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Research Article



Variation in Home Healthcare Use by Dementia Status Among a National Cohort of Older Adults

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Abstract

Background: Medicare-funded home healthcare (HHC) delivers skilled nursing, therapy, and related services through visits to the patient's home. Nearly one-third (31%) of HHC patients have diagnosed dementia, but little is currently known regarding how HHC utilization and care delivery differ for persons living with dementia (PLwD).

Methods: We drew on linked 2012–2018 Health and Retirement Study and Medicare claims for a national cohort of 1 940 community-living older adults. We described differences in HHC admission, length of stay, and referral source by patient dementia status and used weighted, multivariable logistic and negative binomial models to estimate the relationship between dementia and HHC visit type and intensity while adjusting for sociodemographic characteristics, health and functional status, and geographic/community factors.

Results: PLwD had twice the odds of using HHC during a 2-year observation period, compared to those without dementia (odds ratio [OR]: 2.03; p < .001). They were more likely to be referred to HHC without a preceding hospitalization (49.4% vs 32.1%; p < .001) and incurred a greater number of HHC episodes (1.4 vs 1.0; p < .001) and a longer median HHC length of stay (55.8 days vs 40.0 days; p < .001). Among post-acute HHC patients, PLwD had twice the odds of receiving social work services (unadjusted odds ratio [aOR]: 2.15; p = .008) and 3 times the odds of receiving speech-language pathology services (aOR: 2.92; p = .002).

Conclusions: Findings highlight HHC's importance as a care setting for community-living PLwD and indicate the need to identify care delivery patterns associated with positive outcomes for PLwD and design tailored HHC clinical pathways for this patient subpopulation.

Keywords: Alzheimer dementia, Cognitive function, Home care, Home healthcare, Medicare

Of an estimated 5.4 million persons living with dementia (PLwD) in the United States, the majority (70%) are aging in place in the community rather than moving to facilities such as nursing homes as their dementia progresses (1). PLwD often have significant and overlapping medical and social care needs requiring concurrent management (2,3). The Medicare home healthcare (HHC) benefit directly addresses common needs for community-living PLwD that may otherwise go unmet (4), including skilled healthcare delivery in the home, assistance with activities of daily living (ADLs), and training for family care partners (4,5). HHC provides skilled nursing, rehabilitation therapies, aide, social work, and other services delivered through visits to the patient's home across a defined episode of care. Medicare enrollees are eligible for HHC if they are certified by a physician as being homebound and requiring temporary skilled nursing and/or therapy. To continue receiving HHC, patients must be recertified by a physician every 60 days. There is no means-testing for HHC and no copayment is required for Medicare Part A beneficiaries. Eligible beneficiaries may be referred to HHC for post-acute care (ie, for rehabilitation and recovery following a hospitalization) or directly from the community. An estimated 31% of HHC patients have a diagnosis of dementia (6).

Due to intermittent staff presence in the home, HHC delivery relies on the patient to self-manage their care in between visits (eg, perform physical therapy exercises, implement dietary changes). Capacity for this kind of self-management may be significantly reduced in PLwD due to decreased memory and executive function. Thus, PLwD require significant support from family/unpaid and/or paid caregivers during the HHC episode (7) and those with no or limited caregiver availability may struggle to implement the care plan. Additionally, PLwD generally have more significant psychosocial needs and greater functional limitations compared to those without

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dementia (8,9). These factors, along with previous work that finds HHC patients with dementia are at greater risk for institutionalization, urinary tract infection, and hospitalization (10–12), suggest that PLwD may require different patterns of HHC delivery in order to meet their unique care needs.

Prior research suggests that healthcare spending, including spending on HHC, increases following a dementia diagnosis (2,13). Dementia is also linked to HHC referral pathways; 3 prior studies have found that patients who enter HHC via community referral (ie, without an immediately preceding hospital or post-acute skilled nursing facility stay) are more likely to have dementia, compared to post-acute patients (14– 16). However, there is limited information regarding specific patterns of HHC delivery by dementia status. Ankuda et al. (15) found that PLwD receive a greater proportion of visits later in the episode and Burgdorf et al. (17) found that patients with dementia receive a greater overall number of nursing, physical therapy, and occupational therapy visits. Both studies restricted their analyses to participants' first (index) HHC episodes.

