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## Return to community living and mortality after moving to a long-term care facility: a nationally representative cohort study

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### Abstract

**Background:** Recent long-term care facility (LTCF) policy has focused on transitioning nursing home (NH) residents back to community settings, yet we lack recent descriptions of this phenomenon and how it compares in assisted living (AL).

**Methods:** Using the National Health and Aging Trends Study, we studied adults over age 65 who had moved from community living into an LTCF between 2011 and 2018. Persons or their proxies reported residence in annual interviews. NH was defined by facility staff. ALs were multi-unit buildings helping with activities of daily living. We excluded temporary short-stay NH patients and independent AL residents. Our primary outcome was cumulative incidence of return to community living, with death as co-primary outcome and modeled as a competing risk, stratified by NH vs. AL entry. We identified covariates (age, gender, race/ethnicity, dementia, activity limitations, and prior living arrangement) associated with return to community living through bivariate and multivariable logistic regression.

**Results:** Among 739 participants, weighted mean age was 84 years (SD 7.5), 66% were women, 13% were non-White, 57% had dementia, and 41% entered NH. At 1, 2, and 4 years, the cumulative incidence of return to community living was 2.9% (95% CIs: 1.9–4.3%), 6.4% (4.7–8.4%), and 7.4% (5.5–9.8%); the cumulative incidence of death was 28% (95% CIs: 24–31%), 44% (40–48%) and 66% (61–70%). Outcomes were similar in persons entering NH versus AL. Older persons (aOR 0.88, 95% CI 0.83–0.94), those with dementia (aOR 0.33, 95% CI 0.12–0.88), and those previously living alone (aOR 0.39, 95% CI 0.17–0.89) were less likely to return.

**Conclusions:** Few returned to community living after entering either NH or AL. Mortality was similar. Results highlight limits in transitioning persons out of LTCFs and the need to observe AL use to ensure policies do not merely displace persons between institutional care sectors.

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Author Contributions

All authors meet the criteria for authorship stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals:

Study concept and design: KL, KC

Acquisition of data: KL

Analysis and interpretation of data: KL, IC, KC

Preparation of the manuscript: KL, IC, KC

Conflict of Interest

The authors report no conflicts of interest.

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## Keywords

Nursing home; assisted living facility; care settings; return to community living; long-term care facilities

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## Background

Since 2007, the Centers for Medicare & Medicaid Services (CMS) have funded the Money Follows the Person (MFP) demonstration.<sup>1</sup> MFP's aim is to offer new nursing home (NH) residents alternatives to institutional-based care, by providing grants to establish state-based transition programs and increase home and community based services. In evaluations, the MFP program has appeared successful. States transitioned over 100,000 NH residents back to the community from 2008 to 2020.<sup>2</sup> Minnesota's initiative reported an 11% absolute increase in NH residents discharged to the community without changes in mortality or NH re-admissions post-discharge.<sup>3,4</sup>

Yet even as the CMS fund efforts to reduce institutional care, assisted living (AL) has been growing as an alternative—and at times, equally institutional—care setting for persons in need of assistance as they age.<sup>5</sup> There are now approximately 1 million licensed AL beds compared to 1.7 million NH beds.<sup>6</sup> AL populations increasingly look like NH populations in terms of functional status and frailty: around half require help with activities of daily living and have moderate to severe dementia.<sup>7</sup> In other words, NH and AL are two forms of long-term care facilities (LTCFs) available in the US, and their residents may differ more in terms of socioeconomic factors and ability to pay than medical conditions or need for care.<sup>8–10</sup>

Despite these similarities and the growing societal interest to de-institutionalize care for older persons, little is known about how return to community living and mortality compare between these two settings. A 2019 scoping review found few studies have examined return to community living in the US.<sup>11</sup> Each year over 300,000 persons in the US move into a NH or AL.<sup>12</sup> Moves happen in anticipation of or in response to irreversible declines in health and function. These long-term moves are distinct from short-term stays in NHs for rehabilitation or respite.<sup>13</sup> One study of Medicare data from 2013 found 7.1% of long-term NH residents admitted post-hospitalization were discharged home within 1 year.<sup>14</sup> A separate national study from 1999 of AL residents from found less than 1% returned to community living after 7 months, while approximately 7% transitioned to a NH.<sup>15</sup> But more recent national data of how often NH and AL residents leave their facilities are not available.

