Title

Functional and clinical needs of older hospice enrollees with coexisting dementia.

Permalink

https://escholarship.org/uc/item/2mf8822r

Journal

Journal of the American Geriatrics Society, 71(3)

Authors

Cenzer, Irena
Smith, Alexander
Hunt, Lauren
et al.

Publication Date

2023-03-01

DOI

10.1111/jgs.18130

Published in final edited form as:
J Am Geriatr Soc. 2023 March ; 71(3): 785–798. doi:10.1111/jgs.18130.

Functional and Clinical Needs of Older Hospice Enrollees with Coexisting Dementia

Krista L. Harrison, PhD[a,b,c], **Irena Cenzer, PhD**[a], **Alexander K. Smith, MD, MPH, MS**[a,d], **Lauren J. Hunt, RN, PhD, FNP-BC**[b,c,f], **Amy S. Kelley, MD, MSHS**[e,g], **Melissa D. Aldridge, PhD, MBA**[e,g], **Kenneth E. Covinsky, MD, MPH**[a,d]

[a]Division of Geriatrics, Department of Medicine, University of California San Francisco, San Francisco, California, United States. 490 Illinois Street, San Francisco, CA 94143 USA

[b]Philip R. Lee Institute for Health Policy Studies, University of California San Francisco, San Francisco, California, United States.

[c]Global Brain Health Institute, University of California San Francisco

[d]San Francisco Veterans Affairs Medical Center, 4150 Clement Street −181G, San Francisco, CA 94121 USA

[e]Department of Geriatrics and Palliative Medicine, Mount Sinai

[f]Department of Physiological Nursing, University of California San Francisco, San Francisco, California, United States. 2 Koret Way, San Francisco, CA 94143 USA

[g]James J. Peters Bronx VA Medical Center

Abstract

Background: The Medicare Hospice Benefit increasingly serves people dying with dementia. We sought to understand characteristics, hospice use patterns, and last-month-of-life care quality ratings among hospice enrollees with dementia coexisting with another terminal illness as compared to enrollees with a principal hospice diagnosis of dementia, and enrollees with no dementia.

Methods: We conducted a pooled cross-sectional study among decedent Medicare beneficiaries age 70+ using longitudinal data from the National Health Aging and Trends Study (NHATS) (last interview before death; after-death proxy interview) linked to Medicare hospice claims (2011–2017). We used regression analyses, adjusted for age and gender, to determine characteristics of interest comparing hospice enrollees with coexisting dementia to two groups: 1) those with a principal dementia diagnosis, and 2) enrollees with no dementia.

Corresponding Author: Krista Harrison, PhD, UCSF Division of Geriatrics, Box 1265, 490 Illinois Street, Floor 08, San Francisco, CA 94143, Phone: 415.502-4684, Fax: 415.514.0702, krista.harrison@ucsf.edu, Twitter: @klharrisonPhD.

Author Contributions: All authors meet the criteria for authorship stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals and contributed as follows: 1) substantial contributions to conception and design (KLH, KC, AKS, IC), or acquisition of data (AS), or analysis (IC) and interpretation of data (all); drafting the article (KH) or revising it critically for important intellectual content (all); and 3) final approval of the version to be published (all). This paper was improved by feedback from colleagues associated with the UCSF Claude D. Pepper Older Americans Independence Center (3P30AG044281) and DEVELOP AD P01 (P01AG066605). Dr. Kelley's efforts were completed under her Mount Sinai affiliation, before her employment at NIA.

Conflict of Interest: The authors have no conflicts of interest.

Results: Among 1,105 decedent hospice enrollees age 70+, 40% had coexisting dementia, 16% had a principal dementia, and 44% had no dementia. In adjusted analyses, enrollees with coexisting dementia had high rates of needing help with 3–6 activities of daily living, similar to enrollees with principal dementia (62% vs. 67%). Enrollees with coexisting dementia had high clinical needs, similar to those with no dementia, e.g., 63% vs. 61% had bothersome pain. Care quality was worse for enrollees with coexisting dementia versus principal dementia (e.g., 61% vs. 79% had anxiety/sadness managed) and similar to those with no dementia. Enrollees with coexisting dementia had similar hospice use patterns as those with principal diagnoses, and higher rates of problematic use patterns compared to those with no dementia (e.g., 16% vs. 10% live disenrollment, p=0.004).

Conclusions: People with coexisting dementia have functional needs comparable to enrollees with principal diagnoses of dementia, and clinical needs comparable to enrollees with no dementia. Changes to hospice care models and policy may be needed to ensure appropriate dementia care.

Keywords

dementia; hospice; end-of-life

Introduction

Alzheimer's disease and related dementia syndromes (ADRD – henceforth referred to as dementia) are often terminal diagnoses affecting 5.8 million people in the United States.[1] Hospice is a model of care that aims to provide person-centered care and optimize quality of life for people who are dying. Yet the Medicare Hospice Benefit, which provides care to 52% of decedents in the United States in 2019,[2] was not designed for people with dementia (PWD) and their care communities.[3] Common needs among PWD include behavioral symptoms of dementia, pain and breathing problems, disability and falls, and caregiver burden;[3–6] these could be insufficiently addressed if hospice processes developed for cancer are followed. Most research on end-of-life care for PWD has focused on hospice recipients who have dementia as principal diagnosis and indication for hospice care. When people are dying from advanced dementia, they are eligible for hospice when bedbound, incontinent, and unable to speak intelligibly;[7] enrollees with principal diagnoses of dementia also experience burdensome symptoms like pain and breathlessness.[8,9] Yet older persons at the end of life frequently have many coexisting conditions. Dementia may coexist with another terminal diagnosis that precipitates hospice care.[10]

Hospice employees are required to distinguish between principal and coexisting dementia at admission because criteria for hospice eligibility are pinned to specific isolated terminal conditions. Regulatory pressures that influence hospice clinician's choice and documentation of both principal and coexisting diagnoses have also changed over time.[11] Examples include clarifying the allowable subset of ICD-9 diagnoses designating dementia as primary terminal hospice diagnosis, discontinuing other primary diagnoses commonly used for PWD such as 'debility' and 'failure to thrive', and implementing ICD-10 coding with greater dementia specificity.[11] As such, it can be difficult to disaggregate hospice subpopulations with coexisting conditions and their distinct needs. Beyond administrative coding, diagnoses also inform creation of care plans. Lack of recognition of coexisting dementia among enrollees could result in needs being unmet or mismanaged, for example, if coexisting dementia is misdiagnosed and treated as delirium.

In 1990, 7% of hospice patients were estimated to have dementia in addition to another terminal illness.[12] Since then, our understanding of what is and is not dementia, and our diagnostic standards, have evolved. A study using hospice Medicare claims data from 2013 estimated that 45% of all hospice recipients had a dementia diagnosis (either as principal diagnosis or coexisting condition).[13] A more recent study using the Health and Retirement Study, which has robust methods of dementia ascertainment, found 30% of decedent hospice enrollees had dementia coexisting with another terminal illness.[10] Having coexisting dementia was associated with increased odds of a long hospice enrollment (longer than 6 months) and live disenrollment. However, these data sources do not allow for assessment of potential unmet needs for functional and symptom management, behavioral symptoms, and caregiver involvement, nor measures of end-of-life care quality. Understanding the prevalence and specific needs of older hospice enrollees who are either dying from advanced dementia or with coexisting dementia is an essential step toward ensuring care models and policies adequately address those needs.

