhance early and informed end-of-life decision-making.

8. **End of Life in Boys and Young Men With Duchenne Muscular Dystrophy - The Perspective of Dying Men and Their Families: A Systematic Review and Thematic Synthesis of Qualitative Evidence**

Authors: Chrastina, Jan and Haroková, Martina

Publication Date: 2025a

Journal: Omega 92(2), pp. 589–619

Abstract: Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; Understanding the perceptions and experiences related to the end of life (EoL) of boys and men with Duchenne muscular dystrophy from their own and/or family perspective is limited based on the available qualitative empirical studies. This systematic review was done with a thematic synthesis of qualitative evidence according to the PRISMA Statement Guidelines and the SPIDER search tool. The review included empirical, qualitative, and relevant full-text studies published in 2000-2023 in the EBSCO Discovery Service, ISI Web of Science, Scopus, PubMed, and ProQuest databases. From o total of eight included qualitative studies, four main key themes were identified: "Being a parent/caregiver" - psychosocial aspects, needs, and experiences; "Communication about EoL with healthcare and other professionals" - positive experiences and personal shortcomings; "Discussions about…" - the issue of EoL, dying and death; and "End of life" - end-of-life care, planning and the need for palliative care.

---

9. **'Planning for Dying While Planning for the Future': A Qualitative Evidence Review of the Severity and Unpredictability of Progression, Dying, and End of Life in People With Late-Onset Forms of Spinal Muscular Atrophy and Their Families**

Authors: Chrastina, Jan and Haroková, Martina

Publication Date: 2025b

Journal: Omega , pp. 302228251388825

Abstract: Spinal muscular atrophy (SMA) is a severe, life-limiting neuromuscular condition associated with progressive disability and premature death. The condition significantly affects the quality of life of patients and their families, often resulting in psychological distress and unmet care needs. Despite growing clinical interest, qualitative evidence on the lived experiences of individuals with late-onset SMA types (II, III, IV) remains limited. This review aimed to synthesize qualitative findings on patient and family experiences in the context of complex symptomatology, unpredictable progression, burdensome caregiving, anticipatory grief, and end-of-life processes. A systematic search across EBSCO Discovery Service, Web of Science, SCOPUS, PubMed, and ProQuest identified 785 studies, of which seven met the inclusion criteria. The review followed PRISMA and SPIDER guidelines, and thematic synthesis revealed three key themes: (1) SMA as a serious condition with challenging symptomatology; (2) Severity of psychosocial impacts of SMA; (3) SMA in the context of experienced loss and premature death.

10. **Hope at the end of life: Can hope endure when life nears its end?.**

Authors: Corpuz, J. C.

Publication Date: 2025

Journal: Palliative & Supportive Care 23, pp. e198

---

11. **Teaching Where Life Ends: Peer-Assisted Learning in Hospice as a Model for End-of-Life Nursing Education**

Authors: Elliott, Gail M. C. and Knowlton, Mary C.

Publication Date: 2025

Journal: Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association 27(6), pp. 297–304

Abstract: Competing Interests: The authors have no conflicts of interest to disclose.; Nursing educational programs are expanding clinical learning opportunities to encompass the hospice/palliative/supportive sphere of care, as outlined in the American Association of Colleges of Nursing Essentials to prepare practice-ready nursing graduates. This article outlines one school's journey to integrate end-of-life clinical experiences across the curriculum, starting with beginning nursing students using a peer-assisted learning model at an inpatient hospice facility. Pairing senior and beginning nursing students using the peer-assisted learning model together in the hospice setting requires specific and differentiated objectives and goals for each set of students. Students appreciated feeling welcomed in this specialty setting, engaging in hands-on care, and deepening their understanding and comfort with end-of-life care. Faculty valued an environment that offered a unique way for students to develop tangible and power skills and required less faculty oversight. Using this educational structure, hospice nurses are in a unique position to model best practices and engage nursing students in a setting that excels in providing holistic, patient-centered care. Lessons learned and implications for practice are provided, including reflective journal assignments mapped to competency-based education subcompetencies. (Copyright © 2025 by The Hospice and Palliative Nurses Association. All rights reserved.)

---

12. **Are we Growing Leaders? Exploring Leadership Training in Hospice and Palliative Medicine Fellowship**

Authors: Flint, Lynn A.;Wallingford, Greg;Tatum, Paul;Bruno, Julie;Fernandez, Helen and Carey, Elise C.

