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December 2025

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1. **Navigating Improper Care Settings: Nurses' Experiences Assisting Oncological Patients at the End of Life in Surgical Departments**

Authors: Bearzot, Sara;Ortez, Giulia;Cadorin, Lucia;Ghirotto, Luca and Bressan, Valentina

Publication Date: 2026

Journal: Cancer Nursing 49(1), pp. 3–11

Abstract: Competing Interests: The authors have no conflicts of interest to disclose.; Background: Despite the growing preference for end-of-life care at home, numerous oncological patients continue to spend their final moments in surgical wards. This incongruity in settings may contribute to "dysthanasia," unnecessarily prolonging futile treatments and resulting in undue suffering. As frontline caregivers, nurses frequently bear the brunt of these challenging situations for patients and their families.; Objective: To investigate the experiences of nurses providing care to terminally ill oncological patients inappropriately admitted to surgical departments.; Methods: We adopted a phenomenological descriptive study. Nurses purposefully selected from 7 distinct surgical units at a University Hospital in Northeast Italy were recruited. Data collection took place through open-ended semistructured interviews. The interview content was analyzed using Colaizzi's framework.; Results: The study with 26 participants revealed emotional challenges, especially for less-experienced nurses. Diverse perspectives among nurses emphasized the need for better palliative care knowledge. Despite the commitment to quality care, collaboration challenges and discordant goals with physicians impacted comprehensive care delivery.; Conclusions: Dysthanasia relates to participants' challenges in caring for oncological patients in inappropriate settings, hindering transparent communication and exacerbating discordance with doctors.; Implications for Practice: Communication and collaboration among healthcare professionals, particularly nurses, and surgeons are crucial. Ongoing education in end-of-life care, coupled with advance care planning, empowers patients, aligns treatment choices, and prevents dysthanasia across diverse healthcare settings. (Copyright © 2024 Wolters Kluwer Health, Inc. All rights reserved.)

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2. **Caring Amid Complexity: Intensive Care Nurses' Perceptions and Experiences of End-Of-Life Care-A Qualitative Study**

Authors: Korsah, Emmanuel Kwame;Schmollgruber, Shelley and Abukari, Alhassan Sibdow

Publication Date: 2026

Journal: Nursing in Critical Care 31(1), pp. e70278

Abstract: Background: End-of-life care in intensive care units presents multifaceted challenges for nurses, whose duties include balancing clinical responsibilities with the emotional and ethical complexities of caring for dying patients and their families.; Aim: This study aimed to explore the perceptions and experiences of intensive care nurses regarding the provision of end-of-life care in the adult intensive care unit.; Study Design: This qualitative study utilised an exploratory descriptive design, sampling 16 experienced intensive care nurses with at least 5 years of intensive care experience from an 18-bed multidisciplinary tertiary hospital's intensive care unit. Data were collected through face-to-face, semi-structured interviews and analysed using inductive thematic analysis. The research adhered to the Consolidated Criteria for Reporting Qualitative Studies guidelines.; Findings: Four major themes were developed: 'emotional toll on nurses', 'challenges in communicating with families', 'ICU physical environmental challenges' and 'feeling powerless and excluded'. Personal attachments led to burnout and emotional strain, underscoring the emotional toll on nurses. Grief, family denial and tense nurse-family relationships all exacerbated communication issues. Nurses reported that physical environmental factors, including overcrowding and a lack of privacy, exacerbated stress levels. Finally, they expressed a sense of helplessness stemming from their exclusion from decision-making, which in turn led to moral distress and frustration.; Conclusions: The study highlights the urgent need to enhance intensive care unit end-of-life care by addressing systemic barriers, fostering interprofessional collaboration and strengthening nurse education and emotional support systems. Nurses must be empowered as key contributors to decision-making and supported in their roles as caregivers and communicators during end-of-life care.; Relevance to Clinical Practice: Improving end-of-life care in intensive care units necessitates a comprehensive approach that encompasses training in communication and palliative care, reconfiguring intensive care environments to facilitate family presence and implementing staff well-being initiatives. These changes are crucial for fostering a dignified end-of-life experience and promoting sustainable nursing practices in intensive care settings. (© 2025 The Author(s). Nursing in Critical Care published by John Wiley & Sons Ltd on behalf of British Association of Critical Care Nurses.)

