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A National Study of Disenrollment from Hospice Among People with Dementia

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Abstract

Background: People with dementia (PWD) are at high risk for hospice disenrollment, yet little is known about patterns of disenrollment among the growing number of hospice enrollees with dementia.

Design: Retrospective, observational cohort study of 100% Medicare beneficiaries with dementia aged 65 and older enrolled in the Medicare Hospice Benefit between July 2012 and December 2017. Outcome measures included hospice-initiated disenrollment for patients whose rate of decline ceased to meet the Medicare hospice eligibility guideline of “expected death within 6 months” (extended prognosis) and patient-initiated disenrollment (revocation). Hospice, regional, and patient risk factors and variation were assessed with multilevel mixed-effects logistic regression models.

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Author contributions:

Study conception and design (all authors); data procurement (LJH and AKS), analysis and interpretation of results (all authors); draft manuscript preparation (all authors). All authors reviewed the results and approved the final version of the manuscript.

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The authors have no conflicts of interest to report

Results: Among 867,695 hospice enrollees with dementia, 70,945 (8.2%) were disenrolled due to extended prognosis and 43,133 (5.0%) revoked within 1-year of their index admission. There was substantial variation in hospice provider disenrollment due to extended prognosis (10th–90th percentile 4.5%−14.6%, adjusted median odds ratio (MOR) 1.89, 95% confidence interval (CI) 1.84, 1.93) and revocation (10th–90th percentile 2.5%−10.1%, MOR 2.12, 95% CI 2.06, 2.17). Among hospital referral regions (HRR), there was more variation in revocation (10th–90th percentile 3.5%−7.6%, MOR 1.4, 95% CI 1.34, 1.47) than extended prognosis (10th–90th percentile 7.0%−9.5%, MOR 1.23, 95% CI 1.18, 1.27), with much higher revocation rates noted in HRR's located in the Southeast and Southern California. A number of patient and hospice characteristics were associated with higher odds of both types of disenrollment (younger age, female sex, minoritized race and ethnicity, Medicaid dual-eligibility, Medicare Part C enrollment), while some were associated with revocation only (more comorbidities, newer, smaller, and for-profit hospices).

Conclusions: In this nationally-representative study of hospice enrollees with dementia, hospice disenrollment varied by type of hospice, geographic region, and patient characteristics including age, sex, race and ethnicity. These findings raise important questions about whether and how the Medicare Hospice Benefit could be adapted to reduce disparities and better support PWD.

Keywords

dementia; hospice; disenrollment

Introduction

Of the more than 1.5 million people who enroll in the Medicare Hospice Benefit annually, 15–20% are admitted to hospice with a primary diagnosis of dementia.[1] To be eligible for the Medicare Hospice Benefit, enrollees must have a terminal illness with an expected prognosis of 6-months or less and must also agree to forgo curative treatments. This model is well-suited for people with metastatic cancer who decide to discontinue disease-modifying treatments and primarily need support with pain and symptom management. However, this model may be a mismatch for conditions with unpredictable trajectories and those who primarily need assistance with personal care, behavioral symptoms, and caregiver support, such as people with dementia (PWD).[2,3]

This mismatch places PWD at higher risk for hospice disenrollment (also referred to as "live discharge"). Previous research has found that disenrollment rates are two to four times higher for PWD than people with cancer, especially for disenrollments that occur after 180 days in hospice.[1,4] Determining 6-month prognosis in dementia is notoriously difficult,[5] leading to the scenario in which—after many months in hospice—a PWD's rate of decline ceases to meet the Medicare hospice eligibility guideline of "expected death within 6 months" and they are subject to hospice-initiated disenrollment (also referred to as disenrollment due to extended prognosis). In addition to disenrollment due to extended prognosis, hospice providers may disenroll a patient if they move out of the hospice's service area or transfer to another hospice or, rarely, the hospice determines that there are serious safety concerns for their staff in delivering care for that person ("for cause"). Patients may disenroll from hospice (revocation) due to dissatisfaction with hospice care or to pursue treatments considered “curative” and not covered by Medicare under the hospice benefit.[6] The vast majority of disenrollments are either hospice-initiated due to extended prognosis or patient-initiated due to revocation, accounting for 70–80% of all disenrollments.[7]

High rates of disenrollment among PWD have been a growing area of concern in recent years.[6–8] Hospice disenrollment disrupts care continuity and leads to burdensome transitions at a time of life when people most need the comprehensive and coordinated care that hospice provides.[9–12] Disenrollment may be especially challenging for PWD and their caregivers because— in comparison to other terminal diseases— caring for PWD as they approach end of life places more strain on caregivers.[13] Moreover, there is limited availability of other community-based supports that deliver a similar level of comprehensive care in the home and other residential settings as hospice.[14,15] Federal and state regulators are concerned that high rates of disenrollment due to extended prognosis indicate potentially inappropriate and even fraudulent hospice enrollment of individuals with uncertain prognoses, especially those with dementia, who tend to have long stays and increase profit margins for hospices.[16–19] High rates of revocation may reflect hospices providing insufficient supports for patients and caregivers and attempting to avoid paying for costly hospitalizations.[20]

Even though PWD comprise a large and growing percentage of hospice enrollees and disenrollment is of particular concern for this population, limited research has focused on examining patterns of disenrollment among PWD overall and no national studies to our knowledge have examined patterns of patient- and provider-initiated disenrollment.[21–23] In this study, we sought to assess the frequency of provider-initiated (extended prognosis) and patient-initiated (revocation) disenrollment, examine hospice provider and regional variation in disenrollment, and identify individual patient, hospice provider, and regional predictors of disenrollment.

