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Original Research

Social Connectedness Among Nursing Home Residents with Dementia by Hospice Enrollment

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Abstract

BACKGROUND: Nursing home residents with dementia are at risk for social isolation, particularly in the time period preceding death. Whether hospice enrollment affects social connectedness in this vulnerable population is unclear.

OBJECTIVE: Among nursing home residents with dementia, to describe the prevalence of social connectedness up to 3 months prior to death and to characterize the association of hospice enrollment with social connectedness.

DESIGN, SETTING AND PARTICIPANTS: Decedent cohort study of nursing home residents with dementia in the United States who died in 2018. Data sources include the Minimum Data Set 3.0, the Medicare Master Beneficiary Summary File and Hospice files.

MEASUREMENTS: Main outcome measure is the Social Connectedness Index, a validated measure of social connection in the nursing home based on behavioral symptoms, wandering and receipt of care (range 0-5; 5=socially connected). Multivariable logistic regression characterizes the association of hospice enrollment with social connectedness.

RESULTS: Of 212,253 nursing home decedents with dementia in 2018, 80.4% (n=170,566) were socially connected (SCI=5). In adjusted analysis, relative to not being enrolled in hospice, enrollment in hospice with an admitting diagnosis of dementia was associated with increased odds of being socially connected (adjusted odds ratio (AOR) 1.20; 95% confidence interval (95%CI) 1.16-1.23) but being in hospice for a primary diagnosis other than dementia was associated with decreased odds of social connectedness (AOR 0.92; 95% CI 0.89-0.94).

CONCLUSION: Social connectedness differed among nursing home decedents with dementia by hospice enrollment. Hospice enrollment plays an important role in quality of life for nursing home residents.

Key words: Dementia, social connectedness, loneliness, nursing home, hospice .

Introduction

Dementia is the seventh leading cause of death globally and is significant contributor to disability and functional dependence among older adults (1). Nearly 6 million individuals in the United States are affected by dementia, which is characterized by progressive cognitive decline that leads to inability to perform daily activities and eventually death (2). Underlying causes of dementia include Lewy body dementia, Huntington's Disease, or frontotemporal dementia, but the most common form is Alzheimer's disease and together this group of conditions is referred to as Alzheimer's Disease and Related Dementias (ADRD) (3), and typically leads to functional decline that impairs communication and requires support from caregivers for bathing and grooming. This trajectory often contributes to long term placement in nursing homes.

Nursing homes are a common site of death for persons with dementia, with over half of nursing home residents dying with dementia in 2017 (4). Quality of life and quality of care delivery are major concerns in the nursing home (5, 6). An understudied challenge is loneliness, which is reported to be experienced at higher levels among persons with dementia compared to those without (7). The Surgeon General has recently stressed the importance of loneliness and isolation as a public health crisis and epidemic that has profound effects on health (8). However, loneliness and social connectedness in the nursing home setting for persons with dementia is understudied, and how to address this challenge in the context of ongoing challenges such as nursing home staffing shortages is unclear.

One potential option for nursing home residents approaching death is hospice. Hospice care, particularly in the United States, provides medical, nursing, and support services for individuals with a terminal prognosis, aiming to manage symptoms, minimize unnecessary medical interventions and optimize quality of life (9). Some studies estimate that as many as 1 in 4 nursing home residents are eligible for hospice (10). However, hospice enrollment in the nursing home is low, ranging from 1-6% in the US (10, 11). Factors associated with hospice enrollment in this population include weight loss, worse cognitive status, having goals of care discussions, (12) and the nursing home staff belief in the value of hospice and recognition that the resident is approaching the end of life (13).

Evidence suggests that hospice in the nursing home setting can enhance resident quality of life (9, 14). Aside from providing expertise in symptom management, hospice offers services that are not typically available in

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the nursing home setting. For example, some residents in hospice might be given music therapy visits while others are not, or some might be provided periodic visitations from a volunteer while others may not, all based on the assessment and recommendations of an admitting hospice case manager.

Overall, little is known about whether hospice enrollment in the nursing home setting affects loneliness and social connectedness. To address this knowledge gap, we sought to describe the prevalence of social connectedness in the period preceding death among nursing home residents with dementia and to characterize the association of hospice enrollment with social connectedness using nationally representative decedent cohort of nursing home residents with dementia. Understanding whether hospice can affect social connectedness has the potential to encourage greater hospice use in this vulnerable and growing population.