3. **Dying in a Homophobic Nation: Addressing Healthcare Disparities, Advance Care Planning and Surrogate Decision-Making Challenges for Sexual and Gender Minority Older Adults at End-of-Life**

Authors: Menzer, Heather

Publication Date: 2026

Journal: American Journal of Hospice & Palliative Medicine 43(1), pp. 51–59

Abstract: Promoting autonomy in medical decision-making is an essential part of palliative care. Therefore, palliative care providers should prioritize supporting the autonomy of sexual and gender minority (SGM) older adults, a community that has historically suffered from healthcare disparities. This support is particularly significant when an illness or injury renders a patient unable to make medical decisions, necessitating the designation of a surrogate decision-maker. Surrogate decision-maker policies vary by state and largely do not represent patients whose support systems are outside of the biological family. This article reviews healthcare disparities experienced by SGM older adults, including higher rates of certain health conditions and barriers to accessing care due to stigma and discrimination. It also highlights the compounded challenges faced by SGM individuals who are part of racial and ethnic minority groups. The lack of inclusive surrogate decision-making policies exacerbates these disparities, as many SGM older adults do not have legally recognized partners or children to act as decision-makers. The absence of inclusive policies for surrogate decision-making results in distress for patients, families, loved ones, and medical providers. This article discusses the importance of advance care planning and completion of advance directives for this population to ensure patient wishes are respected. Palliative providers need to advocate for surrogate decision-maker policies that are more inclusive of families of choice.

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

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

Publication Date: 2026

Journal: Journal of Palliative Care 41(1), pp. 105–120

Abstract: Competing Interests: Declaration of Conflicting InterestsThe authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.; Objective: South Asian communities represent one of the largest ethnic minority groups in the UK. Within this group the number of adults requiring palliative and end-of-life care is growing. However, there are often barriers to engagement and underutilization of palliative care services. We aimed to understand the experiences of South Asian patients and/or carers of palliative and end of life care services in the UK. Methods: We conducted a systematic literature review of qualitative data. The review was prospectively registered on PROSPERO (CRD42023442603). Three databases were searched to August 2023. Studies were included if they reported qualitative data on the experiences of South Asian patients, their carers or the perspective of health care staff involved in palliative or end of life care. Quality of studies was assessed using the Critical Appraisal Skills Programme Checklist. Data were analyzed using a thematic meta-synthesis framework. Results: Sixteen studies comprising 407 patients, carers, and healthcare staff were included. The themes identified were: barriers and facilitators to discussing and preparing for end of life; the impact of identity and culture on end-of-life practices and rituals; family roles and expectations regarding palliative care, and navigating challenges across care settings and healthcare interactions. Identified themes highlighted challenges, including language barriers, lack of awareness, and cultural insensitivity. Conclusions: Addressing these gaps through training and culturally appropriate services could significantly enhance the quality and inclusivity of palliative care services for South Asian communities.

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5. **The Lived Experiences of Hospice Healthcare Workers Caring for Adolescents and Young Adults With Advanced Cancer: An Interpretative Phenomenological Analysis**

Authors: Persaud, Nadine;Brearley, Sarah and Walshe, Catherine

Publication Date: 2026

Journal: Journal of Palliative Care 41(1), pp. 60–66

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.; Objective: To understand the lived experience of healthcare workers who provide palliative care to adolescents and young adults living with advanced cancer. Methods: Interpretative phenomenological analysis was the design of this study. Hospice healthcare workers from four pediatric hospices across Canada were recruited through purposive sampling. Semistructured in-person interviews were conducted. Results: Eighteen hospice healthcare workers participated. Two superordinate themes were identified. First, balancing on the tightrope of uncertainty wherein hospice healthcare workers strive to do their best while aiming to take the path of least regret. This theme was underscored by a notion of doing for the adolescents and young adults. Second, acting as a proxy revolves around the importance of fostering relationships with adolescents and young adults through honesty and transparency. The cycle of protection between adolescents and young adults, families, and healthcare providers was emphasized. Conclusions: An action-focused orientation when supporting adolescents and young adults was shared by the healthcare workers. The need to do for adolescents and young adults and the need to protect not only the people they care for but also themselves. More exploration is needed on how healthcare workers who care for adolescents and young adults can be supported while better understanding coping mechanisms.

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6. **The Role, Contribution and Impact of Independent Nurse Prescribers and Advanced Nurse Practitioners to the Children's Hospice Workforce**

Authors: Tatterton, Michael J.;Bethell, Claire;Moody, Amy;McShane, Zoe P.;Stocks, Kathy L. and Charles, Anna E.

Publication Date: 2026

Journal: Illness, Crisis & Loss 34(1), pp. 56–70

Abstract: The care needs of babies, children and young people who use children's hospices have changed over the last decade, with children living for longer, with more complexity. Children's hospice workforces have evolved to continue to meet these needs, including a growth in the number of nurses working at specialist and advanced levels, particularly prescribing. A 15-question survey was sent to all 54 UK children's hospices, which aimed to explore the impact of independent nurse prescribing, and specialist and advanced level nursing practice in UK children's hospices. Forty-one organisations responded, representing 76% of UK children's hospices. Increased autonomy and the ability to respond to the dynamic needs of families, and enabling family choice was recognised and valued by prescribers. Challenges included the breadth of needs of children with life-limiting conditions, and the use of medicines that are either unlicenced or used off-licence. Access to clinical supervision and continuing professional development were highlighted as enablers of prescribing practice.

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7. **Development of the Home Hospice Nursing Care Scale to Support End-of-Life Patients With Cancer and Evaluation of its Reliability and Validity**

Authors: Yoshioka, Saori;Murakami, Shigemi and Oshita, Reiko

Publication Date: 2026

Journal: American Journal of Hospice & Palliative Medicine 43(1), pp. 22–31

Abstract: This study aimed to develop the "Home Hospice Nursing Care Scale" to assess the care provided by visiting nurses to patients with end-stage cancer and evaluate its reliability and validity. A draft of the scale was created based on a descriptive survey conducted among oncology nurse specialists and certified oncology nurses working as home-visit nurses. A questionnaire survey was administered to 1,770 home-visit nurses working at 296 functionally strengthening home-visit nursing establishments. A total of 436 valid responses were obtained (valid response rate: 24.6%). Exploratory factor analysis identified 5 factors comprising 40 items: care that supports the values of the patient and their family members, partnership involving the patient and their family members to maintain home care, care that allows for living with loved ones until end of life, care that supports the daily lives of family caregivers, and care that reconciles the feelings of those involved. Confirmatory factor analysis demonstrated that the goodness-of-fit indices of the model were as follows: GFI = 0.846, AGFI = 0.828, CFI = 0.915, and RMSEA = 0.050. Cronbach's α coefficients ranged from 0.77 to 0.93. Criterion-related validity was verified by the Healthcare Professionals' Attitudes towards Terminal Home Care Scale and Difficulties with Home Palliative Cancer Care Scale. The reliability and validity of the scale was verified, which demonstrates its utility. Future challenges include analyzing factors related to home hospice nursing care and developing an educational program based on the future study. Key words: home hospice, end-of-life, cancer, nursing, scale development, reliability, validity.

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8. **Exploring Emotions and Perceptions of Pediatric Nurses Regarding End-of-Life Care for Children**

Authors: Zartaloudi, Afroditi;Lekas, Christos;Kyritsi, Eleni;Marinaki, Doxa;Dousis, Evangelos;Gerogianni, Georgia;Polikandrioti, Maria;Alikari, Victoria;Dafogianni, Chrysoula;Evangelou, Eleni and Koutelekos, Ioannis

Publication Date: 2026

Journal: Advances in Experimental Medicine and Biology 1487, pp. 503–514

Abstract: Background: Interacting with dying children is one of the most challenging aspects of nursing. Nurses' emotions and perceptions while caring for children at the end of their lives could influence the quality of care provided.; Aim: To investigate emotions and perceptions of pediatric nurses regarding end-of-life care of children.; Methods: 170 pediatric hospital nurses completed a self-reported questionnaire that consisted of questions to collect information related to sociodemographic characteristics as well as questions regarding previous training in the care of dying patients, previous experience in the care of these patients, and, more generally, previous experience with issues related to death.; Results: 68.6% of participants reported being greatly affected by a child's death, mainly feeling sadness/distress (44%), compassion (22%), guilt (22%), and anger (22%). 44.7% felt unprepared to handle death. 73% wished the child would die in their absence, 62.8% believed family care should continue during grieving, while 70.6% felt nurses should join psychological support groups.; Conclusions: Integrating death and end-of-life care concepts into nursing education and practice could enhance the quality of end-of-life care for patients and families. (© 2026. The Author(s), under exclusive license to Springer Nature Switzerland AG.)

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9. **Optimising end-of-life geriatric pharmacotherapy: a hospital-based retrospective cohort study of deprescribing early in the care trajectory before hospice transition**

Author: Alwidyan, Tahani, Parsons, Carole, Alqudah, Abdelrahim, Al-Shudifat, Abdel, Al-Lozi, Abdel and Riziq Khader, Muna

Publication Date: 2025

Publication Details: International Journal of Clinical Pharmacy, 47, (6) pp.1943–1954. , New York, New York: Springer Nature.

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

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

Publication Date: 2025

Journal: Archives of Gerontology and Geriatrics 139, pp. 105994

Abstract: Competing Interests: Declaration of competing interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.; Background: Medications deemed inappropriate and discontinued in the earlier stages of life-limiting disease may become

relevant in palliative care context at the end of life. This study aims to determine the incidence of and factors associated with initiation and reinitiation of medications deemed inappropriate according to the STOPPFrail guideline.; Methods: A retrospective cohort study using linked healthcare reimbursement data. We included nursing home residents aged ≥65 who died with a condition potentially amenable to palliative care between 2015 and 2019 in Belgium. Outcomes were: (1) reinitiation of previously discontinued STOPPFrail-listed medications; and (2) initiation of these medications, regardless of prior use, in the last three months. Log-binomial regression was used to estimate relative risks (RR) with 95 % confidence intervals (CI).; Results: Among 158,689 decedents, 29.7 % had at least one medication initiated, and 16.96 % reinitiated among those with at least one medication discontinued (n = 13,724). By medication type, initiation and reinitiation were significantly higher for symptomatic medications than preventive ones (initiation: 25.5 % symptomatic vs. 6.7 % preventive; reinitiation: 20.3 % symptomatic vs. 11 % preventive). The risk was higher among residents with cancer, who were hospitalized, or taking ≥10 chronic medications.; Conclusions: A significant proportion of residents undergo initiation or reinitiation of medications deemed inappropriate at the end of life per existing guidelines. Many were likely prescribed for palliative purposes. Thus, guidelines on medication appropriateness may need to more explicitly address palliative care contexts. A notable number also received preventive medications, suggesting inappropriate prescribing at the end of life that has received little attention. (Copyright © 2025 Elsevier B.V. All rights reserved.)

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11. **Co-production with marginalised workers: working with homecare workers and managers caring for people approaching end-of-life**

Authors: Bayley, Zana;Forward, Cat;Elliott-Button, Helene;Krygier, Justine;White, Caroline;Pearson, Mark;Walker, Liz;Moss, Colin;Hussain, Jamilla;Taylor, Paul;Wray, Jane;Roberts, Helen and Johnson, Miriam J.

Publication Date: 2025

Journal: Research Involvement and Engagement

Abstract: Background: Co-production is important due to its effectiveness in creating relevant and meaningful outputs for use in social and healthcare practice, however, frontline staff such as homecare workers (also known as aides, personal assistants or domiciliary care workers providing paid care within the home) are a key group within the social care workforce who are under-represented in this approach. Here, we report our coproduction process engaging with this workforce to develop training resources for workers providing end-of-life homecare.; Aim: To co-produce training resources with homecare workers and their managers to support and educate workers delivering end-of-life homecare using evidence from our larger qualitative interview study.; Methods: We conducted a series of 12 co-production workshops with UK-based homecare workers and managers (partners) to design training resources and recommendations for homecare providers informed by research findings. We adopted the five key principles of co-production: Sharing of power; Including all perspectives and skills; Respecting and valuing knowledge; Reciprocity; and Building and maintaining relationships. A co-production advisory group of homecare workers as well as the workshop partners gave valuable oversight throughout the workshop series.; Results: 77 partners (31 homecare workers, 46 managers) participated in 12 workshops (one face-to-face; 11 online). Our

approach enabled power-sharing, inclusivity, respect, collaboration and reciprocity, relationship-building, and identification of effective flexible approaches to co-production. Specific forms of training resources were co-created. Training recommendations (content, delivery formats, access during working hours, etc.) were also developed together. Challenges were non-attendance and lack of engagement by some partners during sessions.; Conclusion: These workshops are the first, to our knowledge, to successfully co-produce end-of-life care training resources with homecare workers and managers, a poorly represented workforce in co-production. Challenges included inconsistent attendance and poor engagement by a minority of partners. The five key principles of co-production enabled true engagement with the process, thereby enriching the final outputs. (© 2025. The Author(s).)

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12. **Personalized music and hypnosis interventions in palliative and end-of-life care at home: A randomized controlled pilot study**

Authors: Bissonnette, Josiane;Côté, Andréanne;Desameau, Peter-Gens;Cossette, Mariève;Pinard, Anne Marie;Arbour, Caroline;Fortin, Gabrielle;Ogez, David and Rainville, Pierre

Publication Date: 2025

Journal: Complementary Therapies in Medicine 95, pp. 103281

Abstract: Competing Interests: Declaration of Competing Interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.; Objectives: To evaluate the preliminary effectiveness of a personalized intervention integrating pre-recorded hypnosis and/or music in palliative and end-of-life care, and explore patient preferences and experiences.; Methods: Forty patients receiving palliative and end-of-life care at home were recruited and randomly assigned to the experimental group or the control/delayed intervention group. Two intervention sessions were conducted within one week, featuring the following modalities tailored to patient preferences: pre-recorded music, hypnosis, or a combination of music and hypnosis. Participants provided self-ratings of their symptoms and distress at predetermined time points using the Edmonton Symptom Assessment Scale and the Distress Thermometer. We used a mixed-effects model to address the quantitative objectives, and we conducted a content analysis to meet the qualitative objectives.; Results: The intervention program significantly reduced participants' distress, showing a medium effect size when comparing the intervention sessions to the control sessions. We also found a medium effect size for improved well-being between groups. Intervention modality did not appear to affect the responses. Participants reported calmness and well-being. The voluntary use of these interventions post-experiment emphasizes their relevance for palliative and end-of-life care. The qualitative findings were consistent with the quantitative results, and revealed additional potential uses and ways to improve the intervention.; Conclusion: The personalized pre-recorded music and hypnosis interventions appear to be effective in reducing distress and show great potential for enhancing the overall well-being of individuals in palliative and end-of-life care. Further studies are needed to determine how these findings can be applied to a broader population. (Copyright © 2025 The Authors. Published by Elsevier Ltd.. All rights reserved.)

13. **Music therapy for end-of-life care**

Authors: Calvache, Jose A.;Collazos Girón, Daniela;Bolaños, Isabela;Bradt, Joke;Dileo, Cheryl and Klimek, Markus

Publication Date: 2025

Journal: The Cochrane Database of Systematic Reviews 12, pp. CD016311

Abstract: Objectives: This is a protocol for a Cochrane Review (intervention). The objectives are as follows: To evaluate the benefits and harms of standard care combined with music therapy for the management of physical symptoms and psychosocial outcomes in individuals receiving end-of-life care, compared with (a) standard care alone or (b) standard care plus other non-music interventions To evaluate the relative benefits and harms of different types of music therapy interventions (e.g. music listening, songwriting, or improvisation as part of a structured therapeutic process) for the management of physical symptoms and psychosocial outcomes in individuals receiving end-of-life care. (Copyright © 2025 The Authors. Cochrane Database of Systematic Reviews published by John Wiley & Sons, Ltd. on behalf of The Cochrane Collaboration.)

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14. **Documented End-of-Life Preferences of People With Parkinson's Disease or Parkinsonism Across Europe**

Authors: Dijkstra, Bauke W.;Muente, Catharina;Garon, Michela;Rosqvist, Kristina;Scharfenort, Monica;Lex, Katharina M.;Poku, Philip;Nixina, Eirini;Taba, Pille;Krikmann, Ülle;Sikk, Katrin;Flanagan, Katie;Schrag, Anette E.;Konitsiotis, Spyros;Makrydimas, Miltiadis;Lorenzl, Stefan;Odin, Per;Pedrosa, David J.;Vissers, Kris C. P.;Groot, Marieke M., et al

Publication Date: 2025

Journal: Movement Disorders Clinical Practice

Abstract: Background: Parkinson's disease and atypical parkinsonism are characterized by motor and non-motor symptoms. As the disease advances, planning for end-of-life (EoL) care becomes increasingly important. However, consensus-based European guidelines for advance care planning and documentation of EoL care preferences for parkinsonism are lacking. Understanding current documentation practices for EoL care across Europe is an essential first step towards formulating such guidelines.; Objectives: Provide an overview of the status of EoL care documentation in selected regions of Austria, Estonia, Germany, Greece, Italy and Sweden.; Methods: Individuals diagnosed with moderate to severe parkinsonism, participating in the PD_Pal trial were enrolled. We reviewed participants' electronic health records (EHRs) and other documentation (eg, advance directives kept at home). A questionnaire was used to extract information on documented EoL care preferences.; Results: One hundred eighty nine participants were included (n = 182 Parkinson's disease; n = 7 atypical parkinsonism). Documented EoL care preferences were identified in 70% of the participants in Germany, 21% in Austria, 17% in Sweden, 7% in Greece, 3% in Italy, and 0% in Estonia. Participants more frequently documented their EoL preferences in advance directives than in EHRs. The content of the documentation was largely general, with limited attention to parkinsonism-specific issues.; Conclusions: We found considerable variability in the presence of EoL care documentation across European regions. Public awareness and availability of advance directive templates likely contributed to the higher percentage of German participants with advance directives. These should be considered as best practices for enabling individuals with parkinsonism to document their preferences and receive care aligned with them. (© 2025 The Author(s). Movement Disorders Clinical Practice published by Wiley Periodicals LLC on behalf of International Parkinson and Movement Disorder Society.)

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15. **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

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16. **Developing palliative and end-of-life care research partnerships in the North East and North Cumbria: A report on the first year of the RIPEN network**

Authors: Frew, Katherine;Atkinson, Joanne;Craig, Dawn;Dalkin, Sonia;Dewhurst, Felicity;Fu, Yu;Grant, Olivia;Mannix, Kathryn;Matthews, Fiona;Paes, Paul;Shenton, Felicity;Stow, Daniel;Todd, Adam;Wakefield, Donna and Hanratty, Barbara

Publication Date: 2025

Journal: Health and Social Care Delivery Research , pp. 1–13

Abstract: Background: The North East is one of the most disadvantaged areas of England with end-of-life care needs shaped by high levels of disability, physical and mental ill health. This programme of work aimed to set the foundation for the development of a palliative and end-of-life care research community, equipped to meet local and national challenges.; Objectives: Develop a self-sustaining research culture in North East palliative and end-of-life care. Build research collaborations around older age, frailty, multiple long-term conditions and inequalities and submit at least one research proposal. Convene a diverse patient and public advisory group.; Methods and Findings: To establish cross-institutional collaborations, we worked with patient and public partners and key stakeholders from local National Health Service trusts, hospices, social care, our National Institute for Health and Care Research infrastructure (Applied Research Collaboration North East and North Cumbria, Policy Research Unit Older People and Frailty, National Institute for Health and Care Research Innovation Observatory, Comprehensive Research Network, and Research Design Service). A series of events were hosted to foster a research culture, including establishing a monthly seminar programme, research sandpits, bespoke research training and dissemination events. A diverse community of patient and public involvement partners was established to support and shape the developing research. Multiple project and two fellowship applications were supported by the partnership. A qualitative study identified issues pertinent to local access to data that could support research.; Conclusions: This work has been a catalyst for palliative and end-of-life care research and practice collaborations to develop. Funding success and ongoing research and training events should provide a platform for sustained research development in this area.; Funding: This article presents independent research funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme as award number NIHR135278.

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17. **End-of-life care by specialist palliative care teams: 10-year retrospective satisfaction evaluation**

Authors: Karakitsiou, Despoina-Elvira;Abarshi, Ebun;Grundy, Anna;Kane, Vijaya and Cox, Sarah

Publication Date: 2025

Journal: BMJ Supportive & Palliative Care

Abstract: Background: The Association for Palliative Medicine (APM) ran a national Specialist Palliative Care (SPC) service evaluation from 2013, using the Family Satisfaction with End-of-Life Care (FAMCARE-2) questionnaire to measure the satisfaction of bereaved main caregivers with SPC services.; Aim: This feature article reviews ten years of the FAMCARE-2 audit (2013-2022), summarising data from bereaved carers via SPC teams alongside a one-off survey involving the service leads.; Results: During the decade, 573 SPC teams across the UK returned 12 573 completed FAMCARE-2 questionnaires, representing 160 SPC services, with a mean of 1048 questionnaires per annum (804-1668). Responses spanned three settings: hospice (48%), home (39%) and hospital (13%).Bereaved caregivers reported highest satisfaction for patients' dignity; 92.2% of respondents were satisfied, while dissatisfaction was highest with the speed deceased patients' symptoms were treated (6.2%). There was no significant difference in satisfaction rate between different SPC teams (home, hospital, hospice) with limited year-to-year variation in responses (Kruskal-Wallis test η2: -0.17).Participation by community-based home care teams increased during the 10-year period, but reduced for hospital specialist teams. The number of questionnaires returned decreased by 40%.Notably, of those responding to the one-off survey, 90% of services found FAMCARE-2 valuable for learning, inspection or reflective practice.; Conclusion: Bereaved caregivers consistently expressed satisfaction with SPC services across settings over the 10-year period. Despite limited applicability of findings due to annual decline in participation and lack of demographic data, FAMCARE-2 remains the only nationally used tool for evaluating SPC in the UK. (© Author(s) (or their employer(s)) 2025. No commercial re-use. See rights and permissions. Published by BMJ Group.)

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18. **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 (John Wiley & Sons, Inc.) 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.

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19. **Using advance care planning to enhance person-centred care at end of life**

Authors: Lawley, Elizabeth;Goodchild, Cathryn;Hine, Paula and Mitchell, Iain

Publication Date: 2025

Journal: Nursing Standard (Royal College of Nursing (Great Britain) : 1987) 40(12), pp. 53–58

Abstract: Competing Interests: None declared; Advance care planning, which enables patients to make informed decisions about their care as they approach the end of their life, has been part of UK policy and strategy for almost two decades. Yet despite evidence of the benefits, advance care planning completion rates are low. This is due, in part, to healthcare professionals' lack of confidence in initiating such conversations and insufficient knowledge of the available advance care planning options. Moreover, although recognising when a patient is approaching end of life can provide nurses with an opportunity to initiate advance care planning discussions, predicting this life stage is inherently difficult. This article provides an overview of advance care planning and the challenges of predicting when someone is nearing end of life. The article also considers how nurses might approach advance care planning discussions with patients in a timely and sensitive manner and discusses some of the options available, such as an advance decision to refuse treatment or advance statements. (© 2025

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20. **PATHS at End of Life: Case-Based Learnings**

Authors: Qualters, Kelley;Lauria, Tara;Kapoor-Hintzen, Neena;Epstein, Andrew S.;Nelson, Judith E. and Rosa, William E.

Publication Date: 2025

Journal: Clinical Journal of Oncology Nursing 29(6), pp. 451–455

Abstract: PATHS (Post-Acute Transition to Home With Supportive Care) is a novel nurse practitioner (NP)-led telehealth intervention that addresses a gap for patients with advanced cancer at the end of life who were discharged from the hospital without a plan for disease-directed treatment or hospice care in place. Through intensive postacute specialty palliative care telehealth visits, PATHS NPs clarify goals of care, manage symptoms, assist with navigating to home-based services, and provide ongoing hospice education. This article describes four PATHS cases and provides lessons learned and clinical implications for nurses and NPs to support improved, high-quality transitional care for patients leaving the hospital to return home at the end of life.

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21. **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

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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.)

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22. **Therapeutic doublethink: Making a case for the acceptability of unrealistic optimism in patients at end-of-life**

Authors: Ying, Irene and Downar, James

Publication Date: 2025

Journal: Clinical Ethics 20(4), pp. 203–208

Abstract: George Orwell coined the term "doublethink" to describe the concept of "holding two contradictory beliefs in one's mind simultaneously, and accepting both of them." Patients at end-of-life may be using "Therapeutic Doublethink" as a psychological mechanism to cope with the cognitive dissonance resulting from accepting a terminal diagnosis and desiring curative therapy. To develop the concept of Therapeutic Doublethink, we explored the literature on Unrealistic Optimism and decision-making, then grounded them in existing psychological and neurobiological concepts. Functional neuroimaging studies can help to explain the biological mechanisms that permit Unrealistic Optimism and Therapeutic Doublethink to exist, including a failure to track less desirable information and a focus on outcomes without considering the actions required to achieve them. These findings help us appreciate the challenges patients face when trying to make "rational" treatment decisions. They also raise questions about the effectiveness and potential harm of truth-telling, which is a common approach used by physicians who are confronted by Unrealistic Optimism. In some cases, physicians may be able to use Therapeutic Doublethink to harness the beneficial aspects of Unrealistic Optimism while simultaneously helping patients accept the terminal nature of their condition. This approach may be conceptually and ethically challenging for many physicians, but has important implications for improving patient care.

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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