

Transitions between skilled home health and hospice for persons living with dementia: a systematic review of literature

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Background: In the United States (US), nearly one third of skilled home health (HH) patients and nearly one half of hospice patients have diagnoses of Alzheimer's disease and related dementias (ADRD), conditions often characterized by a slow decline in cognition and function. Many persons living with dementia (PLWDs) are cared for at home yet may transition between care settings such as skilled HH or hospice, potentially leading to fragmented and poorer care. The purpose of this systematic review was to examine literature pertaining to (I) care transitions for PLWD who are enrolled in skilled HH and hospice in the US, and (II) specifically, care transitions between skilled HH and hospice for PLWD.

Methods: We conducted a systematic review. From March to November 16, 2023, we searched CINAHL, PsychInfo (EBSCO version), and PubMed databases inputting keywords and index terms related to HH, care transition, hospice, and dementia. Articles were included if they were peer-reviewed, primary research studies that were published between 2017–2023 and addressed care transitions for PLWD enrolled in US skilled HH and hospice or transitions between the two settings. We evaluated the quality of each article and extracted relevant data. We described studies by setting while analyzing for similarities and differences between them.

Results: Of 230 studies, 14 met our inclusion criteria. We found that PLWD are at higher risk for early, unsuccessful discharge from—and readmission to—skilled HH; and PLWD are at higher risk for being discharged alive from hospice. Only one study pertained to care transitions for PLWD between skilled HH and hospice.

Conclusions: We included only studies set in the US, as skilled HH and hospice may differ in policy and practice in other countries, which limits our findings. Future work should explore assessment approaches specific to PLWD that lead to higher quality of coordination of care to, from, and between skilled HH and hospice.

Keywords: Persons living with dementia (PLWDs); cognitive impairment; skilled home health; hospice; transitions

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Introduction

Background

In the United States (US), nearly one third of skilled home health (HH) patients and nearly one half of hospice patients have diagnoses of Alzheimer's disease and related dementias (ADRD) (1). Skilled HH in the US is defined as physician-directed skilled care provided by the disciplines of nursing, social work, and/or physical, occupational, or speech therapy to homebound patients, with a focus on rehabilitation, while hospice is defined as comfort-oriented care provided by an interprofessional team to patients with prognoses of 6 months or fewer who choose to discontinue curative treatments (2,3). In the US, 98% of hospice care occurs in the home (4). ADRD are prevalent in both the skilled HH and hospice settings in the US.

ADRD are characterized by chronic progressive global cognitive impairment (5,6). The term, cognitive impairment, has been used as a measure of dementia; therefore, both terms are used in the present review (7,8). Dementia disorders affect people slowly and insidiously, and irreparable brain damage may begin to occur up to twenty years before any symptoms are identified (6). Despite the

6-month prognosis criterion for hospice, determining how long a person living with dementia (PLWD) will survive is difficult (8). Prognosis may be informed by functional status, physical symptoms, poor nutrition, and other criteria (9). Long trajectories of decline toward death for PLWD are evidenced by high, sustained functional impairment in the last 4 years of life, and PLWD have the same predicted functional status scores at 17 months before death as individuals without dementia at 6 months before death (10). However, they receive less healthcare in all settings than those without dementia or cognitive impairment (11,12).

During their long trajectory of decline, PLWD are more likely to be cared for by family care partners. For example, approximately 85% of Americans with probable dementia reside with family, friends, or in community adult assisted living facilities, while 15% live in nursing facilities (13). Family care partners of PLWD are three times more likely to experience caregiver burden in the PLWD's last year of life compared to caregivers of people dying from other diseases (14). PLWD and their care partners are at higher risk for poor outcomes related to care transitions—defined as movements between health care services or locations of care—than their counterparts without dementia or cognitive impairment (15). Services for PLWD should be flexible, tailored, and equitable, but care systems are often fragmented and difficult to navigate (16).

Care transitions for all patients increase risks of medical errors, disruptions in continuity of care, avoidable hospital admissions, and preventable adverse events; however, PLWD have the added risk of cognitive impairment, while their care partners manage and negotiate care with multiple providers, manage illness, and cope with psychosocial issues (17-19). PLWDs are at risk for multiple care transitions during their long trajectory of decline. For example, during the 6-month period post-diagnosis of Alzheimer's disease, the average numbers of patient transitions between care settings have been found to be 2.8 originating from an inpatient setting, 2.4 from a skilled nursing facility, 0.3 from a hospice setting, and 0.7 from a home or outpatient setting (20). The overall cost burden during this period has been high for individuals diagnosed with Alzheimer's disease in a non-ambulatory setting (mean \$41,468), while those diagnosed in ambulatory settings incurred only \$12,597 in costs during the same period, suggesting that PLWD cared for in home and outpatient settings are better managed and cost the healthcare system less than PLWD in institutional settings; and that the earlier PLWD are managed, the

Highlight box

Key findings

- Some literature exists regarding care transitions for person living with dementia (PLWD) who are enrolled in US skilled home health (HH) or hospice. However, there is a dearth of literature that includes dementia or cognitive impairment as a variable in care transitions between the two settings.

What is known and what is new?

