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Authors
Oh, Anna
Patel, Kanan
Boscardin, W John
et al.

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Social Support and Patterns of Institutionalization Among Older Adults: A Longitudinal Study

Anna Oh, RN, MPH, PhD[1], **Kanan Patel, MS**[2], **W. John Boscardin, PhD**[2], **Wendy Max, PhD**[1,3], **Caroline Stephens, GNP, PhD**[4], **Christine S. Ritchie, MD, MSPH**[2], **Alexander K. Smith, MD, MPH, MS**[2,5]

[1]Department of Social and Behavioral Sciences, UCSF

[2]Department of Medicine, Division of Geriatrics, UCSF

[3]Institute of Aging, UCSF

[4]Department of Community Health Systems, UCSF

[5]San Francisco VA Medical Center, San Francisco, CA

Abstract

Background—Most older adults want to remain at home and avoid transition to an institutional setting.

Methods—We used the National Health and Aging Trends Study (NHATS), a nationally representative survey of U.S. adults ages 65 and older to identify participants living at home in 2011 and describe their residential transitions through 2017. We used a Fine & Gray hazards model to estimate the risk of transition into an institutional setting, with death prior to institutionalization considered a competing risk. Primary predictors were social support factors (living spouse, lives with others, presence of social network, and participation in social activities). Covariates included age, gender, race, cognitive status, functional disability, multimorbidity, and Medicaid enrollment.

Results—In 2011, 4,712 NHATS participants were living at home (78±8 years, 57% female, 80% white, 10% probable dementia, 7% 3+ ADL disabilities). By 2017, 58% remained at home, 17% had either transitioned to an institution or died in an institution, and 25% died prior to institutionalization. In multivariable analyses that adjusted for age, gender, race, cognitive status, functional disability, multimorbidity, and Medicaid enrollment, participants were more likely to move out of the home into an institution if they had no social network (0 vs. 3+ people, subhazard

Corresponding author information: Anna Oh, RN, MPH, PhD, Department of Social and Behavioral Sciences, University of California, San Francisco, 3333 California Street, Suite 340, San Francisco, CA 94118, anna.oh@ucsf.edu, @anna0h.

Author contributions

- Study concept and design; acquisition of data; preparation of manuscript: Oh and Smith
- Data analysis and interpretation: Oh, Patel, and Smith
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ratio [sHR] 1.8, 95% confidence interval [CI] 1.2–2.5, p=.003) or lived alone (sHR 1.9, 95% CI 1.6–2.2, p<.0001). Older adults who enjoyed going to the movies, dinner, or the casino and visiting family or friends had a lower probability of institutionalization compared to participants who did not enjoy these activities or did not visit family or friends (adjusted sHR 0.7, 95% CI 0.6–0.9; adjusted sHR = 0.7, 95% CI 0.6–0.9, respectively).

Conclusion—Policy initiatives should target older adults with limited social support in order to reduce the risk of moving from home into an institution.

Introduction

Over 2.1 million people were institutionalized (i.e. transitioned to a nursing home [NH] or residential care facility for the elderly [RCFE]) in 2016 with an annual cost for a private room in a nursing home averaging approximately $100,000.[1,2] Yet most older adults would prefer to age-in-place in their homes.[3] Aging-in-place is sustained through social support and formal resources. Formal resources include home-and-community-based services (HCBS) like adult daycare, in-home support services, care coordination, transportation, and home modification.[4,5] Nonetheless, a complex set of factors leads to institutionalization of many older adults. Prior research has focused on medical, functional, cognitive, and economic predictors of institutionalization among older adults.[6–9]

Social support is derived from marital status, family composition, living arrangements, and participation in social and religious activities. Identifying older adults who need help with daily tasks (instrumental support) and are in need of meaningful social connections (socioemotional support) may reduce risk of institutionalization.[10] Comprehensive literature reviews and a meta-analysis showed instrumental support – being married, living with coresident family members, and having more nonkin social supports – lowered the odds of institutionalization.[7–9] However, this research is outdated and did not factor in sources of socioemotional support.

Thus, the goal of this study was to determine the role of social support in the transition patterns of community-dwelling older adults to institutionalization or death in a nationally representative sample of older adults. We looked at instrumental aspects of social support (living spouse, presence of social network, living with others) and sources of socioemotional support that comes from participation in social activities (church attendance; club meetings, classes or organized activities; going to the movies, dinner, or casino; and visiting family and friends).