Methods

Data Sources. The data sources for this study include the Minimum Data Set 3.0 (MDS 3.0) and linked Medicare administrative files. The MDS 3.0 contains federally required longitudinal assessments of nursing home residents in Medicare or Medicaid-certified long-term care nursing homes. It is completed upon nursing home admission, quarterly, and when there is a significant change in resident status (15, 16). Data collected includes resident-level characteristics, cognitive function, medical diagnoses, functional capabilities, and behavioral symptoms. The Medicare Master Beneficiary Summary Files provides demographic and eligibility information for Medicare and Medicaid. We also used the Medicare Hospice file, which provides information regardless of whether the beneficiary is enrolled in fee-for-service Medicare or Medicare Advantage. This file is based on information from the Centers for Medicare & Medicaid Services (CMS) form 1450 (UB04) and includes the level of hospice care received, diagnoses, dates of service, submitted charges, reimbursement amounts, and hospice provider number.

Study design and sample population. We constructed a decedent cohort of nursing home residents with dementia. We identified Medicare beneficiaries in the MBSF who died in 2018 and had a linked MDS 3.0 record. We limited the population to residents with dementia based on the MDS 3.0 Section I code for Alzheimer's Disease (I4200) and Other Dementias (I4800) (15, 16). We identified hospice enrollment based on associated Medicare Hospice files for each decedent. We classified hospice enrollment for a primary admitting diagnosis of dementia if the hospice file had an ICD-10 code for dementia using on an approach by Bynum et al (17) in the primary position. Hospice enrollees without a dementia diagnosis in the primary position were classified as having a hospice primary admitting diagnosis for a non-dementia condition.

Study Outcomes. Social connectedness was measured in the quarterly MDS assessment closest to death using the Social Connectedness Index (SCI) (18). This validated measure was developed to reflect contact with friends, residents, contact with staff, and conflict with others based on MDS indicators of behavioral symptoms, wandering and receipt of care (18). The SCI scores range from 1 to 5, with higher scores indicating greater social connectedness. For this study, a SCI score of 5 was defined to indicate presence of social connectedness.

Covariates. The covariates included resident demographic information, clinical diagnoses, cognitive impairment and functional status. Demographic information included age, sex, race and ethnicity, and marital status. Race and ethnicity were categorized using variables available in the MDS 3.0., including American Indian/Alaskan Native, Asian/Pacific Islander, Black/not Hispanic origin, White/not Hispanic origin, Hispanic, and multiracial. Cognitive impairment was classified using the Cognitive Performance Scale (19). Clinical comorbidities from Section I were operationalized as either being present or absent. Functional status was classified as self-performance of activities of daily living (ADLs) as limited assistance, extensive assistance, and dependent to total dependence (20).

Data Analysis. We used descriptive statistics to characterize the study population by presence of social connectedness. We used multivariable logistic regression to estimate the odds ratios and 95% confidence intervals (CIs) to characterize the association between hospice enrollment with the outcome of social connectedness after adjustment for decedent characteristics. We used complete case analysis to handle missing data. All analyses were performed using SAS statistical software version 9.4 (SAS Institute, Inc, Cary, NC). This study was approved by the UMass Chan Medical School Institutional Review Board.

Results

This study included 212,253 nursing home decedents with dementia. The majority of the study population were women, White and widowed (Table 1). Overall, the majority had a SCI=5 [n=170,566; 80.4%], indicating presence of social connectedness. Social connectedness differed among men (81.8%) and women (78.1%), as well as by race and ethnicity [Asian/Pacific Islander (87.7%), Black (85.6%), Hispanic (85.6%), White (79.2%), American Indian/Alaskan Native (75.3%)]. Decedents with the mild-moderate cognitive impairment had the lowest prevalence of social connectedness (75.3%) than those with less severe (82.6%) or more severe impairment (77.2%).

