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Care coordination, social support, home health, and hospice: working towards keeping older adults with dementia in the community

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Care Coordination, Social Support, Home Health, and Hospice: Working Towards
Keeping Older Adults with Dementia in the Community

by
Anna Oh

DISSERTATION
Submitted in partial satisfaction of the requirements for degree of
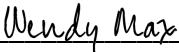DOCTOR OF PHILOSOPHY

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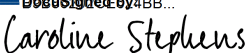DocuSigned by:

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"The greatness of a community is most accurately measured

by the compassionate actions of its members."

-- Coretta Scott King

Abstract

Care coordination, social support, home health, and hospice: working towards keeping older adults with dementia in the community

Anna Oh

Community-dwelling older persons with dementia (PWD) rely on informal, unpaid caregivers (CGs) and formal, paid services and resources in order to age-in-place in the home. Informal support includes families, neighbors, community members, and social support. Formal services and support include home-and-community-based resources, home health, and hospice services. Additional and updated information on informal and formal sources of care is needed in order to first, provide high-quality dementia and end-of-life care for community-dwelling PWD and second, delay the time of moving out of the home and into an institution.

We used the National Health and Aging Trends Study (NHATS), a nationally representative survey, to estimate the risk of transition out of the home and into an institution with sources of social support as our primary predictors. We used NHATS data linked to Medicare claims to specifically examine home health and hospice service use in the last-year-of-life for community-dwelling PWD who died at home. Finally, we reviewed the characteristics of seven care coordination programs for PWD in order to determine the program's core components and facilitators and barriers to delivering collaborative dementia care that support the PWD and their informal CG.

The findings of this dissertation research have the ability to provide insight into the life of community-dwelling PWD prior to moving out of the home and into an institution and prior to death at home. Above all, the findings from this research will support community-dwelling PWD to age-in-place by assuring their social support and formal care needs are addressed and met.

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Chapter 1: Introduction to the dissertation

In the U.S. alone, an estimated 5.7 million Americans have Alzheimer's disease (AD) and 5.5 million of these people are 65 years and older.[1] Annual estimates of the monetary (formal and informal) costs of dementia in the U.S. range from $159 billion to $215 billion.[2] Monetary costs of formal care are attributed to nursing home care and agency-provided home care, with costs borne by families, Medicare, and Medicaid. Costs of informal care are attributed to lost wages because of time spent on caregiving and costs of equivalent service and is provided by families of PWD.

Nursing home placement or institutionalization often occurs with disease progression and when a higher level of care than can be provided in the home is needed. In the early 2000s, almost two-thirds of dementia-related deaths occurred in the nursing home.[3] However, the past fifteen years has seen a shift where deaths in the nursing home have decreased by approximately 20% and the proportion of PWD dying at home has increased.[1,4] This shift reflects most older adults' preference to age-in-place and die in their homes.[5]

In order to live and die in the home and delay institutionalization, PWD rely on informal, unpaid caregivers (CGs) and formal, paid services and resources. Informal CGs are primarily spouses and coresident family members (sources of instrumental support, i.e. provide help with daily tasks) who step in and help with daily tasks and make treatment and economic decisions.[6,7] Formal services and resources include adult day care, in-home support services, care coordination, and transportation (all considered part of home-and-community-based services). Formal programs also provide social care services, medications and symptom management, and appropriate equipment and home adaptations.[8]

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Prior research showed sources of instrumental support and meaningful social connections (socioemotional support) may lower the risk of institutionalization.[9–12] With respect to formal services, few studies have examined home health service and studies of hospice care were done in the nursing home setting rather than the home setting.[3,13] Overall, this research is outdated or limited. In order to provide high-quality end-of-life care for community-dwelling PWD, additional, updated information is needed. This information can guide health care providers, clinicians, health systems, and policymakers to assess needs for social support (instrumental and socioemotional support) and proactively recommend formal services and resources in order to delay institutionalization.

This dissertation addresses the provision of care at the end-of-life that is needed to improve quality of life for PWD and to permit them to remain in their homes until the end of their lives. The first two papers explore the use of social support and formal services used by older adults in the community and the third paper reviews a new model of care for these adults and their caregivers – dementia care coordination programs.