Publication Date: 2025

Journal: Journal of Pain & Symptom Management 70(6), pp. e474–e481

13. **When Autonomy Fails: Ethics, Philosophy, and the Legal Duty of Palliative Care - Reflections on End-of-Life Medicine in the 21st Century.**

Authors: GeberJunior, J. C.

Publication Date: 2025

Journal: Palliative & Supportive Care 23, pp. e200

---

14. **Spiritual and cultural influences on end-of-life care decision-making: a comparative analysis of the Arab Middle East and the United Kingdom**

Authors: Hamdan Alshehri, Hanan;McParland, Chris;Bahri, Hibah Abdulrahim and Johnston, Bridget

Publication Date: 2025

Journal: Current Opinion in Supportive and Palliative Care 19(4), pp. 242–247

Abstract: Purpose of Review: This review seeks to explain the impact of cultural and spiritual factors on end-of-life care decision-making from different countries to assist in the development of coherent responses for palliative care.; Recent Findings: Spiritual and cultural factors shape end-of-life decision-making in the Arab Middle East and the United Kingdom. Arab cultures emphasize dignity through faith and family, leading to collective decisions, while the United Kingdom focuses on individual autonomy. Both allow withdrawal from futile treatment to alleviate suffering, but Arab approaches are more family centric. Additionally, spirituality in Arab cultures is often collective and religious, compared to the personal and secular practices common in the United Kingdom.; Summary: Western and Arab Middle East cultural beliefs influence our understanding of death, dying, and the acceptability of various care options. As people near the end of life, spiritual issues are likely to affect their values and preferences. (Copyright © 2025 The Author(s). Published by Wolters Kluwer Health, Inc.)

---

15. **Cultural considerations at end-of-life for people of culturally and linguistically diverse backgrounds: A critical interpretative synthesis**

Authors: Lambert, Elizabeth;Strickland, Karen and Gibson, Jo

Publication Date: 2025

Journal: Journal of Clinical Nursing 34(12), pp. 5050–5069

Abstract: Purpose/aim: To establish cultural considerations for people from culturally or linguistically diverse backgrounds at the end-of-life in Australia.; Background: Globally, there is a rapidly increasing proportion of the ageing population, and high levels of migration to Australia, the Australian healthcare community must recognise individualised and cultural needs when approaching death and end-of-life care. Many people from culturally and linguistically diverse backgrounds do not traditionally practice the palliative care approaches that have been developed and practised in Australia.; Design: A Critical Interpretive

Synthesis.; Methods: A review protocol was established using PRISMA 2020 guidelines and the literature searched using CINAHL, PubMed, Psych INFO and Medline from January 2011 to 27th February 2021. This search protocol results in 19 peer-reviewed results for inclusion in critical analysis.; Results: Included studies were qualitative (14), quantitative (4) and mixed methods (1). Four themes were identified from the literature: (i) communication and health literacy; (ii) access to end-of-life care services; (iii) cultural norms, traditions and rituals; and (iv) cultural competence of healthcare workers.; Conclusions: Healthcare workers have an essential role in providing care to people with life-limiting illnesses. Cultural considerations during end-of-life care are imperative for the advancement of nursing practice. To achieve effective care for people of culturally and linguistically diverse backgrounds during end-of-life care, healthcare workers need to increase their education and cultural competency. There is inadequate research conducted within specific cultural groups, rural and remote Australian communities and individual cultural competence of healthcare workers.; Implications for Practice: Continuing advancement within nursing practice relies on health professionals adopting a person-centred and culturally appropriate approach to care. To ensure individualised person-centred care is provided in a culturally appropriate way, healthcare workers must learn to reflect on their practice and actively advocate for people with culturally and linguistically diverse backgrounds during end-of-life care. (© 2023 The Authors. Journal of Clinical Nursing published by John Wiley & Sons Ltd.)