Overall, 63.5% (n=134,858) were enrolled in hospice prior to death, of whom 60.4% (n=81,506) were admitted to hospice with a primary diagnosis of dementia and 39.6% (n=53,352) were admitted to hospice for a diagnosis

Table 1. Characteristics of Nursing Home Decedents with Alzheimer's Disease and Related Dementias (ADRD), by Presence of Social Connectedness

	Overall N=212,253	Presence of Social Connectedness [a]	
		Yes n= 170,566	No n= 41,687
Individual Characteristics			
Age Groups			
40-64 years	3,119	1.4%	1.9%
65-69 years	5,861	2.7%	3.1%
70-79 years	36,540	16.8%	18.8%
80-89 years	91,031	42.9%	42.9%
≥90 years	75,702	36.2%	33.3%
Sex			
Female	131,946	63.3%	57.7%
Male	80,307	36.8%	42.3%
Race and Ethnicity			
Multiracial	130	0.07%	0.05%
Asian/Pacific Islander	4,286	2.20%	1.26%
American Indian/Alaskan Native	608	0.27%	0.36%
Black, not Hispanic origin	21,882	11.0%	7.6%
White, not Hispanic origin	175,420	81.5%	87.4%
Hispanic	9,927	5.0%	3.4%
Marital Status			
Married	61,971	28.7%	31.4%
Separated	1,735	0.83%	0.8%
Divorced	20,454	9.5%	10.3%
Never Married	18,360	8.7%	8.4%
Widowed	109,733	52.3%	49.2%
Other Diagnoses			
Cancer	21,843	10.6%	8.9%
Coronary Artery Disease	56,658	27.0%	25.5%
Heart Failure	59,109	28.6%	24.7%
Peripheral Vascular Disease	27,449	13.1%	12.4%
Diabetes	66,429	31.7%	29.8%
Hypertension	170,139	80.8%	77.6%
Asthma	50,102	24.0%	21.8%
Stroke	26,684	13.0%	10.7%
Anxiety	72,050	31.7%	43.1%
Major Depression	104,396	48.6%	51.7%
Manic Depression	6,850	3.0%	4.2%
Schizophrenia	8,101	3.6%	4.9%
Cognitive Performance Scale (CPS)			
Intact - borderline intact: 0 - 2	131,899	62.1%	55.2%
Mild - moderate impairment: 3 - 4	20,714	9.8%	12.3%
Moderately severe impairment - severe impairment: 5 – 6	59,640	28.1%	32.6%
Activities of Daily Living (ADL)			
Independent to limited assistance: 0 - 2	1,607	0.8%	0.7%
Extensive assistance: 3 - 4	114,990	53.2%	58.3%
Dependent to total dependence: 5 - 6	95,656	46.1%	41.0%
Hospice Enrollment			
Not enrolled in hospice	77,395	36.4%	36.7%
Enrolled in hospice for admitting diagnosis other than dementia	53,352	24.0%	29.7%
Enrolled in hospice for admitting diagnosis of dementia	81,506	39.6%	33.6%

a. Social connectedness defined as Social Connectedness Index = 5 (18)

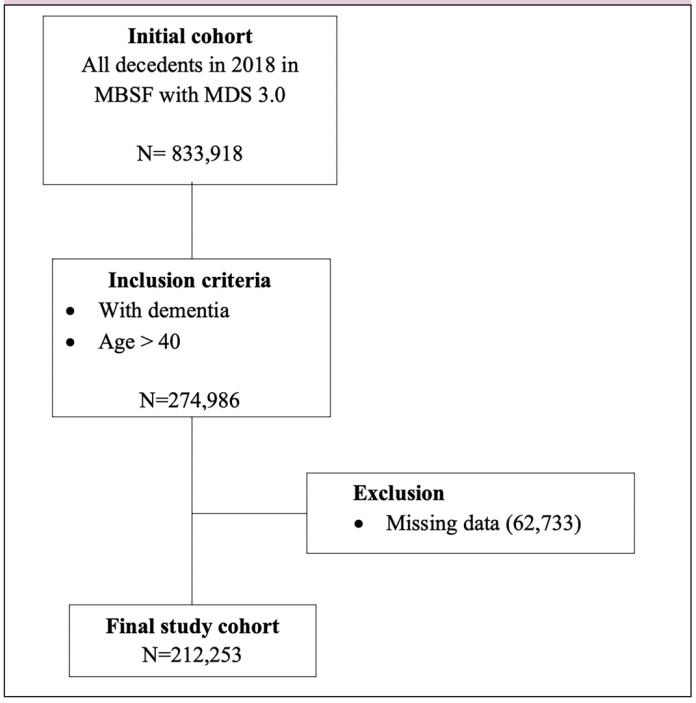
Table 2. Adjusted Association Between Social Connectedness by Hospice Enrollment among Decedents with Alzheimer's Disease and Related Dementia