We used the National Health and Aging Trends Study (NHATS) linked to Medicare claims to 1) estimate the prevalence of dementia among hospice recipients, and 2) describe characteristics, hospice use patterns, and proxy ratings of last month of life care quality for hospice enrollees with coexisting dementia compared to two groups: older adults with a principal hospice diagnosis of dementia, or enrollees with no dementia. Our rationale for including two comparator groups was to inform efforts to address this otherwise-invisible population. Currently, enrollees with coexisting dementia are commonly captured in non-dementia clinical pathways and research studies. However, if those with coexisting dementia more closely resemble those with principal diagnoses of dementia – and needs are distinct from those with no dementia – efforts will be needed to identify the population through screening programs and documentation of secondary hospice diagnoses as well as to ensure needs are adequately addressed.

Methods

Design:

We conducted a pooled cross-sectional study using longitudinal data from NHATS, an annual nationally representative survey of Medicare beneficiaries age 65+. NHATS enrolled new participants in 2011 and 2015 and reinterviews participants yearly. NHATS includes a last month of life survey completed by proxy respondents after the sample person dies. NHATS is conducted by the Johns Hopkins University and is sponsored by the National Institute on Aging (U01AG32947). The Institutional Review Board of the University of California, San Francisco approved this study.

Participants:

Our study sample included decedents who enrolled in NHATS in 2011 or 2015 at age 70+ and used hospice at the end of life (n=1,460). We only included decedents with date of death before the end of year 2017 because of claims data availability. We excluded those who did not have an NHATS sample interview prior to death (n=355), resulting in a final sample of 1,105 participants. Within the cohort of 1,105 decedents, the percent of participants that died in each year ranged from 7% (2011, n=78) to 18% (2016, n=199).

Measures:

Hospice diagnosis: The principal hospice diagnosis is the reason, or indication, for hospice care, the disease that qualifies them for hospice care because they are likely to die from the disease in the following 6 months. To identify principal hospice diagnosis codes, we used the first hospice claim of the last hospice enrollment at least 1+ day before death. Medicare Advantage enrollees who enrolled in hospice had claims reported through the Medicare Hospice Benefit during the study years (2011–2017) and thus are captured in this sample. We examined principal hospice diagnoses for dementia, chronic obstructive pulmonary disorder (COPD), and heart failure. To identify principal hospice diagnoses of dementia in the hospice claims, we used ICD-9 and ICD-10 codes used in prior claims-based dementia research.[14–17] For principal hospice diagnoses of COPD and heart failure we used codes from the Chronic Conditions Data Warehouse[18]; for principal diagnoses of cancer, we used ICD-9 and ICD-10 chapters (Supplementary Text S1).

Coexisting dementia status: To identify coexisting dementia status (e.g., not listed on hospice claims), we used the NHATS interview prior to death completed by the sample person or proxy. We used the validated NHATS algorithm for “probable dementia” based on physician diagnosis, proxy-rated score for the Ascertain Dementia 8 screen, or impairment in memory, orientation, or executive function in cognitive exams.[19] We defined coexisting dementia as the decedents who had a non-dementia principal hospice diagnosis yet probable dementia in NHATS.

Dementia awareness: Among hospice decedents with principal diagnosis and coexisting dementia, we examined awareness of dementia. We assessed prevalence of persons reporting that a “doctor told you that you had dementia” in any round of NHATS. For sample persons with proxy respondents, we assessed prevalence of proxy reporting “dementia” as the reason for the proxy respondent.

Patient characteristics: To understand needs prior to or around the time of hospice admission, we drew demographic, social, functional, clinical, and behavioral characteristics reported by sample person or proxy in the last NHATS sample interview prior to death, which, in this study sample, was a median of 7 months (205 days, range 114–307) before death. Demographic characteristics included age and gender. Social characteristics included race/ethnicity, educational attainment, partnership status, annual income, receipt of Medicaid insurance, having a proxy respondent, and living alone. Functional characteristics included number of impairments in basic and instrumental activities of daily living, falls in the prior year, and bedboundness.[20] Clinical characteristics included self-reported chronic conditions other than dementia, number and length of hospital stays in prior year, and symptoms. Behavioral characteristics (getting lost, not being able to be left alone, and hallucinations) were collected only for sample persons with proxy respondents. We used the NHATS last month of life survey to examine hours of informal caregiver help and location of death. Location of hospice entry was defined using hospice claims.

Hospice use and quality: For outcome measures, we characterized hospice use patterns from claims data, including hospice enrollment of less than/equal to 3 days, hospice enrollment longer than 6 months, live disenrollment from hospice, and live hospice disenrollment after 6 months of hospice. We used NHATS measures of quality of care in the last month of life (n=1,055) with dichotomizations based on our prior work.[21] Measures included overall care rating; management of pain, breathlessness, sadness/anxiety, personal care needs; providing spiritual support, goal consistent care; treating patient with respect, making decisions with family input, keeping family informed, and coordinating care.

Analyses:

We compared hospice enrollees with coexisting dementia to two groups; 1) those with a principal hospice diagnosis of dementia, and 2) enrollees with no dementia (with neither a principal diagnosis of dementia nor coexisting dementia). We first examined differences in demographic, social, functional, and clinical characteristics using age- and gender-adjusted logistic regressions to estimate the prevalence of binary characteristics in each enrollee category. Similarly, we used age- and gender-adjusted quantile regressions to determine the median and interquartile range (IQR) of caregiver hours in the last month in each enrollee category. We used age- and gender- adjusted Poisson regression to estimate mean of number of nights spent in a hospital in the last year. Second, we examined differences in hospice use patterns and assessments of last-month-of-life care using chi-square tests for unadjusted analyses and logistic regression accounting for age, gender, year of death, hospice entry location, number of comorbidities, and census region. After performing regression analyses, we used post-estimation commands to estimate the adjusted predicted probabilities for each outcome measure.

Analysis was conducted using SAS version 9.4 (SAS Institute, Inc) and Stata version 17.0 (StataCorp LLC). All analyses account for the NHATS survey weights.

Results

Spectrum of dementia among hospice enrollees:

Among 1,105 decedents age 70+ enrolled in hospice, 56% had dementia. Of these, 40% (n=439) had dementia coexisting with another terminal illness and 16% had a principal diagnosis of dementia. Among older hospice enrollees with selected non-dementia principal hospice diagnoses, 43% of those with heart failure principal diagnoses had coexisting dementia; 38% of those with cancer principal diagnoses had coexisting dementia, and 34% of those with COPD principal diagnoses had coexisting dementia.