Methods

Study Design, Data Sources, and Sample:

We conducted a retrospective cohort study using national 2012–2017 Medicare data linked to databases of hospices and regional characteristics. We included 100% of Medicare beneficiaries who had their first admission to hospice between July 1st, 2012 and December 31st, 2016 and were admitted to hospice for a diagnosis of dementia (principal diagnosis) (N=894,111). Dementia diagnosis was identified using the hospice claim’s International Classification of Diseases (ICD), 9th revision, or ICD-10 code based on previously validated definitions (Supplementary Methods S1).[24,25] July 1st 2012 was our start date because it was at that time that the Centers for Medicare and Medicaid Services (CMS) began requiring hospices to report occurrence codes identifying disenrollment reason. Participants were followed for 1-year to determine their final disposition (died, were disenrolled, or still a patient at the end of the 1-year follow-up period). We excluded beneficiaries who were aged under 65 (N=14,075), those missing data on final disposition in a 1-year follow-up period (N=5,001) and beneficiaries who we were unable to link to a hospital referral region (N=7,340). Hospice providers were identified using CMS provider numbers and hospice characteristics were obtained from the CMS Provider of Service files, the Hospice Public Use File, and the Hospice Compare database. Regions were defined at the hospital referral region (HRR) by linking hospice zip code to the Dartmouth Atlas. Other regional data was obtained through the Neighborhood Atlas and the National Center for Health Statistics Urban/Rural Classification Scheme.

Main Outcome Variables:

The primary outcomes were: 1) disenrollment due to extended prognosis and 2) disenrollment due to revocation within 1-year of initial admission. We used an algorithm based on hospice claims to identify the reason for disenrollment (Supplementary Methods S2). The choice of a 1-year cutoff was based on several considerations. While Medicare hospice eligibility requires a prognosis of less than 6-months, beneficiaries are not automatically disenrolled at the end of 6-month period and many enrollees—especially those with dementia— are disenrolled after 6-months.[22] We limited our cutoff to 1-year to ensure equal observation periods.

Covariates:

Patient, hospice provider, and regional characteristics were included based on a theoretical approach developed through a review of previous work in this area.[26] Patient-level characteristics obtained from Medicare files included gender, race/ethnicity based on the Research Triangle Institute (RTI) race codes, Medicaid dual-eligibility, Medicare Part C enrollment, comorbidities, care setting (home, assisted living, nursing home), and year of enrollment. Hospice characteristics included hospice size, years in operation, ownership type, the percent of the hospice’s patients with dementia, Hospice Item Set (HIS) scores, and Consumer Assessment of Healthcare Providers and Services (CAHPS-Hospice) quality ratings. Regional characteristics included rural/urban, State certificate of need for hospice, Area Deprivation Index, and the Herfindahl-Hirschman Index of regional hospice market competition. More detail on these variables is available in the Supplementary Methods S3.

Statistical Analysis:

Variation in Disenrollment: To assess variation in hospice provider and regional disenrollment rates, we took a couple of different approaches. First, we developed a series of multilevel mixed-effects logistic regression models to estimate a medians odds ratio (MOR) of disenrollment for hospices and regions for each type of disenrollment. The MOR is a summary statistic that shows the median relative difference in the odds of disenrollment between two randomly selected hospices (or regions) for two patients who are otherwise identical.[27] In other words, it estimates between hospice (or region) variation and thus is useful for evaluating the impact of systems-levels (i.e. providers or region) as determinants of outcomes.[28] For these models, we used death as the reference group to generate the odds ratio, since death is the expected outcome in hospice. We first estimated a null model that included only random intercepts for hospices and HRR (Model 0). We then estimated models that included random intercepts with the addition of patient characteristics (Model 1), hospice characteristics (Model 2), and regional characteristics (Model 3 or fully adjusted model).

Our second approach to estimating hospice and regional variation was to assess and compare disenrollment rates for each hospice and HRR. In this case, we defined the rate of disenrollment as the number disenrolled over the total number of enrollees for each hospice or HRR. We accounted for clustering by including random intercepts for hospice and HRR. For hospice provider variation, we conducted additional analyses to adjust for patient, hospice, and regional characteristics as we did for the MOR estimates.

Predictors of disenrollment: To ascertain independent predictors of disenrollment by type, we first calculated unadjusted odds ratios for each patient, hospice, and regional characteristic using died in hospice as the comparison group. We then used the sequential multi-level mixed effects models described above to account for clustering at the hospice and regional-level and adjustment for all other patient, hospice, and regional variables we considered.

Missingness and Sensitivity Analyses: Missingness for most variables was 1% or less, with the exception that some of the hospice provider variables, including hospice size, proportion of a hospice's patients with dementia, and quality ratings, had rates of missing between 3–10%. Since these data rely on hospice providers self-reporting, and in the case of quality ratings, are not required of hospices below a certain size or years in operation, they are not missing at random. As such, we opted against imputation approach to account for missingness and instead included data for these variables as "not reported". In addition, because some hospice-level variables were highly correlated (e.g. hospice quality ratings with hospice size) and the model would not converge, we ran the models with one set of variables (hospice years in operation, size, and ownership) and another with the other set (hospice quality ratings, hospice's proportion of patients with dementia). This study was approved by the institutional review boards at the University of California, San Francisco and the CMS Privacy Board. We conducted statistical analyses using Stata 17 (StataCorp, LLC), SAS 9.4 (SAS Institute), and R 3.6.2 (R Project).