Methods

Study design and sample

We used 2011-2017 (Rounds 1-7) data from the National Health and Aging Trends Study (NHATS), a nationally representative survey of U.S. adults age 65 and older. The study design and data collection procedures have been described previously.[11] The study sample consisted of 4,712 community-dwelling participants “living independently” at home at study entry in 2011 (baseline) and examined residential transitions, institutionalization, and death of these community-dwelling participants through 2017. Home settings included personal

private residences, self-reported retirement communities, mobile homes, and religious group quarters.

Variables

The primary outcome was time to placement in an institutional setting, defined as moving into a NH or a RCFE between 2012 and 2017. RCFEs include assisted living facilities, board and care, and group homes, and are generally paid for out-of-pocket by people who need a lower level of assistance than a NH provides. NHs and RCFEs were grouped together as RCFE residents still require help with daily care. Residential status was determined by direct responses from survey participants, proxy responses when survey participants were unable to complete the survey, and staff person responses when survey participants were living in an institution.[11]

Primary predictors included the following social support variables measured at baseline (with the exception of living spouse): living spouse (vs. death of a partner prior to baseline or in the previous year [2011–2017]); presence of a social network (zero people, one to two people, or three or more people in network [count variable derived from question that asked for names of and relationships to people who participant talked with most often about important things]); living with others (yes/no); participation in social activities: church attendance; club meetings, classes, or organized activities; going to the movies, dinner, or casino; and visiting family and friends (each activity as an individual measurement: yes/no). Covariates were measured at baseline and included age (<80 or ≥80 years), gender (male/female), race/ethnicity (white, black, Hispanic, and other), cognitive status, functional disability, multimorbidity, and Medicaid enrollment (baseline coverage: yes/no). Cognitive status was a derived variable reflecting three levels of cognitive impairment (no dementia, possible dementia, and probable dementia) based upon a combination of information that included self-reported doctor diagnosis of dementia, a score on the AD8 Dementia Screening Interview from proxy responses, and a cognition battery on memory, orientation, and executive function.[12] Functional disability was a derived variable of requiring assistance with activities of daily living (ADLs) (none, one or two ADLs, and three or more ADLs). ADLs included needing assistance with eating; bathing; toileting; dressing; going outdoors; moving inside one's home; and transferring in and out of bed. Multimorbidity was a derived, categorical variable reflecting number of self-reported doctor diagnoses of coexisting conditions (zero or one condition; two or more conditions): heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, and cancer.

Statistical analysis

We used standard descriptive statistics to summarize the baseline characteristics of the participants at entry to study. We used sampling weights provided by the NHATS to account for differential probabilities of selection and to adjust for any potential bias related to nonresponses.[11]

The sequence of transitions was summarized using Sankey diagrams. A Sankey diagram is a flow diagram developed in engineering that shows different states (i.e. residence locations in our figure) and transitions over time.[13] Participants started at home at baseline and were

tracked each year on whether they (i) remained alive in the same setting as the previous year, (ii) died prior to institutionalization, (iii) transitioned to either a NH/RCFE and were alive, or (iv) transitioned and died or died in a NH/RCFE.

We used a Fine & Gray competing risks hazards model to estimate the time to institutionalization, with death prior to institutionalization considered a competing risk.[14] Competing risk is considered a superior approach to survival analysis when subjects are exposed to more than one event or outcome of interest and the focus is on cause-specific hazards rather than standard hazards.[14] Here, participants experienced the competing risk when they died during follow-up and were not institutionalized (i.e. did not experience the outcome or event of interest). Participants were censored if they were alive at home in 2017 (Round 7) or lost to follow up in the years prior to 2017.

We estimated subhazard ratios (sHR) to determine the unadjusted and adjusted association between each potential risk factor and institutionalization. We adjusted for factors shown in prior studies to be associated with institutionalization: age, gender, race/ethnicity, cognitive status, functional disability, multimorbidity, and Medicaid enrollment.[6–8]

Sankey diagrams were created using RStudio (v1.1.383). All statistical analyses were completed using STATA version 14.2 (StatCorp, College Station, TX), with a two-tailed $P<.05$ used to define statistical significance.

Results

Baseline characteristics

4,712 NHATS participants were living at home in 2011. Baseline characteristics of the cohort included a mean age of 78 years (standard deviation [SD] 8.0), 57% female, 80% white, 10% probable dementia, and 7% needed help with three or more ADLs (Table 1).

Transitions

By 2017, 2,726 participants (58%) remained at home, 1,193 participants (25%) died in a non-institutional setting, 135 (3%) were institutionalized and living, and 658 (14%) were institutionalized and died (Figure 1). Of those who were alive in each year, the percentage of those who transitioned from one setting to another year-to-year averaged 3.6% (range 3.0%-4.1%). Of note, 1% on average per year transitioned to an RCFE and 2% to a NH; while almost 90% of study participants remained in the same setting (range 87.0%-90.1%). Once participants were institutionalized, very few (20 from RCFE and 10 from NH over 6 years) moved back into the home. Using population estimates, 21.3 million older adults living at home in 2011 and on average 426,000 of these individuals transitioning to institutional settings per year thereafter.

Predictors of institutionalization

The lack of social support (no social network, individuals who live alone, and lack of participation in social activities) were strong predictors of transitioning out of the home and into an institution (Table 2). Participants who had no social network (zero people in network) had a higher probability of institutionalization compared to participants with three

or more people in their social network (adjusted sHR=1.8, 95% CI 1.2–2.5). Participants who lived alone at baseline were 90% more likely to be institutionalized compared to those who lived with other people (adjusted sHR=1.9, 95% CI 1.6–2.2). In addition, participation in certain social activities was a strong predictor of delaying the transition out of the home and into an institution. Older adults who enjoyed going to the movies, dinner, or the casino and visiting family or friends had a lower probability of transition compared to participants who did not enjoy these activities or did not visit family or friends (adjusted sHR 0.7, 95% CI 0.6–0.9; adjusted sHR = 0.7, 95% CI 0.6–0.9, respectively). In addition, participants over 80 years; white participants, participants with possible or probable dementia, functional disability (requiring help with one to two ADLs), and with two or more coexisting conditions, were institutionalized at higher rates compared to participants younger than 80 years, Black and Hispanic participants, participants with no dementia, no functional disability, and zero or one coexisting condition.

Discussion

We found that social support, specifically defined as the lack of social network, living alone, or lack of participation in social activities, were significant in predicting institutionalization in a nationally representative survey of U.S. adults age 65 years and older. Our findings provides an updated evaluation of social support as risk factors for institutionalization and complements existing research on the medical, functional, and cognitive predictors of institutionalization.[6–9]

We found that older adults with zero people in their social network, who live alone, and who do not enjoy going out and visiting family or friends were institutionalized at higher rates compared to older adults with social networks, who live with others, and who enjoy going out and visiting family or friends. All of these predictors are markers for social isolation, defined as the complete or near-complete lack of contact with society.[15,16] Social isolation and loneliness is a growing public health problem due to its five-fold increase over the past three decades and associations with poor health status, mortality, and higher Medicare expenditures.[17–20]

In order to combat social isolation, a recent report by Perissinotto et al[21] recommends screenings, targeted interventions, and interdisciplinary team engagement. Screenings can occur at the Welcome to Medicare and annual wellness visits, utilize the predictors we found, and use short and validated measures such as the Berkman-Syme Social Network Index.[18] Targeted interventions (e.g. online resources and community programs) focus on the mechanism in which to enhance social support and increase social connectedness, and incidentally could offer social support.[21] Connect2Affect is an initiative spearheaded by AARP that has assembled an online directory of programs and services to help build social connections. Mon Ami in the San Francisco Bay Area offers companion services by matching older adults with college students. Additional community programs include home visits with care coordinators and nurses and the Program of All-Inclusive Care for the Elderly, which provides transportation to day health centers from the home.[22–24]

Currently, many older adults and their families who need long-term services and supports pay out-of-pocket for residential care communities or rely on unpaid care in the home.[25] Transition to RCFEs are appropriate when community-dwelling older adults require more intensive care needs and may provide the older adult with an additional source of social support.[26] For continued care in the home, we recommend a continued push to cover home visits under Medicare with particular eligibility criteria, such as the presence of Alzheimer's or multiple functional impairments.[18,27] Community programs mentioned earlier would benefit from continued support, e.g. through shifting of Medicaid funds toward successful programs or expanded support for Medicaid waivers that financially cover HCBS.[28,29] Both home visit and HCBS providers should be trained to recognize loneliness and social isolation.