Findings regarding functional, clinical, and behavioral characteristics at the interview before death were similar in both unadjusted (not shown) and comparisons adjusted for age and gender (Table 1).

Awareness of dementia:

Among those with coexisting dementia, 59% reported a doctor telling them they had dementia in any round of NHATS and 69% of proxy respondents cited dementia as the reason for the proxy (Table 1). By comparison, among those with principal diagnoses of dementia, 78% reported a doctor’s diagnosis and 90% had proxy respondents because of dementia.

Functional characteristics:

Older enrollees with coexisting dementia had rates of needing help with 3–6 ADL similar to those with a principal diagnosis of dementia (Table 1). In contrast, functional needs of enrollees with coexisting dementia were substantially higher than those with no dementia. This included needing help with toileting (41% vs 8%), transferring (53% vs 12%), and medication management (85% vs. 34% did not do by self) (all p values <0.001) (Figure 1a, Table 1). Those with coexisting dementia had a higher prevalence of falls in the prior year (62% vs. 47%, p=0.001), and being semi- or fully bedbound (72% vs. 35%, p<0.001) compared to enrollees with no dementia. Both enrollees with coexisting dementia and principal dementia received substantial help from informal caregivers in the last month of life (coexisting dementia: median of 152 hours, interquartile range [IQR] 36, 435; principal dementia: median of 93 [IQR 14, 364] hours, p=0.065). Those with coexisting dementia received three times more help than enrollees with no dementia (median 49 hours [IQR 16–150], p<0.001).

Clinical characteristics:

Enrollees with coexisting dementia had greater multimorbidity than those with principal dementia (69% had 3+ chronic conditions vs. 56%, p=0.011 – Table 1) and more breathing problems (40% vs. 21%, p<0.001 – Figure 1b). Enrollees with coexisting dementia similarly high rates of clinical needs compared to those with no dementia, e.g., 63% vs. 61% had bothersome pain, and even higher prevalence of depression (52% vs. 22%, p<0.001) and anxiety (37% vs. 16%, p<0.001) (Figure 1b). Among those with proxy respondents (37%), dementia behaviors were prevalent at similar levels, e.g., hallucinations were prevalent among 43% of enrollees with coexisting dementia and 54% of those with a principal dementia diagnosis(p=0.093) (Table 1).

Location of care:

Slightly more enrollees with coexisting dementia than with principal diagnoses of dementia entered hospice at home (47% coexisting vs. 37% principal, p=0.072) and died at home (48% vs. 37%, p=0.061) (Table 1). A similar proportion of enrollees with coexisting dementia versus no dementia entered hospice at home (47% vs. 54%, p=0.171) and died at home (48% vs. 47%, p-value=0.911).

Hospice use:

There were almost no differences in patterns of hospice use between those with coexisting and principal diagnoses of dementia, adjusted for age, gender, year of death, hospice entry setting, number of comorbidities, and census region (Table 2; unadjusted Figure 2a). Average total length of stay in hospice was 22 days (range 7–94) for enrollees with coexisting dementia and 32 days (10–117) for those with a principal diagnosis of dementia (p=0.163, data not shown). One notable difference was that a larger percentage of enrollees with coexisting dementia had 3 or fewer days of hospice enrollment (14% vs. 8% principal diagnosis, p=0.01, Table 1). In contrast, adjusted analyses patterns of hospice use differed substantially between enrollees with coexisting versus no dementia. Average total length of stay in hospice was 22 days (range 7–94) for enrollees with coexisting dementia and 15 days (6–55) for those with no dementia (p=0.013, data not shown). Compared to enrollees with no dementia, a smaller percentage of enrollees with coexisting dementia were enrolled for 3 days or less (8% coexisting vs. 20% no dementia, p=0.022); a larger percentage were enrolled more than 6 months (14% vs. 5%, p<0.001); and a larger percentage experienced live discharge from hospice (16% vs. 10%, p=0.004) (Table 1).

Quality of last month of life care:

We also found two indicators of lower-quality last month of life care for enrollees with coexisting versus a principal diagnosis of dementia: a lower percentage with anxiety/sadness always managed (61% vs. 79%, p=0.017) and a smaller percentage of decisions made with enough patient/family input (88% vs. 95%, p=0.047) (adjusted Table 3; unadjusted Figure 2b). No differences were observed in measures of last-month-of-life care quality comparing enrollees with coexisting versus no dementia.

Discussion

We found 56% of hospice enrollees age 70+ have dementia; 40% had dementia coexisting with another terminal illness and 16% had a principal diagnosis of dementia. In comparison to hospice enrollees with no dementia, both those with a principal hospice diagnosis of dementia and those with dementia coexisting with another terminal illness need extensive ADL and IADL supports (Figure 1a). The population of older enrollees with coexisting dementia is large and yet not reflected in many descriptions of hospice enrollees that either focus on principal diagnoses or combine enrollees with principal and coexisting dementia into a single group. This study provides detail on the specific needs of older hospice enrollees with coexisting versus principal diagnoses of dementia.

The philosophy of hospice care centers respecting the moral agency of dying people and their families.[22] In practice, this means the hospice model assumes that the dying person is able participate in decision-making processes and that family members are to provide daily help with functional and symptom management needs outside of biweekly visits from hospice nurses and other members of the interdisciplinary hospice team. Yet to be eligible for hospice with a principal diagnosis of dementia (e.g. 16% of enrollees in this study), older hospice enrollees are unable to speak and need help with nearly all activities of daily living,[23] meaning 24/7 caregiving support is needed. In addition, this study shows that over twice as many older hospice enrollees (40%) have dementia coexisting with another terminal illness, like heart failure. People with existing dementia may be able to express some care preferences but their functional needs are comparable to enrollees with principal diagnoses of dementia and clinical needs are comparable to enrollees with no dementia. This misalignment between expectations and resources of the hospice model compared to the needs of people with dementia and their families is evident in the literature. Prior qualitative research found that hospice staff perceive people with dementia and their surrogate decision-makers to be unprepared for end-of-life care decisions at hospice admission.[24] For people with coexisting or principal dementia, their daily needs far surpass what the Medicare Hospice Benefit supports or organizations may be equipped for, leaving gaps to be filled by family, friends, or paid caregivers.[3,25,26] Though hospice clinicians develop care plans specific to the circumstances and preferences of each enrollee and family, resources (such help from home health aides) must be carefully stewarded within the payment model of the Medicare Hospice Benefit.

Our data indicates a third or more of enrollees with coexisting dementia (or their proxies) may be unaware of dementia coexisting with another terminal illness, raising concern that care management plans and prescribing patterns may not be appropriately tailored to dementia. This is of particular concern given that standard order sets used in hospice (sometimes called a comfort kit) could exacerbate behavioral symptoms of dementia.[27–32] Our data shows behavioral symptoms of dementia, like getting lost or hallucinating, are prevalent among both those with coexisting and principal diagnoses of dementia. Moreover, home hospice care typically relies upon the patient or caregivers to deliver medications; while 44% of enrollees with no dementia could self-manage medications a median of 7 months before death in this study, this was not true for 85% of enrollees with coexisting dementia. Finally, home hospice relies upon family and friends to provide support for activities of daily living,[25,26] which might make sense among older enrollees with no dementia, 85% of whom have fewer than 3 ADL impairments in the survey round before death. In contrast, 62% of those with coexisting dementia and 67% of those with a principal dementia diagnosis have 3–6 ADL impairments, suggesting profound need for daily caregiving. Indeed, older enrollees with coexisting dementia had three times as many hours of caregiver help in the prior month (median 152 hours) compared to those with no dementia (median 49 hours).