We thus conducted an updated study of return to community living among older persons entering either NH or AL using data from a nationally representative survey and excluding short-stay patients. We were interested in: 1) what percent of persons who move into LTCFs return to community living (also known as “community discharge”), 2) when does it happen, 3) what percent die and 4) whether rates differ between persons entering NHs versus ALs. We explored factors associated with return to community living.

## Methods

### Data sources

We completed an observational cohort study using the National Health and Aging Trends Study (NHATS), a nationally representative cohort of Medicare beneficiaries in the continental US aged 65 and older followed since 2011 with annual in-person interviews of participants, their proxies, and/or facility staff.<sup>16</sup> The NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG032947) through a cooperative agreement with the Johns Hopkins Bloomberg School of Public Health and approval from their Institutional Review Board.

### Study participants

We included participants reporting new entry to NH or AL from a community-dwelling residence between 2011 and 2018 (see Supplementary Figure S1). Residence was NH if facility staff said the participant lived in a NH. Residence was AL if participants indicated they lived in a multi-unit or age-restricted building (eg, a “group home” or “residential care facility”) that offered help with medications, bathing or dressing. In buildings with multiple levels of care, residence was the section where the participant lived. Independent living sections of buildings with multiple levels of care, senior’s homes, retirement communities, apartments, and homes were considered “community-dwelling”. We included decedents if proxies reported the participant lived in an AL or NH prior to death. We excluded persons indicating their stay was temporary to avoid planned short stays for rehabilitation or respite.<sup>13</sup>

### Outcomes

Our primary outcome was return to community living and was assessed through 2019; 2020 data were excluded to remove potential influence from the COVID-19 pandemic. Return to community living was defined as the first round participants subsequently reported no longer residing in an LTCF. Our co-primary outcome was death, as 1-year mortality in NH residents is over 30% and over 10% in AL residents.<sup>17,18</sup> Time to outcome was calculated using self-reported data on the month and year participants moved in, moved out or died. Secondary outcomes were transitions from NH to AL and vice-versa.

### Covariates

We used Bradley and Andersen’s model of long-term care – which theorizes utilization depends on disability, enabling factors, attitudes, norms, and perceived control – to select covariates (see Supplemental Figure S2).<sup>19</sup> Covariates were from the round before LTCF entry. Demographics included age, gender, and race/ethnicity. Non-White race categories (Black, Hispanic, and Other) were collapsed to protect against complementary disclosure per the NHATS Data Use Agreement. Disability was measured as dementia, a count of chronic conditions (heart disease, arthritis, diabetes, lung disease, stroke, cancer), physical performance, and activity limitations. Enabling factors were education, income, metropolitan status, census region, Medicaid status, home ownership, marital status and prior living arrangement. Perceived control was approximated with self-rated health.

Dementia was categorized as none or possible/probable using a validated algorithm.<sup>20</sup> Physical performance was measured using the NHATS Short Physical Performance Battery (SPPB).<sup>21</sup> Activity limitations were defined as difficulty or assistance in mobility activities (getting out of bed and getting around inside) and self-care activities (bathing, dressing, toileting, and eating), congruent with Katz' Activities of Daily Living (ADLs).<sup>22</sup> We included use of assistive devices for mobility (eg, canes, walkers) as a limitation.<sup>23</sup> Income was imputed from survey responses and divided into five ranges defined by the Survey of Consumer Finance for 2007 adjusted to 2011 dollars.<sup>24</sup>

### Missingness

We know the years when participants moved or died, but some did not report a month. We used the first imputation set from a five nearest neighbor imputation to provide missing months. SPPB was missing in 17% of our cohort, prior living arrangement in 6%, and missingness of other covariates was < 5%.

### Analyses

Data were analyzed from January 13, 2022 to October 5, 2022. We reported baseline covariates and compared NH versus AL entrants using bivariate analyses. We determined cumulative incidence of return to community living, modeling death as a competing risk and stratified by NH vs. AL entry. We used a Fine and Gray competing risks regression model to determine if outcomes differed between NH and AL entrants (stcrreg in Stata).

