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## End-of-life Health Care Use Among Socially Isolated and Cognitively Impaired Older Adults

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### Abstract

**Background:** Social Isolation is common in the last years of life, especially among individuals with cognitive impairment, but it is unknown if social isolation is related to end-of-life health care use.

**Methods:** We used nationally-representative 2006–2018 Health and Retirement Study (HRS) data linked to Medicare claims, including adults age 65 interviewed in the last four years of life (N=2,380). We used a validated social isolation scale and three social isolation subscales: 1) household contacts (marital status, household size, nearby children), 2) social network interaction (with children, family, and friends), and 3) community engagement. End-of-life health outcomes included 2+ ED visits in the last month of life, hospitalizations or ICU stays in the last 6 months of life, and any hospice use. Cognitive impairment (CI) was defined using the validated Langa-Weir methodology. We used logistic regression to test the association of each social isolation measure with each end-of-life outcome, adjusting for sociodemographic covariates, and tested for interaction terms with CI ( $p < 0.2$ ).

**Results:** The mean age of our sample of decedents was 81.2 (SD=9.9), 53% were female, 8% Black, and 4% Hispanic. Overall social isolation and the community engagement subscale were not associated with end-of-life health care use. Fewer household contacts was associated with lower hospice use (aOR=0.74,  $p=0.005$ ). There were significant interaction terms between the social network interaction subscale and CI for emergency department use ( $p=0.009$ ) and hospitalizations ( $p=0.04$ ), and a trend for ICU stays ( $p=0.15$ ); individuals with both low social network interaction and CI had lower health care use across all three outcomes compared to other groups.

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**Conclusions:** Individuals with fewer household contacts had lower hospice use, and cognitively impaired individuals with low social network interaction had fewer end-of-life ED visits, hospitalizations, and ICU stays. Clinicians should consider mobilizing external support services to ensure access to goal-concordant care for older adults with limited end-of-life social contact when needed.

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## INTRODUCTION

Nearly a quarter of US older adults are socially isolated in their last years of life, defined as having no regular social interaction with friends, family, or society.<sup>1</sup> Accessing healthcare services in the last months of life may be particularly challenging for older adults who are socially isolated. Older adults often experience worsening cognition, physical function, and symptoms near the end of life. Consequently, they often depend on others to help facilitate medical care and advocate on their behalf with care teams. Cognitive impairment may add an additional layer of vulnerability to social isolation as individuals may be unable to independently mobilize social support and lack insight into services they need as their medical conditions progress.<sup>2</sup> The 2018 National Consensus Project for Quality Palliative Care included social aspects of care as a core domain for the provision of high quality medical care to patients with serious illness at end of life.<sup>3</sup> Yet, little is known about how social isolation among older adults relates to different patterns of medical care at the end of life. An understanding of how social isolation contributes to different end-of-life health care can inform the design and implementation of clinical interventions targeting social risk factors and their downstream consequences.

In this study, we therefore use a nationally-representative cohort of older adult decedents linked to Medicare claims data with established quality metrics of end-of-life health care use, including: any hospice use prior to death, hospitalizations and intensive care unit (ICU) use in the last 6 months of life, and emergency department (ED) visits in the last month of life.<sup>4,5</sup> Our objective was to determine if socially isolated older adults have different patterns of end-of-life health care use, and the role of cognitive impairment in moderating that relationship. Conceptual frameworks suggest social isolation impacts health care use through health-related behaviors, reduced preventive care use (i.e. enrolling in hospice) and a lack of support in managing complex medical care plans.<sup>6</sup> In prior literature among the general population of older adults, social isolation was associated with higher Medicare spending and overall costs of care attributed to unplanned hospitalizations and emergency department visits.<sup>7</sup> We therefore hypothesized that social isolation would be associated with lower hospice use and higher emergency department use, inpatient hospitalizations, and intensive care unit (ICU) use at the end of life, with the highest rates among older adults with cognitive impairment.