- There is a prevalence of PLWD or cognitive impairment in US skilled HH and hospice. Dementia is a terminal illness with a long trajectory of decline, during which PLWD and their care partners are at risk for multiple care transitions. Skilled HH is rehabilitation-focused care, while hospice is comfort-focused care.
- Evidence shows that PLWD benefit from longer episodes of care in either setting, but recent US policy changes have encouraged early disenrollment from both settings. Transitions between skilled HH and hospice may disrupt care and bring risks for poor outcomes. We found only one study that included dementia or cognitive impairment as a variable in care transitions between skilled HH and hospice.

What is the implication, and what should change now?

- Future work is critically needed to explore assessment approaches specific to PLWD that lead to higher quality of coordination of care to, from, and between skilled HH and hospice.

longer they can avoid intensive healthcare resource use (20).

For PLWD, a transition may involve moving from one healthcare service to another, or it may involve being discharged from a healthcare service into the care of their informal care partners. In the present review, a care transition for PLWD includes being discharged from or admitted to a health service; or being transferred from one health service to another. Discharges from skilled HH to community or from hospice to community are also considered care transitions for the purposes of this review because care partners of PLWD must find alternate services to support their caregiving (21).

Involvement of mid-level practitioners in care transitions may affect outcomes for PLWD. For example, in both nursing home- and community-dwelling Medicare beneficiaries with ADRD, adjusted hospitalization rates were lower and hospice rates were higher for individuals with higher proportions of involvement by a nurse practitioner or physician's assistant during their final 9 months of life (22). PLWD are at risk for multiple care transitions, and support is needed to optimize outcomes.

Home-based care is an umbrella term used to describe all care provided in the home, and it is growing among older adults (1). For example, in the US, some type of home-based care has been accessed by 44.4% of PLWD, who are more likely to be female, non-Hispanic/Latino, and residing in metropolitan areas and in residential facilities (23). Growing diversity in the US may affect the demographic make-up of home-based care in the future (24). Home-based care, which can include skilled HH and hospice, is a growing setting with benefits for PLWD. For example, benefits include familiar environments and routines, which have been shown to decrease neuropsychiatric symptoms (NPS) and improve health outcomes for PLWD (25-27). Further, in post-hospitalization, many patients prefer to rehabilitate in skilled HH versus an inpatient setting because services are provided in the person's home (28). As well, skilled HH is gaining attention as a site of long-term care with potential for palliative care and transitions to hospice (29-31).

The decision to pursue hospice care is like no other healthcare decision because it involves considering existential issues, adapting to new health care services, and coping with a shift in goals of care from cure to comfort (32-34). Hospice has been found to benefit PLWD since it is associated with improved symptom management and care partner satisfaction, decreased care partner

burden, preventing hospitalization, and discontinuing unnecessary medications (35). Approximately one-half of all US Medicare hospice beneficiaries have primary or comorbid diagnoses of ADRD (5). Such a prevalence exists despite the Center for Medicare and Medicaid Services' (CMS) 2016 implementation of a 2-tier payment system reducing reimbursement for hospice stays longer than 60 days, which has been associated with reductions in the total number of hospice patients with ADRD (36,37). Evidence supports that ADRD diagnoses are prevalent in hospice, that hospice care benefits PLWD and their care partners, but that PLWD are at higher risk for live discharge than their counterparts without ADRD (5,38-43). Live discharge from hospice for PLWD and their care partners has been described as distressing and confusing; associated with numerous losses; and referred to disparagingly as being expelled from hospice (21). Once discharged from hospice, PLWD may transition to HH or other services which may disrupt continuity of care and bring risks of poor outcomes. In the US, the number of transitions between skilled HH and hospice is unlimited by policy (2,3).

Rationale and knowledge gap

Previous literature has shown that PLWD are at risk for multiple care transitions, associated with poor outcomes (17-20). However, there is a gap in knowledge regarding PLWD and care transitions related to the specific settings of skilled HH and hospice. Chen *et al.* conducted a review of literature studying the impact of HH on end-of-life outcomes for PLWD (11). They found that HH may be associated with a lower risk of acute care utilization in the late period (e.g., last 90 days before death) but a higher risk in the late period (e.g., last 15 days); that HH may increase palliative care referrals; and that advance care planning was an important factor influencing end-of-life outcomes. They also found that challenges for HH providers in medical decision-making and initiating palliative care may require further training and external support. Hirschman *et al.* conducted an integrative review and found that existing measures focus heavily on the outcomes of healthcare resource use and cost rather than the elements of transitional care or care coordination for PLWD and their care partners (44). Chen *et al.*'s and Hirschman *et al.*'s articles were excluded from our results because they were reviews and did not fit our inclusion criteria. Given the

Table 1 Inclusion and exclusion criteria

Included	Excluded
English-language	Non-English language
Peer-reviewed	Non-peer reviewed
Published between 2017–2023	Published before 2017
Primary research articles	Literature reviews, meta-analyses, study protocols, and opinion pieces
Addressed care transitions related to dementia or cognitive impairment in the settings of home health or hospice	Did not address care transitions related to dementia or cognitive impairment in the settings of home health or hospice
Set in the United States	Set in non-United States countries

gap in literature, we sought to examine care transitions of PLWD related to the settings of skilled HH and hospice.