The purpose of the first dissertation paper, "Social support and patterns of institutionalization among older adults: a longitudinal study" (in review) and its supplemental appendix 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. The supplemental appendix examined the interactive effects of social support and cognitive impairment (participants with probable dementia [n=692] vs. participants with no dementia [n=3,406]). We theorized that PWD with sources of instrumental and socioemotional support would have lower risks of institutionalization.

The second dissertation paper, "Home health and hospice service use at the end-of-life among community-dwelling older adults with dementia" examined home health and hospice service use in the last year of life among community-dwelling PWDs who died at home. The purpose of this study was to describe patterns of formal service use and precipitating causes for the services, which have not been described before. More importantly, we wanted to compare the profile and resulting formal service use patterns of these PWD who were able to die at home (n=226) with people without dementia who died at home (n=228). A secondary objective was to distinguish features that allowed community-dwelling PWD to effectively age-in-place.

The purpose of the third dissertation paper "Care coordination for people with dementia and their informal caregivers: key components, workforce implications, and implementation considerations going forward" was to examine seven care coordination programs – another resource for community-dwelling PWD – and their characteristics (unique environments, processes, and implementation processes). Our aim was that this examination would provide examples for other primary care practices and academic medical centers that are looking to expand or transform the mechanisms they currently use to deliver dementia care. This narrative literature review examined the core components of seven previously implemented dementia care coordination programs; identified facilitators and barriers to delivering dementia care in these care coordination programs; and provided implementation considerations as health systems initiate linkages with community-based resources. We used the Consolidated Framework for Implementation Research to compare programs and help identify the facilitators, barriers, and implementation considerations.

The final chapter presents a synthesis of the dissertation research on the role and influence of social support and formal services (home health, hospice, and care coordination) on

supporting community-dwelling PWD. This final chapter discusses the implications of these

findings for clinical practice, policy, and offers suggestions for future research.

References

1. Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2018;14(3):367-429. doi:10.1016/j.jalz.2018.02.001

2. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med*. 2013;368(14):1326-1334. doi:10.1056/NEJMsa1204629

3. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc*. 2005;53(2):299-305. doi:10.1111/j.1532-5415.2005.53118.x

4. Taylor CA, Greenlund SF, McGuire LC, Lu H, Croft JB. Deaths from Alzheimer's Disease — United States, 1999–2014. *MMWR Morb Mortal Wkly Rep*. 2017;66:521-526. doi:10.15585/mmwr.mm6620a1

5. Barrett L. *Home and Community Preferences of the 45+ Population 2014*. AARP Research Center; 2014. https://www.aarp.org/content/dam/aarp/research/surveys_statistics/il/2015/home-community-preferences.doi.10.26419%252Fres.00105.001.pdf.

6. Wolff JL, Spillman BC, Freedman VA, Kasper JD. A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Intern Med*. 2016;176(3):372-379. doi:10.1001/jamainternmed.2015.7664

7. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The Disproportionate Impact Of Dementia On Family And Unpaid Caregiving To Older Adults. *Health Aff Proj Hope*. 2015;34(10):1642-1649. doi:10.1377/hlthaff.2015.0536

8. Mogan C, Lloyd-Williams M, Harrison Dening K, Dowrick C. The facilitators and challenges of dying at home with dementia: A narrative synthesis. *Palliat Med*. 2018;32(6):1042-1054. doi:10.1177/0269216318760442

9. Miller EA, Weissert WG. Predicting elderly people's risk for nursing home placement, hospitalization, functional impairment, and mortality: A synthesis. *Med Care Res Rev MCRR*. 2000;57(3):259-297. doi:10.1177/107755870005700301

10. Kasper JD, Pezzin LE, Rice JB. Stability and changes in living arrangements: Relationship to nursing home admission and timing of placement. *J Gerontol B Psychol Sci Soc Sci*. 2010;65(6):783-791. doi:10.1093/geronb/gbq023

11. Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. *Med Care*. 2009;47(2):191-198. doi:10.1097/MLR.0b013e31818457ce

12. Cohen S. Social relationships and health. *Am Psychol*. 2004;59(8):676-684. doi:10.1037/0003-066X.59.8.676

13. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc*. 2010;58(12):2284-2291. doi:10.1111/j.1532-5415.2010.03185.x

Chapter 2: Social support and patterns of institutionalization among older adults: a longitudinal study

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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 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.