## METHODS

### Study Sample

We used a nationally-representative cohort from the Health and Retirement Study, 2006–2018 linked to Medicare claims including adults ≥ 65 years old interviewed biennially until death.<sup>8</sup> In 2006, the HRS began administering an extensive Psychosocial Leave-Behind

Questionnaire (LBQ) including a comprehensive 15-item measure of social isolation.<sup>1,9</sup> Our study cohort included HRS participants who died by 2018, who completed the LBQ within four years of death, and agreed to Medicare linkage. A four year timeframe was used since one's social life tends to be stable or more isolated in this timeframe,<sup>1</sup> and the extended timeframe increased statistical power for subgroup comparisons. Overall, 4,559 primarily community-dwelling HRS participants completed the LBQ in one of the two HRS interviews prior to death and 2,689 were enrolled in fee-for-service Medicare for at least 6 months before death with available Medicare linkage data. We excluded 309 participants with incomplete responses to the LBQ, resulting in a final sample of 2,380 decedent subjects.

### **Social Isolation**

Social Isolation was defined based on three dimensions of social relationships as outlined by Shankar et al. (2011), published social isolation scales,<sup>7,10–13</sup> and prior conceptual frameworks on social relationships and health.<sup>6,14,15</sup> Each of the three dimensions was standardized to create a separate subscale ranging from 0–2 points with more points indicating more social connections. First, we measured *household and core contacts* including: marital status, household size, and having nearby children. Local or in-home contacts are important to the provision of end-of-life support (e.g. managing medications, ADL needs) and qualifying for home hospice. Second, we measured *social network interaction*, which assessed the frequency of contact with children, family, or friends through in-person meetings, phone, or e-mail.<sup>7</sup> Social network interaction reflects the web of connections between relationships and a pathway to the provision of material and psychosocial support; this domain was strongly tied to health care use in a prior study.<sup>7</sup> Third, we examined *community engagement*, including the frequency of participation in religious services, other community groups, or community volunteering. Community engagement can indicate the level of integration with one's local community and the ability to navigate local health systems.<sup>6,14,15</sup> The three subscales (each scored 0–2) were combined to create an overall social connectedness scale which ranged from 0–6 points, with 2 or less points representing social isolation.<sup>1,10</sup>

### **End-of-life Health Care Outcomes**

End-of-life health outcomes were based on prior literature on quality indicators for end-of-life care,<sup>4,5,16–18</sup> and included 2+ ED visits in the last month of life, hospitalizations or ICU stays in the last 6 months of life, and any hospice use. For all outcomes we included HRS decedents enrolled in Medicare Fee-for-Service in the last 6 months of life, as the outcomes are not reliably captured in Medicare Advantage. ED visits were defined based on Medicare inpatient and outpatient claims.<sup>19</sup>

### **Sociodemographic, Clinical, and Functional Measures**

Cognitive impairment included Cognitive Impairment Not Dementia (CIND) or Dementia using the previously validated Langa-Weir methodology.<sup>20</sup> A 27-point summary score was derived from 3 items: 1) immediate and delayed 10-noun free recall, 2) serial sevens, and 3) counting backwards test. Respondents were grouped as Normal (12–27 points), Cognitively Impaired but not Dementia (CIND) (7–11 points), and Dementia (0–6 points)

based on diagnostic information from the HRS Aging, Demographics, and Memory Study cohort.<sup>21–23</sup> Sociodemographic factors included age, sex, marital status, race/ethnicity (White, Black, Hispanic/Latinx, and “Other”), education, and net worth.<sup>1</sup> Clinical factors included self-reported chronic conditions, including diabetes, heart disease, lung disease, cancer, hypertension, and stroke. Functional measures included difficulty performing six Activities of Daily Living (ADLs) (bathing, dressing, transferring, toileting, eating, walking across a room), difficulty performing five Instrumental Activities of Daily Living (IADLs) (using a phone, managing finances, taking medications, shopping for groceries, and preparing hot meals), and difficulty walking one block.