---

16. **Psycho-existential distress in hospice patients and their caregivers**

Authors: Mercadante, Sebastiano;Travia, Marco;Valle, Alessandro;Noce, Gugliemo;Sanzo, Flavia;Dabbene, Marcella;Lo Cascio, Alessio;Casuccio, Alessandra and Adile, Claudio

Publication Date: 2025

Journal: BMJ Supportive & Palliative Care

Abstract: Competing Interests: Competing interests: None declared.; Aim: To assess the psycho-existential distress of patients and their caregivers in a specific setting, like hospice.; Methods: Patients consecutively admitted to two hospices for a period of 8 months were enrolled. At admission (T0), patients were assessed by a routine data recording: age; gender; Edmonton Symptom Assessment Scale (ESAS); Memorial Delirium Assessment Scale (MDAS); Cut down, Annoy, Guilt, Eye-opener (CAGE); Karnofsky level; primary diagnosis; education; religiosity and comorbidities. Psycho-existential distress was assessed at T0 by the Psycho-existential Symptom Assessment Scale (PeSAS). The measurements were repeated 1 week after comprehensive palliative care treatment.; Results: 159 patients and 87 caregivers were considered. The majority of patients had a cancer diagnosis (88.7%). Non-cancer patients were older (p<0.0005), had a lower Karnofsky (p<0.0005) and higher cognitive decline (MDAS, p<0.0005). After 1 week of comprehensive palliative care treatment, significant changes were observed for most ESAS items and total ESAS in both patients and caregivers. PeSAS items were mild-moderate. All symptoms of PeSAS, except for depression, significantly decreased after 1 week of comprehensive palliative care with a significant decrease in total PeSAS. Caregivers showed similar psycho-existential distress, but total PeSAS did not significantly change. There was a positive correlation between patients and caregivers in the changes from T0 to T7 (Δ) for PeSAS (p=0<004) and total ESAS (p=0.005).; Conclusions: Admission to hospice improved both physical symptoms and psycho-existential distress in patients significantly and non-significantly in caregivers. (© Author(s) (or their employer(s)) 2025. No commercial re-use. See rights and permissions. Published by BMJ Group.)

---

17. **End of Life in Patients With Advanced Non-curable Cancer: Patient Considerations Around the Moment of Death**

Authors: Moreno, Socorro;Medina-Rico, Mauricio;Osorio Clavijo, Katalina;Rodríguez, Nicole,A.;Vicuña Jiménez, Víctor,M.;Calvache, Jose A. and de Vries, Esther

Publication Date: 2025

Journal: Omega 92(2), pp. 831–848

Abstract: Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; There is limited knowledge regarding Colombian patients with advanced cancer preferences regarding their final moments, place of death, and post-death wishes. To better understand these preferences, we conducted 23 in-depth interviews with patients between the ages of 28 and 78 receiving treatment at two academic hospitals and the National Cancer Institute. While many participants desired a peaceful death, few were comfortable discussing the topic of death directly. Some younger participants expressed an interest in euthanasia but had not received any guidance or support. While several participants preferred a home death, some expressed a desire to die in a hospital due to better symptom control. Additionally, when discussing post-death wishes, some participants expressed frustration about being unable to have these conversations with their loved ones and their preferences for funeral arrangements. Socioeconomic and geographical factors significantly impacted the wishes and preferences expressed, with many individuals hesitant to initiate difficult conversations.

---

18. **Improving Care for Those Living With Serious Illnesses and Individuals Approaching End of Life: A Decade of Investments.**

Authors: Munevar, Dianne;Riggle, Shelby L.;Martinez, Lia;Snyder, Rani and Fulmer, Terry

Publication Date: Oct ,2025

Journal: Journal of the American Geriatrics Society 73(10), pp. 2988–2994

Abstract: BACKGROUND: The mission of The John A. Hartford Foundation (JAHF) is to improve the care of older adults. Since 1982, JAHF has invested more than $724 million to advance the aging and health fields. The focus of this article is JAHF's serious illness and end-of-life priority area. This article seeks to understand the impact of JAHF's investment in this priority area and how JAHF's grantmaking strategy contributed to this impact. **METHODS**: NORC at the University of Chicago (NORC) conducted this assessment from August 2024-January 2025. It was conducted using a three-phase, mixed-methods approach. The assessment included a thorough document review of all grant documentation, the development of an impact framework to summarize outcomes and key program metrics, and surveys and interviews with partners. **RESULTS**: This assessment identified five outcomes,

each supported by key program metrics; outcomes include 1) increasing access to services through sharing best practices; 2) providing professional training to the health care workforce; 3) influencing public discourse through community engagement and messaging; 4) informing public policy through research, recommendations, and technical assistance; and 5) increasing collaboration and partnerships through network building. **CONCLUSIONS**: This assessment highlights JAHF's role of catalyst, collaborator, and convener. JAHF's approach to grantmaking-including mission alignment, commitment, flexibility, active engagement, and focus on collaboration-contributed to the impact achieved by grantees.