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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.

References

1. Harris-Kojetin L, Sengupta M, Lendon J, Rome V, Valverde R, Caffrey C. *Long-Term Care Providers and Services Users in the United States, 2015-2016*. Hyattsville, MD: National Center for Health Statistics; 2019. https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf.

2. Genworth. *Summary of 2016 Survey Findings*. https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/131168_050516.pdf. Accessed May 28, 2019.

3. Barrett L. *Home and Community Preferences of the 45+ Population 2014*. AARP Research Center; 2014. https://www.aarp.org/content/dam/aarp/research/surveys_statistics/il/2015/home-community-preferences.doi.10.26419%252Fres.00105.001.pdf.

4. Tang F, Pickard JG. Aging in Place or Relocation: Perceived Awareness of Community-Based Long-Term Care and Services. *J Hous Elder*. 2008;22(4):404-422. doi:10.1080/02763890802458429

5. Young Y, Kalamaras J, Kelly L, Hornick D, Yucel R. Is Aging in Place Delaying Nursing Home Admission? *J Am Med Dir Assoc*. 2015;16(10):900.e1-900.e6. doi:10.1016/j.jamda.2015.07.017

6. Wolinsky FD, Callahan CM, Fitzgerald JF, Johnson RJ. The Risk of Nursing Home Placement and Subsequent Death Among Older Adults. *J Gerontol*. 1992;47(4):S173-S182. doi:10.1093/geronj/47.4.S173

7.   Miller EA, Weissert WG. Predicting elderly people's risk for nursing home placement, hospitalization, functional impairment, and mortality: a synthesis. *Med Care Res Rev MCRR*. 2000;57(3):259-297. doi:10.1177/107755870005700301

8.   Gaugler JE, Duval S, Anderson KA, Kane RL. Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatr*. 2007;7:13. doi:10.1186/1471-2318-7-13

9.   Kasper JD, Pezzin LE, Rice JB. Stability and changes in living arrangements: relationship to nursing home admission and timing of placement. *J Gerontol B Psychol Sci Soc Sci*. 2010;65(6):783-791. doi:10.1093/geronb/gbq023

10.   Cohen S. Social relationships and health. *Am Psychol*. 2004;59(8):676-684. doi:10.1037/0003-066X.59.8.676

11.   Kasper JD, Freedman VA. *National Health and Aging Trends Study User Guide: Rounds 1-7 Final Release*. Baltimore: Johns Hopkins University School of Public Health; 2018. http://www.nhats.org.

12.   Kasper JD, Freedman VA, Spillman BC. *Classification of Persons by Dementia Status in the National Health and Aging Trends Study*. Baltimore: Johns Hopkins University School of Public Health; 2013. https://www.nhats.org/scripts/documents/DementiaTechnicalPaperJuly_2_4_2013_10_23_15.pdf. Accessed May 25, 2017.

13.   Huang C-W, Lu R, Iqbal U, et al. A richly interactive exploratory data analysis and visualization tool using electronic medical records. *BMC Med Inform Decis Mak*. 2015;15:92. doi:10.1186/s12911-015-0218-7

14.   Fine JP, Gray RJ. A Proportional Hazards Model for the Subdistribution of a Competing Risk. *J Am Stat Assoc*. 1999;94(446):496-509. doi:10.2307/2670170

15. Klinenberg E. Social Isolation, Loneliness, and Living Alone: Identifying the Risks for Public Health. *Am J Public Health*. 2016;106(5):786-787. doi:10.2105/AJPH.2016.303166

16. McPherson M, Smith-Lovin L, Brashears ME. Social Isolation in America: Changes in Core Discussion Networks over Two Decades. *Am Sociol Rev*. 2006;71(3):353-375. doi:10.1177/000312240607100301