Results

Our final cohort included 867,695 Medicare beneficiaries with a principal diagnosis of dementia admitted to 4,614 different hospices in 301 HRR's. 140,994 (16.3%) were disenrolled for any reason. Of those disenrolled, 70,594 (50.3%) were due to extended prognosis and 43,133 (30.6%) revoked, and the remainder were disenrolled for another reason (Figure 1). The median length of stay was 169 days (IQR 86, 239) for disenrolled due to extended prognosis and 67 days (IQR 19, 157) for revocation. Characteristics of the cohort are shown in Table 1 and expanded characteristics in Supplementary Table 1.

Hospice Provider Variation

The median adjusted disenrollment rate among hospices was 8.0% (10th–90th percentiles 4.5%−14.7%) for disenrollment due to extended prognosis and 4.7% (10th–90th percentiles 2.6%−10.1%) for revocation (Figure 2). In fully adjusted models the MOR was 1.86 (95% CI 1.82, 1.91) for disenrollment due to extended prognosis and 2.09 (95% CI 2.03, 2.14) for revocation (Table 2). Fully adjusted findings were only slightly attenuated from unadjusted and sequentially adjusted findings (Supplementary Table S2 and S3, and Supplementary Figure S1).

Regional Variation

The median adjusted disenrollment rate among HRR's was 8.2% (10th–90th percentile 7.0% −9.5%) for disenrollment due to extended prognosis and 4.7% (10th–90th percentile 3.5% −7.6%) for revocation (Figure 3). There were notably higher rates of revocation (10%−18%) in several Southeastern HRR's and Southern California (Figure 3b, Supplementary Table S4). In fully adjusted models, the MOR was 1.23 (95% CI 1.18, 1.27) for disenrollment due to extended prognosis and 1.40 (95% CI 1.34, 1.47) for revocation (Table 2). As with hospice variation, fully adjusted findings were only slightly attenuated from unadjusted and sequentially adjusted findings (Supplementary Table S1 and Supplementary Table S2).

Predictors of Disenrollment

A number of characteristics were associated with both types of disenrollment, while several were only associated with revocation (Table 2). Characteristics associated with higher odds of disenrollment due to extended prognosis include younger age (AOR 2.29, 95% CI 2.17, 2.41), female sex (AOR 1.51, 95% CI 1.48, 1.54), minoritized race and ethnicity (AOR 1.24, 95% CI 1.20, 1.28 for Black PWD), Medicaid dual-eligible (AOR 1.28, 95% CI 1.25, 1.30), Medicare Part C enrollee (AOR 1.03, 95% CI 1.01, 1.05), residing at home (AOR 1.62, 95% CI 1.58, 1.66) or assisted living (AOR 1.62, 95% CI 1.58, 1.66) versus a nursing home. These characteristics were also all associated with revocation, although odd ratios were substantially larger for minoritized race and ethnicity (AOR 1.54, 95% CI 1.48, 1.60 for Black PWD), living at home (AOR 2.41, 95% CI 2.34, 2.48) and assisted living (AOR 1.84, 95% CI 1.77, 1.91), and smaller for female sex (AOR 1.10, 95% CI 1.08, 1.13). Having more comorbidities (AOR 1.40, 95% CI 1.36, 1.44) and hospices that were newer (AOR 1.42, 95% CI 1.30, 1.55), smaller (AOR 1.34, 95% CI 1.15, 1.57), and for-profit (1.08, 95% CI 1.02, 1.14) were associated with higher odds of revocation but not extended prognosis.

Discussion

In this comprehensive study of national patterns of disenrollment among hospice enrollees with dementia, we found substantial systems-level and patient-level variance in disenrollment rates due to extended prognosis and revocation that persisted after adjusting for a number of known potential confounders. Hospice-to-hospice variation was especially prominent: we estimate that, on average, which hospice a person receives care from is associated with approximately double the odds of disenrollment due to extended prognosis or revocation. Although regional variation was less pronounced than hospice provider variation, there was a noteworthy pattern of higher revocation rates in the Southeastern U.S and Southern California. While some patient and hospice characteristics were associated with both types of disenrollment (younger age, female sex, racial and ethnic minoritized groups, Medicaid dual-eligible, residence type), others were only associated with revocation (more chronic conditions, newer, smaller hospices, and for-profit hospices). Given that hospice disenrollment disrupts care continuity and may signify vulnerabilities in the Medicare Hospice Benefit, our findings raise important questions as to how hospice and other models of care can be adapted to reduce disparities and best support the needs and trajectories of PWD approaching the end of life.[29]

Our findings expand upon previous work examining hospice disenrollment in several ways. Previous national studies examining hospice and/or regional variation in disenrollment have focused on all hospice enrollees or people with cancer, and analyses of PWD have been limited in scope.[30–32] Our study provides a detailed exploration into disenrollment in PWD, a population that has been growing rapidly in hospice and one that has been a focus of interest for regulators given concerns about potentially inappropriate hospice enrollment and disenrollment among this population. A deeper understanding of disenrollment patterns for PWD is critical since patterns differ substantially from people with cancer and other terminal conditions, tending to occur with greater frequency and after longer hospice stays.[4,30,31] The few previous studies focused on disenrollment in the dementia population have been limited to single-site or regional studies[21,23], or relied on hospice survey responses that may be subject to selection bias.[22] Finally, while previous national studies of hospice disenrollment have examined regional variation at the state-level[30,32], linkages to the Dartmouth Atlas facilitated by our large sample size enabled assessment of granularity in geographical variation that may be particularly relevant for state-level hospice policies.