Objective

The purpose of the present systematic review was to examine literature pertaining to (I) all care transitions for PLWD who are enrolled in skilled HH and hospice in the US and (II) specifically, care transitions between skilled HH and hospice for PLWD in the US. Results will inform interested parties on the effects of care transitions for PLWD in these two settings, which may lead to policy and practice changes to optimize care. Results will inform future research on health outcomes for PLWD in care transitions related to skilled HH and hospice. We present this article in accordance with the PRISMA reporting checklist (45) (available at <https://apm.amegroups.com/article/view/10.21037/apm-23-524/rc>).

Methods

A systematic review is a structured, comprehensive synthesis of literature to determine the best evidence available to address a healthcare question (46). The question was, “What is the literature pertaining to care transitions for PLWD enrolled in skilled HH and hospice and specifically between the two settings?” The review protocol was not formally registered. Study materials and data extracted from included studies can be obtained by contacting the corresponding author.

Eligibility

Inclusion criteria included English-language, peer-reviewed articles set in the US and published between 2017 and 2023 that addressed care transitions for PLWD or

cognitive impairment related to skilled HH and hospice. The rationale for the timeframe was due to our intention to find evidence that might reflect recent US policy changes affecting PLWD in skilled HH and hospice (37,47,48). Exclusion criteria included articles older than the timeframe, did not fit the topic, and literature reviews, meta-analyses, study protocols, and opinion pieces. Inclusion and exclusion criteria appear in *Table 1*.

Search strategy and study selection

We employed a reference librarian (C.K.) to assist in the search. From March to July 21, 2023, and again on November 16, 2023, we searched CINAHL, PsychInfo (EBSCO version), and PubMed databases inputting keywords and index terms related to home health, care transition, hospice, and dementia (*Appendix 1*). The term, cognitive impairment, has been used as a measure of dementia—due to patient needs for reminders, levels of assistance, and levels of disorientation and delirium—and this approach is consistent with conceptual frameworks used to describe cognitive decline associated with dementia (7,8,49,50). Therefore, we included the search term, cognitive impairment.

Two authors (S.E.B., R.A.F.) reviewed articles independently. A three-step strategy was employed. Step 1 involved viewing titles and abstracts; Step 2 involved reading the full article content of studies identified for inclusion from Step 1; and Step 3 involved a manual search of reference lists for additional studies. We constructed a PRISMA flowchart to describe the selection process (*Figure 1*).

Data extraction

We extracted relevant data including problem/purpose,

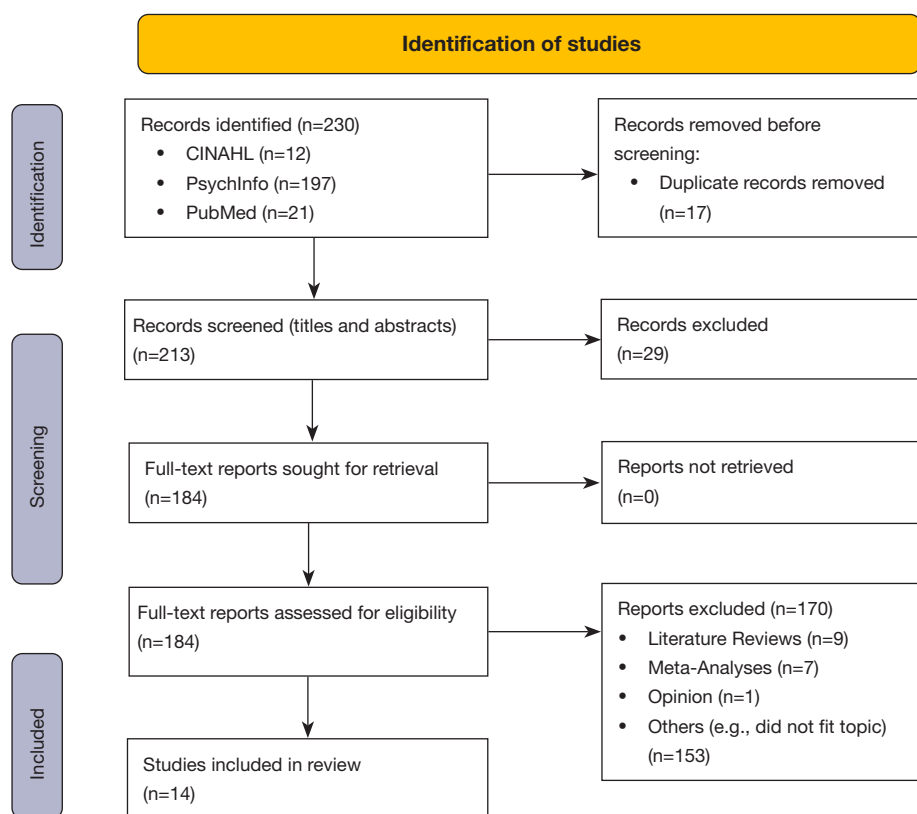


Figure 1 Prisma 2020 flow diagram.

design, sample, methods, instruments, findings, implications, and limitations. Information from included studies was extracted by authors S.E.B. and R.A.F. independently. Author G.L.T. resolved disagreements and checked for accuracy.

Quality assessment

Following Chen *et al.*'s example, we used the Critical Appraisal Skills Programme (CASP) tool kit to appraise the quality of the studies (<https://casp-uk.net/casp-tools-checklists/>) (11,51). Studies were rated as strong, moderate, or weak. Ratings were based on design, data collection method, intervention integrity, appropriate analysis, and implications for practice. Two authors (S.E.B., R.A.F.) appraised studies independently. Discrepancies were resolved through consensus.

Data synthesis

We narratively described the data on care transitions

between HH and hospice for PLWD. We used synthesis, which is a textual approach to the data and involves an overall assessment of the robustness of the evidence. We described each of the studies and then grouped them by setting, while analyzing for similarities and differences between them (52). We were unable to conduct a meta-analysis due to methodological heterogeneity across studies.

Results

Of the 230 retrieved studies, 14 met the criteria for inclusion and are listed in *Table 2* (38-43,53-60). Articles included were set in the US, published between 2017–2023, and were primarily quantitative studies involving descriptive or regression analyses of administrative datasets. One included study was qualitative. Results were grouped into three categories based on the research questions: Care Transitions for PLWD or Cognitive Impairment Enrolled in Skilled Home Health; Care Transitions for PLWD or Cognitive Impairment Enrolled in Hospice; and Care Transitions between Skilled Home Health and Hospice for

Table 2 Characteristics of studies included in the review (38-43,53-60)

Source & country	Purpose	Design	Sample	Methods	Instruments	Findings	Implications	Limitations	Quality
Burke <i>et al.</i> , 2022 (53), USA	Compare outcomes of post-acute care between HH and SNF following hospitalization among Medicare beneficiaries with dementia	Retrospective cohort analysis	977,946 Medicare beneficiaries with diagnosis of dementia, discharged from hospital between January 1 2015 and December 31, 2016. Included only the first hospitalization followed by post-acute stay per beneficiary.	3-year look-back. 2-stage least-squares regressions	MedPAR, MDS, OASIS, Hospice, and MBSF	30.4% received HH after hospital discharge and 69.6% went to SNF	SNF may be overutilized. SNF may be used as a bridge to long-term care. PLWD may benefit more from a supportive home environment than a transition from one unfamiliar facility to another. CPs may need more support for round-the-clock ADL support	Dementia diagnoses may underestimate the true prevalence of dementia, especially given the change from ICD-9 to ICD-10 codes	Strong
De Vleminck <i>et al.</i> , 2018 (43), USA	Characterize hospices that serve PLWD, to compare patterns of hospice disenrollment for PLWD and without dementia, and to evaluate patient-level and hospice-level characteristic associated with hospice disenrollment	Longitudinal cohort study	149,814 hospice enrollees cared for by 577 hospices	Generalized linear models, multivariable logistic regression	Medicare hospice claims data & National Hospice Survey	4.9% had primary diagnosis of dementia. Hospices caring for PLWD were more likely to be for-profit and serve a large (>30%) percentage of nursing home patients. Disenrollment for PLWD more associated with dementia diagnosis than with hospitalization; PLWD more likely to be disenrolled after 165 days if served by smaller hospices and hospices serving a small percentage of nursing home patients	All hospices should have the right expertise in providing quality care for PLWD. Hospice disenrollment rates and the reason for disenrollment should be a reportable hospice quality measure	Data collected 2008–2010 may not reflect current data. Instruments did not include reasons for disenrollment. May not be generalizable to the 7% of hospices that are not Medicare-certified, hospice users who are not Medicare beneficiaries or who are enrolled in managed care	Strong
Clayton <i>et al.</i> , 2021 (38), USA	Examine the prevalence of live hospice discharge and understand the experiences of families and hospice staff who have experienced live hospice discharge	Mixed methods	5,648 hospice discharges. Five family caregivers. Six hospice staff	Review of administrative data for hospice admissions; focus groups for narrative data	NA	Dementia was the most prevalent live discharge diagnosis	Regulatory guidelines for hospice eligibility need increased flexibility to accommodate protracted and less predictable patient decline. Patients, families, and hospice staff need alternative ways to support patients and families when live discharge is necessary	None listed	Strong
Hunt <i>et al.</i> , 2022 (58), USA	What impacts a Medicare client experiencing dementia to disenroll from hospice or continue in hospice?	Retrospective, observational cohort study	867,695 Medicare hospice first-time enrollees with dementia	Used national 2012–2017 Medicare data linked to databases of hospices and regional characteristics	CMS Provider of Service Files, Hospice Public Use File, Hospice Compare database	Hospice disenrollment varies by type of hospice, geographic region, age, gender, race, and ethnicity	2016 Medicare Hospice Payment Reform reduced payments to hospice agencies if clients remained longer than 60 days. States are instituting laws to regulate the opening of new hospice agencies	This was a data study. Did not have information on the client's preferences and beliefs around end-of-life care. Results may not be up-to-date since the data set ended in 2017, and major revision to Medicare have been made. The competing risk nature of the outcomes since mortality would prevent disenrollment. Race and ethnicity are not self-reported	Strong
Knox <i>et al.</i> , 2021 (55), USA	Determine the association between patient factors and successful discharge to community after HH for PLWD	Retrospective	790,439 Medicare HH beneficiaries	Multilevel logistic regression	Home Health Base File, OASIS data, MedPAR, and Beneficiary Summary files	Beneficiaries with ADRD had a significantly lower odds of successful discharge to community than those without ADRD	Prioritization of evidence-based mobility and self-care interventions combined with robust episodes of care has the potential to improve rates of successful discharge to community after HH for PLWD	ADRD definition was based on ICD-10, which has been shown to have poor sensitivity	Strong
Knox <i>et al.</i> , 2022a (54), USA	Identify home health utilization factors associated with successful community discharge for beneficiaries with and without ADRD	Retrospective	535,691 patients, 18.0% with ADRD	Multilevel logistic regression	Medicare Home Health Base File, OASIS data, and the Beneficiary Summary File	Longer HH episodes were associated with an increased likelihood of successful discharge from HH; and this association was stronger for PLWD	Shifts to shorter duration of care may have a detrimental effect on the health and rehabilitation of PLWD	Stages of dementia were not differentiated. OASIS data collection may not be consistent across clinicians or agencies	Strong
Knox <i>et al.</i> , 2022b (56), USA	Examine the association between dementia severity and risk of early discharge from HH	Retrospective	91,302 Medicare beneficiaries with ADRD	Multilevel logistic regression	Dementia Severity Scale. Medicare Home Health Base File, OASIS, Medicare Provider Analysis and Review, and Beneficiary Summary File	Highest rate of early discharge in PLWD occurred in Stage 4 dementia	Future research should examine additional factors that may contribute to early discharge from HH for PLWD	No gold standard for ADRD severity by which to compare this study's dementia severity scale	Moderate

Table 2 (continued)

Table 2 (continued)

Source & country	Purpose	Design	Sample	Methods	Instruments	Findings	Implications	Limitations	Quality
Luth <i>et al.</i> , 2021 (40), USA	Examine how home hospice and nurse visit frequency relate to dying in hospice within the Medicare-intended 6-month period	Retrospective cohort study. Multivariable survival analyses	3,837 patients with dementia who met study criteria and received hospice services from 2013 to 2017 in one non-profit hospice agency. Original data included 23,526 patients	Used electronic medical records of patients receiving hospice care from 2013 to 2017 in New York City	Charlson Comorbidity Index. Palliative Performance Scale	39% of hospice patients experienced live discharge or long length of stay. 61% died within 180 days of enrollment. Home hospice patients were more likely to experience live discharge or long length of stay. Frequency of nurse visits was associated with patient death	Hospice guidelines may need to permit longer stays so home hospice patients can remain continuously enrolled saving families the costs associated with live discharge	Data was from a single not-for-profit hospice agency. Reasons for long length of stay or live discharge are not in the data. Home hospice patients received visits from facility nurses that are not included in the data. Researchers could not understand the mechanisms linking home hospice, nurse visits, and risk of expected death through the use of retrospective data	Strong
Luth <i>et al.</i> , 2020 (39), USA	Identify demographic, health, and hospice service factors associated with live discharge due to condition stabilization or failure to decline among hospice patients with dementia	Retrospective cohort study	2,629 hospice patients with dementia aged 65 or over who died in hospice care or were discharged live due to a stabilized disease process. Large not-for-profit hospice agency in New York	Review structured fields in electronic medical records	Palliative Performance Scale (PPS) upon admission. Thirty-three comorbidities were measured using the Charlson Comorbidity Index ³¹ and the total number of serious illnesses	Compared with white hospice patients with dementia, African American and Hispanic hospice patients with dementia experienced increased risk of live discharge; longer length of service; more days between nurse visits. 7% were discharged live (72% female; 98% no Medicaid; 73% not married; 32% of Hispanic patients were discharged live	Interventions to reduce live discharge due to condition stabilization or failure to decline should be tailored to meet the needs of African American, Hispanic, and home hospice patients. Live discharge from hospice is a burdensome and disruptive transition for PLWD and their caregivers. Examine the decision-making process behind referring PLWD to hospice to identify areas for education and improvement	Data is from only one hospice agency. Results may not be generalizable. Racial & ethnic issues may be related to socioeconomic status. EMR does not identify the rationale for live discharge from hospice	Strong
Osakwe <i>et al.</i> , 2022 (60), USA	Examine sociodemographic and clinical characteristic present on admission to HH associated with discharge to hospice	Cross-sectional, descriptive	489,230 Medicare HH patients age ≥65 who had a start-of-care OASIS in 2017	Andersen Behavior Model, descriptive statistics	OASIS data	Patients with severe ADL dependence and patients with cognitive impairment had significantly shorter time to discharge to home hospice	The HH setting provides a critical opportunity to identify patients at EOL, provide goals of care discussions, and facilitate timely referral to hospice	No diagnosis data	Strong
Russell <i>et al.</i> , 2017 (42), USA	Report frequencies and associated risk factors for four distinct causes of live discharge from hospice	Retrospective cohort study	9,190 adult hospice patients	Logistic regression	Agency electronic health record	Characteristics associated with live discharge: Revocation associated with younger age, racial and ethnic minorities, those without advance directives. Acute hospitalization was the most frequent reason for live discharge	Interventions that prepare patients and caregivers for EOL at home and improving awareness of supportive services available through hospice may help to reduce live discharge and promote hospice enrollment	Single hospice agency. Retrospective design does not allow for attributing causal relationships	Strong
Teno <i>et al.</i> , 2022 (41), USA	Assess trends in place of care before hospice enrollment	Retrospective cohort study	15,203,083 Medicare decedents age ≥66 years	Descriptive statistics and logistic regression	Medicare Residential History File	Among hospice enrollees, 27.7% transitioned from community, 31.8% from hospital, and 10.1% from SNF	The place of care before hospice reflects the functional trajectory in the last year of life. Decedents enrolled in hospice from the community need to be interpreted with other potential markers of the quality of hospice care	Only Medicare beneficiaries were included. Hospital considered place of care before hospice enrollment for those who transferred from hospital to home health and then to hospice but died within three days of discharge from hospital	Strong
Wladkowski & Endguidanos, 2023 (57), USA	Explore perceptions of hospice re-enrollment among caregivers of PLWD following a live discharge from hospice	Qualitative	22 hospice caregivers	Semistructured interviews	Interview guide	Caregivers believed they needed to wait for a crisis to re-enroll in hospice; unsure about appropriateness of hospice if PLWD could not stay on service until death	Medicare should reform the hospice benefit for PLWD	–	Strong
Zhang <i>et al.</i> , 2023 (59), USA	Compare healthcare utilization and mortality after hospice live discharge among Medicare patients with and without ADRD	Retrospective cohort study	153,696 Medicare patients discharged alive from hospice between 2014–2019	Descriptive statistics	Medicare claims data	PLWD discharged alive from hospice were more likely to have ED visits and less likely to be readmitted to hospice 30 days after live discharge; 180 days post-discharge, they were more likely to be readmitted to hospice. Black patients had significantly worse outcomes after hospice live discharge than white patients	Further investigation is warranted of initial hospice enrollment. The lower mortality and prolonged survival time of ADRD patients after hospice live discharge requires better decision-making regarding when to start hospice benefits and improved planning and care coordination following a hospice live discharge. Policymakers should further explore ways to incentivize longer term care coordination between hospice and other providers, and to better scrutinize hospice enrollment for certain patient sub-groups such as those with ADRD	Use of claims data might be less precise. Patient satisfaction was not examined	Strong

HH, home health; SNF, skilled nursing facility; MedPAR, Medicare Provider Analysis and Review; MDS, minimum data set; OASIS, Outcome and Assessment Information Set; MBSF, Master Beneficiary Summary File; PLWD, person living with dementia; CPs, care partners; ADL, activities of daily living; ICD, International Classification of Diseases; NA, not applicable; CMS, Center for Medicare and Medicaid Services; ADRD, Alzheimer's disease and related dementias; EMR, electronic medical record; EOL, end of life; ED, emergency department.

PLWD. *Figure 1* illustrates the study flow.

Care transitions for PLWDs or cognitive impairment enrolled in skilled HH

Four studies were found specific to care transitions for persons with dementia or cognitive impairment enrolled in skilled HH (53-56). Studies focused on discharge to community, demographics, readmission to HH, and readmission to hospital. Identified factors related to PLWD and transitions to and from HH included presence of cognitive impairment, stage of dementia, dependence for activities of daily living (ADL), and symptom burden.

When being discharged from the hospital, PLWD are more likely to be institutionalized in a skilled nursing facility than to transfer to skilled HH, even though PLWD may benefit more from a supportive home environment, and rates of mortality and readmission to the hospital are the same between the two settings (53). Longer skilled HH episodes for PLWD have been associated with successful discharge—remaining in community without hospital readmission or death—than short episodes for PLWD (54). Results in this category showed that PLWD in skilled HH are more likely than their counterparts without ADRD to have unsuccessful discharge to community and readmission to skilled HH. Unsuccessful discharge to community is defined as readmission to the hospital during skilled HH, unplanned hospitalization after discharge from skilled HH, or mortality (55). PLWD with early discharge from skilled HH—defined as missing more than two planned therapy visits—are more likely to have stage 4 dementia which represents more independence and a higher level of functioning (56). The literature in this category shows that PLWD benefit from the home setting and longer episodes of skilled HH care; but they are at higher risk for early, unsuccessful discharge to community, and higher rates of readmission to skilled HH than their counterparts without ADRD.

Care transitions for PLWDs enrolled in hospice care

Nine studies examined care transitions for PLWD enrolled in hospice care (38-43,57-59). Studies centered on live discharge from hospice and post-discharge characteristics.