Mismatches between patient/family needs and hospice care models may be influencing measures of the quality of last-month-of-life care. For example, though overall quality ratings were high, fewer proxies of enrollees with coexisting dementia reported that anxiety or sadness was always managed (61%) or that decisions were made with enough patient/family input (88%) compared to proxies of enrollees with a principal diagnosis of dementia (79% and 95%, respectively). This finding raises concerns that hospice is not adequately addressing the emotional needs of enrollees with coexisting dementia. Yet hospice care seems better than the alternative: care quality among hospice enrollees with either principal or coexisting dementia seems to be higher than for decedents with dementia who did not enroll in hospice, as shown in a recent study using the same dataset and quality measures.[21]

Findings regarding hospice use patterns align with a recent study using data from the Health and Retirement Study (HRS) which estimated 45% of older hospice enrollees had either principal or coexisting dementia and extends our understanding in several ways.[10] NHATS interviews participants more frequently than HRS, allowing us to detail the needs of enrollees with dementia closer to time of death (and hospice enrollment). NHATS also includes additional detail on characteristics and quality measures relevant to understanding potential discrepancies between needs and current care models. In the NHATS study, we observed similar patterns of hospice use as ascertained in the HRS data when comparing hospice enrollees with coexisting dementia versus no dementia. Differences in hospice use patterns between enrollees with coexisting and principal diagnoses of dementia likely stem from differences in how NHATS and HRS characterize settings, and the fact that that HRS includes nursing home residents in baseline assessments. A recent study using 100% Medicare claims found 8% of enrollees with principal dementia were disenrolled for extended prognosis[33] (compared to 5% identified in this study).

There are a variety of innovations aiming to improve end-of-life care for PWD. Programs like Aliviado Health aim to improve dementia expertise of clinicians within hospice, home health, and long-term care models.[34–36] The UCLA Alzheimer's & Dementia Care co-management program shows positive end-of-life outcomes.[37] Medicare Advantage (MA) organizations are testing value-based insurance design, in which the MA plan pays for and oversees hospice benefits rather than the Medicare Hospice Benefit.[38–40] One concern with this is that incentives to control costs will put older adults with serious illness – like PWD – at risk of receiving lower quality care.[39,40] There is some evidence that PWD have lower satisfaction in MA[41] and perceptions of end-of-life care are lower.[42] Though not specific to PWD, Veterans Affairs (VA) expanded palliative care and hospice services over the last 20 years and saw significant improvements in access, preferred location of death, and family satisfaction with care.[43] VA home-based primary care provides coordinated, interdisciplinary care to seriously ill and functionally impaired older adults like those with PWD; receipt of additional community-based hospice services further improves satisfaction.[44]

Limitations:

NHATS does not capture baseline information about demographics and dementia status for those living in nursing homes at time of the first NHATS interview and thus this study may underestimate the population of older hospice enrollees in nursing home settings, which may include a higher prevalence of persons with principal diagnoses of dementia. The NHATS epidemiologic definition of dementia may not match the true incidence of pathology-proven dementia. Small sample sizes and CMS cell size suppression policies prevent us from examining patterns by race/ethnicity/heritage. These datasets do not allow for examination of differences by hospice ownership type.

Conclusion:

Over half of persons receiving hospice care in the U.S. have dementia. Given that the majority of Medicare hospice beneficiaries are over age 70[2], our findings indicate hospice should be reoriented around a dementia paradigm and careful identification of the subpopulation with coexisting dementia. Our data support ensuring that enrollees with either coexisting dementia or principal diagnoses have adequate daily support for help with functional impairments, psychiatric symptoms, and medication management.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Funding Sources and Previous Presentations:

Funding:

Research reported in this publication was supported by a supplement to the UCSF Claude D. Pepper Older Americans Independence Center funded by the National Institute On Aging (NIA) of the National Institutes of Health (NIH) under Award Number P30AG044281 (3P30AG044281-08S1). Investigators' time was additionally supported in part by funding from the NIH/NIA grants P01AG066605 (all); K01AG059831 (KLH), R01AG0577513 (AKS); K24AG068312 (AKS), R01AG054540 (ASK), K24AG062785 (ASK), K07AG060270 (MDA), P30AG044281 (KC); NIH/National Institute of Nursing Research (NINR) R01NR018462 (MDA); K76AG074924 (LJH).

Sponsor's Role:

Research reported in this publication was supported by the National Institute On Aging of the National Institutes of Health under Award Number P30AG044281. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. No sponsor was involved in the design, methods, recruitment, data collection, analysis, or preparation of the paper.

References

1. 2022 Alzheimer's disease facts and figures. Alzheimers Dement. Published online March 14, 2022. doi:10.1002/alz.12638
2. National Hospice and Palliative Care Organization. 2021 Edition: Hospice Facts and Figures. National Hospice and Palliative Care Organization; 2021. Accessed March 29, 2022. https://www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2021.pdf
3. Lassell RKF, Moreines LT, Luebke MR, et al. Hospice interventions for persons living with dementia, family members and clinicians: A systematic review. Journal of the American Geriatrics Society. 2022;70(7):2134–2145. doi:10.1111/jgs.17802 [PubMed: 35441699]
4. Harrison KL, Allison TA, Garrett SB, Thompson N, Sudore RL, Ritchie CS. Hospice staff perspectives on caring for people with dementia: a multi-site, multi-stakeholder study. Journal of Palliative Medicine. 2020;In press.
5. Harrison KL, Garrett SB, Halim M, et al. "I didn't sign up for this": perspectives from persons living with dementia and care partners on challenges, supports, and opportunities to add geriatric neuropalliative care to dementia specialty care. Journal of Alzheimer's disease : JAD. Published online In Press.
6. Harrison KL, Ritchie CS, Patel K, et al. Care Settings and Clinical Characteristics of Older Adults with Moderately Severe Dementia. J Am Geriatr Soc. 2019;67(9):1907–1912. doi:10.1111/jgs.16054 [PubMed: 31389002]
7. Mitchell SL, Miller SC, Teno JM, Kiely DK, Davis RB, Shaffer ML. Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs hospice eligibility guidelines. JAMA. 2010;304(17):1929–1935. doi:10.1001/jama.2010.1572 [PubMed: 21045099]
8. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. N Engl J Med. 2009;361(16):1529–1538. doi:10.1056/NEJMoa0902234 [PubMed: 19828530]
9. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. J Am Geriatr Soc. 2010;58(12):2284–2291. doi:10.1111/j.1532-5415.2010.03185.x [PubMed: 21143437]