Our study also builds on previous work by comparing patterns in disenrollment due to extended prognosis and revocation, which revealed interesting differences in the relationships between the characteristics we examined and the reason for disenrollment. The interplay of health-related factors, sociodemographic factors, patient beliefs, and hospice's motivation to enroll and capacity to support PWD that may help explain these findings should be a focus of future research. Higher likelihood of disenrollment due to extended prognosis in PWD who were younger, female, had fewer chronic conditions, and were not nursing home residents may reflect better general health and greater challenges with estimating prognosis that cannot be measured with Medicare data.[33] Higher disenrollment for extended prognosis among Medicaid recipients and racial and ethnic minority groups may reflect hospice enrollment earlier in the disease course when prognosis may be less certain. For disadvantaged groups, hospice may be used as a "backdoor" to accessing additional supports and services, such as personal care aides, which are not widely available through Medicare or otherwise, although this hypothesis needs to be examined in future research. Higher rates of revocation may occur because certain patients are more reluctant to forgo curative treatments (e.g. younger PWD with potentially more years to live), hospices are unable to meet the needs of patients with high symptom and illness burden (e.g. higher number of comorbidities), or hospice providers failing to adapt to the cultural or language needs of the patients (e.g. racial and ethnic minority groups).[34–36]

Hospices' incentives and capacity to support PWD may help to explain why hospice organizational characteristics (smaller, newer, and for-profit) were associated with higher likelihood of disenrollment due to revocation but not extended prognosis. Evidence indicates that for-profit hospices provide fewer visits with less experienced staff.[37] Newer and smaller hospices may not have available resources (e.g. experienced staff available after-hours) to provide sufficient support to patients and families. This may lead to higher rates of revocation if patients and families do not perceive hospice as providing additional benefit,[38] or else lead to revocations associated with hospital admissions during crises if hospice staff are not available in a timely manner.[39] In the case of disenrollment due to extended prognosis, our finding that there were no differences between hospices with different organizational characteristics may reflect challenges inherent in assessing prognosis in dementia,[40] or else may reflect other financial incentives for smaller, newer, and for-profit hospices to adjust their patterns of disenrollment to maximize profitability, such as delaying disenrollment until the hospice is approaching their aggregate cap or under threat of audit.[17,33] It is noteworthy, however, that hospice provider variation persisted after taking into account these factors, indicating that there may be other hospice-level characteristics, such as the hospice culture around disenrollment practices, that may partially explain observed variation.

Our findings have several policy and research implications. Hospice reform and regulation has been an active area of interest for policymakers in recent years. At the federal level, 2016 Medicare Hospice Payment Reform, which reduced payments to hospices for long-stays (after 60 days), was specifically designed as a hospice-level intervention to disincentivize long hospice enrollments among PWD and others with non-cancer diagnoses.[41] Future studies should evaluate how this policy affects disenrollment among PWD, including impacts on rates and variation in disenrollment and shifts in reasons for disenrollment, as well as weighing costs and benefits of any potential reduction in rates of disenrollment with reductions in hospice access. States are also beginning to establish laws regulating hospice, such as a law passed in California in October 2021 placing a 1-year moratorium on new licenses for hospices. This law was passed based on concerns over rapid growth in number of hospices in the State, intense competition for patients, and potentially illegal practices among hospices, such as kickbacks to referring providers. Future research should evaluate whether these laws achieve their intended effects of targeting hospices that engage in illegal or unethical practices more prevalent in some areas, while also evaluating potential unintended consequences on hospice access occurring in other areas.

These findings raise important questions regarding if and how the Medicare Hospice Benefit should be adapted to the needs and trajectories of PWD or whether an overhaul in the approach to end-of-life care for PWD through development and implementation of other care models is required.[42,43] Expanding hospice eligibility criteria by eliminating the 6-month prognosis requirement and allowing for concurrent curative treatments have been proposed as solutions, but expanding hospice eligibility faces significant challenges of how to define the target population and cost implications for Medicare.[43] Alternatively, support for PWD approaching end of life may be better achieved through the development of other care models, such as a comprehensive dementia care benefit or wider availability of home-based palliative care.[44–47] The Medicare Advantage hospice carve-in demonstration project currently underway provides an opportunity to test some alternative models and their integration with hospice care.

This study has several limitations. Because this study relied on administrative data, we lacked information on factors that might indicate the appropriateness of the PWD's disenrollment, such as preferences and beliefs around end-of-life treatments. Also, our data period only extends through December 2017 and it is unclear whether findings generalize to current day given changes in the hospice industry, Medicare hospice reform, and Medicare Advantage penetration, among other changes. However, given that the most recent year is within the last 5 years, our findings are likely still relevant and can help inform research efforts to evaluate recent trends in hospice use for PWD and the impacts of industry and policy changes that may affect hospice care for PWD. Another limitation is the competing risk nature of our outcomes (e.g. if someone died earlier in their stay they could not also be disenrolled). Although we adjusted for a number of factors that could influence the ability to accurately predict prognosis and thus time to death (e.g. age and sociodemographic status), it is possible that there are unmeasured confounders that might impact how long someone lives after enrollment. We opted against a competing risks survival model because the timing of disenrollment for extended prognosis tends to occur at regular intervals timed around recertification, which would have violated assumptions of this approach. The RTI race and ethnicity variable is not based on self-report and confines people to only one race and ethnicity category. However, the RTI algorithm has been shown to have much greater accuracy for identifying people who identify as Hispanic or Asian compared to the Medicare enrollment database.[48] The use of hospital referral region as a geographical unit is designed around hospital markets, not hospice markets. However, to date no hospice referral regions have been delineated, and research has shown that the use of HRR's can be appropriate for understanding hospice use patterns.[49,50]