We used bivariate and multivariable logistic regression to determine predictors of return to community living within 2 years.<sup>25</sup> Low event rate limited how many covariates we could include in our model. We *a priori* specified sequential multivariable models: 1) age, gender, and race/ethnicity; 2) adding ADL limitations and dementia, and; 3) adding previously living with others and entry into NH vs. AL. We reported predicted probability of return to community living at the 25<sup>th</sup> and 75<sup>th</sup> percentile of age. For all analyses, we used analytic weights from enrollment year to correct for oversampling of minority populations and those over age 85. A two-sided p-value of 0.05 or less was statistically significant. We did not adjust for multiple comparisons. All analyses were conducted using StataSE 16.1 (StataCorp, College Station, TX, USA).

We completed sensitivity analyses. The first confirmed imputation of missing months improved outcome estimates (see Supplementary Figure S3). The second included independent living (IL) residents in our AL definition; IL provides fewer services to a more functional population, but is often co-located with AL (see Supplementary Table S4).<sup>26</sup>

### Results

Our cohort included 739 LTCF entrants. With weights, mean age was 84 years (SD 7.5), 66% were women, 13% were non-White, 57% had dementia, and 41% entered a NH. Mean follow-up time was 23 months. Compared to AL, NH entrants were more likely to be non-White (18% vs. 10%), have dementia (66% vs. 50%), have more chronic conditions and functional impairments, and fewer socioeconomic advantages such as education and income (see Table 1).

Thirty-six persons (7%) returned to community living after LTC entry. Eleven percent of AL entrants later moved to a NH, and 4% of NH entrants moved to AL. At 1, 2, and 4 years, the cumulative incidence of return to community living was 2.9% (95% CIs: 1.9–4.3%), 6.4% (4.7–8.4%), and 7.4% (5.5–9.8%), respectively; incidence of death was 28% (95% CIs: 24–31%), 44% (40–48%) and 66% (61–70%). Neither return to community living (subhazard ratio = 1.26,  $p = 0.552$ ) nor death (subhazard ratio = 0.98,  $p = 0.881$ ) differed between NH and AL entrants (see Figure 1).

In adjusted models, older persons (aOR 0.88, 95% CI 0.83–0.94), those with dementia (aOR 0.33, 95% CI 0.12–0.88), and those previously living alone (aOR 0.39, 95% CI 0.17–0.89) were less likely to return to community living (see Table 2). Predicted probability of return was 8.2% (95% CI 5.0–11.3%) for a 79 year old, 2.5% (95% CI 0.6–4.4%) for an 89 year old, and 0.7% (95% CI 0.0–1.6%) for an 89 year old person with dementia who previously lived alone.

Including IL in our AL definition increased cumulative incidence of return to community living (8.2% vs. 7.4% at 4 years), reduced mortality (54% vs. 66% at 4 years), and yielded age as the only significant predictor in multivariable regression (aOR 0.90, 95% CI 0.86–0.94).

## Discussion

Using nationally representative data, we found persons entering NHs versus ALs differed in function and socioeconomic status but experienced similar exit outcomes. In both, the cumulative incidence of return to community living (7%) was much lower than the cumulative incidence of death (66%) over 4 years and did not significantly differ between NH and AL entrants. Almost 90% who returned to community living did so within 2 years of entry. Return was less likely in older persons, those with dementia, and those previously living alone. Outcomes were sensitive to how AL was defined. When we included IL residents, the cumulative incidence of return to community living increased and mortality decreased.

Findings are relevant to policymaking for a few reasons. First, we corroborate other research showing that once people enter LTCFs, they rarely return to community living—especially as they stay longer and when housing challenges and cognitive challenges exist.<sup>27,28</sup> Transition efforts targeting older persons after they have entered NHs (such as MFP) may thus have limited ability to reduce overall LTCF stays, and efforts to avoid LTCF entry in the first place may be of greater yield.<sup>29</sup> Such efforts include not only bolstering home and community based services, but also investing in single points of entry (eg, “navigation hubs”) to ensure good candidates for those services (eg, younger persons without dementia living with others) are routed to alternatives.<sup>30,31</sup>

Second, we surprisingly found that AL entrants had similar mortality to NH entrants. This corroborates arguments that the AL and NH populations have become increasingly similar in acuity and need for health care, even though AL populations tend to be wealthier, White, and more mobile at entry.<sup>9,10</sup> Efforts to truly reduce institutional care and promote

aging-in-place must therefore monitor AL utilization to ensure we are not merely displacing persons who would otherwise enter a NH into an institutional AL.