	Presence of Social Connectedness	
	Adjusted Odds Ratio	**95% Confidence Interval**
Decedent Enrollment Status		
Not enrolled in hospice	1	
Enrolled in hospice for admitting diagnosis other than dementia	0.92	0.89-0.94
Enrolled in hospice for admitting diagnosis of dementia	1.20	1.16-1.23
Individual Characteristics		
Age		
40-64 years	1	
65-69 years	1.09	0.98 – 1.21
70-79 years	1.10	1.01 – 1.21
80-89 years	1.20	1.10 – 1.31
≥90 years	1.28	1.18 – 1.40
Sex		
Female	1	
Male	0.74	0.73 – 0.76
Race and Ethnicity		
White, not of Hispanic origin	1	
Asian/Pacific Islander	1.71	1.56 - 1.88
American Indian/Alaskan Native	0.81	0.67 - 0.97
Black, not of Hispanic origin	1.42	1.37 - 1.48
Hispanic	1.56	1.47 - 1.65
Multiracial	1.53	0.94 - 2.51
Marital Status		
Married	1	
Not Married (Widowed, Never Married, Separated, Divorced)	1.01	0.99 – 1.04
Other Diagnoses		
Cancer	1.19	1.15 - 1.24
Coronary Artery Disease	1.04	1.01 - 1.07
Heart Failure	1.10	1.08 - 1.13
Peripheral Vascular Disease	1.00	0.97 - 1.04
Diabetes	1.01	0.98 - 1.03
Hypertension	1.10	1.08 - 1.15
Asthma	1.12	1.09 - 1.15
Stroke	1.17	1.13 - 1.21
Anxiety	0.63	0.61 - 0.64
Major Depression	1.00	0.98 - 1.02
Manic Depression	0.81	0.77 - 0.87
Schizophrenia	0.83	0.78 - 0.87
Cognitive Performance Scale (CPS)		
Intact/borderline intact: 0 - 1	1	
Mild to moderately severe impairment: 2 - 4	0.63	0.61 – 0.66
Severe to very severe impairment: 5 – 6	0.70	0.68 – 0.72
Activities of Daily Living (ADL)		
Independent to limited assistance: 0 - 2	1	
Extensive assistance: 3 - 4	0.84	0.73 – 0.95
Dependent to total dependence: 5 - 6	1.12	0.98 – 1.28

other than dementia. Social connectedness varied by hospice enrollment, with highest prevalence among those enrolled in hospice with a primary diagnosis of dementia (39.6%) (Table 1).

In adjusted analysis, relative to not being enrolled in hospice, being enrolled in hospice with an admitting diagnosis of dementia increased the odds of being socially connected (adjusted odds ratio [AOR]=1.20; 95% confidence interval (95%CI) 1.16-1.23), but enrollment in hospice for a primary diagnosis other than dementia decreased the odds of social connectedness (AOR 0.92; 95% CI 0.89-0.94) (Table 2). Other factors associated with social connectedness include older age and being female. There were also differences by race and ethnicity. Relative to being White, being Asian/Pacific Islander (AOR 1.71; 95% CI 1.56-1.88), Hispanic (AOR 1.56; 95% CI 1.47-1.65), and Black not of Hispanic origin (AOR 1.42; 95% CI 1.37-1.48) were associated with greater odds of social connectedness, while being American Indian/Alaskan Native was associated with lower odds (AOR 0.81; 95% CI 0.67-0.97) (Table 2).

Figure 1. Flowchart of sample inclusion and exclusion



Discussion

This national analysis of nursing home decedents with dementia provides evidence that social connectedness in the nursing home setting can vary by hospice enrollment prior to death. While prior research has begun to describe social connectedness among nursing residents with dementia (21), to our knowledge, this is the first study to focus on decedents with dementia and the role of hospice.

The Surgeon General has urged the severity of the isolation and loneliness epidemic and expressed the importance of improving connectedness for a healthy life (8). He highlighted the need for more attention focused on improving social connectedness to combat social isolation and feelings of loneliness. Prior evidence suggests that an isolated and sedentary lifestyle is associated with poor mental and physical health and can otherwise increase the risk of dementia and premature death (8, 22). Whether social isolation comparably exacerbates the progression of dementia and poor outcomes among those with the diagnosis is unclear. Regardless, older adults with dementia living in nursing homes are a vulnerable population whose quality of care has received heightened attention with the National Partnership to Improve Dementia Care in Nursing Homes (23). This study brings additional attention to the quality of life of this population in important time period preceding death.