In conclusion, we found that among people with dementia, hospice disenrollment varied by type of hospice, geographic region, and patient characteristics including age, sex, race and ethnicity. These findings raise important questions about whether and how the Medicare Hospice Benefit could be adapted to reduce disparities and better support this growing population. Ultimately a major overhaul in the approach to hospice and end-of-life care for PWD may be required to ensure seamless, coordinated care that is adapted to the needs, trajectories, and prognosis of PWD.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key Points

- We know little about the frequency, variation, and risk factors for disenrollment from hospice among people with dementia.
- In this national study of 867,695 people with dementia enrolled in the Medicare Hospice Benefit, hospice disenrollment varied by type of hospice, geographic region, and patient characteristics including age, sex, race and ethnicity.

Why does this paper matter?

Our findings highlight both systems-level and patient-level variance associated with hospice disenrollment among persons with dementia, raising important questions about whether and how the Medicare Hospice Benefit could be adapted to reduce disparities and better support this growing population.

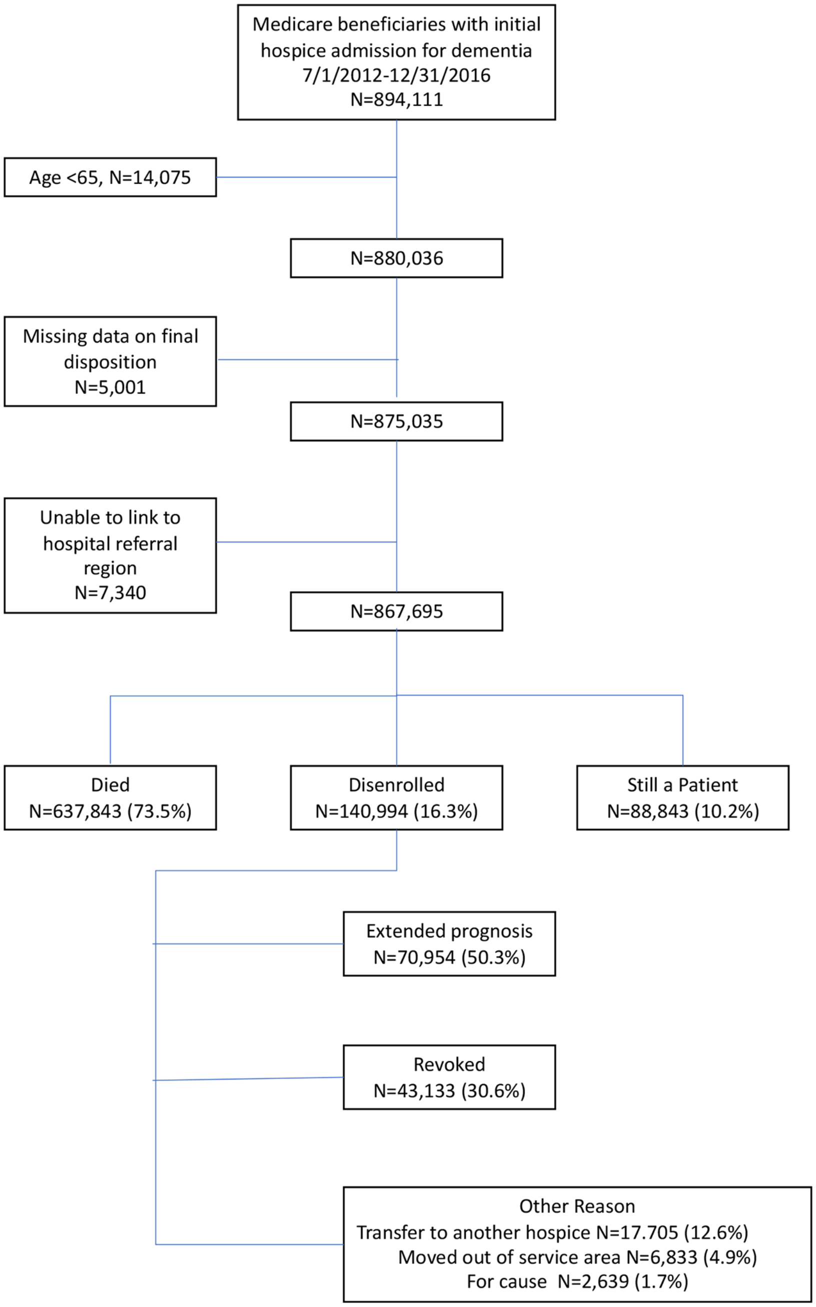

Figure 1.