PLWD are at risk for long hospice stays as well as live discharge from hospice. For example, among those with long hospice stays, dementia has been found to be the predominant diagnosis; however, PLWD are up to four

times more likely to experience live discharge, for which Black or African Americans and Hispanic Americans are at higher risk (38-43). Live discharge from hospice affects caregiver decisions about re-enrollment in hospice because the care partners believe they need to wait for a medical crisis to re-enroll or are unsure of the appropriateness of the hospice service if their loved one cannot continuously receive it until death (57). In 2016, Medicare Hospice Payment Reform reduced payments to hospice agencies if clients remained longer than 60 days, thus providing impetus for live discharge of such patients (37,58). Predictors of live discharge from hospice for PLWD include younger age, being female, racial and ethnic minorities, dual eligibility for Medicare and Medicaid, and residing at home or in an assisted living facility (58).

Once PLWD are discharged from hospice, they have higher rates of emergency department use, lower rates of hospitalization, lower mortality, longer survival time, and initially lower but gradually increasing rate of hospice readmission than their counterparts without ADRD (59). Of these, Black patients have significantly worse outcomes than white patients (59).

Care transitions between skilled HH and hospice for PLWD

Only one study included results regarding the relationship between cognitive impairment and care transitions between skilled HH and hospice (60). Among all beneficiaries, people with cognitive impairment, severe ADL dependence, high symptom burden, and identification with Black and Hispanic race or ethnicity were found to have a shorter time receiving skilled HH services before transitioning to hospice care (60). Osakwe *et al.*'s study was the only one of our findings that addressed ADRD or cognitive impairment as a variable in transitions between skilled HH and hospice (60).

Discussion

In this systematic review, we aimed to highlight findings on (I) care transitions for PLWD enrolled in skilled HH and hospice and (II) specifically, care transitions for PLWD between skilled HH and hospice. We identified a gap in the literature: There was only one study providing evidence on care transitions between the two settings for PLWD (60).

For all US Medicare decedents regardless of diagnosis, Oh *et al.* found that 19.9% received HH only, 25.8% hospice only, and 18.8% had received both skilled HH and

hospice, at some point during their last 6 months of life (61). The finding that 18.8% received both HH and hospice during the last 6 months of life may indicate care transitions between the two settings. It is unknown what proportion of these decedents were PLWD.

Our findings are notable because they point to the propensity for PLWD to experience care transitions that involve skilled HH and hospice, which holds implications for policy, research, and practice. We found that in skilled HH care, PLWD benefit from longer episodes, but they are at higher risk for early, unsuccessful discharge to community, and they are at higher risk for both a shorter time to transition to hospice and for readmission to HH, especially among minoritized patients. Appropriate timing of referral to hospice for PLWD may be affected by the limitations of current prognostic assessment tools based on functional status, since PLWD may show other predictors of decline related to social determinants of health, quality of life, or neuropsychiatric symptoms which are not included in many prognostic assessments (62,63). These limitations in prognostication may contribute to greater risk of long lengths of stay or live discharge from hospice, in turn affecting caregiver decisions about re-enrollment in hospice care. We did not find support for the phenomenon of PLWD transitioning between skilled HH and hospice. It may be that the phenomenon does not exist; however, it is possible that the transition may not be direct, involving a third care setting such as a skilled nursing facility or hospital (64). For example, crisis events may prompt hospitalization between the skilled HH and hospice settings for PLWD. That is, a PLWD in skilled HH may experience a crisis and transition to the hospital where goals of care conversations take place, and then transition to hospice care. Likewise, a PLWD receiving hospice care may choose to revoke the hospice benefit in favor of hospitalization, and then transition to skilled HH. Another possibility contributing to the lack of literature on this topic involves methodological choices affecting inclusion and exclusion criteria in research.

Current US policy may affect care transitions between skilled HH and hospice for PLWD. For example, in January 2020, the CMS implemented the Patient-Driven Groupings Model (PDGM), designed to place greater emphasis on a patient's clinical, health, and functional characteristics when determining the payment rate in HH (47,48). PDGM disincentivizes skilled HH agencies from admitting patients with chronic and complex conditions, such as ADRD, that require more visits and longer durations of

care (47). As well, current US hospice regulations reducing reimbursement after 60 days of enrollment dissuade providers from admitting and recertifying patients with chronic conditions such as ADRD, even though the literature supports that PLWD and their care partners benefit from hospice services (35,36). Therefore, adjusting hospice eligibility criteria for PLWD and developing integrated models of care across the continuum may ensure that PLWD and their care partners have the support they need (39). Alternatives include dementia care management programs and home-based palliative care, which could either integrate with or replace hospice services (38,39). Home-based care, including longer lengths of stay in skilled HH and hospice, has been shown to benefit PLWD, but current US policy on skilled HH and hospice discourages long lengths of stay. Given the prevalence of ADRD diagnoses in both settings, the preference for and benefits of home-based care among PLWD, and current US policy encouraging discharge from each service, a deeper examination of transitions between skilled HH and hospice is necessary. That is, PLWD may be experiencing multiple care transitions between the two Medicare-reimbursed home-based services, but research is needed to examine this. Future research should examine such transitions in non-US countries, as policies and practices may vary.

Future research should examine health outcomes related to PLWD who transition between skilled HH and hospice, with methodological approaches that capture this population appropriately. Further, future research should test precision health approaches, including clinical decision support tools, which move beyond current prognostic assessment tools used in HH and hospice for PLWD (62,63). These precision health approaches could be ultimately integrated into health systems to prompt health care providers to have goals-of-care conversations with PLWD and their caregivers to determine appropriate services such as skilled HH and hospice (62). Implications for practice include staff education and communication training about end-of-life trajectories and needs for PLWD and their care partners in HH and hospice.

For PLWD and their care partners, services should be tailored and equitable (12). Our findings hold implications for practice, supporting those of Mogan *et al.*'s narrative synthesis which underscored the importance of generating innovative strategies such as compassionate community palliative care initiatives for care provision for PLWD, who are at risk for multiple care transitions including skilled HH and hospice (65). Further, having one designated healthcare

provider has been recommended to guide PLWD and their care partners throughout the disease trajectory to assuage fragmentation in dementia care (66).

Care transitions toward end of life carry various effects on clients, family members, and health care providers; therefore, all interested parties may need education about skilled HH, end-of-life care, hospice care, and palliative care (67,68). Positive care transitions have been associated with family decision-making strategy education as well as general education about care transitions, end of life, hospice, and palliative care, which take place early in the dementia disease process (68,69).

Facilitators of hospice discussions in the skilled HH setting have included interdisciplinary team-based clinical review, clinical decision support tools to determine hospice eligibility, and staff training (30). Several models exist for communicating about such themes (70-72). For example, Bigger *et al.* tested the COMFORT® communication model among the skilled HH interprofessional team and found that it was feasible and highly acceptable for training the team in discussing palliative care, hospice care, and advance care planning with skilled HH patients and their care partners and may assist providers in supporting PLWD and their care partners in avoiding inappropriate care transitions and facilitating goal-concordant care (29,71).

Strengths and limitations

We comprehensively and systematically searched the literature by applying a wide range of search terms related to our topic. We critically appraised the quality of the studies using a standardized tool. Limitations of evidence in the literature appear in *Table 2*. Although the timeframe was intended to reflect recent US policy changes, it may have limited the results. For example, no included studies listed provider comfort with discussing end-of-life themes as a potential variable affecting care transitions for PLWD. Limitations of the review process include the lack of meta-analysis. There was also a limitation in that we did not include hospitalization as a potential care transition between the two settings of HH and hospice. Further, the research was limited by the inclusion criteria of studies set in the US, as skilled HH and hospice may look different in other countries, based on policy and practice. Finally, the literature on hospice did not differentiate between home hospice and in-patient hospice.

Conclusions

Evidence shows that both HH and hospice benefit PLWD and their care partners (25-27,35). Our findings illustrate there is a high risk of care transitions for PLWD, especially for those from racial and ethnic minoritized groups; however, we found a gap in the literature specifically regarding transitions between skilled HH and hospice for PLWD. Given PLWD's long trajectory of decline, future research should include dementia or cognitive impairment as a factor in studying care transitions for PLWD enrolled in skilled HH and hospice. In addition, future work should explore assessment approaches specific to PLWD that lead to higher quality of coordination of care to, from, and between skilled HH and hospice.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Appendix 1 Databases, search terms, and results

PubMed results

("home health" OR "home care" OR homecare OR "Home Care Services"[Mesh] OR "home nurs*" OR "Home Health Nursing"[Mesh] OR "Home Health Aides"[Mesh])

AND

(transition* OR "Transitional Care"[Mesh] OR path* OR transfer* OR refer* OR "live discharge*")

AND

(hospice* OR "Hospice Care"[Mesh] OR "Hospices"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh])

AND

(dementia OR "Dementia"[Mesh] OR Alzheimer* OR Alzheimer's OR "Alzheimer Disease"[Mesh] OR "cognitive impairment*" OR "Cognitive Dysfunction"[Mesh])

11/16/23

Limits: 2017-present

Results: 21

CINAHL results

("home health" OR "home care" OR homecare OR MH "Home Health Care" OR "home nurs*" OR MH "Home Nursing" OR MH "Home Nursing, Professional" OR MH "Home Health Aides")

AND

(transition* OR MH "Transitional Care" OR path* OR transfer* OR refer* OR "live discharge*")

AND

(hospice OR MH "Hospice Care" OR MH "Hospice Patients" OR MH "Hospice and Palliative Nursing" OR MH "Hospices")

AND

(dementia or Alzheimer* OR Alzheimer's OR MH "Alzheimer's Disease" OR MH "Dementia Patients" OR MH "Dementia" OR "cognitive impairment*")

11/16/23

Limits: 2017-present

Results: 12

PsycInfo results

("home health" OR "home care" OR homecare OR DE "Home Care" OR DE "Home Care Personnel" OR "home nurs*")

AND

(transition* OR path* OR transfer* OR refer* OR "live discharge*")

AND

(hospice OR DE "Hospice")

AND

(dementia OR Alzheimer* OR Alzheimer's OR DE "Alzheimer's Disease" OR DE "Dementia" OR "cognitive impairment*")

11/16/23

Limits: 2017-present

Results: 197