### Statistical Analysis

We fit separate logistic regression models to determine if social isolation and each social isolation sub-scale was associated with each end-of-life outcome after adjusting for age, sex, race, education, multimorbidity, and time between interview and death. We did not adjust for ADL disability (possible mediator) or net worth (collinearity with education), however, a sensitivity analysis with these adjustments yielded highly similar results. In each model, we added an interaction term between social isolation and each social isolation sub-scale with cognitive impairment. Analysis revealed a relatively consistent interaction term ( $p < 0.2$ ) between the social network interaction sub-scale and cognitive impairment in predicting end-of-life health care use. We therefore present sample characteristics stratified by level of social network interaction (Table 1), and the adjusted probabilities of end-of-life health care use stratified by cognitive impairment and social network interaction derived from multiple regression models (Figure 1). All analyses accounted for the complex sampling design, differential probability of selection, and differential probability of response to core and leave-behind questionnaires. We did not adjust for multiple comparisons as the goal of the analysis was exploratory in nature.<sup>24</sup> In addition, we conducted a sensitivity analysis restricting our sample to individuals answering interview questions in the last year of life which yielded similar results. All analyses were performed using STATA 17.0 and SAS 9.4.

## RESULTS

Our sample had a mean age of 81 (SD=10) was 53% female, 8% Black, 4% Hispanic, and 46% had cognitive impairment (Table 1). Approximately 14% had 2+ ED visits, 46% any hospice use, 73% were hospitalized, and 40% utilized the ICU at the end of life.

The overall social isolation measure and the community engagement sub-scale were not associated with end-of-life health care use (Table 2). Having few household or core contacts was associated with a 26% lower odds of hospice use (aOR: 0.74, 95% CI: 0.6–0.9,  $p=0.005$ ). In addition, there were significant interaction terms between the social network interaction sub-scale and cognitive impairment for ED use ( $p=0.01$ ) and hospitalizations ( $p=0.04$ ), and a non-significant interaction term for ICU stays ( $p=0.15$ ). Individuals with low social network interaction and cognitive impairment had lower health care use across all three outcomes compared to other groups (Figure 1).

## DISCUSSION

In a nationally-representative cohort of older adult decedents, we examined if patterns of end-of-life health care use differed by the presence of social isolation. Contrary to our hypothesis, we found no association between overall social isolation and end-of-life health care use. Instead, results pointed to the relevance of certain dimensions of social isolation to end-of-life health care. First, individuals with few household or core contacts had lower hospice use. We hypothesize this finding is related to the need for a live-in primary caregiver to receive home hospice, a significant barrier to enrollment among individuals living alone with no nearby family members. Second, older adults with low social network interaction and cognitive impairment had fewer ED visits, hospitalizations, and ICU stays in the last months of life compared to those with higher network interaction and/or not cognitively impaired. This finding diverges from prior literature showing that socially isolated older adults have higher Medicare spending and overall costs of care attributed to acute care use.<sup>7,25,26</sup> We hypothesize that an actively involved social network plays a different role in end-of-life health care use compared to earlier in the lifespan. Earlier in the lifespan, an involved social network may preserve health and healthy behaviors which allow individuals to avoid acute care use.<sup>6</sup> In contrast, at the end of life, older adults may have unavoidable health needs due to worsening symptoms, sudden medical illness, and progression of chronic illness. Consequently, social networks may be facilitating health care access and hospice use among older adults with and without cognitive impairment for these end-of-life health care needs.