---

19. **Kinlessness and end-of-life care quality: does race and ethnicity matter?.**

Authors: Pei, Yaolin;Zhou, Zexi;Ge, Shaoqing;Qi, Xiang;Wang, Kaipeng;Mao, Weiyu and Wu, Bei

Publication Date: Nov 05 ,2025

Journal: Journals of Gerontology Series B-Psychological Sciences & Social Sciences 80(12)

Abstract: OBJECTIVES: Close family members provide the majority of end-of-life (EoL) caregiving. However, the number of kinless older adults (defined as lacking children and a partner) is increasing. Moreover, non-White older adults are more likely to rely on close families to provide care at the EoL than their White counterparts. Therefore, we examined the association between kinlessness and the quality of EoL care among older adults and the intersectional effect of kinlessness and race/ethnicity on EoL quality. **METHODS**: Data were derived from the combined Rounds 2-11 of the National Health and Aging Trends Study. The working sample included 3,045 older adults who were over 65 and living in the community or residential care facilities at the last interview. We used ordered logistic regression to examine both the independent effect of kinlessness and its intersection with race/ethnicity on the quality of EoL care among older adults. **RESULTS**: A total of 7.7% of decedents were kinless at the EoL. Kinless older adults were less likely to receive higher-rated EoL care than those with kin, with non-White older adults being disproportionately affected compared to their White counterparts. **DISCUSSION**: These results highlight a significant disadvantage for non-White kinless older adults, who had worse EoL care quality. From a policy standpoint, there is a need to invest more in supporting alternatives to the family-centered model in EoL care delivery for those without close kin.

20. **Quality of end-of-life care, quality of dying and death, and grief in bereaved family caregivers.**

Authors: Pokpalagon, Piyawan;Chaiviboontham, Suchira;Siripitayakunkit, Apinya;Junda, Tiraporn;Jaiboon, Petcharaporn and Khunpinit, Kulisara

Publication Date: Nov 10 ,2025

Journal: BMC Nursing 24(1), pp. 1382

Abstract: BACKGROUND: The World Health Organization approximates that around 56.8 million individuals require palliative care annually, with 25.7 million of them being in the final stage of life. Ensuring high-quality care, particularly towards the end of life, can significantly enhance the quality of dying and death (QODD) for terminally ill patients. This, in turn, may alleviate grief among their loved ones following their passing. This descriptive study seeks to explore the correlation between the quality of end-of-life care (EOLC), QODD, and the experience of grief among bereaved family caregivers. **METHODS**: A total of 318 participants, the primary family caregivers of patients who died within 3-12 months, were recruited for this study by the purposive sampling method. The instruments used for collecting data included (1) the participant demographic data form, (2) the family APGAR questionnaire, (3) The Family Satisfaction with the End-of-Life Care (4) the quality of dying and death questionnaire (QODD), and (5) the inventory of complicated grief. The data were analyzed by using descriptive statistics, and Spearman rank-order correlation coefficient. **RESULTS**: The results showed that bereaved family caregivers had satisfaction with the quality of care and their perceptions of QODD at a moderate level. Bereaved family caregivers had 74.8% of normal grief. The quality of EOLC and QODD had a significant negative correlation with grief in bereaved family caregivers. The quality of EOLC also had a significant positive correlation with the QODD. **CONCLUSION**: Improving the quality of EOLC, can improve the QODD and help bereaved family caregivers cope with grief. Copyright © 2025. The Author(s).

---

21. **Perceived Value of Transfusion Access and Hospice Services Among Patients With Blood Cancers**

Authors: Raman, Hari S.;Cronin, Angel M.;Huntington, Scott F.;Uno, Hajime;Brennan, Caitlin;Hurley, Susan Lysaght;Tidswell, Anna;Kaufman, Richard M.;Lanahan, Sarah M.;Johnson, Kimberly S.;Tulsky, James A.;Abel, Gregory A. and Odejide, Oreofe O.