10. Aldridge MD, Hunt L, Husain M, Li L, Kelley A. Impact of Comorbid Dementia on Patterns of Hospice Use. J Palliat Med. 2022;25(3):396–404. doi:10.1089/jpm.2021.0055 [PubMed: 34665050]
11. Centers for Medicare & Medicaid Innovation. Medicare Program; FY 2014 Hospice Wage Index and Payment Rate Update; Hospice Quality Reporting Requirements; and Updates on Payment Reform.; 2013. Accessed February 11, 2019. https://www.federalregister.gov/documents/2013/08/07/2013-18838/medicare-program-fy-2014-hospice-wage-index-and-payment-rate-update-hospice-quality-reporting
12. Hanrahan P, Luchins DJ. Access to hospice programs in end-stage dementia: a national survey of hospice programs. J Am Geriatr Soc. 1995;43(1):56–59. [PubMed: 7806741]
13. Harris-Kojetin L, Sengupta M, Park-Lee E, et al. Long-Term Care Providers and services users in the United States: data from the National Study of Long-Term Care Providers, 2013–2014. Vital Health Stat 3. 2016;(38):x–xii; 1–105.
14. De Vleminck A, Morrison RS, Meier DE, Aldridge MD. Hospice Care for Patients With Dementia in the United States: A Longitudinal Cohort Study. J Am Med Dir Assoc. Published online November 16, 2017. doi:10.1016/j.jamda.2017.10.003
15. Taylor DH, Østbye T, Langa KM, Weir D, Plassman BL. The accuracy of Medicare claims as an epidemiological tool: the case of dementia revisited. J Alzheimers Dis. 2009;17(4):807–815. doi:10.3233/JAD-2009-1099 [PubMed: 19542620]
16. Thunell J, Ferido P, Zissimopoulos J. Measuring Alzheimer's Disease and Other Dementias in Diverse Populations Using Medicare Claims Data. J Alzheimers Dis. 2019;72(1):29–33. doi:10.3233/JAD-190310 [PubMed: 31524159]
17. Østbye T, Taylor DH, Clipp EC, Scoyoc LV, Plassman BL. Identification of Dementia: Agreement among National Survey Data, Medicare Claims, and Death Certificates. Health Serv Res. 2008;43(1 Pt 1):313–326. doi:10.1111/j.1475-6773.2007.00748.x [PubMed: 18211532]
18. Chronic Conditions Data Warehouse. Accessed August 1, 2021. https://www2.ccwdata.org/web/guest/condition-categories
19. Kasper JD, Freedman VA, Spillman BC. Classification of Persons by Dementia Status in the National Health and Aging Trends Study. Technical Paper #5. Johns Hopkins University School of Public Health; 2013.
20. Harrison KL, Ritchie CS, Hunt LJ, et al. Life expectancy for community-dwelling persons with dementia and severe disability. J Am Geriatr Soc. 2022;70(6):1807–1815. doi:10.1111/jgs.17767 [PubMed: 35357694]
21. Harrison KL, Cenzer I, Ankuda CK, Hunt LJ, Aldridge MD. Hospice Improves Care Quality For Older Adults With Dementia In Their Last Month Of Life. Health Aff (Millwood). 2022;41(6):821–830. doi:10.1377/hlthaff.2021.01985 [PubMed: 35666964]
22. Kirk TW, Jennings B, eds. Hospice Ethics: Policy and Practice in Palliative Care. 1 edition. Oxford University Press; 2014.
23. Sclan SG, Reisberg B. Functional assessment staging (FAST) in Alzheimer's disease: reliability, validity, and ordinality. Int Psychogeriatr. 1992;4 Suppl 1:55–69.
24. Harrison KL, Allison TA, Garrett SB, Thompson N, Sudore RL, Ritchie CS. Hospice Staff Perspectives on Caring for People with Dementia: A Multisite, Multistakeholder Study. J Palliat Med. 2020;23(8):1013–1020. doi:10.1089/jpm.2019.0565 [PubMed: 32130076]
25. Wachterman MW, Luth EA, Semco RS, Weissman JS. Where Americans Die - Is There Really "No Place Like Home"? N Engl J Med. 2022;386(11):1008–1010. doi:10.1056/NEJMp2112297 [PubMed: 35275480]
26. Harrison KL. The Hidden Curriculum Of Hospice: Die Fast, Not Slow. Health Aff (Millwood). 2021;40(5):844–847. doi:10.1377/hlthaff.2021.00259 [PubMed: 33939517]
27. Gerlach LB, Kales HC. Managing Behavioral and Psychological Symptoms of Dementia. Clin Geriatr Med. 2020;36(2):315–327. doi:10.1016/j.cger.2019.11.010 [PubMed: 32222304]
28. Gerlach LB, Powell V, Zhang L, Bynum JPW, Maust DT. The Most Common Medications Billed to the Medicare Hospice Benefit Among Hospice Beneficiaries in the U.S. J Pain Symptom Manage. 2021;62(3):e3–e6. doi:10.1016/j.jpainsymman.2021.05.016

29. Gerlach LB, Kales HC. Pharmacological Management of Neuropsychiatric Symptoms of Dementia. Curr Treat Options Psychiatry. 2020;7(4):489–507. doi:10.1007/s40501-020-00233-9 [PubMed: 33344107]
30. Gerlach LB, Park PS, Shireman TI, Bynum JPW. Changes in medication use among long-stay residents with dementia in Michigan during the pandemic. J Am Geriatr Soc. 2021;69(7):1743–1745. doi:10.1111/jgs.17161 [PubMed: 33834488]
31. Maust DT, Strominger J, Bynum JPW, et al. Prevalence of Psychotropic and Opioid Prescription Fills Among Community-Dwelling Older Adults With Dementia in the US. JAMA. 2020;324(7):706–708. doi:10.1001/jama.2020.8519 [PubMed: 32808997]
32. Gerlach LB, Zhang L, Strominger J, et al. Variation in Benzodiazepine and Antipsychotic Prescribing Among Hospice Agencies. J GEN INTERN MED. Published online April 25, 2022. doi:10.1007/s11606-022-07604-3
33. Hunt LJ, Gan S, Boscardin WJ, et al. A national study of disenrollment from hospice among people with dementia. J Am Geriatr Soc. Published online June 7, 2022. doi:10.1111/jgs.17912
34. David D, Lin SY, Groom LL, Ford A, Brody AA. Aliviado Mobile App for Hospice Providers: A Usability Study. J Pain Symptom Manage. 2022;63(1):e37–e45. doi:10.1016/j.jpainsymman.2021.07.019 [PubMed: 34389414]
35. Lin SY, Schneider CE, Bristol AA, et al. Findings of Sequential Pilot Trials of Aliviado Dementia Care to Inform an Embedded Pragmatic Clinical Trial. Gerontologist. 2022;62(2):304–314. doi:10.1093/geront/gnaa220 [PubMed: 33377138]
36. Schneider CE, Bristol A, Ford A, et al. The Impact of Aliviado Dementia Care-Hospice Edition Training Program on Hospice Staff's Dementia Symptom Knowledge. J Pain Symptom Manage. 2020;60(2):e7–e13. doi:10.1016/j.jpainsymman.2020.05.010
37. Jennings LA, Hollands S, Keeler E, Wenger NS, Reuben DB. The Effects of Dementia Care Co-Management on Acute Care, Hospice, and Long-Term Care Utilization. J Am Geriatr Soc. 2020;68(11):2500–2507. doi:10.1111/jgs.16667 [PubMed: 32573765]
38. VBID Model Hospice Benefit Component Overview | CMS Innovation Center. Accessed September 14, 2022. https://innovation.cms.gov/innovation-models/vbid-hospice-benefit-overview
39. Ankuda CK, Morrison RS, Aldridge MD. The 2021 Medicare Advantage Hospice Carve-In. JAMA. 2021;326(23):2367–2368. doi:10.1001/jama.2021.21161 [PubMed: 34842906]
40. Teno JM. Carving in Hospice to Medicare Advantage—Potential Unintended Consequences. JAMA Health Forum. 2021;2(7):e212269. doi:10.1001/jamahealthforum.2021.2269 [PubMed: 36218768]
41. Meyers DJ, Rivera-Hernandez M, Kim D, Keohane LM, Mor V, Trivedi AN. Comparing the care experiences of Medicare Advantage beneficiaries with and without Alzheimer's disease and related dementias. Journal of the American Geriatrics Society. 2022;70(8):2344–2353. doi:10.1111/jgs.17817 [PubMed: 35484976]
42. Ankuda CK, Kelley AS, Morrison RS, Freedman VA, Teno JM. Family and Friend Perceptions of Quality of End-of-Life Care in Medicare Advantage vs Traditional Medicare. JAMA Netw Open. 2020;3(10):e2020345. doi:10.1001/jamanetworkopen.2020.20345 [PubMed: 33048130]
43. Sullivan DR, Teno JM, Reinke LF. Evolution of Palliative Care in the Department of Veterans Affairs: Lessons from an Integrated Health Care Model. J Palliat Med. 2022;25(1):15–20. doi:10.1089/jpm.2021.0246 [PubMed: 34665652]
44. Kinder D, Smith D, Ersek M, et al. Family reports of end-of-life care among veterans in home-based primary care: The role of hospice. J Am Geriatr Soc. 2022;70(1):243–250. doi:10.1111/jgs.17486 [PubMed: 34585735]
45. Freedman VA, Kasper JD. Hours of Care in Rounds 1 and 2 of the National Health and Aging Trends Study. NHATS Technical Paper #7. Johns Hopkins University School of Public Health Accessed March 29, 2022. https://www.nhats.org/sites/default/files/2021-01/Hours_of_Care_in_NHATS_Rounds_1_and_2_April2014.pdf
46. Kumar V, Ankuda CK, Aldridge MD, Husain M, Ornstein KA. Family Caregiving at the End of Life and Hospice Use: A National Study of Medicare Beneficiaries. J Am Geriatr Soc. 2020;68(10):2288–2296. doi:10.1111/jgs.16648 [PubMed: 32602571]

47. Luth EA, Prigerson HG. Associations between Race and Dementia Status and the Quality of End-of-Life Care. J Palliat Med. 2018;21(7):970–977. doi:10.1089/jpm.2017.0638 [PubMed: 29620949]

48. Makaroun LK, Teno JM, Freedman VA, Kasper JD, Gozalo P, Mor V. Late Transitions and Bereaved Family Member Perceptions of Quality of End-of-Life Care. J Am Geriatr Soc. 2018;66(9):1730–1736. doi:10.1111/jgs.15455 [PubMed: 29972587]

KEY POINTS

- Hospice increasingly cares for people with dementia: 56% of hospice enrollees ages 70 and older are estimated to have dementia; 40% had dementia coexisting with another terminal illness and 16% had a principal diagnosis of dementia.
- Older hospice enrollees with coexisting dementia have high needs; their functional needs are similar to older adults with principal diagnosis of dementia, and their clinical and symptom needs are similar to hospice enrollees with no dementia.
- **Why does this matter**? Understanding the size and specific needs of older hospice enrollees who have dementia as a coexisting condition as well as principal hospice diagnosis is an essential step toward ensuring care models and policies suit those needs.