Although lower rates of acute care among older adults with cognitive impairment and low social network interaction use may be perceived as less burdensome, it is unclear if these low rates are concordant with patient wishes or are due to a lack of support in accessing desired health services. Prior qualitative research suggests both explanations may play a role.<sup>2</sup> Individuals who have smaller social networks and are cognitively impaired may actively avoid health care and social activities due to apathy (a frequent symptom or sign of cognitive impairment),<sup>27</sup> a preference to stay home and avoid others, lack of insight into serious medical needs, or wanting to conceal cognitive impairment from others.<sup>2</sup> Alternatively, they may have trouble navigating fragmented, complex health systems on their own, even to address acute changes in their medical condition or uncontrolled symptoms.<sup>2</sup> These challenges may be amplified by a lack of instrumental support since socially isolated older adults are more likely to be homebound,<sup>28</sup> lack a health care proxy to facilitate health care decisions,<sup>29</sup> and have difficulty accessing transportation.<sup>30</sup> The latter experience is clearly problematic and may have detrimental consequences for well-being, safety, and quality of life. Clinicians should therefore be aware that limited social contact is associated with lower end-of-life health care use among individuals with cognitive impairment and ensure access to goal-concordant care through the mobilization of external support services when needed.

Our study has limitations. First, social isolation was measured in the last four years of life in order to increase our power for statistical analysis, but this may not reflect an individual's social situation in the last 6 months of life when health care use was examined. We conducted a sensitivity analysis restricting our sample to individuals answering interview

questions in the last year of life which yielded similar results. We further adjusted for time between interview and death in multivariate models. Prior literature indicates individuals on average are more isolated in the last months of life compared earlier in the lifespan,<sup>1</sup> suggesting our approach provides reasonable and conservative estimates. Second, a small number of participants were excluded due to not agreeing to Medicare linkage (consent rate: 87%) and our sample did not include Medicare Advantage populations which may limit generalizability. Third, there may be selection bias related to incomplete LBQ data (for example, non-responders to LBQ were slightly more likely to be Black or Latinx). We addressed this through adjustments for race/ethnicity in our multivariate model and weights distributed with the HRS dataset that adjust for non-response to the LBQ.<sup>9</sup>

In conclusion, we found that individuals with few household contacts had reduced hospice use, and those with cognitive impairment and low social network interaction had fewer ED visits, ICU stays, and hospitalizations at the end of life. Clinicians should be aware of the role of social relationships in efforts to promote goal-concordant care and quality of life among older adults with serious illness, cognitive impairment, or approaching the end of life.