Publication Date: 2025

Journal: JAMA Network Open 8(11), pp. e2541719

Abstract: Key Points: Question: What is the importance of access to blood transfusions compared with routine hospice services for patients with blood cancers who are potentially hospice eligible? Findings: In this survey study of 200 patients with blood cancers with a physician-estimated life expectancy of 6 months or less, respondents placed the greatest importance on transfusion access, while routine hospice services were considered relatively less important. Meaning: In this study, the high value placed on transfusion access suggests that this factor is central to hospice decision-making and highlights the need for novel hospice delivery models that incorporate palliative transfusion access for patients with advanced blood cancers. This survey study assesses the perceptions of the importance of access to blood transfusions and other routine and nonroutine hospice services among patients with blood cancers who would be eligible for hospice care. Importance: Although patients with blood cancers have the lowest rates of hospice use in oncology, there are sparse data regarding their perceptions of the services that hospice can provide. Lack of transfusion access in hospice has been posited as a key barrier to enrollment; however, data are limited regarding patients' assessment of the importance of transfusions compared with routine hospice services. Objective: To examine the importance that patients with blood cancers who are potentially hospice eligible place on access to transfusions compared with routine hospice services. Design, Setting, and Participants: This multicenter, cross-sectional survey study using a best-worst scaling instrument was conducted from October 1, 2020, to November 1, 2022, at the Dana-Farber Cancer Institute (Boston, Massachusetts) and the Yale Cancer Center (New Haven, Connecticut). Adult patients (aged 18 years or older) diagnosed with blood cancers who had a physician-estimated life expectancy of 6 months or less were included. Main Outcomes and Measures: The main outcome was the importance that patients placed on routine hospice services (eg, visiting nurse) and nonroutine services (eg, transfusion access) using a best-worst scaling instrument. A hierarchical bayesian multinominal logistic regression of participants' responses was fit to assess the mean standardized importance score (SIS) for each service. Results: Among 331 eligible patients, 200 completed the survey (median age, 70.0 years IQR, 62.5-76.0 years]; 133 66.5%] male), with a response rate of 60.4%. The most common diagnosis was leukemia (73 36.5%]). Transfusion access was considered the most important service (mean SIS, 20.53 95% CI, 19.42-21.63]), followed by telemedicine (mean SIS, 18.45 95% CI, 17.33-19.57]). The 3 least important services reported were peer support (mean SIS, 5.06 95% CI, 4.10-6.02]), social work (mean SIS, 4.35 95% CI, 3.53-5.16]), and chaplaincy (mean SIS, 1.80 95% CI, 1.21-2.39]). Conclusions and Relevance: In this survey study of patients with blood cancers who were potentially hospice eligible, access to blood transfusions had the highest importance relative to routine hospice services. The high value placed on transfusion access suggests that this factor plays a crucial role in hospice decision-making and argues that innovative hospice models that incorporate access to palliative transfusions may increase hospice use and improve end-of-life care for this patient population.

---

22. **Symptoms matter - symptom diversity and trajectory across different phases of heart failure: from diagnosis to end of life**

Authors: Seckin, Muzeyyen;Stewart, Simon and Johnston, Bridget

Publication Date: 2025

Journal: Current Opinion in Supportive and Palliative Care 19(4), pp. 234–241

Abstract: Purpose of Review: Heart failure is a complex, progressive and life-limiting condition that affects individuals beyond physical symptoms. Psychosocial and behavioural symptoms, such as anxiety, depression, cognitive impairment, and social withdrawal, substantially impact their quality of life. Despite increasing recognition of multidimensional symptom burden across heart failure trajectory, these non-physical symptoms are often under-recognised by clinicians and researchers. This review summarises current contemporary evidence on symptom experiences from diagnosis of heart failure through to end-of-life, highlighting key features along this continuum.; Recent Findings: Understanding full symptom profile including physical, psychological, social, and behavioural dimensions is essential to improving symptom management and overall care. However, limited evidence exists on symptoms experienced prior to and during formal diagnosis of heart failure. While some studies identify classic symptoms, the broader spectrum, including symptom normalisation and behavioural adaptations, remains poorly understood. Variation in symptom perception across populations underscores the need for a more individualised and culturally responsive approach.; Summary: A systematic and person-centred symptom assessment strategy is critical, particularly during advanced and end-of-life stages of heart failure. Integrating under-recognised symptoms into routine care, through multidisciplinary collaboration, can improve outcomes, enhance care quality, and better support individuals and families throughout the course of the illness. (Copyright © 2025 Wolters Kluwer Health, Inc. All rights reserved.)