Third, it may be important to consider how community discharge from AL differs from community discharge from NH. Most AL is paid for privately, and thus community discharge from AL may not reflect a resident or surrogate decision maker's preference but rather exhaustion of financial resources to keep paying for care.<sup>15</sup> Further research is needed to better understand why people leave LTCFs, especially in light of increased scrutiny and fear of LTCFs since the COVID pandemic.<sup>32</sup>

Our study's strengths include the longer follow-up time, use of a nationally representative cohort with prospectively collected and self-reported data on residence to identify transitions into LTCFs, and our exploration of different LTCF definitions. These may explain differences in our outcomes rates compared to previous work. For example, our annual rate of return from NH was lower than previously reported<sup>14</sup> and our annual rate of return from AL was higher than previously reported.<sup>15</sup> Still, age, dementia, and previously living alone predicted return to community living, consistent with theoretical models that explain LTCF use depends on disabilities and enabling factors and other research on why people move into LTCFs.<sup>19,33</sup> Other studies of AL populations reported lower mortality, but defined their cohort using zip codes to geographically identify large AL facilities based on mailing address, thus including unassisted persons living in IL and only those who lived long enough for their mailing address to change.<sup>18</sup> Our mortality estimates are closer to that reported in smaller studies,<sup>34</sup> and may thus be more accurate.

This work has several limitations. The low event rate left us underpowered to detect more predictors and interaction effects between them. NH residents may be underrepresented in a national survey like the NHATS, despite efforts to retain participants. We did not update covariates over time, though some (eg, function) may change as persons enter LTCFs.

## Conclusion

Approximately 7 percent of new NH or AL residents over 65 return to community living after 4 years, with most returning in 2 years. Return was less likely in older persons with dementia who previously lived alone. Mortality was similar in new NH and AL residents after excluding persons living in independent living. These results highlight the limits of transitioning persons out of LTCFs and the need to monitor AL use when tracking efforts to reduce institutional care in the US.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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### Sponsor's Role

Funding sources were used to support the authors during the completion of this study. They had no role in the design, methods, recruitment, data collection, analysis or preparation of this paper.

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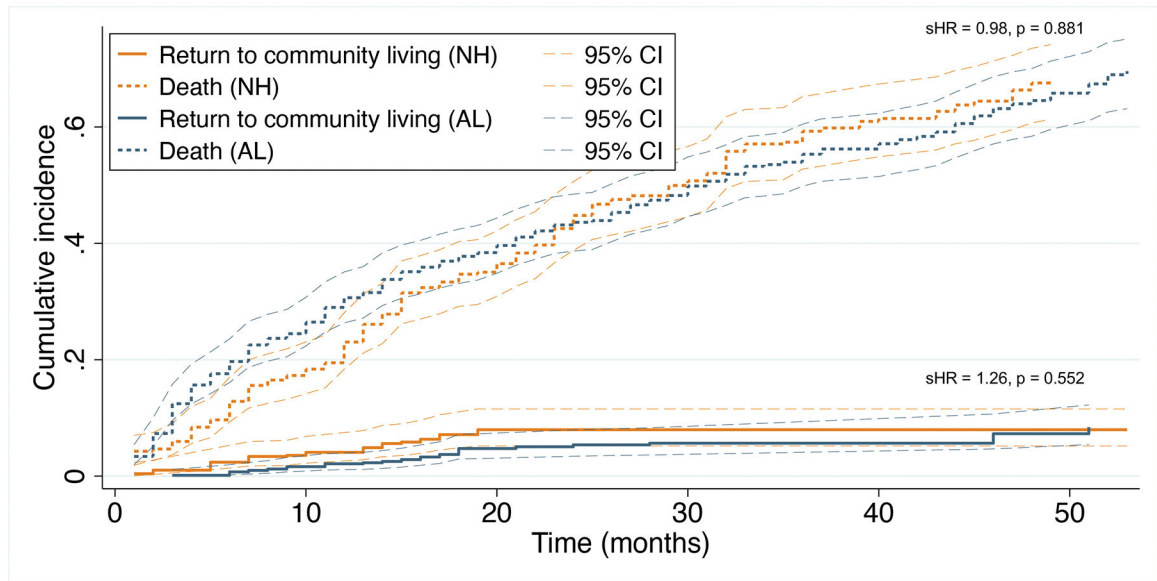
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**Key points:**

- Approximately 7 percent of persons entering a nursing home (NH) or assisted living (AL) for long-term care (excluding those in independent living areas) return to community living within 4 years; most that do return in 2 years.
- Despite dependent assisted living residents having more socioeconomic advantages and better function at entry, they were no more likely to return to community living than nursing home residents and had a similar cumulative incidence of mortality of 66% after 4 years.
- Older persons with dementia who previously lived alone were very unlikely (<1%) to return to community living.

**Why does this matter?**

Policies to reduce long-term care facility (LTCF) use in the US have largely focused on transitional programs to return persons to community living after entering nursing homes. Given how rarely persons returned to community living while these programs were in existence, efforts should be re-directed at preventing long-term care entry in the first place. It is likely easier to avoid LTCF entry in younger persons without dementia who previously lived with others. Finally, the similarities between new NH and AL residents raises the possibility that we are merely displacing older persons from NH settings to AL settings, and thus efforts to truly reduce institutional-based care must observe how both care settings are used.



**Figure 1.** Survival curves for return to community living after nursing home (NH) or assisted living facility (AL) entry, with death modeled as a competing risk.

**Table 1.**

Baseline characteristics of persons newly entering nursing homes and assisted living facilities in the National Health and Aging Trends Study (NHATS).

| Covariate   | Overall                     | By LTCF type   |                | p-value <sup>a</sup> |
|---|-----------------------------|----------------|----------------|----------------------|
|   |                             | NH             | AL             |                      |
|   | n (weighted %) <sup>b</sup> | n (weighted %) | n (weighted %) |                      |
| Overall, row %  | 739 (100)                   | 317 (41)       | 422 (59)       |                      |
| <b>Predictors</b>   |                             |                |                |                      |
| Age, mean (SD)  | 84 (7.4)                    | 84 (8.0)       | 85 (7.0)       | 0.207                |
| Women gender  | 490 (66)                    | 217 (67)       | 273 (65)       | 0.685                |
| Non-White race/ethnicity <sup>c</sup>                       | 166 (13)                    | 102 (18)       | 64 (10)        | <0.001               |
| Dementia  | 427 (57)                    | 213 (66)       | 214 (50)       | 0.003                |
| Number of chronic conditions (0–6) <sup>d</sup> , mean (SD) | 2.6 (1.0)                   | 2.7 (1.0)      | 2.5 (1.0)      | 0.011                |
| SPPB score (0–12), mean (SD)                                | 3.1 (2.8)                   | 2.2 (2.5)      | 3.6 (2.7)      | <0.001               |
| Number of ADL impairments (0–6) <sup>e</sup> , mean (SD)    | 2.6 (2.2)                   | 3.1 (2.2)      | 2.3 (2.0)      | <0.001               |
| Education   |                             |                |                | 0.001                |
| Less than high school                                       | 188 (21)                    | 104 (28)       | 84 (16)        |                      |
| High school   | 234 (34)                    | 103 (36)       | 131 (32)       |                      |
| More than high school                                       | 302 (45)                    | 101 (36)       | 201 (51)       |                      |
| Income  |                             |                |                | <0.001               |
| Lowest  | 308 (38)                    | 168 (51)       | 140 (29)       |                      |
| Lower   | 167 (22)                    | 73 (23)        | 94 (22)        |                      |
| Middle  | 136 (20)                    | 48 (16)        | 88 (22)        |                      |
| Higher  | 74 (12)                     | 16 (5)         | 58 (16)        |                      |
| Highest   | 54 (8)                      | 12 (4)         | 42 (11)        |                      |
| Medicaid covered  | 138 (17)                    | 96 (27)        | 42 (10)        | <0.001               |
| Urban area  | 572 (78)                    | 239 (76)       | 333 (79)       | 0.521                |
| Census region   |                             |                |                | 0.001                |
| Northeast   | 137 (19)                    | 73 (25)        | 64 (15)        |                      |
| Midwest   | 210 (28)                    | 92 (28)        | 118 (28)       |                      |
| South   | 249 (33)                    | 125 (38)       | 124 (30)       |                      |
| West  | 143 (20)                    | 27 (9)         | 116 (27)       |                      |
| Marital status  |                             |                |                | 0.154                |
| Married   | 211 (32)                    | 83 (31)        | 128 (33)       |                      |
| Separated/divorced  | 83 (14)                     | 45 (18)        | 38 (11)        |                      |
| Widowed   | 403 (49)                    | 169 (45)       | 234 (52)       |                      |
| Never married   | 34 (5)                      | 19 (6)         | 15 (4)         |                      |
| Owens own home  | 372 (56)                    | 152 (52)       | 220 (58)       | 0.288                |