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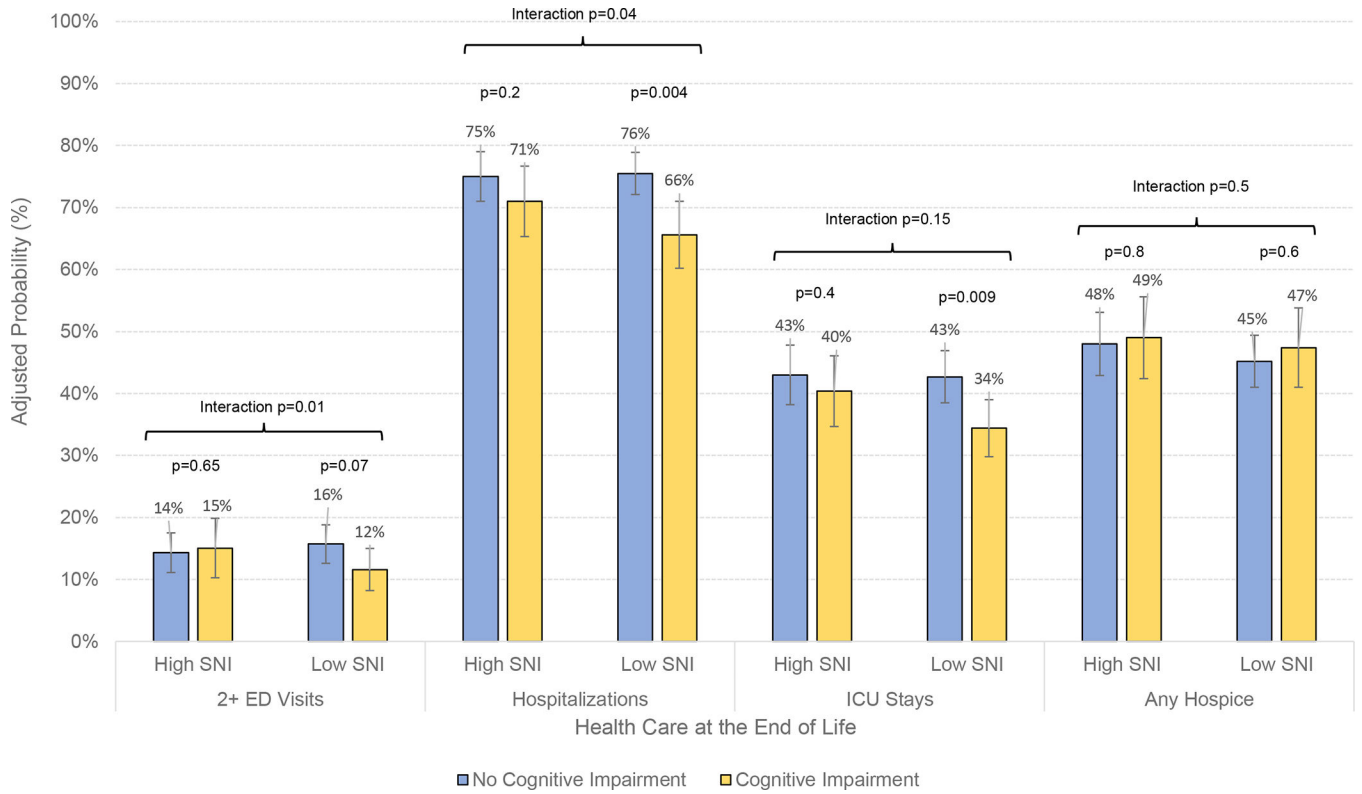
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**KEY POINTS:**

- In a nationally-representative cohort of 2,380 older adults in the last years of life, we examined if patterns of end-of-life health care use differed by level of social isolation, or social isolation subscales including lack of household contacts, low social network interaction, and low community engagement.
- Individuals with fewer household contacts (unmarried, no nearby children, living alone) had less hospice use at the end of life.
- Cognitively impaired individuals with low social network interaction had fewer end-of-life emergency department visits, intensive care unit stays, and hospitalizations.

**Why does this matter?**

Clinicians should be aware that limited social contact is associated with lower end-of-life health care use among individuals with and without cognitive impairment and ensure access to goal-concordant care through the mobilization of external support services when needed.



**Figure 1. The Adjusted Probability of Health Care Use by Social Network Interaction and Cognitive Impairment**

Adjusted probabilities were derived from multivariate logistic regression models adjusting for age, gender, race/ethnicity, education, multimorbidity, and time between interview and death, and testing for interaction terms between the Social Network Interaction (SNI) subscale and cognitive impairment. End-of-life health care outcomes were drawn from fee-for-service Medicare claims data (2006–2018) for each participant and included 2+ ED visits in the last month of life, hospitalizations in the last 6 months of life, ICU stays in the last 6 months of life, and any hospice use. Interaction p-values indicate whether interaction terms between SNI and cognitive impairment were significant. Individual p-values indicate whether there were significant differences in health care use by cognitive impairment, stratified by level of social network interaction.

**Table 1.**

Select characteristics in 2006–2018 HRS decedents, linked to Medicare (N=2,380)