---

23. **What matters to patients with cancer receiving home care at the end of life? A qualitative study comparing patients' and healthcare professionals' views**

Authors: Thoresen, Lisbeth;Aas, Eline;McCaffrey, Nikki;Engel, Lidia;Løkkevik, Nina;Michel, Yvonne Anne and Bjørnelv, Gudrun,Maria Waaler

Publication Date: 2025

Journal: International Journal of Qualitative Studies on Health and Well-Being 20(1), pp. 2517358

Abstract: Purpose: To improve care for patients in the last phase of life, healthcare professionals (HCPs) need to understand what matters to them in terms of care and follow-up. Therefore, in our study, we investigated how patients with cancer in Norway who are receiving home care perceive their situations and what matters to them at the end of life and compared it with HCPs' views on what matters to such patients.; Methods: Following a qualitative design, we conducted in-depth interviews with eight patients with late-stage cancer living at home and four focus group interviews with 21 hCPs, mainly nurses. Patients and HCPs were recruited from two municipalities in Southeast and mid-Norway. The study period lasted from December 2020 to October 2022. We performed reflexive, thematic analyses of both data sets.; Results: The views of all eight patients and all 21 hCPs were interpreted according to five themes: cancer impacts all aspects of life, navigating the healthcare system, living with dying, the paramount importance of relationships, and dying at home.; Conclusion: Entering the end of life, patients feel exhausted, lonely, and abandoned. They lack confidence in HCPs and the healthcare system. HCPs characterized plans and predictability as being important during end-of-life care, whereas patients were often hesitant to talk about and plan for the last phase of life.

---

24. **Family caregivers at the crossroads - considerations, values and the decision to involve volunteers in end-of-life home care: A qualitative study**

Authors: van Leussen, Carolien;Thölking, Thessa and van Wijngaarden, Els

Publication Date: 2025

Journal: International Journal of Nursing Studies 172, pp. 105206

Abstract: Competing Interests: Declaration of competing interest The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Els van Wijngaarden reports financial support was provided by VPTZ Nederland. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.; Background: Family caregiving is often essential in fulfilling a patient's wish to die at home. While relatives may sometimes experience this role as an obligation, they frequently also find it rewarding. However, caregiving can be burdensome, particularly in the final stages of life, when care demands intensify and sometimes lead to unplanned hospital admissions. Volunteers can provide crucial support to help family caregivers sustain their caregiving efforts.; Objective: This Dutch study examines the considerations and underlying values that shape caregivers' decisions to accept volunteer assistance.; Method: A phenomenological research approach was conducted involving 22 interviews with family caregivers (partners and children) of deceased individuals who had received volunteer-supported end-of-life care at home. Purposive sampling was used for recruitment (June - September 2023) to ensure diversity. Inclusion criteria were close involvement during the final phase of life of a loved one who had passed away at home within the past year. The interviews were thematically analyzed in Atlas.ti. Subsequently the data were synthesized into composite narratives to contextualize caregivers' voices. This enhances the accessibility of findings for healthcare professionals, particularly community nurses and general practitioners, who often introduce the option of volunteer involvement.; Results: Family caregivers' considerations regarding volunteer support are complex and multifaceted. Their commitment to care is strong, and accepting support from volunteers was regularly experienced as failing. This perception is compounded by uncertainty about the duration of care and the increasingly confined living space, which deepens the bond between family caregiver and relative. The emotional and physical burden grows, while caregivers often hesitate to act without the patient's approval and struggle to acknowledge their own limits. The desire to spend as much time as possible with a relative, combined with the wish to be present at the moment of their passing, makes the decision-making process regarding the acceptance of a volunteer more complex. Healthcare professionals play a pivotal role in facilitating discussions about volunteer support.; Conclusions: This study highlights the complex considerations individuals face in the process of deciding to accept volunteer support during a relative's final stages of life. Driven by an intense sense of duty and the value of shared time, caregivers often prioritize caregiving over their own needs, which leads to fatigue and reluctance to seek external help. Introducing volunteer support, while beneficial, can evoke feelings of inadequacy, underscoring the need for healthcare professionals to approach these situations with sensitivity to emotional and familial dynamics. (Copyright © 2025 The Authors. Published by Elsevier Ltd.. All rights reserved.)