Limitations of this study include use of baseline data that did not include any changes in cognitive and functional status (i.e. deterioration or improvements) that occurred over the five years. We also did not examine if a hospitalization occurred prior to transition into a nursing home, whether hospice or palliative care was available to participants prior to death or distinguish differences between care provided in RCFE versus institution. Earlier initiation of hospice and palliative care could encourage care concordant with patient preferences.[30]

The passage of the Affordable Care Act has supported interventions and policies that support older adults to age-in-place. More importantly, our findings on social support can inform the development of prognostic tools that identify community-dwelling older adults who are at-risk for institutionalization over a multi-year period.

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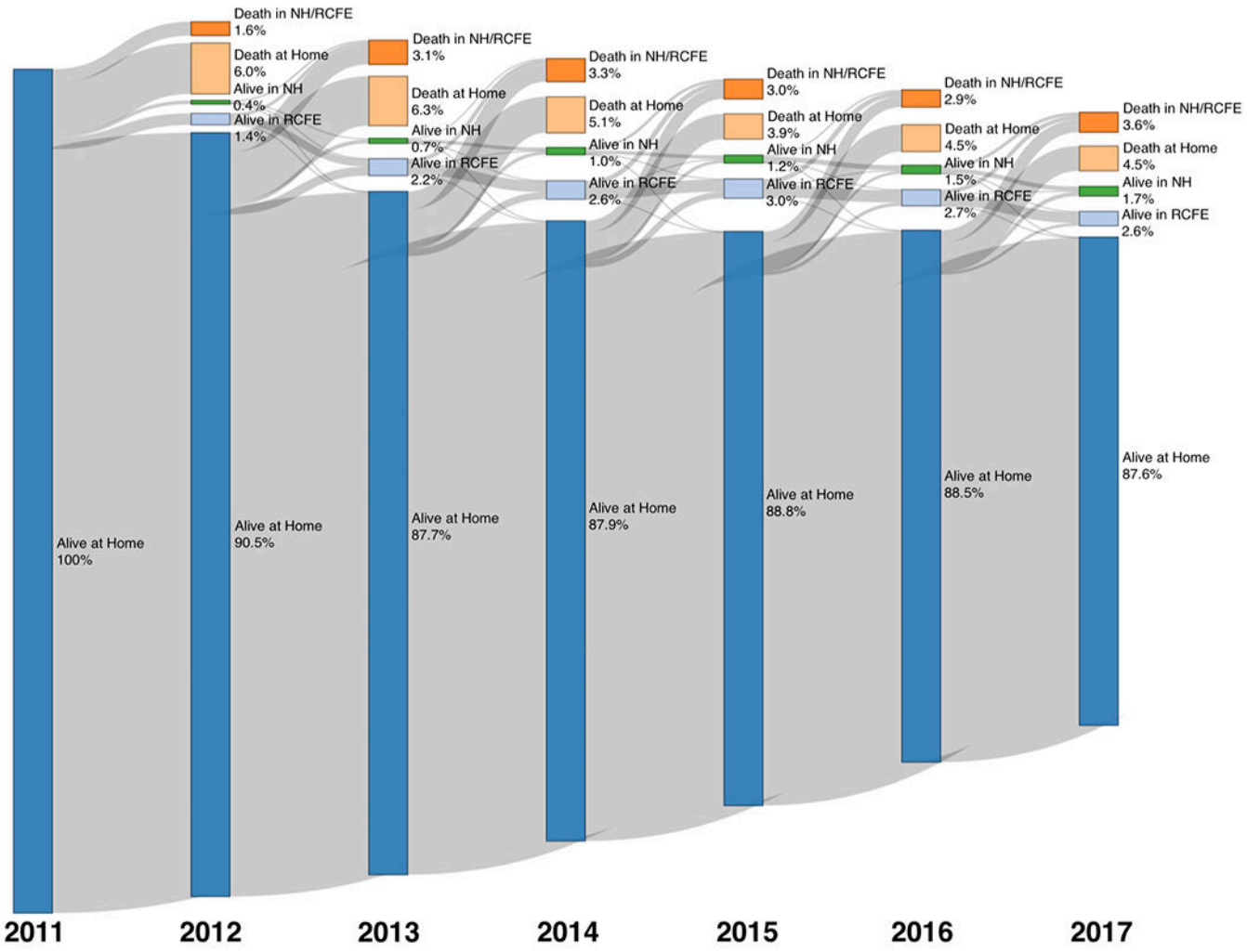

Figure 1.

Sequence of residential transitions*, institutionalization, and death in a longitudinal, nationally representative study of older adults from 2011-2017

*Percentages refer to percent of participants who transitioned to each residential setting from respective residential settings in the previous year NH Nursing home; RCFE Residential care facility for the elderly

Table 1.

Baseline Characteristics of Participants

Characteristics	**N = 4,712 (%)***
Age (years)	
<80	2,589 (70.7)
≥80	2,123 (29.3)
Female	2,759 (57.1)
Race/ethnicity	
White	3,339 (80.5)
Black	994 (8.2)
Hispanic	237 (6.6)
Other	142 (4.6)
Dementia	
No dementia	3,406 (76.7)
Possible dementia	614 (10.6)
Probable dementia	692 (9.7)
Functional disability (needs help with)	
0 ADL	3,555 (82.4)
1-2 ADLs	627 (10.4)
3+ ADLs	530 (7.2)
Multimorbidity (multiple coexisting conditions)†	
0-1	1,391 (35.0)
2+	3,319 (65.0)
Has Medicaid†	724 (12.3)
Spouse is deceased or experienced spouse death in last year (2011–2017)	2,127 (46.5)
Social network†	
0	297 (6.6)
1-2	2,834 (64.8)
3+	1,212 (28.5)
Lives alone†	1,614 (29.8)
Participation in social events (in last month)†	
Church attendance	2,720 (56.8)
Club meetings, classes, or organized activities	1,716 (37.4)
Enjoyment activities (movie, dinner, gambling)	3,409 (78.2)
Visited family or friends	4,001 (87.4)

*Based on weighted population estimates

†With some missing values: multimorbidity (n=2), Medicaid (n=110), social network (n=369), live alone (n=16), church attendance (n=3), club meetings, classes, or organized activities (n=4), enjoyment activities (n=5), visited family or friends (n=4)

Table 2.

Association between Predictors and Time to Institutionalization

Variable	Adjusted sub Hazard Ratio [95% Confidence Interval]	p-value
Age (years)		
<80	1.0 [Reference]	
≥80	3.2 [2.7, 3.9]	<0.0001
Sex		
Male	1.0 [Reference]	
Female	0.99 [0.8, 1.2]	0.90
Race		
White	1.0 [Reference]	
Black	0.7 [0.6, 0.9]	0.002
Hispanic	0.4 [0.2, 0.6]	<0.0001
Other	0.6 [0.3, 1.1]	0.11
Dementia		
No dementia	1.0 [Reference]	
Possible dementia	1.8 [1.5, 2.4]	<0.0001
Probable dementia	2.8 [2.2, 3.7]	<0.0001
Functional disability		
0 ADL	1.0 [Reference]	
1-2 ADLs	1.4 [1.2, 1.8]	0.002
3+ ADLs	1.3 [1.0, 1.8]	0.07
Multimorbidity (multiple coexisting conditions)		
0-1	1.0 [Reference]	
2+	1.3 [1.0, 1.6]	0.01
Has Medicaid (no)	1.0 [Reference]	
Yes	1.6 [1.3, 2.0]	<0.0001
Spouse is deceased or experienced spouse death in last year (2011-2017) (none)	1.0 [Reference]	
Yes	1.1 [0.9, 1.4]	0.18
Social network		
3+	1.0 [Reference]	
1-2	1.1 [0.9, 1.4]	0.27
0	1.8 [1.2, 2.5]	0.003
Lives alone (no)	1.0 [Reference]	
Yes	1.9 [1.6, 2.2]	<0.0001
Church attendance (no)	1.0 [Reference]	0.35
Yes	0.9 [0.8, 1.1]	0.35

Variable	Adjusted sub Hazard Ratio [95% Confidence Interval]	p-value
Club meetings, classes, or organized meetings (no)	1.0 [Reference]	
Yes	0.9 [0.7, 1.0]	0.13
Enjoyment activities (movie, dinner, gambling) (no)	1.0 [Reference]	
Yes	0.7 [0.6, 0.9]	0.001
Visited family or friends (no)	1.0 [Reference]	
Yes	0.7 [0.6, 0.9]	0.006