| Covariate                                    | Overall                     | By LTCF type   |                | p-value <sup>a</sup> |
|--|-----------------------------|----------------|----------------|----------------------|
|  |                             | NH             | AL             |                      |
|  | n (weighted %) <sup>b</sup> | n (weighted %) | n (weighted %) |                      |
| Previously living alone                      | 336 (45)                    | 134 (41)       | 202 (48)       | 0.065                |
| Self-rated health                            |                             |                |                | <b>0.034</b>         |
| Excellent                                    | 48 (7)                      | 19 (6)         | 29 (8)         |                      |
| Very good                                    | 158 (24)                    | 54 (18)        | 104 (27)       |                      |
| Good   | 224 (28)                    | 98 (30)        | 126 (27)       |                      |
| Fair   | 208 (27)                    | 95 (29)        | 113 (26)       |                      |
| Poor   | 93 (13)                     | 50 (17)        | 43 (11)        |                      |
| <b>Outcomes</b>                              |                             |                |                |                      |
| Return to community                          | 36 (7)                      | 17 (7)         | 19 (6)         | 0.525                |
| Subsequent transition (NH to AL or AL to NH) | 58 (8)                      | 11 (4)         | 47 (11)        | <b>&lt;0.001</b>     |

LTCF = long-term care facility, NH = nursing home, AL = assisted living, SPPB = Short Physical Performance Battery, ADL = activity of daily living.

Bolded p-values are significant ( $p < 0.05$ ).

<sup>a</sup> p-values calculated using bivariate logistic regression for continuous variables and chi-squared tests for categorical variables.

<sup>b</sup> Analytic weights from year of NHATS enrollment were applied to calculate a weighted percentage more representative of the US population.

<sup>c</sup> Non-white race/ethnicities included: Black, Hispanic, American Indian, Asian, Native Hawaiian, and Other.

<sup>d</sup> Conditions included self-reported heart disease, arthritis, diabetes, lung disease, stroke, and/or cancer.

<sup>e</sup> Limitations included any difficulty or assistance in self-care activities (bathing, dressing, toileting, and eating) or difficulty, assistance, or use of assistive devices for mobility activities (getting out of bed and getting around inside).

**Table 2.**

Association of covariates with return to community living using bivariate and multivariable logistic regression.

|                                | <b>OR (95% CI)</b>      | <b>Model 1 aOR (95% CI)</b> | <b>Model 2 aOR (95% CI)</b> | <b>Model 3 aOR (95% CI)</b> |
|--------------------------------|-------------------------|-----------------------------|-----------------------------|-----------------------------|
| Age (per year)                 | <b>0.87 (0.82–0.92)</b> | <b>0.88 (0.83–0.93)</b>     | <b>0.88 (0.83–0.93)</b>     | <b>0.88 (0.83–0.94)</b>     |
| Gender, man                    | 2.15 (0.99–4.63)        | 1.48 (0.65–3.39)            | 1.61 (0.68–3.80)            | 1.36 (0.57–3.22)            |
| Race/ethnicity, non-white      | 1.79 (0.52–6.24)        | 1.32 (0.37–4.68)            | 1.37 (0.39–4.83)            | 1.42 (0.41–4.87)            |
| ADL limitations (per activity) | 0.91 (0.76–1.09)        |                             | 0.99 (0.83–1.18)            | 0.96 (0.79–1.17)            |
| Dementia                       | <b>0.35 (0.15–0.82)</b> |                             | <b>0.37 (0.15–0.90)</b>     | <b>0.33 (0.12–0.88)</b>     |
| Previously living alone        | <b>0.38 (0.18–0.79)</b> |                             |                             | <b>0.39 (0.17–0.89)</b>     |
| NH vs. AL                      | 1.28 (0.59–2.80)        |                             |                             | 1.21 (0.51–2.87)            |

Bolded values are statistically significant ( $p < 0.05$ ). No adjustments were made for multiple comparison.

OR = unadjusted odds ratio (bivariate analysis), aOR = adjusted odds ratio (multivariable analysis), CI = confidence interval, ADL = activity of daily living, NH = nursing home, AL = assisted living facility.