---

25. **Bereaved informal carers' experience of an interventional clinical research project at the end-of-life: a qualitative interview study.**

Authors: White, Miriam;Connolly, Michael and Davies, Andrew

Publication Date: Oct 29 ,2025

Journal: BMC Palliative Care 24(1), pp. 275

Abstract: BACKGROUND: This qualitative study was undertaken to obtain feedback from informal carers about their experiences of involvement in a cluster randomised trial of clinically-assisted hydration in the last days of life ("CHELsea II trial"). **METHODS**: Informal carers that had taken part in the trial post-bereavement postal survey, and had expressed an interest in taking part in further research, were approached about this post-bereavement qualitative study. Interviews were conducted remotely, using a semi-structured interview schedule that asked about the impact of the research on patient / their end-of-life care, the impact of the research on the informal carer, and the informal carers views on research at the end-of-life. The interview transcripts were thematically analysed. **RESULTS**: Fifteen informal carers took part in the study prior to thematic saturation. Invariably informal carers reported that there was no negative impact on the patient or themselves, and were positive about taking part in future end-of-life research (if the situation occurred). The analysis generated three themes: (a) Purpose , helping, and no disruption; (b) Preparing for what was to come; and (c) Timing of research at the end-of-life. **CONCLUSIONS**: This study confirms that research can be undertaken in patients at the end-of-life without negatively impacting the experience. Moreover, patients and their informal carers want to take part in such research, as it provides them with purpose during this time, and gives them the chance of helping future patients. **TRIAL REGISTRATION**: ISRCT Registry (registry number - ISRCTN65858561) - registered 14/09/2021.

Copyright © 2025. The Author(s).

---

26. **Establishing Goals of Care and End-of-Life Care in the Intensive Care Unit. A Period Prevalence Study.**

Authors: Yeo N.Y.;Deane A.M.;KentishBarnes N.;Wong H.Z.;Sundararajan K. and Reddi, B. A. J.

Publication Date: 2025

Journal: Omega , pp. 302228251395847

Abstract: Identifying patient's goals and values at end of life is essential to providing patient-centred care. The purpose of this prospective cohort study was to describe the changes in goals of care and the nature of end-of-life care during admission to two intensive care units in South Australia. Under a quarter of patients had their goals of care documented on admission to the intensive care unit and among those who subsequently survived to hospital discharge, only 32% had their goals of care documented on hospital discharge. Most deaths in the intensive care unit occurred after withdrawal of life-sustaining interventions. Data from 154 family meetings were collected and consensus was achieved among all parties in most meetings. In this study, fewer than one in four patients had goals of care documented on admission to intensive care with marginal increases by ICU discharge. This represent an area of care that could be improved.

27. **Barriers to peaceful end-of-life care for older patients with advanced chronic illnesses.**

Authors: Zhao, Lian Jun;Kongsuwan, Waraporn and Chinnawong, Tippamas

Publication Date: Oct 02 ,2025

Journal: International Journal of Palliative Nursing 31(10), pp. 508–514

Abstract: BACKGROUND: Many older patients with advanced chronic illnesses have not experienced a peaceful end of life in China. **AIM**: To explore the barriers to peaceful end-of-life care for older patients with advanced chronic illnesses from the perspectives of male nurses. **METHODS**: A qualitative study was used. Ten male nurses in Guiyang City who met the inclusion criteria participated in individual interviews via telephone with audio recording. The interview transcriptions were analysed by using the content analysis method. Trustworthiness was established by following Lincoln and Guba's criteria. **FINDINGS**: Barriers to peaceful end-of-life care include not prioritising end-of-life care; not respecting the patient's autonomy to die; not having a comfortable caring environment for dying; family caregivers' lack of knowledge and experience in end-of-life care; and traditional and cultural beliefs regarding death and painkillers. **CONCLUSION**: The findings need to be given due consideration to improve the quality of peaceful end-of-life care for older patients with advanced chronic illnesses.

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

Disclaimer: