

Interventions and Predictors of Transition to Hospice for People Living With Dementia: An Integrative Review

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Abstract

Background and Objectives: Goal-concordant transition to hospice is an important facet of end-of-life care for people living with dementia. The objective of this integrative review was to appraise existing evidence and gaps focused on interventions and predictors of transition to hospice and end-of-life care for persons living with dementia across healthcare to inform future research.

Research Design and Methods: Using integrative review methodology by Whittemore and Knafl, 5 databases were searched (PubMed, CINAHL, Web of Science, Google Scholar, and Cochrane Database for Systematic Reviews) for articles between 2000 and 2023. The search focused on dementia, hospice care, transitions, care management and/or coordination, and intervention studies.

Results: Fourteen articles met inclusion criteria after critical appraisal. Most were cross-sectional in design and conducted in nursing homes and hospitals in the U.S. persons living with dementia had multiple chronic conditions including cancer, diabetes, heart disease, and stroke. Interventions included components of hospice decision-making delivered through advance care planning, checklist-based care management for hospice transition, and palliative care for those with severe dementia. Predictors included increasing severity of illness including functional decline, organ failure, intensive care use, and the receipt of palliative care. Other predictors were related to insurance status, race and ethnicity, and caregiver burden. Overall, despite moderate to high-quality evidence, the studies were limited in scope and sample and lacked racial and ethnic diversity.

Discussion and Implications: Prospective, multisite randomized trials and population-based analyses including larger and diverse samples are needed for improved end-of-life dementia illness counseling and hospice care transitions for persons living with dementia and their caregivers.

Keywords: Dementia, Hospice, Intervention, Transitional care

Background and Objectives

Approximately half of Medicare hospice recipients have a primary or secondary diagnosis of Alzheimer's disease or Alzheimer's disease-related dementias (2023 Alzheimer's Disease Facts and Figures, 2023). Timely and goal-concordant care transitions to hospice care can result in improved quality of dementia care at the end of life, such as in the context of comorbid dementia and serious illness (Aldridge et al., 2022). Transitions to hospice care can occur from any healthcare setting where persons living with dementia receive care. For example, persons living with dementia may transition to hospice care while residing in the nursing home or other long-term care setting, receiving care in the inpatient setting, or directly from home healthcare (Bigger, Foreman, et al., 2024; Teno et al., 2022). However, while many persons living with dementia may be clinically eligible for hospice care and benefit from improved end-of-life care quality and increased

support and quality of life for caregivers, they often do not receive it (Harrison et al., 2022; Lin et al., 2022).

Clinicians often struggle to convey the benefits of hospice care to caregivers of persons living with dementia (Oh et al., 2022). Additionally, access to hospice care is a barrier to hospice use, which is complicated by varied clinician preparedness to offer and discuss the benefits of hospice care (Murali et al., 2022; Trandel et al., 2023; Zehm et al., 2020). Additionally, persons living with dementia do not always fit the criteria for a terminal illness, which is needed to establish hospice eligibility. Persons living with dementia often experience longer lengths of stay in hospice and have unpredictable illness trajectories at the end of life, which may lead to multiple recertifications or live discharge (Wallace & Wladkowski, 2024). Further, many hospices have become wary of admitting persons living with dementia due to increased regulation from the Centers for Medicare and Medicaid Services

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surrounding hospice eligibility, which may not always align with end-of-life dementia illness progression.

Persons living with dementia are likely to have multiple transitions in the last years of life, particularly in the last 180 days of life, with racially and ethnically minoritized individuals afflicted most heavily (Lin et al., 2022). The transition to hospice is a unique care moment for persons living with dementia and their caregivers. This transition requires tailored dementia illness counseling and serious illness communication that balances the nuance of an unpredictable illness trajectory with goals, cultures, values, and preferences of patients and caregivers. Improving the delivery of this approach can lead to better care, bereavement, and quality of life outcomes for caregivers and persons living with dementia at the end of life (Yeh et al., 2021). However, in the setting of limited knowledge and understanding of what hospice care provides, caregivers may have difficulty with deciding to transition to hospice (Oh et al., 2022; Trandel et al., 2022). The evidence base that informs best practices is limited, and strategies to orchestrate hospice transitions for this clinically complex population of older adults are not well described (Johnson et al., 2008; Wiggins et al., 2019). Because care transitions are heavily determined by caregiver burden and distress, cultural preferences, limited knowledge, and prognostic uncertainty, targeted efforts to explore these phenomena have the potential to generate improved and responsive care and communication before hospice transitions (Csikai & Martin, 2010).

Across healthcare settings, greater access to palliative care, serious illness communication, and dementia-tailored care management and training of healthcare professionals are necessary steps for improving and increasing transitions to hospice care for persons living with dementia (Bigger, Zanville, et al., 2024; Brody et al., 2016). Moreover, increased understanding of predictors of transitions to hospice for persons living with dementia can lead to greater precision in intervention development to facilitate transitions to hospice. Using high-quality, evidence-based, equity-focused approaches to improve care delivery surrounding hospice transitions is essential for advancing this body of science.

Therefore, evidence that informs tailored interventions, policy initiatives, and clinical workflow and practice guidelines for hospice transitions about persons living with dementia will fill gaps in care and advance the science. The objective of this integrative review was to (1) appraise evidence reporting

on interventions and predictors of transitions to hospice and end-of-life care for persons living with dementia and their caregivers across healthcare settings and (2) illuminate existing gaps in evidence that preclude the development of interventions to improve transitional care to hospice for this clinically complex, high-need population.

Research Design and Methods

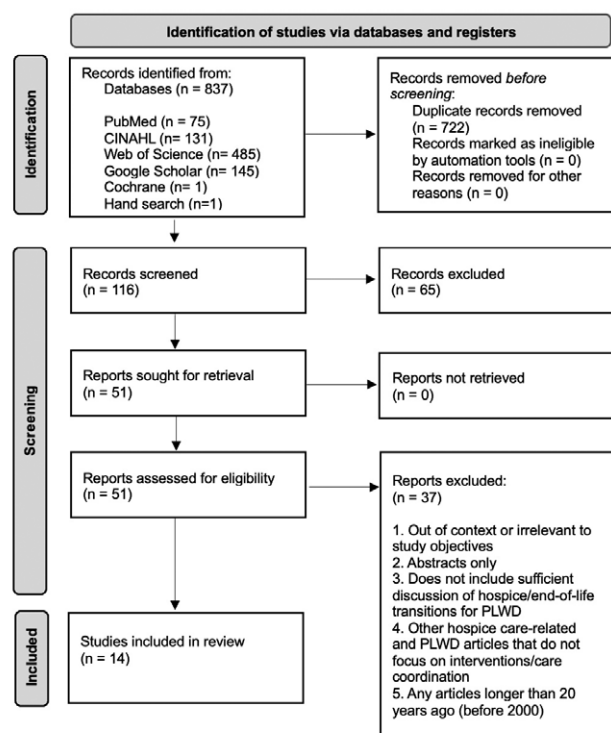
Search Strategy

Guided by a medical reference librarian and following rigorous integrative review methodology (Whittemore & Knafl, 2005), PubMed, CINAHL, Web of Science, Google Scholar, and Cochrane were strategically searched for both qualitative and quantitative articles. The integrative review methodology was used because the phenomenon and occurrence of a hospice transition are dependent on the experiences and views of those involved (e.g., care partners of persons living with dementia, persons living with dementia, and healthcare professionals) in addition to healthcare services-based interventions and predictors. Integrative reviews are also helpful when randomized controlled trials for the topic are limited.

The initial search was completed by two members of the research team (K. P. Murali and S. Gogineni). Conceptualization for the review began in April 2023. After finalizing the search strings and ensuring optimal methodology, the final search and literature appraisal process was completed between October 2023 and January 2024, and we refined it if new literature emerged. We finalized the review in August 2024 mainly to ensure that we included any new literature. After identification of the searches that provided the most relevant articles, the optimal search string was finalized. Searches were conducted by both researchers independently in each of the six databases using the same search strings. Key search terms and strings that were used to search the databases are provided in Table 1. The articles were then screened for duplicates using the EndNote reference manager. Once all duplicates were removed, the researchers (K. P. Murali and S. Gogineni) independently conducted a title and abstract screen. The PRISMA diagram with search strategies and article yields is portrayed in Figure 1 (Page et al., 2021). PRISMA was used to conduct a methodical search for transparency in the process. We completed the PRISMA diagram to map how articles were identified, selected, and appraised before

Table 1. Search Strategy

Database	Search strings
PubMed	("Hospice Care"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh] OR "Hospices"[Mesh] OR "Terminal Care"[Mesh] OR hospice*[TW] OR "end of life"[TW]) AND ("Patient Transfer"[Mesh] OR "Transitional Care"[Mesh] OR "Case Management"[Mesh] OR "Case Managers"[Mesh] OR "care coordination"[TW] OR "transition* care"[TW] OR "care transition*"[TW] OR "care transition"[TIAB:-2]) AND ("Dementia"[Mesh] OR dementia[TW])
CINAHL	((MH "Hospice Patients") OR (MH "Hospices") OR (MH "Hospice Care") OR (MH "Terminal Care+") OR (MH "Terminally Ill Patients+")) OR ("end of life" OR hospice*) AND ((MH "Transitional Care") OR (MH "Transfer, Discharge") OR (MH "Case Management") OR (MH "Case Managers"))) OR ((care N2 (transition* OR coordinat*)) AND ((MH "Dementia+") OR (MH "Dementia Patients"))) OR dementia
Web of Science	("Hospice Care"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh] OR "Hospices"[Mesh] OR "Terminal Care"[Mesh] OR hospice*[TW] OR "end of life"[TW]) ("Patient Transfer"[Mesh] OR "Transitional Care"[Mesh] OR "Case Management"[Mesh] OR "Case Managers"[Mesh] OR "care coordination"[TW] OR "transition* care"[TW] OR "care transition*"[TW] OR "care transition"[TIAB:-2]) ("Dementia"[Mesh] OR dementia[TW])
Google Scholar	hospice/end-of-life care and care transitions and dementia
Cochrane	hospice/end-of-life care and care transitions and dementia



Alt Text: The PRISMA diagram presents the article identification and screening process.

Figure 1. PRISMA diagram. PLWD = persons living with dementia.

analysis and synthesis of findings. The PRISMA checklist was used to guide the preparation of the reporting of findings for this review. This review was registered on Prospero (CRD42024564474).

Study Eligibility

Articles were included if they met the following criteria: (1) focused on dementia and hospice transitions, and (2) included a focus on interventions, care management and/or coordination, and/or clinical trials focused on hospice, palliative care, and end-of-life care transitions for persons living with dementia (PLWD) and caregivers. The articles were excluded if they were irrelevant to study objectives, only provided abstracts, and did not include sufficient information about hospice transitions specifically focused on dementia. We focused on articles relating to persons living with dementia, predictors of transitions to hospice, and current interventions that exist to facilitate transitional care processes. Articles were published between the years 2000 and 2023. This time parameter was based on the significant advancements made within the fields of hospice, palliative care, and dementia care over the last two decades including the benefits of both palliative care and hospice care for this complex population (Eisenmann et al., 2020; Harrison et al., 2022).

Article Selection

After completion of the title/abstract screen, 51 articles were selected for the full-text review. The full-text review was performed by two investigators (K. P. Murali and S. Gogineni) independently utilizing the inclusion and exclusion criteria. After the review, 18 articles were included for quality appraisal. The final included articles comprised both qualitative and quantitative studies relating to interventions,

barriers, and burden of care that are present for persons living with dementia who may be eligible for transition or transitioning to hospice. All researchers agreed that 18 articles would undergo full-text review and appraisal. After appraisal and further review of the reported evidence, four articles were excluded as they did not sufficiently meet the study objectives or include a focus on the transition to hospice as either an intervention or predictor.

Quality Appraisal of Evidence

To appraise the quality of articles, three investigators (S. Gogineni, T. Sadarangani, and K. P. Murali) independently used the Crowe Critical Appraisal Tool (CCAT) Form (Crowe & Sheppard, 2011). The CCAT is a reliable and valid tool that assists researchers in assessing the quality of the science and research evidence of articles with an internal consistency of 0.83 (Cronbach's alpha; Crowe et al., 2012). The CCAT tool allows for detailed quality and rigor assessments of each of the following sections: (1) preliminaries (title, abstract, text); (2) introduction (background and objective); (3) design; (4) sampling; (5) data collection; (6) ethical matters; (7) results; and (8) discussion. Each section was ranked from 0 to 5, and each article received a final score from 0 to 40 from each investigator. Higher scores indicated higher quality. After the quality appraisal, CCAT scores were averaged among the investigators, and disagreements were addressed. Out of the 18 articles appraised, two were excluded due to irrelevance to the integrative review objectives. An additional two were excluded after investigators agreed that they did not meet study inclusion criteria such as a sufficient focus on predictors or transition to hospice for persons living with dementia. Ultimately, the final number of articles after quality appraisal was 14, which was agreed upon by all investigators.

Data Extraction

Data from the included articles were extracted. The extracted information included the authors and publication year, title, objectives, design, setting, population, sample number, results, strengths, limitations, and averaged CCAT score (Table 2). Data extraction was completed and reviewed by two investigators (S. Gogineni and K. P. Murali). After relevant data elements were extracted, the synthesis of evidence was carried out by all investigators, and conclusions were generated based on team discussions.

Data Synthesis

All study team members reviewed the evidence into interventions and predictors. The team examined whether the interventions were implemented or in the development phases. It was noted that three of four interventions had been implemented (Hanson et al., 2019; Moyo et al., 2022; Toles et al., 2022). One study was focused on intervention development (Prater et al., 2023). Next, specific components of the intervention studies (e.g., sample size, inclusion of underrepresented groups, patient, and caregiver-centered outcomes) were discussed to assess the comprehensiveness of the state of the science to identify gaps and gather recommendations for future research. Predictors across each of the remaining studies were reviewed and delineated to understand demographic and clinical factors associated with hospice transition. Each investigator had the opportunity to review the extracted data presented in Table 2. During the process of synthesizing

Table 2. Summarized Evidence of Included Studies

Author (year)	Title/objective	Design, setting, population, and sample	Results	Strengths/limitations	Crowe Score (out of 40)
Epstein-Lubrow et al. (2015)	Hospice referral after inpatient psychiatric treatment of individuals with advanced dementia from a nursing home To assess discharge disposition following inpatient psychiatric treatment for advanced dementia	Design: A descriptive analysis, brief report utilizing MDS Setting: Medicare minimum data set (MDS) data of nursing home (NH) residents Sample: 1,027 NH decedents	In the last 90 days of life, 1,027 (0.15%) persons received inpatient psychiatric treatment before death and place of death was determined. The discharge dispositions included hospice ($n = 132$, 12.9%), NH without hospice ($n = 728$, 70.9%), NH with hospice ($n = 73$, 7.1%), home without hospice ($n = 32$, 3.1%), and hospice at home ($n = 16$, 1.6%). The rate of transition as a result of referral to hospice services for advanced dementia was low	Strengths: Large sample size and robust analyses for examining transition to hospice and hospice referral after inpatient psychiatric treatment Limitations: There was limited information about factors that contribute to discharge disposition with or without hospice services	33
Ernecoff et al. (2018)	Concordance between Goals of Care (GOC) and treatment decisions for persons with dementia To describe family decision-makers' preferred GOC and perceptions of goal-concordant care for NH residents with late-stage dementia	Design: Secondary data analysis of baseline and 9-month family decision-maker interviews and chart reviews. This study compared subsequent treatments when families chose a primary goal of comfort versus other goals Setting: 22 NHs in North Carolina Sample: 302 dyads of NH residents and family decision-makers	Families reported their GOC at baseline and in follow-up interviews. The treatment orders, hospice, and hospital transfers were compared after selecting comfort as the primary goal versus other goals of care. Families chose comfort for 66% of residents at baseline, and 80% at 9 months or death. 49% were in concordance with the nursing home staff on the primary goal at baseline and that increased to 69% at the follow-up	Strengths: Prospective data collection and validated outcome measures Limitations: Findings were exploratory with limited generalizability due to the study being focused in one state. The use of retrospective chart reviews could not capture care decisions and outcomes	34
Gozalo et al. (2011)	End-of-life transitions among nursing home residents with cognitive issues To examine healthcare transitions among Medicare decedents with advanced cognitive and functional impairment who were nursing home residents 120 days before death	Design: Retrospective study that linked Medicare Minimum Data Set (2000 through 2007) Setting: NH Sample: 474,829 NH decedents	19% of the sample population had one or more burdensome transitions. Black and Hispanic individuals (and those without an advance directive) were at a higher risk. Longer time in ICU, feeding tube, stage IV ulcer, and late enrollment in hospice were associated with nursing home residents within the highest quintile of transitions	Strengths: Study revealed predictors of burdensome transition and factors that led to later hospice transition Limitations: Lack of information on patient preferences; Unable to assess end-of-life quality measures and outcomes	35
Hanson et al. (2019)	Triggered palliative care for late-stage dementia: A pilot randomized trial To test dementia-specific specialty palliative care triggered by hospitalization	Design: Randomized controlled trial Setting: Hospital Sample: 62 dyads of persons with late-stage dementia and family decision-makers	Intervention was feasible and completion of the protocol ranging between 77% (family two-week call) and 93% from the initial consultation. There was no difference among the hospital and emergency department visits in the intervention versus control. The intervention group had more of the palliative care domains addressed and was more likely to get hospice. The intervention groups were more likely to discuss goals of care, prognosis, and decisions to avoid hospitalization. Consultations were found to result in improved decision-making and outcomes	Strengths: Strong addition to a limited field of research and promising results to foster research and intervention development for triggered palliative care Limitations: Short duration of specialty palliative care; enrollment was limited due to short hospital stays and caregiver stress	37

Table 2. Continued

Author (year)	Title/objective	Design, setting, population, and sample	Results	Strengths/limitations	Crowe Score (out of 40)
Lackraj et al. (2021)	Implementation of specialist palliative care and outcomes for hospitalized patients with dementia To determine whether implementation of hospital-based specialist palliative care was associated with differences in treatment intensity outcomes for hospitalized patients with dementia	Design: Retrospective cohort study Setting: 51 hospitals in New York that either did or did not implement a palliative care program between 2008 and 2014 Sample: 82,068 hospitalized persons with dementia	82,118 patients diagnosed with dementia experienced acute hospitalization. Among them, 41,227 individuals (equivalent to 50.27%) received treatment in hospitals that had integrated a palliative care program. In contrast to patients treated in hospitals lacking palliative care services, those with dementia who received care in hospitals after the introduction of palliative care were 35% more likely to be discharged to hospice	Strengths: Additional evidence that the utilization of hospice care is a movable outcome of specialist palliative care Limitations: Differences between hospitals and lack of information about the timing and specifics of palliative care delivery such as number and availability of palliative care providers; institutional cultural differences related to palliative care	36
Miller et al. (2017)	Specialty palliative care consultations for nursing home residents with dementia To examine the impact of expanded palliative care access for NH residents with moderate to severe dementia	Design: Retrospective cohort design; NH consultation data from two palliative care organizations Setting: North Carolina and Rhode Island Sample: 505 NH residents with moderate-to-very severe dementia who died between 2006 and 2010 across 31 NH	With earlier consultation (vs no consultation), hospitalization rates in the seven days before death were on average 13.2 percentage points lower and with later consultation 5.9 percentage points lower. The consultations appeared to decrease acute care and burdensome transitions without PLWD spending additional Medicare. Earlier consultations showed greater reductions	Strengths: Matched controls in a similar time; examination of outcomes during the last 30 days of life which minimized bias Limitations: Unable to see the association between palliative care consultations and use of acute care versus hospice; unable to match nursing homes and limited generalizability	36.5
Moyo et al. (2022)	Effect of a video-assisted advance care planning intervention on end-of-life health care transitions among long-stay nursing home residents To determine the relationship between an advance care planning (ACP) video intervention, Pragmatic Trial of Video Education in Nursing Homes (PROVEN), and end-of-life healthcare transitions among long-stay nursing home residents with advanced illness	Design: Pragmatic cluster randomized clinical trial Setting: February 2016 to May 2019 in 360 nursing homes (119 intervention, 241 control) Population: Long-stay NH residents 65 years who died during the trial who had advanced dementia	Video topics included goals of care, hospice transitions, hospitalization, and advance care planning Decedents with advanced illness in the intervention group has less hospital transfer in the last 90 days of life than the control arm. There was no difference between the two trial arms when comparing the number of decedents with multiple hospital transfers or late transitions to hospital or hospice	Strengths: Promising intervention that could inform future efforts to reduce late transitions and burdensome care Limitations: Trend of reduced hospital transfer rates during the trial; lack of information on resident or family preferences; low intervention fidelity	34.5
Oud (2017)	Predictors of transition to hospice care among hospitalized older adults with a diagnosis of dementia in Texas: A population-based study To identify factors associated with hospice use in the inpatient setting and patterns of escalation of care to ICU setting preceding discharge to hospice	Design: Retrospective, population-based cohort study. Setting: Texas, United States (Inpatient Public Use Data File TIPUDF (2001–2010)) Sample: 889,008 hospitalized persons with dementia	40,669 persons with dementia were discharged to hospice. Hospice transitions increased between 2001 and 2010, 908 to 7,398 respectively. These involved admission to the ICU prior to discharge in 45.2% of them. Organ failure development, number of organs in failure, and mechanical ventilation use were prevalent. Additionally, minoritized individuals, uninsured, or noncommercial primary insurance holders were less likely to discharge to hospice	Strengths: Robust data set with a diverse population; population-based approach to analysis Limitations: Dementia severity could not be identified; other clinical contributors to hospice transitions (procedures, severity of illness, etc.) could not be examined	34.5

Table 2. Continued

Author (year)	Title/objective	Design, setting, population, and sample	Results	Strengths/limitations	Crowe Score (out of 40)
Prater et al. (2023)	Hospice transitions from the perspective of the caregiver: A qualitative study and development of a preliminary hospice transition checklist To explore caregiver experiences and perceptions on the transition to hospice and to develop a preliminary checklist for hospice transition	Design: Qualitative descriptive study using semistructured interviews and descriptive inductive/deductive thematic analysis Setting: United States Sample: 19 adult caregivers of patients had enrolled in hospice and died in the year prior (January to December 2019)	Four themes that were identified for the framework: hospice intake, preparedness, burden of care, and hospice resources. A checklist was created that included factors that caregivers thought could contribute to successful hospice care transitions and how to improve the transitional process	Strengths: An initial checklist was created for hospice agencies to improve their transition process; can be modified for future intervention development Limitations: Lack of racial and ethnic diversity of sample	35
Sullivan, de Rosa, et al. (2022)	Dementia caregiver burdens predict overnight hospitalization and hospice utilization To determine sociodemographic and caregiver burdens associated with overnight hospitalization, hospice utilization, and hospitalization frequency among persons with dementia	Design: Cross-sectional analysis using National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC) data. Logistic and proportional odds regression Setting: United States Sample: 899 persons with dementia and caregivers in 2015	Caregivers financial difficulty or felt like their burden was too much to manage, persons with dementia were 5.60 times more likely to have overnight hospitalizations. Caregivers that had emotionally difficulty resulted in the person with dementia being 5.89 times more likely to use hospice than caregivers that did not report having emotional difficulty	Strengths: Robust data; subjective care burden factors associated with use of hospice in the national data set linking their primary caregivers in dyads were studied Limitations: Overnight hospitalization and use of hospice could have been affected by the presence of other caregivers; unable to know other factors that contributed to hospice use as a result of caregiver burden (frequency of care responsibilities, behavioral symptoms of person with dementia, etc.)	35.5
Sullivan, Bo, et al. (2022)	Predicting hospice transitions in dementia caregiving dyads: An exploratory machine learning approach To identify quality of life and social determinants of health factors associated with hospice use among people living with dementia and their caregivers	Design: Secondary data analysis of the NHATS and NSOC data using multiple machine learning Setting: United States Sample: 117 PLWD and primary caregivers	Factors associated with hospice use included comorbid diabetes, a regular physician, a good memory rating, not relying on food stamps, not having chewing or swallowing problems, and whether health prevents them from enjoying life. Primary caregivers' age, income, census, number of days of help provided by caregiver per month, and whether health prevents them from enjoying life was associated with hospice use	Strengths: Exploratory models created a starting point for future research; precision health approaches Limitations: Unable to assess for barriers to care; unclear applicability of research findings to practice	36
Toles et al. (2022)	Adapting the Connect-Home transitional care intervention for the unique needs of people with dementia and their caregivers: A feasibility study To assess fidelity, acceptability, preliminary outcomes, and mechanisms of the Connect-Home ADRD transitional care intervention	Design: Feasibility study Setting: Two skilled nursing facilities in the Southeastern United States Sample: 19 persons living with dementia and caregiver dyads	Intervention was shown as feasible and acceptable as dyads stated it was easy to use and helpful. The Connect-Home ADRD adaptations included home support for management of symptoms of dementia and support for the transition to hospice	Strengths: Acceptability and feasibility of the intervention; use of structured interviews with persons living with dementia and caregivers Limitations: Sample size; limited racial and ethnic diversity; unable to test for efficacy	34

Table 2. Continued

Author (year)	Title/objective	Design, setting, population, and sample	Results	Strengths/limitations	Crowe Score (out of 40)
Wiggins et al. (2019)	Understanding the factors associated with patients with dementia achieving their preferred place of death: A retrospective cohort study To understand preferences for place of death among people with dementia; to identify factors associated with achieving these preferences	Design: Retrospective cohort study Setting: Coordinate My Care (Electronic Palliative Care Coordination System) Setting: 1,047 persons with dementia who died between December 2015 and March 2017	803 decedents had information on the preferred and actual place of death. The care home or home was the most common preferred place of death at 58.8% ($n = 474$), 83.7% ($n = 672$) actually died in their preferred place and this was more likely for those that were most functionally impaired. When the goals of treatment focused on symptomatic relief, more people with dementia were able to die in their preferred place of death	Strengths: Preferences of the person with dementia were available; preferred place of death examined; large sample Limitations: Limited generalizability to other populations; other variables unknown such as place of residence and the presence of caregivers	33.5
Yeh et al. (2021)	Improving end-of-life care for persons living with dementia: Bereaved caregivers' observations and recommendations To assess satisfaction with and elicit recommendations for improving end-of-life care experiences of persons with dementia from the perspective of bereaved caregivers	Design: Cross-sectional study (survey) Setting: California, United States Sample: 53 caregivers of decedent persons with dementia	Caregivers felt that there were gaps present in provider communication about progression of disease continuity of care and coordination at the end of life prior to transitions and preferred location of death. Most caregivers shared views that providers should talk about the end-of-life decisions and care with persons with dementia during the earlier stages of the disease	Strengths: Caregiver perspectives were garnered specific to end-of-life care and decisions; evidence that earlier conversations about transitions and end-of-life care may be desired Limitations: Potential for recall bias due to cross-sectional interviews of bereaved caregivers; limited racial/ethnic diversity	35

Notes: ICU = intensive care unit; PLWD = persons living with dementia.

evidence, the major limitations and strengths of each article were considered.

Results

Overall Summary of Reviewed Articles

After critical appraisal, 14 articles met the inclusion criteria: seven retrospective cohort studies; four secondary data analyses; two randomized control trials; one feasibility study; one survey study; and one qualitative study. These studies also included population-based cohort and cross-sectional analysis designs. Most studies were conducted in nursing homes, home care, or hospital setting. Electronic data sources were utilized for secondary analyses (National Health and Aging Trends Survey or the Minimum Data Set). Studies were largely conducted in the United States or using U.S.-based data.

Studies in this review reflect findings inclusive of over persons living with dementia and their caregivers or surrogate decision-makers and/or dementia-caregiver dyads. Across the 14 articles, the sample populations mainly consisted of White participants and a limited number of Black participants. The representation in studies and reporting of participants from other racial and ethnic backgrounds and underrepresented groups was scant. The average patient age was 85 years old, and the average caregiver and/or surrogate decision-maker age was 58 years old. Across studies, most persons living with dementia had multiple chronic conditions including cancer, diabetes, cardiovascular disease, lung disease, stroke, and mental illness.

Hospice Transitions Interventions

Among the articles, three interventions included a primary or secondary focus on the person living with dementia and/or their caregivers. Each intervention focused on the transition to hospice care including decision-making, transitional care and intake processes, or palliative care integration in the later stages of dementia illness. The interventions were: the Connect-Home ADRD intervention, a transitional care intervention in home care (Toles et al., 2022); the video-assisted advance care planning (ACP) intervention (Moyo et al., 2022), and triggered palliative care for late-stage dementia (Hanson et al., 2019).

The Connect-Home ADRD intervention was utilized for continued care for dementia-caregiver dyads. The intervention was a transition care program that offered pre-discharge and postdischarge components for persons living with dementia focused on care planning, dementia-related safety, symptom management, and access to a dementia caregiving specialist. This intervention was developed to reduce avoidable hospital transfers and hospitalizations for persons living with dementia and their caregivers (Toles et al., 2022). The dementia caregiving specialist also engaged caregivers in conversations about the appropriate level of care when the needs of the person living with dementia surpassed caregiver capacity and resources. In some of these cases, caregivers were supported in the arrangement of the home care to hospice transition. The intervention was deemed feasible and acceptable, and it was delivered to more than 84% of dyads in the study. However, the study was limited in sample size and representation of racial and ethnic groups.

The video-assisted ACP intervention involved five videos (6 to 10 min each) in English or Spanish, covering topics such as general goals of care, goals of care for advanced

dementia, hospice, hospitalization, and ACP. Each nursing home identified ACP video champions or social workers, who were responsible for offering the videos to participants and tracking whether the videos were watched. Control locations continued their usual ACP practices. Outcomes included burdensome treatments, hospital transfers in the last 90 days of life, multiple hospital transfers, and late transitions such as hospital transfers in the last 3 days or hospice admission in the final day before death. The video-assisted ACP intervention showed a modest reduction in the number of hospital transfers in the last 90 days of life among nursing home residents. Although one-third of decedents enrolled in hospice in the last 90 days of life in the intervention, it was not associated with a significant difference in late transitions to hospice or hospitalization. The study did not include family or resident preferences on hospital transfers and had low intervention fidelity (Moyo et al., 2022).

A pilot RCT implemented by Hanson et al. (2019) was created to examine the impact of dementia-specific palliative care for advanced or late-stage dementia illness. In this study, dyads randomized to the intervention group received specialty palliative care consultations during hospitalization. They received follow-up using transitional care telephonic support by a palliative care nurse practitioner. The consultation protocol addressed various aspects of dementia care, including prognosis, symptom management, caregiver support, and goals of care decision-making, and provided families with an informational booklet. The intervention group received assistance with completing the Medical Orders for Scope of Treatment (MOST) form and postdischarge care. Control participants received standard hospital care and Alzheimer's Association caregiving resources, with specialty palliative care available only upon request. The participants enrolled in the intervention were likely to have increased communication and conversations about prognosis and decisions related to late-stage dementia care. Participants in the intervention group were more likely to receive hospice and avoid rehospitalization.

A qualitative study by Prater et al. (2023) was conducted to develop a preliminary hospice transitions checklist for later expansion and intervention development. The intervention was qualitative and was intended to inform future intervention development. This checklist, intended to be expanded upon and tested in future work, was developed from interviews with many caregivers of persons living with dementia that could be incorporated into the transition process to hospice. This study was limited in scope and sample and racial/ethnic diversity, similar to other available interventions.

The available evidence suggests that intervention development in this area of hospice transitions for persons living with dementia is limited. However, despite limited evidence, the study team agreed that the existing interventions were of moderate to high quality.

Predictors of Transitions to Hospice for People With Dementia

The remaining articles reported on secondary data analyses, a survey, and retrospective cohort studies using large data. These studies examined associations between demographic and clinical characteristics, and factors and predictors of transition to hospice for persons living with dementia. Several predictors of hospice transitions were noted in the evidence base. Each is discussed below.

Palliative care integration

In this review, receiving palliative care in the hospital and nursing home setting was associated with hospice transition for persons living with dementia. In an examination of 51 hospitals based in NY state, inpatient specialist palliative care was associated with a significantly increased likelihood of discharge to hospice for hospitalized persons living with dementia. Those who received specialist palliative care in teaching hospitals were more likely to experience a transition to hospice (Lackraj et al., 2021). Similarly, Miller and colleagues (2017) examined the value of implementing palliative care consultations in nursing homes for persons with moderate to severe stages of dementia on burdensome transitions to hospice. Palliative care receipt also led to earlier hospice transitions, particularly related to decreases in transitions in the 3 days before death (Miller et al., 2017). Persons living with dementia with a preferred place of death of the nursing home or home were more likely to die at home or at their preferred place of death when symptom management and relief were prioritized as delivered through an electronic health record palliative care coordination system (Wiggins et al., 2019).

Clinical condition and frequent care transitions

Persons living with dementia who experienced serious or critical illness with declining cognitive and physical functioning with multiple chronic conditions led more frequently to a transition to hospice care (Oud, 2017). The development of single or multiorgan failure was associated with hospice transition. Furthermore, escalation of care to the care unit was associated with hospice transitions, which were typically late in the illness trajectory (Gozalo et al., 2011). Tube feeding orders, stage IV pressure ulcers, and longer lengths of stay in the ICU were associated with hospice enrollment (Gozalo et al., 2011).

While comfort-focused care was a priority for many nursing home residents and their families, the presence of such orders was not associated with hospice transition but highlighted the need for greater inclusion of comfort-focused treatment plans in later-stage dementia and illness communication (Ernecoff et al., 2018). For severe neuropsychiatric symptomatology, inpatient psychiatric care was associated with low transitions to hospice care despite the potential clinical need for palliative care or eligibility for hospice care (Epstein-Lubow et al., 2015).

Sociodemographic factors

Sociodemographic characteristics were associated with or predictive of greater or lesser hospice use. For example, the type of health insurance a PLWD held predicted the odds of transitioning to hospice care. Persons living with dementia on Medicaid had a significant association with hospice use (Sullivan, Bo, et al., 2022). Additionally, utilization of hospice among minoritized groups was low; thus, individuals' racial and ethnic background was associated with lower transition to hospice compared to White persons living with dementia.

Caregiver burden

Caregivers of persons living with dementia also have an important role in whether or not the individual transitioned to hospice. The experience of caregivers and subjective reports of burden, including emotional difficulty, were important predictors of hospice. Caregivers with high levels

of emotional difficulty and burden with assisting PLWD were 5.89 times more likely to use hospice (Sullivan, de Rosa, et al., 2022). Caregivers' experiences with quality communication surrounding timely referrals to hospice were also noted. Caregivers expressed a desire to receive greater high-quality communication about dementia disease progression, which influenced their satisfaction with care. The preferred place of death of the person living with dementia being honored was also expressed as a core caregiver concern regarding hospice transitions (Yeh et al., 2021).

Discussion and Implications

This review highlights the state of the science related to the transition to hospice for persons living with dementia, which is a unique point and opportunity in the dementia illness trajectory. Before hospice transitions, persons living with dementia often experience significant decline, cognitively, physically, and behaviorally, which can lead to increased caregiver burden and distress. Thus, these findings support what is known about greater palliative care integration for hospice transitions. Palliative care specifically focuses on symptom management, care coordination, caregiver support, and serious illness communication, all of which are integral when supporting the person living with dementia at the end of life (Ferrell et al., 2018). Palliative care integration can be a bridge that bolsters caregivers through the burden and stress of end-of-life caregiving and decision-making to eventual hospice use, which is beneficial for providing high-quality care and improving the quality of life for caregivers of persons living with dementia (Harrison et al., 2022).

Among the included studies, different approaches were taken across healthcare settings to engage caregivers and patients in hospice decision-making conversations. Despite assessments of comfort-focused care, incorporation of ACP and end-of-life orders, and integration of palliative care, there remains a need for dementia-specific illness counseling and end-of-life communication in earlier stages of illness. Assisting and guiding caregivers in decision-making conversations in the earlier stages of disease can help with reducing processing difficulties in the later stages, particularly when needed dementia trajectory and serious illness and prognosis-related understanding can be established. In other words, much of the evidence indicates that conversations about hospice and resultant transitions seem to be occurring late in the illness trajectory for persons living with dementia. This finding necessitates a renewed focus on timing and delivery of goal-concordant care through effective serious illness communication while also providing dementia-specific education to caregivers such that they can make informed decisions at the end of life.

Despite the limited scope of studies, data support that communication delivered in a variety of modalities (e.g., video-assisted care planning, triggered palliative care, care coordination/continuity) was mostly feasible and acceptable. However, studies also highlighted that optimized communication would focus on both dementia and hospice, which may lead to successful guidance of the person living with dementia and their caregiver in hospice care.

The presence of frequent hospitalizations and burdensome care transitions in the setting of clinical worsening before hospice is characteristic of the dementia end-of-life experience. This review shows that hospitalizations, specifically those

that lead to ICU-level care and organ failure, may lead to hospice transitions. Additionally, for persons living with dementia who have several behavioral symptoms, more research is needed to understand optimal transitions to hospice from inpatient psychiatric hospitalizations. Further complicating the experience of hospice transition, long hospice lengths of stay after successful enrollment heighten the challenge of communicating its benefits and supporting decision-making with dementia care partners. Currently, there are no tools to determine when persons living with dementia are truly eligible for hospice, as it is heavily dependent upon clinician assessment within the constraints of CMS-mandated hospice eligibility criteria. Given the complexity of hospice lengths of stay for persons living with dementia and unclear guidance on hospice eligibility, live discharge is an unwanted and negative outcome of hospice use for this complex population, resulting in greater burdensome transitions, particularly heightened for racially and ethnically diverse individuals (Luth et al., 2024).

Interventions that focus on reducing acute care transitions and improving the facilitation of the hospice care transition are needed. These interventions should focus on earlier counseling and targeted outreach to caregivers through care management in the community-based setting (e.g., home healthcare) as one potential solution that can potentially lead to better end-of-life care and reduction of late hospice transitions. However, the evidence base related to home healthcare to hospice transitions remains limited (Bigger, Foreman, et al., 2024). Simultaneously, frequent assessment and tracking of the clinical facets of decline, including greater physical dependence on caregivers, immobility, tube feeding, and severe neuropsychiatric symptoms, should also be considered opportunities to engage earlier in the hospice decision-making process across care settings.

The evidence is consistent with the literature on disparities in hospice use among persons living with dementia. Black and Hispanic persons living with dementia are less likely to use hospice compared to White persons living with dementia, and there is a critical void in tailored interventions that can improve equity in hospice care use (Lin et al., 2022). As the evidence base is lacking, standards and guidelines for the provision of culturally sensitive care are still needed for optimal care management and training and education of the dementia care workforce. As racial and ethnic minorities are also more likely to receive intensive services before death, future research exploring hospice transitions for persons living with dementia should prioritize diversification of research participants through greater recruitment and retention of those who have been understudied in dementia and end-of-life care research (Jones et al., 2021; Luth et al., 2022).

Limitations

The limitations of this integrative review are important to note. Although moderate to high-quality evidence for transitional care programs to hospice was available in the scant number of interventions, many are limited significantly by a lack of generalizability and underrepresentation of minoritized and marginalized groups, which are disproportionately affected by dementia. Specifically, the intervention-specific evidence base was limited in the racial, ethnic, socioeconomic, sexual, gender, and geographic diversity of sample participants. There remains a dearth of practicable and efficacious evidence that can be implemented to better facilitate the transition to hospice for persons living with dementia. Further,

existing interventions have not yet been studied in multisite clinical trials. Concurrently, while predictors of hospice transitions have been well described, it is unclear if these same predictors are associated with hospice transition for underrepresented groups and marginalized communities, and the magnitude of such associations remains underexplored.

Practice and Hospice Policy Considerations

A major clinical practice consideration is addressing caregiver preferences on hospice decision-making related to dementia care that centers on the emotional and physical difficulty of caregiving. Providing this tailored care requires attention to the training and education of the aging workforce, including assessing preparedness and knowledge related to dementia illness, and palliative and hospice care (Murali et al., 2022). From a clinical practice perspective, interdisciplinary clinicians who care for persons living with dementia should recognize caregiver burden as a potential early indicator of a need for hospice transition; however, how and when to operationalize burden as a trigger for serious illness communication is challenging to determine as a burden may fluctuate with ever-changing care needs.

Greater support for dementia caregivers contemplating this decision of a hospice transition is an essential yet often missing piece of communication at the end of life. They may agree that they are overburdened but feel guilt or other emotions about starting hospice. Caregivers may feel like they are effectively losing the person living with dementia all over again and that use of hospice care may also trigger or worsen anticipatory grief and contribute to care partner burden (Włodkowski, 2016). The hospice transition also means acknowledging a new and final phase of care, where there is potential for disagreement among family members about the decision. These issues are not new but enduring and poignant, as it is also challenging for clinicians to bring up the hospice transition to caregivers, and they themselves may be the ones to put off the transition discussion (Schulman-Green et al., 2004, 2005).

A major policy implication is related to hospice eligibility criteria. Timely assessments of hospice eligibility that are responsive to patient and family preferences about end-of-life care goals are critical for high-quality care delivery and include physician assessment of clinical status, prognosis, and mortality. However, hospice eligibility criteria for dementia are not always clearly defined given the vast variation in clinical and subclinical presentations of dementia at the end of life. Therefore, better assessment and screening for dementia-specific hospice eligibility are needed, highlighting a key policy issue related to hospice care delivery that requires further study. Another area of hospice policy that can be strengthened is related to the longer lengths of stay for persons with dementia and the burden and stress of transitioning out of hospice that similarly strains both the caregiver and healthcare team (Hunt & Harrison, 2021).

Conclusion

Overall, the evidence base suggests that developing interventions that support the timely, goal-concordant transition to hospice using high-quality, culturally sensitive, and targeted care strategies is needed for improved serious illness care and communication in the healthcare setting. These interventions can help with better tracking and management of patient and

family care preferences along the illness trajectory and may result in better prediction of later illness decisions surrounding hospice care. Ultimately, the goal is to support caregivers as they make these difficult decisions about end-of-life care. Earlier exposure to hospice information and counseling, with the involvement of all healthcare team members and regular check-ins, may be needed to better prime caregivers for hospice decision-making and improve end-of-life care transitions for persons living with dementia.

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Conflict of Interest

None.

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Preregistration Statement

Details of the protocol for this integrative review were registered on PROSPERO and can be accessed at https://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42024564474. This integrative review was also registered on Open Science Framework at https://osf.io/6swb3/?view_only=fd03465a16b74552af328d0b598439e4

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