The present study expands available knowledge by analyzing the relationship between dementia status and patterns of HHC utilization across multiple episodes, among a national cohort of community-living older adults from the Health and Retirement Survey (HRS). The present study aims to examine measures of HHC utilization that affect reimbursement and overall healthcare costs, and/or have been linked to HHC outcomes for high-need patient populations. These measures include referral source, length of stay, and visit type and intensity (18–21). We describe how these measures vary by dementia status and specifically investigate the interaction of dementia status and referral source in affecting HHC visit type and intensity. Findings are relevant to ongoing efforts to improve community-based management of dementia and enhance supports for PLwD and their families.

Method

Data

Data were drawn from 5 linked data sets: the HRS, Medicare Fee-for-Service HHC claims, the Outcomes and Assessment Information Set (OASIS), the Centers for Disease Control Social Vulnerability Index (SVI), and the USDA Rural-Urban Commuting Area (RUCA) codes. HRS is a biennial, nationally representative survey of older adults (51 years and older) with rich information regarding sociodemographic characteristics, health and function, and economic status. OASIS is the standardized patient assessment instrument required for each Medicare-funded HHC episode and includes HHC clinician reports regarding patient clinical and functional status. The SVI captures social vulnerability at the census tract level based on U.S. census data including the proportion of the population who are living below the poverty level, unemployed, members of a minority racial/ethnic group, living in crowded housing, etc. (22). RUCA codes are public data that classify geographic areas as being metropolitan or nonmetropolitan based on measures of population density and urbanization (23).

Sample

Our analytic sample included older adults (65 and older) who participated in the biennial HRS surveys in 2012, 2014, or 2016. We excluded those who did not have linked Medicare Fee-for-Service claims data for 24 months post HRS interview, whose dementia status was missing from the HRS, who resided in a nursing home or other congregate living setting (eg, assisted living facility), and who did not receive at least 1 HHC episode for which OASIS data were available. We then performed an exact match of PLwD to those without dementia on age, sex, and survey wave to improve comparability between groups when analyzing utilization patterns during HHC associated with factors other than the 3 matching variables. Among the 3 436 observations from 2 448 unique individuals who met our selection criteria, 2 591 observation periods from 1 940 unique participants were matched and included in the final analytic sample (see Supplementary Figure A1 for greater detail on exclusion criteria).

Measures

Dementia status

We determined dementia status using the Hurd et al. regression-based algorithm to predict cognitive status from HRS interview components (24). Hurd's algorithm draws on multiple HRS items reflecting cognitive function and physical functional limitation and has demonstrated the greatest accuracy (specificity 89.8%, sensitivity 77.9%) when compared to other algorithms designed for determining dementia status from HRS data (25). We determined participant dementia status was allowed to vary across survey waves (see Supplementary Table A1 for the data set and time point associated with each variable).

HHC utilization

We constructed 5 measures describing HHC utilization: any HHC admission (yes/no), number of HHC episodes, length of stay in days, referral source (post-acute/communityentry), and number/type of visits received. Any HHC admission was based on Medicare claims for 2 years following the HRS survey. HHC "episodes" are 60-day certification periods; although a patient may receive multiple successive episodes, they must be recertified by a physician every 60 days to continue receiving care. For example, an individual who received 120 days of continuous HHC would have incurred 2 HHC episodes. We defined episodes by HHC admission and recertification dates included in OASIS and claims. (Note: Beginning in 2020, HHC payment periods were shortened to 30 days, but certification is still required every 60 days.)

Length of stay was defined as the total number of days from HHC admission to discharge, operationalized as the median length of stay for all of an individual's HHC stays during each 2-year period. Referral source indicates whether the individual was referred to HHC following an acute care episode or directly from a community provider. We considered referral source to be "post-acute" if OASIS and/or Medicare claims data reported the patient was discharged from institutional acute or post-acute care within 14 days preceding HHC admission, and "community" otherwise. Finally, we considered the number of visits received during each episode using Medicare claims data, including skilled nursing, physical therapy, occupational therapy, personal care aide, medical social work, and speech-language pathology visits. We created 2 variables for each visit type: a binary indicator of whether the individual received any visits and a count of the number of visits received. We considered visit use and intensity across

2 time frames: the first 30 days of HHC (the current payment period) and the first 60 days of HHC (the certification period).

Covariates

We drew measures of individual characteristics from HRS, including age, sex, race/ethnicity, educational attainment, Medicaid enrollment, and number of self-reported chronic conditions. From the start of care OASIS assessment data for the index episode in each observation period, we determined overall functional impairment and hospitalization risk. Overall functional impairment was operationalized as a composite ADL impairment score, which considered limitation in dressing upper body, dressing lower body, eating, grooming, bathing, toilet transferring, toilet hygiene, transferring, and ambulation, and ranges from 0 (no impairments) to 9 (impairments in all activities), as described in prior literature (26,27). We defined hospitalization risk as the number of items that the HHC clinician selected from a list of potential risk factors for hospitalization, including recent decline in mental/emotional/behavioral status, multiple hospitalizations in the past year, history of falls, taking 5 or more medications, frailty indicators, and "other" risk factors. We determined whether the individual lived in a metropolitan area based on the RUCA code for their zip code of residence at the time of HRS survey. We measured community social vulnerability using the SVI percentile ranking for the individual's census tract of residence at the time of HRS survey; SVI values indicate a percentile ranking ranged from 0 to 1, with higher values indicating greater vulnerability.

Statistical Analyses

We first calculated the percentage of PLwD and without dementia who experienced any HHC admission within 2 years of HRS and computed the unadjusted odds ratio (aOR) comparing these groups. Next, we limited our analyses to the matched sample of those with any HHC utilization and compared patient and community characteristics between PLwD and their matched controls using Rao–Scott chi-square tests. We also compared the 5 measures of HHC use (any HHC admission, number of HHC episodes, length of stay, referral source, and number/type of visits received) by dementia status.

Finally, we examined the impact of interacted dementia status and referral source on HHC utilization using 2 approaches. First, we used multivariable logistic regression to model whether the individual received any visits by visit type. Next, we used multivariable negative binomial regression to model the number of visits received by visit type, restricting the sample to those who received at least 1 visit of the given visit type. In both approaches, we fit separate models for each of the 6 visit types and set post-acute referral and no dementia as the reference group.

All models adjusted for the same covariate panel. Guided by the Andersen Behavioral Model of Health Services Use (28), we selected predisposing (sociodemographic), enabling (community), and need (health and functional status) measures for inclusion that were either associated with healthcare utilization in prior literature (eg, Medicaid enrollment) and/or were strongly predictive of our outcomes of interest in unadjusted models (eg, ADL limitations at HHC start of care). These covariates include age, sex, race/ethnicity, Medicaid enrollment, number of comorbidities, ADL limitations, hospitalization risk, living in a metropolitan zip code, and census tract-level SVI. All models were weighted using HRS survey weights to account for complex survey design. Analyses were conducted using SAS version 9.4 (SAS Institute, Cary, NC) and Stata version 16.0 (StataCorp LLC, College Station, TX).

Results

Any HHC Admission

Among a national cohort of community-living older adults, PLwD had 2 times the odds of any HHC admission during a 2-year observation period, compared to those without dementia (odds ratio [OR]: 2.03; 95% confidence interval: 1.73–2.38; p < .001). Among PLwD, 39.7% experienced at least 1 HHC episode during a 2-year observation period, compared to 14.3% of those without dementia (p < .001; Supplementary Figure A2).

HHC Patient Sample Characteristics

The matched sample included 2 591 survey and observation periods for 1 940 unique individuals who incurred at least 1 HHC episode (see Supplementary Figure A3 for details of improved covariate balance following exact match). PLwD displayed higher levels of social and clinical vulnerability. Compared to those without dementia, a greater proportion of PLwD were Black non-Hispanic (15.1% vs 6.5%; p < .001) or Hispanic/Latino (13.2% vs 3.1%; p < .001; Table 1). PLwD were more likely to be Medicaid-enrolled (23.1% vs 8.0%; p < .001), to reside in census tracts with a higher average SVI percentile ranking (0.55 vs 0.48; p < .001), and had a greater number of functional impairments (4.17 vs 3.21; p < .001) upon HHC admission.

Unadjusted Differences in HHC Utilization by Dementia Status

PLwD incurred a greater number of HHC episodes (1.4 vs 1.0; p < .001), longer median length of stay in HHC (55.8 days vs 40.0 days; p < .001), and were more likely to be referred from the community (49.4% vs 32.1%; p < .001) compared to those without dementia (Figure 1). Within the first 30 days of HHC, a greater proportion of patients with dementia received any personal care aide (27.3% vs 19.9%; p = .02), medical social work (22.5% vs 12.6%; p < .001), or speech-language pathology visits (12.1% vs 6.2%; p = .001) compared to patients without dementia (Figure 2). However, patients without dementia received a greater median number of skilled nursing (4.4 vs 3.8; p < .001), physical therapy (5.00 vs 3.94; p < .001), and speech-language pathology visits (1.7 vs 0.95; p = .008). (These relationships persisted when considering the first 60 days of HHC, except those without dementia were no longer observed to receive a significantly greater number of skilled nursing visits; see Supplementary Figure A4.)

Adjusted Models of HHC Visit Type and Intensity by Dementia Status

In multivariable models adjusting for sociodemographic characteristics, health and functional status, and community factors, dementia status was associated with both visit type and visit intensity during post-acute episodes. Among post-acute patients, PLwD had twice the odds of receiving any medical social work visits (aOR: 2.15; p = .008), and 3 times the odds of receiving any speech-language pathology visits (aOR: 2.92; p = .002) compared to those without dementia (Figure Table 1. Characteristics of Community-Living Older Home Health Patients, by Dementia Status (matched sample*; n = 2 591)

$n (col %) or mean \pm SESociodemographic characteristicsAge<75Not reportable (NR)**276 (4.7)75–7974 (12.1)559 (12.6)80–84112 (21.4)587 (22.6)85+269 (62.8)690 (60.1)Female sex322 (69.1)1 412 (69.7)Race/ethnicityVVWhite, non-Hispanic299 (70.4)1 679 (88.9)Black, non-Hispanic104 (15.1)279 (6.5)Hispanic/Latino70 (13.2)117 (3.1)Other non-HispanicNR (1.3)37 (1.5)Medicaid-enrolled113 (23.1)244 (8.0)Health and functional statusZ.78 (0.08)2.24 (0.06)Overall functional impairment (0–9)4.17 (0.11)321 (0.07)Number of clinician-reported risks for hospitalization084 (18.0)332 (14.5)1164 (32.1)828 (37.3)2_2 +231 (49.9)952 (48.2)Community characteristicsVVVV$	Characteristic	Persons Living With Dementia $(n = 479; \text{ weighted } n = 1 \ 681 \ 885)$	Persons Without Dementia ($n = 2$ 112; weighted $n = 8$ 135 915)	p Value
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Notes: SE = standard error.

*Exact match of individual with and without dementia on age, sex, and core survey year.

**Figure NR due to cell size limitations included in the Data Use Agreement.



Figure 1. Home healthcare (HHC) admission and utilization, by patient dementia status. *Community-living older adults responding to Health and Retirement Survey in 2010, 2012, 2014, or 2016, who received at least 1 home health episode within 2 years following each survey wave. 1 940 unique individuals with 2 591 observation periods. Persons without dementia matched on age, sex, and survey core year to persons living with dementia. **Community-entry referral source determined by claims and Outcomes and Assessment Information Set data, defined as having no inpatient or short-term skilled nursing facility stay within 14 days preceding HHC admission.

3). PLwD also received a greater number of medical social work (adjusted incidence rate ratio [aIRR]: 2.10; p = .006) and speech-language pathology visits (aIRR: 3.03; p = .001) compared to those without dementia (Figure 4). Community

referral into HHC was observed to decrease visit intensity regardless of dementia status. Observed relationships largely persisted when considering the first 60 days of HHC (see Supplementary Tables A2 and A3 for full results by 30- and 60-day time frames, respectively).

Discussion

We found that, among a national cohort of communityliving older adults, PLwD were heavier users of HHC as measured by entry into HHC and length of stay. However, findings regarding visit intensity during the HHC episode are more nuanced. During an HHC episode, patients with dementia were more likely to receive any medical social work or speech-language pathology visits but received fewer skilled nursing or physical therapy visits. In adjusted models considering both dementia status and referral source, we observed that community referral was associated with reduced utilization intensity regardless of dementia status (particularly for skilled nursing and physical and occupational therapy). Findings indicate that communityliving PLwD are more likely to access HHC than persons without dementia. Given their longer length of stay, greater likelihood for community referral, and higher odds for receiving social work or speech-language pathology visits, HHC patients with dementia may have distinct care needs compared to those without dementia.



Figure 2. Home healthcare (HHC) service mix and visit intensity during first 30 days of HHC stay, by visit type and patient dementia status (matched sample*; n = 2 591). *Community-living older adults responding to Health and Retirement Survey in 2010, 2012, 2014, or 2016, who received at least 1 home health episode within 2 years following each survey wave. Persons without dementia matched on age, sex, and survey core year to persons living with dementia. Median number of visits received among those who received at least 1 visit, by visit type.



Figure 3. Types of visits received during first 30 days of home healthcare (HHC) as a function of dementia status and HHC referral source, results of adjusted models* (matched sample**; n = 2591). *Logistic models adjusting for: race, age, sex, Medicaid enrollment, number of comorbidities, functional impairment, hospitalization risk, living in a metropolitan zip code, and census tract-level social vulnerability index. Main predictor variable is the interaction of dementia status (persons living with dementia compared to persons without dementia) and HHC referral source (post-acute vs community-entry). **Community-living older adults responding to Health and Retirement Survey in 2010, 2012, 2014, or 2016, who received at least 1 home health episode within 2 years following each survey wave. Persons without dementia.

Findings from the present study suggest that HHC providers may use a dementia diagnosis to screen for those likely to need speech-language pathology or social work services during post-acute episodes. Speech-language pathology helps address speech and swallowing issues and is linked to improved function and quality of life for PLwD facing challenges in these areas (29). Social work has immense potential value in helping PLwD and their families navigate psychological stress, adapt to changing social roles, and connect to community services (9,30). Social work services are historically underutilized during Medicare-funded HHC and provided only following a request from the nurse or physical therapist



Figure 4. Home healthcare (HHC) visit intensity during first 30 days of HHC as a function of dementia status and HHC referral source, results of adjusted models* (matched sample**; *n* = 2 591). *Negative binomial models adjusting for: race, age, sex, Medicaid enrollment, number of comorbidities, functional impairment, hospitalization risk, living in a metropolitan zip code, and census tract-level social vulnerability index. Main predictor variable is the interaction of dementia status (dementia vs no dementia) and HHC referral source (post-acute vs community-entry). **Community-living older adults responding to Health and Retirement Survey in 2010, 2012, 2014, or 2016, who received at least 1 home health episode within 2 years following each survey wave. Persons without dementia matched on age, sex, and survey core year to persons living with dementia.

leading the HHC episode (31). While we observed that PLwD were more likely to receive any social work visits, there was no significant difference in the number of social work visits received by dementia status and we observed low utilization of social work regardless of dementia status (median number of 0.9 visits for PLwD and 0.5 visit for those without dementia). It may be that social work referrals are occurring later in the HHC episode, limiting the ability of social workers to conduct more than 1 visit before the patient is discharged, and/or that social workers are overextended and scheduling timely visits is challenging. This is concerning given prior qualitative work in which dementia care partners emphasized the importance of early connection to social work in helping them successfully provide support during the HHC episode (32).

While the literature base remains small, available research suggests that longer length of stay and greater visit intensity are linked to lower risk of readmission and institutionalization for PLwD receiving HHC (20,33,34). We observed that PLwD have longer length of stay but experience relatively lower visit intensity compared to those without dementia, particular for nursing and therapy services. Existing prospective payment structures incentivize HHC providers to limit the number of visits in order to lower costs and maximize profits (18). The Medicare Payment Advisory Commission reports a decline in the number of visits during HHC episodes from 2017 to 2021, with particularly large average annual decreases in the number of social work (-21%), occupational therapy (-18%), and aide (-19%) visits (35). This trend predates coronavirus disease 2019 (COVID-19) but accelerated during the pandemic, likely due to workforce shortages and infection concerns.