Cohort Flow Diagram

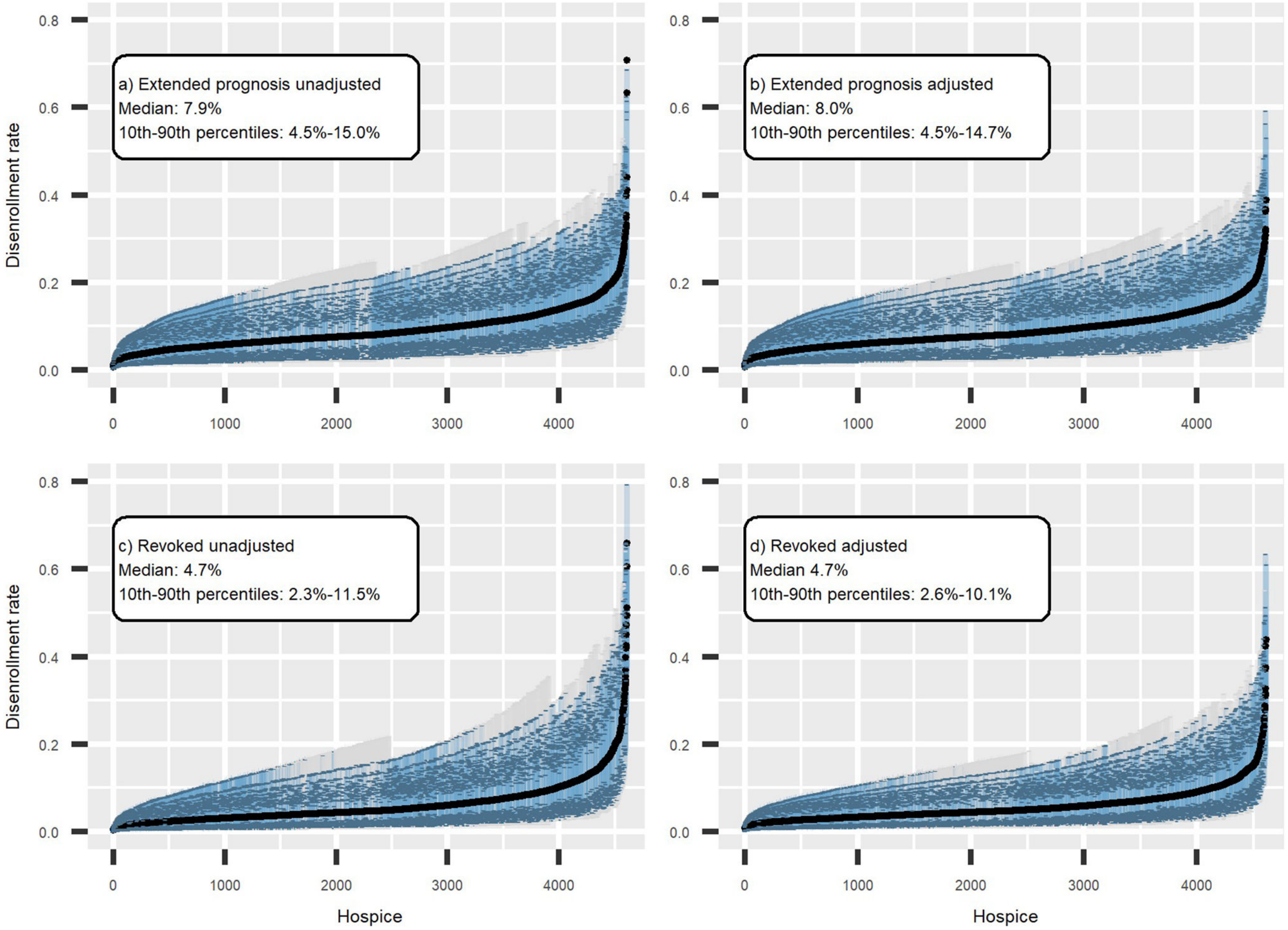

Figure 2.

Variation in Hospice Provider Disenrollment Rates of Hospice Enrollees with Dementia. Note: Each black dot represents an individual hospice provider and blue bars represent 95% confidence intervals. Error bars for hospices with less than 10 admission per year are shown in grey due to large standard error bars. Unadjusted models include random effects for hospice and region and adjusted models include random effects plus fixed effects for patient, hospice, and regional characteristics.

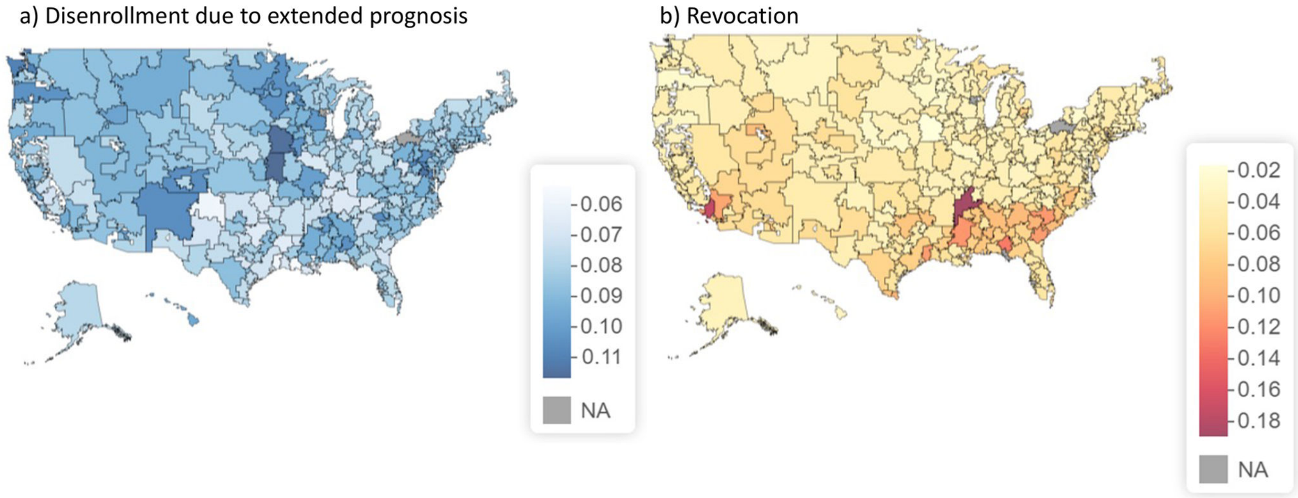

Figure 3.