Characteristics		Overall (N=2,380) N (%) <sup>2</sup>	High social network interaction <sup>1</sup> (N=1,058) N (%) <sup>2</sup>	Low Social network interaction <sup>1</sup> (N=1,352) N (%) <sup>2</sup>	p-value
<b>Characteristics</b>					
Age at last interview	50–64	149 (9)	64 (9.4)	85 (8.7)	0.03
	65–74	621 (24.8)	299 (26.1)	322 (23.8)	
	75–84	937 (33.8)	434 (35.5)	503 (32.5)	
	85+	673 (32.4)	261 (28.9)	412 (35)	
Sex	Female	1236 (52.6)	595 (55.6)	641 (50.4)	<0.001
Marital Status	Married/Partnered	1197 (45.8)	528 (46.6)	669 (45.2)	0.7
Race/Ethnicity	White/Caucasian	2001 (85.9)	862 (84.8)	1139 (86.7)	0.13
	Black/African American	253 (8.2)	143 (9.7)	110 (7.2)	
	Hispanic	94 (4.4)	41 (4.2)	53 (4.5)	
	Others	32 (1.5)	12 (1.2)	20 (1.7)	
Education	Less than High School	595 (26.0)	280 (26.9)	315 (25.3)	0.05
	GED	123 (5.7)	47 (4.9)	76 (6.2)	
	High-school graduate	791 (31.7)	376 (34.8)	413 (22.1)	
	Some College	490 (20.8)	195 (19.1)	295 (21)	
	Bachelors or above	380 (15.8)	158 (14.3)	222 (16.8)	
Net Worth <sup>3</sup>	<6,000	393 (18.9)	160 (16)	233 (20.9)	0.04
	6,000–<81,000	483 (21.1)	225 (23.6)	258 (19.2)	
	81,000–<239,000	569 (22.8)	270 (25.2)	299 (21)	
	>=239,000	935 (37.3)	403 (35.2)	532 (38.8)	
Comorbidities	Multimorbidity (2+)	1151 (48)	518 (49.1)	633 (47.2)	0.56
	Cancer	695 (28.8)	308 (28.8)	387 (28.8)	0.62
	Diabetes mellitus	742 (31.0)	347 (32.2)	395 (30.1)	0.10
	Lung disease	544 (23.0)	241 (22.7)	303 (23.3)	0.93
	Stroke	494 (21.6)	203 (20.7)	291 (22.3)	0.46
	Heart Disease	1183 (49.7)	526 (51.1)	657 (48.7)	0.32
Activities of Daily Living (ADL) Dependence	Any ADL dependence	520 (25.9)	197 (22)	323 (28.6)	0.04
	Walking	211 (11.7)	81 (10.2)	130 (12.8)	0.43
	Dressing	323 (16.8)	122 (13.8)	201 (19)	0.03
	Eating	122 (7.2)	40 (5.3)	82 (8.6)	0.22
	Bathing	340 (18.4)	125 (15.6)	215 (20.4)	0.11
	Toilet	103 (6.5)	34 (4.9)	69 (7.7)	0.06

Characteristics		Overall (N=2,380)	High social network interaction <sup>1</sup> (N=1,058)	Low Social network interaction <sup>1</sup> (N=1,352)	p-value
		N (%) <sup>2</sup>	N (%) <sup>2</sup>	N (%) <sup>2</sup>	
	In/Out of bed	150 (9.3)	50 (7.2)	100 (10.7)	0.10
Instrumental Activities of Daily Living (IADL) Difficulty	Any IADL difficulty	871 (43.1)	345 (38.3)	526 (46.5)	<0.001
	Preparing Meals	636 (31.6)	228 (24.8)	408 (36.5)	<0.001
	Shopping	730 (36.3)	289 (32.5)	441 (39.1)	0.003
	Medications	179 (11.8)	62 (9.7)	117 (13.3)	0.07
	Telephone	284 (17.3)	85 (12.2)	199 (21)	<0.001
	Finances	500 (26.3)	203 (23.5)	297 (28.4)	0.07
Cognition <sup>4</sup>	Normal	1403 (54.2)	641 (56.8)	762 (52.2)	0.03
	CIND/Dementia	977 (45.8)	417 (43.2)	560 (47.8)	

Abbreviations: CIND – Cognitive Impairment Not Dementia; P-values were determined using Rao-Scott Chi-Square tests.