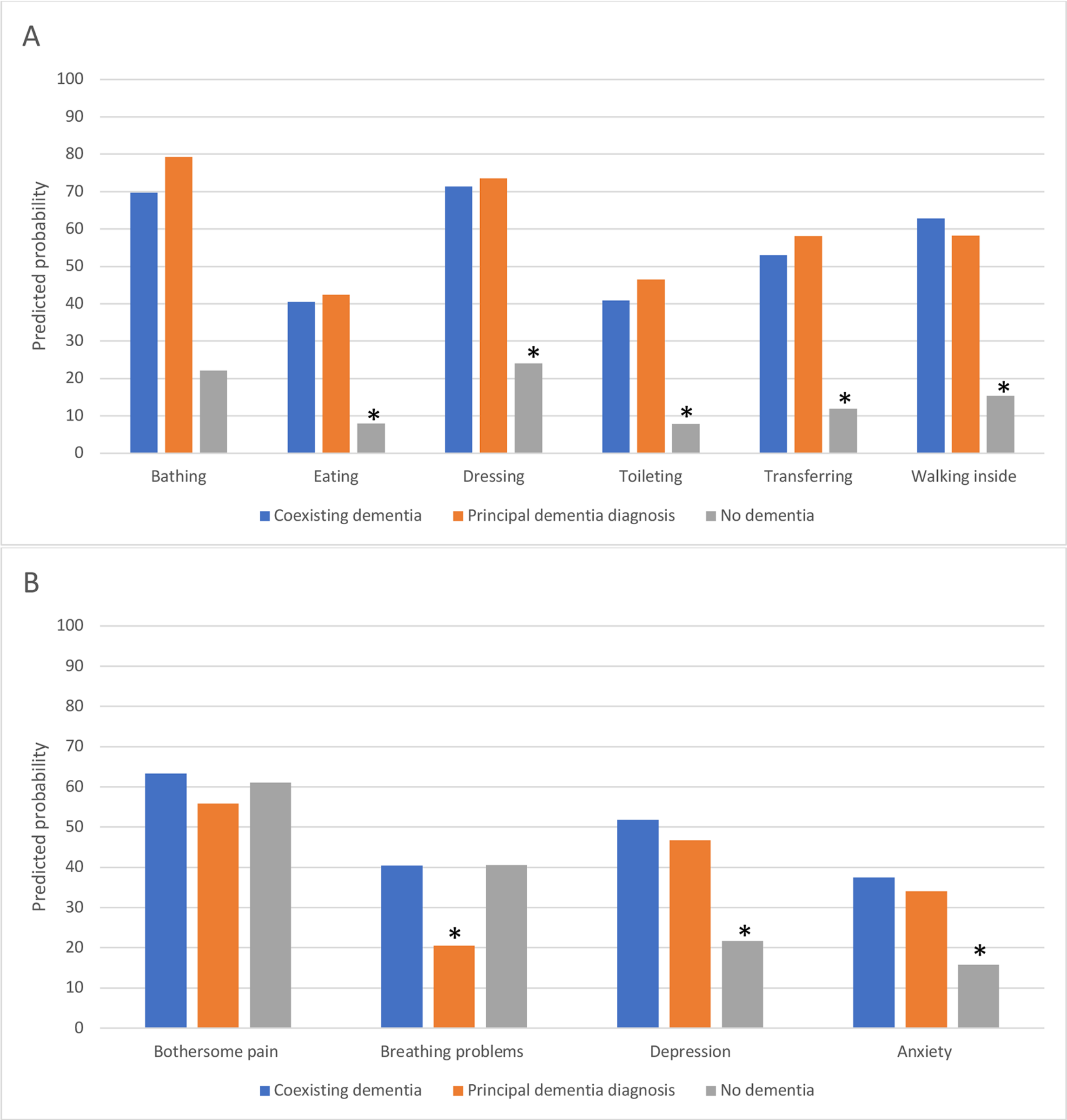

Figure 1:

Adjusted differences of deficiencies in functional and symptom support, comparing older hospice enrollees by dementia status. This figure compares activities of daily living that sample persons did not do or needed help with (panel A) and symptoms (panel B) across older hospice enrollees with coexisting dementia (e.g. with a different principal hospice diagnosis, n=432), a principal diagnosis of dementia (n=186), and no dementia (n=487), adjusted for age and gender. We present predicted probabilities based on logistic regressions; bigger numbers indicate more need for help or more burden of symptoms. Asterisks indicate differences of $p<0.05$ in comparison to older hospice enrollees with coexisting dementia.

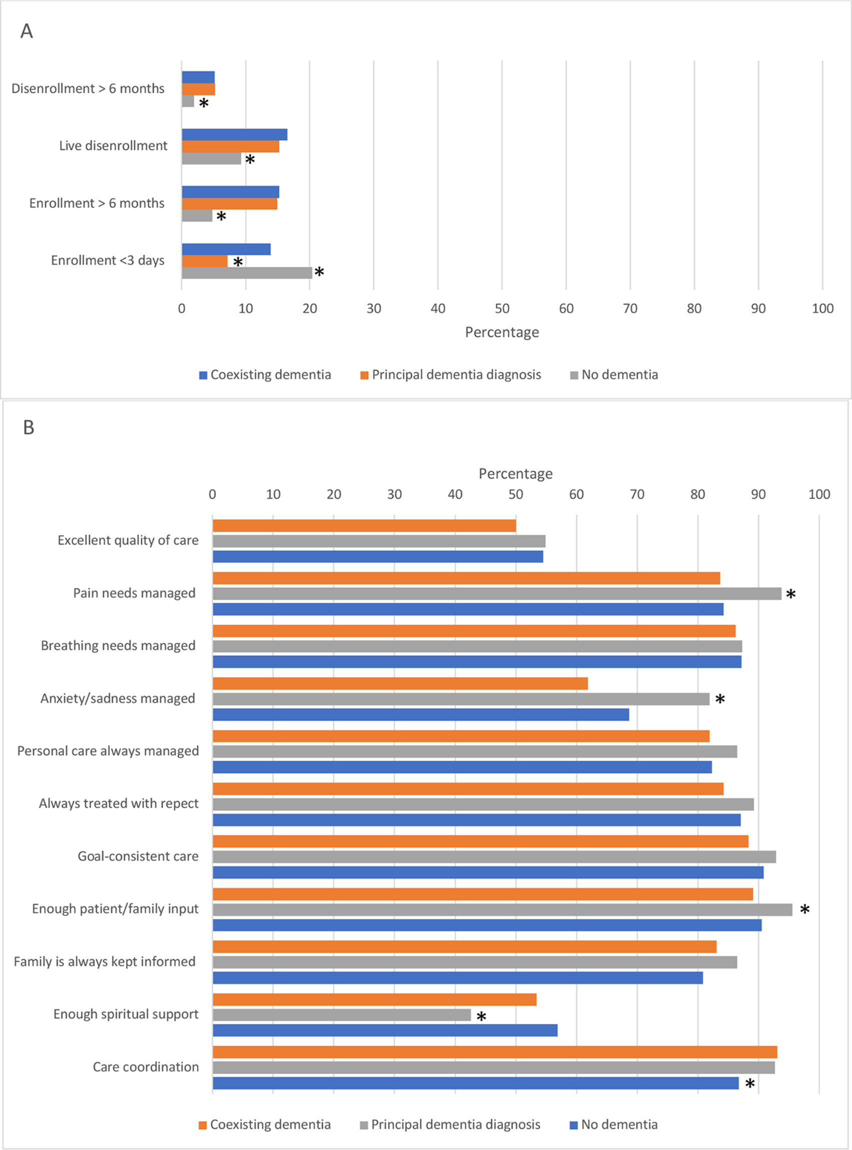

Figure 2:

Unadjusted differences in hospice use and last month of life care quality comparing older hospice enrollees by dementia status. This figure compares prevalence of outcome measures of hospice use (panel A) and last month of life quality (panel B) across older hospice enrollees with coexisting dementia (e.g., with a different principal hospice diagnosis, n=432), a principal diagnosis of dementia (n=186), and no dementia (n=487). Asterisks indicate differences of $p<0.05$ in comparison to older hospice enrollees with coexisting dementia. Measures for last-month-of-life care quality defined as per prior work[21] and dichotomized to build off prior literature[42,46,47]: overall ratings of care (excellent vs. very good-to-poor); right amount of management of pain, dyspnea, and sadness/anxiety (if symptom present – referred to as “managed”); always meeting personal care needs (vs. usually to never, e.g. “personal care managed”); enough spiritual support; decisions made that the participant would have wanted, e.g. “goal consistent care”; patient always “treated with respect" (vs. usually to never); no decision made without enough "patient/family input" (vs. yes); family always kept informed of patient condition (vs. never, e.g. "family informed"); clear which of multiple doctors were in charge of care ("care coordinated"), and late transitions in the last 3 days of life[48]

Table 1:

Demographic, social, functional, and clinical characteristics hospice enrollees with coexisting dementia compared to enrollees with principal diagnoses of dementia or no dementia, adjusted for age and sex