Variation in Hospital Referral Region (HRR) Disenrollment Rates of Hospice Enrollees with Dementia. Note: Proportion disenrolled in each HRR is indicated using a color scale, with darker colors indicating higher proportion disenrolled. Disenrollment probability was estimated with a multilevel model that included random effects for hospice provider and region. Because some hospices could be linked to multiple HRRs, we selected the zip code for the hospice that had the greatest number of patients as the primary zip code for that hospice, which resulted in several HRR's having no data on disenrollment rate. NA=not applicable

Table 1.

Characteristics of Medicare Beneficiaries Enrolled in Hospice with a Principal Diagnosis of Dementia by Final Disposition.

	Died (N=637,848)	**Disenrolled: Extended prognosis (N=70,954)**	**Disenrolled: Revocation (N=43,133)**
	n (%)	**n (%)**	**n (%)**
Patient-Level			
Age			
65–69	13822 (2.2%)	2261 (3.2%)	1643 (3.8%)
70–74	31550 (4.9%)	4564 (6.4%)	3270 (7.6%)
75–79	65531 (10.3%)	8616 (12.1%)	6002 (13.9%)
80–84	121424 (19.0%)	14222 (20.0%)	9174 (21.3%)
85–89	173717 (27.2%)	18954 (26.7%)	11221 (26.0%)
90–94	153951 (24.1%)	15649 (22.1%)	8309 (19.3%)
95+	77842 (12.2%)	6688 (9.4%)	3514 (8.1%)
Female	410444 (64.3%)	51500 (72.6%)	28001 (64.9%)
Race and Ethnicity			
White	550019 (86.2%)	58922 (83.0%)	32400 (75.1%)
Black	42861 (6.7%)	6006 (8.5%)	5107 (11.8%)
Hispanic	30925 (4.8%)	3987 (5.6%)	4117 (9.5%)
Asian and Pacific Islander	9370 (1.5%)	1437 (2.0%)	1056 (2.4%)
Native American	1574 (0.2%)	181 (0.3%)	139 (0.3%)
Other	3099 (0.5%)	421 (0.6%)	314 (0.7%)
Medicaid dual eligible	204255 (32.0%)	24394 (34.4%)	14734 (34.2%)
Medicare Part C enrollee	170723 (26.8%)	20565 (29.0%)	11735 (27.2%)
Chronic conditions			
0–2	237860 (37.3%)	28822 (40.6%)	14730 (34.2%)
3–4	240567 (37.7%)	26496 (37.3%)	16171 (37.5%)
5+	159421 (25.0%)	15636 (22.0%)	12232 (28.4%)
Residence type			
Home	211804 (33.2%)	30038 (42.3%)	22384 (51.9%)
Assisted living	106120 (16.6%)	15290 (21.5%)	7197 (16.7%)
Nursing home	241579 (37.9%)	23039 (32.5%)	10258 (23.8%)
Hospice Provider-Level			
Hospice years in operation			
Newest quartile (0–8 years)	149198 (23.4%)	18524 (26.1%)	15009 (34.8%)
Oldest quartile (25–33 years)	168371 (26.4%)	17046 (24.0%)	8685 (20.1%)
Hospice size			
Smallest quartile (11–307 beneficiaries/year)	148047 (23.2%)	19141 (27.0%)	14682 (34.0%)
Largest quartile (1560–22,871 beneficiaries/year)	163024 (25.6%)	15947 (22.5%)	9449 (21.9%)

	Died (N=637,848)	Disenrolled: Extended prognosis (N=70,954)	Disenrolled: Revocation (N=43,133)
	n (%)	**n (%)**	**n (%)**
Hospice ownership			
Non-profit	243009 (38.1%)	26022 (36.7%)	12411 (28.8%)
For-profit	313090 (49.1%)	36093 (50.9%)	25891 (60.0%)
Government	10483 (1.6%)	1372 (1.9%)	523 (1.2%)
Hospice Item Set Composite Measure Score[a]			
< 90	126612 (19.8%)	14181 (20.0%)	9317 (21.6%)
>= 90	473657 (74.3%)	50771 (71.6%)	28825 (66.8%)
CAHPS Hospice Score[b]			
Lowest quartile of scores	162154 (25.4%)	17857 (25.2%)	11255 (26.1%)
Highest quartile of scores	121840 (19.1%)	12837 (18.1%)	6511 (15.1%)
Proportion dementia patients			
Lowest proportion quartile (0–0.16)	162515 (25.5%)	16960 (23.9%)	8445 (19.6%)
Highest proportion quartile (0.29–0.72)	145088 (22.7%)	16979 (23.9%)	11491 (26.6%)
Regional-Level			
Rural	97537 (15.3%)	10471 (14.8%)	6473 (15.0%)
State has Certificate of Need for hospice[c]	171975 (27.0%)	17596 (24.8%)	11190 (25.9%)
Local hospice market competition[d]			
Least competitive quartile	166024 (26.0%)	17491 (24.7%)	9380 (21.7%)
Most competitive quartile	150814 (23.6%)	17860 (25.2%)	13162 (30.5%)
Area Deprivation Index Rank[e]			
Least deprived (1–20)	96197 (15.1%)	12208 (17.2%)	6034 (14.0%)
Most deprived (81–100)	37561 (5.9%)	4295 (6.1%)	3585 (8.3%)

[a] The Hospice Item Set Composite Measure is a quality measure that assesses whether hospice providers complete all seven high-priority care processes around admission. Scores less than 90 indicate lower completion rates.