The 2020 implementation of a new Medicare HHC payment model, the Patient-Driven Groupings Model (PDGM),

may further incentivize limiting visits for PLwD in particular. PDGM is intended to tie reimbursement more closely to HHC patient acuity but does not directly account for dementia status in risk adjustment and reduces payments for community episodes relative to post-acute episodes (36). These provisions have prompted concerns that PDGM may have the unintended consequence of reducing HHC access and/or quality for PLwD (15,17), a concern supported by our finding that PLwD are more likely to enter HHC following a community referral. However, no work to date has examined changes in HHC use post-PDGM for this subpopulation. Additionally, as Medicare Advantage uptake continues to increase, there is a need for research that elucidates potential differences in care delivery by payment source (Medicare Advantage compared to Fee-for-Service) in HHC. Variation in benefit design and cost-sharing across Medicare Advantage plans likely affects HHC utilization and care delivery patterns, creating the opportunity to better understand how specific clinical workflows affect outcomes for PLwD.

Use of home-based clinical care among Medicare Fee-for-Service enrollees has grown significantly over the past decade (37), as part of a broader trend of rebalancing care toward home and community settings to decrease costs and better align with patient preferences. However, accessing homebased clinical care and related social services remains challenging due to fragmented payment and delivery systems, pervasive workforce shortages, and high costs for patients and families (38-40). HHC is an exception in many ways, as it requires no copayment for Medicare Fee-for-Service enrollees and is widely available (41), making this form of home-based clinical care an accessible option for many PLwD. Additionally, eligibility criteria for HHC (ie, being homebound and requiring temporary skilled care) are broad and rely heavily on physician interpretation (35), which may be influenced by an older adult's dementia status. Thus, the greater propensity for HHC entry among older adults with dementia, and particularly community referral into HHC, may represent an appropriate use of this benefit in response to common needs of this population (including needs for nursing care in the home, ADL support, and family caregiver training (4)) as well as a response to difficulty accessing other forms of home-based clinical care or differences in how physicians apply eligibility criteria.

Regardless of the underlying impetus for accessing HHC, patients with dementia may require targeted clinical pathways to meet their unique needs. There has been a proliferation of dementia-focused clinical workflows in institutional care settings, but this work is just beginning in HHC, and few models have been fully tested (42). There is a need to innovate within the existing HHC benefit to improve services for the increasingly complex HHC patient population, including PLwD. These efforts could include improved cross-setting communication and better engagement of caregivers. Poor information transfer is a hallmark of hospital to HHC transitions (43) and more than half of older adults with diagnosed dementia do not have this diagnosis captured in their HHC referral documentation (12). As a result, HHC providers are not always aware that they are caring for a PLwD, a lack of visibility that may hamper their ability to design responsive care plans. Improved data transfer, potentially through expanded electronic health record interoperability, could assist HHC clinicians in recognizing the unique needs of PLwD under their care. Finally, reliance on family caregivers and/or paid aides is an integral component of aging in place with dementia (3,44), and these additional supports are critical to enacting the HHC plan of care for PLwD (7). Yet, available evidence indicates a lack of systematic caregiver engagement and coordination within HHC (32,45,46). Improving HHC for PLwD must include the development and dissemination of improved models for assessing and supporting caregivers (32), and mobilizing additional social supports for PLwD who do not have available caregivers.

Strengths of the present study include reliance on a nationally representative sample, access to rich data at the individual, family, and community levels, and investigation of novel research questions. Additionally, using HRS data to capture dementia minimizes the impact of underdiagnosis in claims and is particularly relevant for capturing dementia among Black and/or Hispanic individuals, who are more likely to experience dementia but less likely to receive a timely diagnosis (47,48). Limitations include exclusion of Medicare Advantage enrollees, due to unavailable claims data for this population and use of 2012–2018 data, which do not reflect potential utilization shifts following the simultaneous service disruptions of the COVID-19 pandemic and the 2020 implementation of a new Medicare HHC payment system.

Findings from the present study demonstrate that HHC is an important care setting for PLwD who reside in the community, and that HHC patients with dementia are likely to have distinct care needs compared to those without dementia. To preserve access to this form of home-based clinical care for PLwD, there is a need to monitor the impacts of recent Medicare HHC payment system changes and investigate the impacts of payment source (Medicare Advantage compared to Fee-for-Service) on HHC access and care delivery patterns. Additionally, findings indicate the potential value of innovative, scalable care models within HHC that are tailored to the unique needs of PLwD.

Supplementary Material

Supplementary data are available at *The Journals of Gerontology, Series A: Biological Sciences and Medical Sciences* online.

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Conflict of Interest

None.

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Author Contributions

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