Characteristics	**Overall**	**Coexisting dementia (N=432)**	**Principal dementia diagnosis (N=186)**	**p-value[1]**	**No dementia (N=487)**	**p-value[2]**
Awareness of Dementia						
Has a doctor ever diagnosed them with dementia	NR	58%	78%	<0.001	NR	NR
For proxies, is proxy because of dementia (N=438)	NR	69%	89%	<0.001	NR	NR
Demographics and social characteristics						
Age at Death	85.7 ± 8.5	87.3 ± 9.1	87.8 ± 7.6	0.477	83.9 ± 7.7	<0.001
Age 90+	459 (32%)					
Women	654 (58%)	59%	60%	0.963	55%	0.260
Black, Hispanic, American Indian, Asian, Native Hawaiian, Pacific Islander, and/or multiple	281 (15%)	21%	21%	0.966	10%	<0.001
Less than High School	362 (29%)	32%	26%	0.165	27%	0.202
Unmarried, divorced, widowed[4]	742 (63%)	64%	62%	0.546	62%	0.418
Lowest quartile annual income ($0–12,000)[3]	286 (23%)	25%	27%	0.798	20%	0.091
Medicaid Insurance	228 (20%)	24%	27%	0.509	14%	0.003
Proxy respondent	438 (37%)	64%	73%	0.058	4%	<0.001
Living alone	474 (44%)	39%	51%	0.011	46%	0.048
Functional characteristics						
3–6 ALD impairments[5]	444 (39%)	62%	67%	0.334	15%	<0.001
≥4 IADL impairment[6]	603 (53%)	81%	86%	0.200	22%	<0.001
Did not take medication by self in last month	692 (61%)	85%	88%	0.429	34%	<0.001
Falls in the last year	580 (55%)	62%	62%	0.908	47%	0.001
Semi- or completely bedbound[7]	623 (55%)	72%	76%	0.468	36%	<0.001
Number of hours of caregiver help in the last month (median [IQR])[8]	77 (21–260)	152 (36–435)	93 (14–364)	0.065	49 (16–150)	<0.001
Clinical Characteristics						
≥3 Chronic conditions[9]	715 (66%)	69%	56%	0.011	68%	0.818
1+ Hospital stays in last year	531 (50%)	53%	52%	0.881	48%	0.233
Number of nights for hospital stays >0 (Mean [95% CI])	2.5 (1.8–3.3)	3.3 (1.6–4.9)	1.6 (1.3–1.9)	0.011	2.3 (1.9–2.6)	0.085
Dementia Behavior (proxy only, N=438)						
Ever get lost in a familiar environment	NR	37%	45%	0.155	NR	NR

Characteristics	**Overall**	**Coexisting dementia (N=432)**	**Principal dementia diagnosis (N=186)**	**p-value**[1]	**No dementia (N=487)**	**p-value**[2]
Unable to be left alone for an hour or so	NR	68%	51%	0.012	NR	NR
Hear or see things that were not really there	NR	43%	54%	0.093	NR	NR
Proportion at home						
At entry to hospice[10]	546 (49%)	47%	37%	0.072	54%	0.171
Place of death[11]	494 (46%)	48%	37%	0.061	47%	0.911

NOTES

[*] NR = not reportable due to sample size

[1] p-value comparing coexisting dementia vs principal diagnosis of dementia

[2] p-value comparing coexisting dementia vs no dementia

[3] Includes social security, pension, earned income, retirement account withdrawals, interest/dividends etc. at baseline; missing values were replaced using the income imputations provided by NHATS.

[4] Unpartnered respondents (widowed, divorced, separated, never married, other) versus partnered respondents (married or living together).

[5] Indicates people who received help or did not do Activities of Daily Living (ADL)

[6] Instrumental Activities of Daily Living (IADL) included not doing the following activities by self in the prior month: laundry, shopping, preparing food, managing money, or taking medications. Answers regarding don’t know or refused were combined with the answer indicating not applicable (e.g. not taking any medications).

[7] Bedboundedness based on frequency, difficulty, and need for help getting out of bed, as previously defined[20]

[8] Hours of caregiver help defined per NHATS technical paper #7; no helper is defined as 0 hours[45]

[9] Chronic conditions come from the NHATS round before death and include: heart attack or heart disease, hypertension, diabetes, lung disease, stroke, cancer, hip fracture/break

[10] Location of hospice entry was defined using hospice claims and dichotomized as “home” versus anywhere else, including hospice facility.

[11] Location at death defined using the NHATS last month of life survey and dichotomized as “at sample person or someone else’s home” versus in a hospital, nursing home, hospice residence, in transit, or somewhere else.

Table 2:

Adjusted Comparison of Hospice Use Patterns of Older of Hospice Enrollees with Coexisting Dementia, a Principal Hospice Diagnosis of Dementia, or No Dementia[1]

	Coexisting dementia (N=432)	**Principal dementia diagnosis (N=186)**	**p-value[2]**	**No dementia (N=487)**	**p-value[3]**
Last hospice enrollment <= 3 days	14%	8%	0.01	20%	0.022
Longest hospice enrollment > 6 months	14%	15%	0.680	5%	<0.001
Any live disenrollment from hospice	16%	16%	0.987	10%	0.004
Live disenrollment after 6 months	5%	5%	0.680	2%	0.069

NOTES

[1] Adjusted for age, gender, year of death, hospice entry location, # comorbidities, census region. We used post-estimation commands to estimate the adjusted predicted probabilities for each outcome measure after running logistic regressions.

[2] p-value comparing coexisting dementia vs principal diagnosis of dementia

[3] p-value comparing coexisting dementia vs no dementia

Table 3:

Adjusted Comparison[1] of Last Month of Life Quality Measures[2] for Older of Hospice Enrollees with Coexisting Dementia, a Principal Hospice Diagnosis of Dementia, or No Dementia (n=1,055)

Hospice Characteristics	**Coexisting dementia (N=416)**	**Principal diagnosis of dementia (N=180)**	**p-value**[2]	**No dementia (N=459)**	**p-value**[3]
Excellent quality of care	50%	54%	0.362	55%	0.232
Pain needs managed[4]	85%	93%	0.099	83%	0.816
Breathing managed[4]	87%	88%	0.842	86%	0.878
Anxiety or sadness managed[4]	61%	79%	0.017	71%	0.079
Personal care needs always managed	82%	88%	0.085	81%	0.857
Enough spiritual support[5]	55%	44%	0.022	55%	0.951
Goal consistent care[6]	89%	93%	0.074	90%	0.365
Always treated with respect	85%	90%	0.106	87%	0.465
Enough patient/family input	88%	95%	0.047	91%	0.302
Family always informed	83%	87%	0.334	81%	0.543
Care coordinated[7]	92%	92%	0.996	86%	0.051

NOTES

[1] Adjusted for age, gender, year of death, hospice entry location, # comorbidities, census region.

[2] p-value comparing coexisting dementia vs principal diagnosis of dementia. Adjusted for age, gender, year of death, hospice entry location, # comorbidities, census region. We used post-estimation commands to estimate the adjusted predicted probabilities for each outcome measure after running logistic regressions.

[3] p-value comparing coexisting dementia vs no dementia.

[4] Assessed as if symptom was present, did sample person get help managing the symptom, and if yes, did they the right amount of help managing the symptom management of pain.

[5] Enough spiritual support was defined as doctors, nurses, or other health professional taking with the sample person about their religious beliefs as much as they wanted in the last month of life.

[6] "Goal consistent care" was defined as no decision made about care or treatment that the participant would not have wanted.

[7] "Care coordinated" such if multiple doctors were involved in care in the last month of life that it was clear which of multiple doctors were in charge of care.