[b] The CAHPS Hospice Survey is a national survey of family members or friends who cared for a patient who died while under hospice care. Quartiles are based on the proportion of respondents rating the hospice a 9 or 10, with 10 indicating the best possible score (i.e. in the lowest quartile 48–76% of CAHPS respondents rated the hospice a 9 or 10).

[c] In a state with a Certificate of Need program, a state health planning agency must approve major capital expenditures for certain health care facilities, in this case, a hospice agency.

[d] Calculated using the Herfindahl-Hirschman Index. See Supplementary Methods S3 for more information.

[e] The Area Deprivation Index assesses relative neighborhood disadvantage based on domains of income, education, employment, and housing quality. It has been adapted to the Census Block Group and made publicly available by the Neighborhood Atlas®.

CAHPS=Consumer Assessment of Healthcare Providers and Systems.

Table 2.

Hospice Provider and Regional Median Odds Ratio and Patient, Hospice, and Regional Predictors of Disenrollment for Extended Prognosis and Revocation (Versus Death in Hospice) in Hospice Enrollees with Dementia.

	Extended Prognosis (N=70,954)	**Revocation (N=43,133)**
	Adjusted[a] Odds Ratio 95% Confidence Interval	**Adjusted[a] Odds Ratio 95% Confidence Interval**
Hospice Provider Median Odds Ratio[b]	1.89 (1.84, 1.93)	2.12 (2.06, 2.17)
Regional Median Odds Ratio	1.22 (1.17, 1.27)	1.41 (1.35, 1.48)
Patient-Level		
Age		
65–69	2.29 (2.17, 2.41)	2.62 (2.45, 2.80)
70–74	2.01 (1.92, 2.09)	2.24 (2.13, 2.37)
75–79	1.79 (1.73, 1.85)	1.96 (1.88, 2.05)
80–84	1.55 (1.50, 1.60)	1.65 (1.58, 1.72)
85–89	1.41 (1.36, 1.45)	1.44 (1.39, 1.50)
90–94	1.26 (1.22, 1.30)	1.21 (1.16, 1.26)
95+	reference	reference
Female	1.51 (1.48, 1.54)	1.10 (1.08, 1.13)
Race and ethnicity		
White	reference	reference
Black	1.24 (1.20, 1.28)	1.54 (1.48, 1.60)
Hispanic	1.13 (1.09, 1.18)	1.51 (1.44, 1.58)
Asian and Pacific Islander	1.31 (1.23, 1.40)	1.60 (1.48, 1.73)
Native American	0.94 (0.79, 1.11)	1.15 (0.94, 1.40)
Other	1.12 (1.00, 1.24)	1.27 (1.12, 1.45)
Medicaid dual eligible	1.28 (1.25, 1.30)	1.24 (1.21, 1.27)
Enrolled in Medicare Part C	1.03 (1.01, 1.05)	1.09 (1.06, 1.12)
Chronic conditions		
0–2	reference	reference
3–4	1.01 (0.99, 1.03)	1.23 (1.20, 1.27)
5+	0.94 (0.91, 0.96)	1.40 (1.36, 1.44)
Residence type		
Home	1.62 (1.58, 1.66)	2.41 (2.34, 2.48)
Assisted living	1.76 (1.71, 1.81)	1.84 (1.77, 1.91)
Nursing home	reference	reference
Hospice Provider-Level		
Hospice years in operation		

	Extended Prognosis (N=70,954)	**Revocation (N=43,133)**
	Adjusted[a] Odds Ratio 95% Confidence Interval	**Adjusted[a] Odds Ratio 95% Confidence Interval**
Newest quartile (0–8 years)	1.03 (0.96, 1.10)	1.42 (1.30, 1.55)
Oldest quartile (25–33 years)	reference	reference
Hospice Size		
Smallest quartile (11–307 beneficiaries/year)	1.08 (0.95, 1.23)	1.34 (1.15, 1.57)
Largest quartile (1560–22871 beneficiaries/year)	reference	reference
Hospice Ownership		
Non-profit	reference	reference
For-profit	1.02 (0.97, 1.06)	1.08 (1.02, 1.14)
Government	0.85 (0.75, 0.96)	0.98 (0.83, 1.14)
Regional-Level		
Rural	0.96 (0.93, 0.99)	1.01 (0.97, 1.05)
State has Certificate of Need for hospice	0.96 (0.87, 1.05)	1.09 (0.96, 1.23)
Local hospice market competition		
Least competitive quartile	reference	reference
Most competitive quartile	0.96 (0.92, 1.00)	1.04 (0.98, 1.09)
Area Deprivation Index rank		
Least Deprived	reference	reference
Most Deprived	0.89 (0.85, 0.94)	1.02 (0.97, 1.08)

[a] Models constructed using multi-level mixed effects logistic regression and are adjusted for all other variables included in this table.

[b] The median odds ratio is a summary statistic that shows the median relative difference in the odds of disenrollment between two randomly selected hospice providers or regions in two otherwise identical patients.