Hospice can provide additional services and visits to hospice enrollees in all settings, including within the nursing home. This is important, particularly in the US, where the staffing of nursing homes is well known to be extremely challenging, so much so that nursing home industry leaders are appealing to federal policy makers to remove requirements for minimum nursing home staff levels (24). Unlike models of hospice care outside of the US in which patients are directly admitted to a free-standing hospice house (25), nursing home residents stay at the nursing home facility to receive care, where some argue that staffing is insufficient to ensure basic quality care delivery (26). Thus, any hospice staff services are in addition to the baseline nursing home staff services (27), which in the US are currently required to include a total nurse staffing standard of 3.48 hours per resident day (HPRD), which must cover at least 0.55 HPRD of direct registered nurse (RN) care and 2.45 HPRD of direct nurse aide care (28), not including ancillary staff or other supports such as recreational therapy. Thus, hospice's ability to provide additional case management, nursing visits, and additional services such as music therapy can explain how hospice can provide greater opportunity to socialize with nursing home residents. Interestingly, while everyone in the study had a diagnosis of dementia, there was a difference between social connectedness by whether the decedent was enrolled in hospice with dementia as the admitting diagnosis or not. One possible explanation for this finding is that persons who met the criteria for hospice admission based on dementia likely had different severity of cognitive and functional impairment compared to those in hospice for another diagnosis (29), thus perhaps experience different levels of social connectedness as a result. Further study is needed to better understand this finding.

Other studies indicate that hospice in nursing homes is beneficial to residents. When nurses, nurses' aides, and social workers were asked to describe a positive experience while caring for dying patients in the nursing home, hospice involvement emerged as a recurring theme (14). Similar findings are reported by families (30). Additionally, the concurrent use of hospice in the

nursing home improves management of symptoms and perceived quality of care by family members (12). Hospice has been reported to provide better pain control, better communication, and coordinated care efforts (31), which contributes to a better quality of life during their last month of life (32).

Despite this, there are substantial barriers to hospice enrollment in the nursing home. One barrier in the US is cost. Hospice does not provide room and board in a skilled nursing facility (SNF), so families must pay these costs for patients who are still in the SNF before transitioning to hospice. Medicare does not allow the concurrent use of Part A for a stay in a SNF and the Medicare Hospice benefit. SNF patients with private insurance must pay for room and board out of pocket while receiving hospice care. However, for those covered by both Medicare and Medicaid, the hospice provider covers the cost of room and board at the SNF at a significantly reduced rate (33). The cost could make families not only hesitant to choose hospice care, but unable to afford it, making it less accessible and ultimately disincentivizing people to enroll in hospice (34, 35). Another possible limitation to accessing hospice care is geographic proximity. One older study indicates that the mean time to a hospice was 15 minutes, the range was 0 to 403 minutes, with substantial variation across states within the USund (36). A more recent study, however, notes that the number of hospice agencies with common ownership to nursing homes nearly quintupled in number between 2005 and 2015, and represented almost 1-in-5 hospice agencies participating in the US Medicare program (37).

When interpreting our findings, it is important to take into account several limitations. First, we used data only from 2018, before there was heightened attention from the Surgeon General to loneliness as a public health issue. Second, while the measurement of SCI captures key domains of contact with family, contact with friends and residents, contact with staff, and conflict with others, the SCI weighs heavily towards data measuring residents' conflict with others was the most salient indicator (as opposed to contacts) of social connectedness. Further work is needed to better understand the actual quality of social connection measured among nursing home residents by this measure. Mitigating these limitations, social connectedness in nursing home residents is understudied and need greater attention.

Enhancing the quality of life for older adults in the nursing home remains an important challenge. If hospice can reduce loneliness for nursing home residents in the months preceding death, the greater efforts to address the challenges to hospice enrollment in this setting could contributed to improved quality of life. In this way, existing services external to nursing homes can be mobilized to address the needs of residents in their final days of life.

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Ethical standards: Institutional Review Board Statement: This study was approved by the UMass Chan Medical School Institutional Review Board. Informed Consent Statement: We were granted a waiver of consent by the UMass Chan Medical School Institutional Review Board for this study population as the dataset is largely de-identified and we will have no names or contact information and no way to obtain consent. Data Availability Statement: Data use is governed by a data use agreement with the Center for Medicare and Medicaid Services; data are not available to non-signatories.

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