<sup>1</sup> Social Network Interaction was determined using a 12-item scale indicating less than monthly interaction with children, family, or friends through in-person meetings, phone, or email [1]

<sup>2</sup> Raw numbers are removed for any cell sizes with N<25 (indicated by a \*) per Medicare reporting guidelines. Percentages in the table are column percentages; percentages shown in the table are adjusted for survey weights and thus may not correspond directly to the unadjusted N listed in each cell

<sup>3</sup> Net Worth was calculated as sum of all assets minus the sum of all debts

<sup>4</sup> Cognitive Impairment was defined using the Langa-Weir method.

**Table 2.**

Adjusted association between social isolation and social isolation subscales with end-of-life health care use

End-of-life Health Care	Overall		No Cognitive Impairment		Cognitive Impairment		p-value of interaction <sup>I</sup>
	aOR (95% CI)	p-value	aOR (95% CI)	p-value	aOR (95% CI)	p-value	
<b>2+ ED visits in last month</b>							
Social Isolation	1.02 (0.7,1.5)	0.92	1.33 (0.8,2.2)	0.26	0.81 (0.4,1.5)	0.51	0.2
Social Isolation Subscales							
Low Social Network Interaction	0.94 (0.7,1.3)	0.68	1.31 (1,1.8)	0.01	0.62 (0.4,1.1)	0.076	0.009
Low Community Engagement	0.99 (0.7,1.3)	0.93	0.8 (0.5,1.2)	0.30	1.3 (0.8,2.1)	0.28	0.12
Few Household/core contacts	0.8 (0.5,1.3)	0.36	-	-	-	-	-
<b>Any Hospice</b>							
Social Isolation	0.9 (0.7,1.1)	0.38	-	-	-	-	-
Social Isolation Subscales							
Low Social Network Interaction	0.91 (0.7,1.1)	0.39	-	-	-	-	-
Low Community Engagement	0.96 (0.8,1.1)	0.62	-	-	-	-	-
Few Household/core contacts	0.74 (0.6,0.9)	0.005	0.66 (0.5,0.8)	0.001	0.85 (0.6,1.2)	0.37	0.11
<b>Hospitalization in last 6 months</b>							
Social Isolation	0.84 (0.7,1.1)	0.18	1.41 (0.9,2.1)	0.01	0.62 (0.4,0.9)	0.014	0.007
Social Isolation Subscales							
Low Social Network Interaction	0.87 (0.7,1.1)	0.20	1.1 (0.8,1.5)	0.50	0.72 (0.5,1)	0.038	0.04
Low Community Engagement	0.92 (0.7,1.2)	0.50	1.17 (0.9,1.5)	0.25	0.82 (0.6,1.1)	0.23	0.11
Few Household/core contacts	1.08 (0.8,1.4)	0.56	-	-	-	-	-
<b>ICU stay in last 6 months</b>							
Social Isolation	0.8 (0.6,1)	0.09	-	-	-	-	-
Social Isolation Subscales							
Low Social Network Interaction	0.91 (0.7,1.1)	0.31	1.02 (0.8,1.3)	0.88	0.77 (0.6,1)	0.087	0.15
Low Community Engagement	0.93 (0.8,1.1)	0.45	-	-	-	-	-
Few Household/core contacts	0.92 (0.7,1.2)	0.46	-	-	-	-	-

Adjusted odds ratios are derived from multivariate logistic regression models adjusting for age, gender, race/ethnicity, education, multimorbidity, and time between interview and death.

<sup>I</sup>P-value for significance interaction term between social isolation measures and cognitive impairment. Interaction terms are displayed if p-values are <0.2. Household contact items included marital status, household size, and presence of children <10 miles away; Community engagement items included frequency of volunteering, participating in community groups, and religious services; Social Network Interaction items included the frequency of interaction with children, family, or friends through in-person, e-mail, or phone; Overall Social Connectedness was defined by combining the Household, Social Network Interaction, and Community Engagement subscales to create a 0–6 point scale with 0–2 points categorized as socially isolated.