17. Cudjoe TKM, Roth DL, Szanton SL, Wolff JL, Boyd CM, Thorpe RJ. The Epidemiology of Social Isolation: National Health & Aging Trends Study. *J Gerontol B Psychol Sci Soc Sci*. March 2018. doi:10.1093/geronb/gby037

18. Flowers L, Houser A, Noel-Miller C, et al. *Medicare Spends More on Socially Isolated Older Adults*. AARP Public Policy Institute; 2017. doi:10.26419/ppi.00016.001

19. Uchino BN. Social support and health: a review of physiological processes potentially underlying links to disease outcomes. *J Behav Med*. 2006;29(4):377-387. doi:10.1007/s10865-006-9056-5

20. Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspect Psychol Sci J Assoc Psychol Sci*. 2015;10(2):227-237. doi:10.1177/1745691614568352

21. Perissinotto C, Holt-Lunstad J, Periyakoil VS, Covinsky K. A Practical Approach to Assessing and Mitigating Loneliness and Isolation in Older Adults. *J Am Geriatr Soc*. February 2019. doi:10.1111/jgs.15746

22. Friedman SM, Steinwachs DM, Rathouz PJ, Burton LC, Mukamel DB. Characteristics Predicting Nursing Home Admission in the Program of All-Inclusive Care for Elderly People. *The Gerontologist*. 2005;45(2):157-166. doi:10.1093/geront/45.2.157

23. Peikes D, Chen A, Schore J, Brown R. Effects of care coordination on hospitalization, quality of care, and health care expenditures among Medicare beneficiaries: 15 randomized trials. *JAMA*. 2009;301(6):603-618. doi:10.1001/jama.2009.126

24. Fraze TK, Beidler LB, Briggs ADM, Colla CH. 'Eyes In The Home': ACOs Use Home Visits To Improve Care Management, Identify Needs, And Reduce Hospital Use. *Health Aff (Millwood)*. 2019;38(6):1021-1027. doi:10.1377/hlthaff.2019.00003

25. Willink A, Davis K, Mulcahy J, Wolff JL. *Use of Paid and Unpaid Personal Help by Medicare Beneficiaries Needing Long-Term Services and Supports*. Commonwealth Fund; 2017. https://www.commonwealthfund.org/publications/issue-briefs/2017/nov/use-paid-and-unpaid-personal-help-medicare-beneficiaries-needing.

26. Grabowski DC, Stevenson DG, Cornell PY. Assisted living expansion and the market for nursing home care. *Health Serv Res*. 2012;47(6):2296-2315. doi:10.1111/j.1475-6773.2012.01425.x

27. Davis K, Willink A, Schoen C. Medicare Help At Home | Health Affairs. Health Affairs. https://www.healthaffairs.org/do/10.1377/hblog20160413.054429/full/. Published April 13, 2016. Accessed February 5, 2019.

28. O'Malley Watts M, Musumeci M, Ubri P. *Medicaid Section 1115 Managed Long-Term Services and Supports Waivers: A Survey of Enrollment, Spending, and Program Policies*. The Henry J. Kaiser Family Foundation; 2017:25. http://files.kff.org/attachment/Report-Medicaid-Section-1115-Managed-Long-Term-Services-and-Supports-Waivers.

29. Centers for Medicare and Medicaid Services. *PACE Fact Sheet*.; n.d. https://www.cms.gov/Medicare/Health-Plans/pace/downloads/PACEFactSheet.pdf.

30. Teno JM, Gozalo PL, Bynum JPW, et al. Change in end-of-life care for Medicare

beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and

2009. *JAMA*. 2013;309(5):470-477. doi:10.1001/jama.2012.207624

Table 2.1 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 2.2 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]	0.18
Yes	1.1 [0.9, 1.4]	
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

Variable	Adjusted sub Hazard Ratio [95% Confidence Interval]	p-value
Church attendance (no)	1.0 [Reference]	
Yes	0.9 [0.8, 1.1]	0.35
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
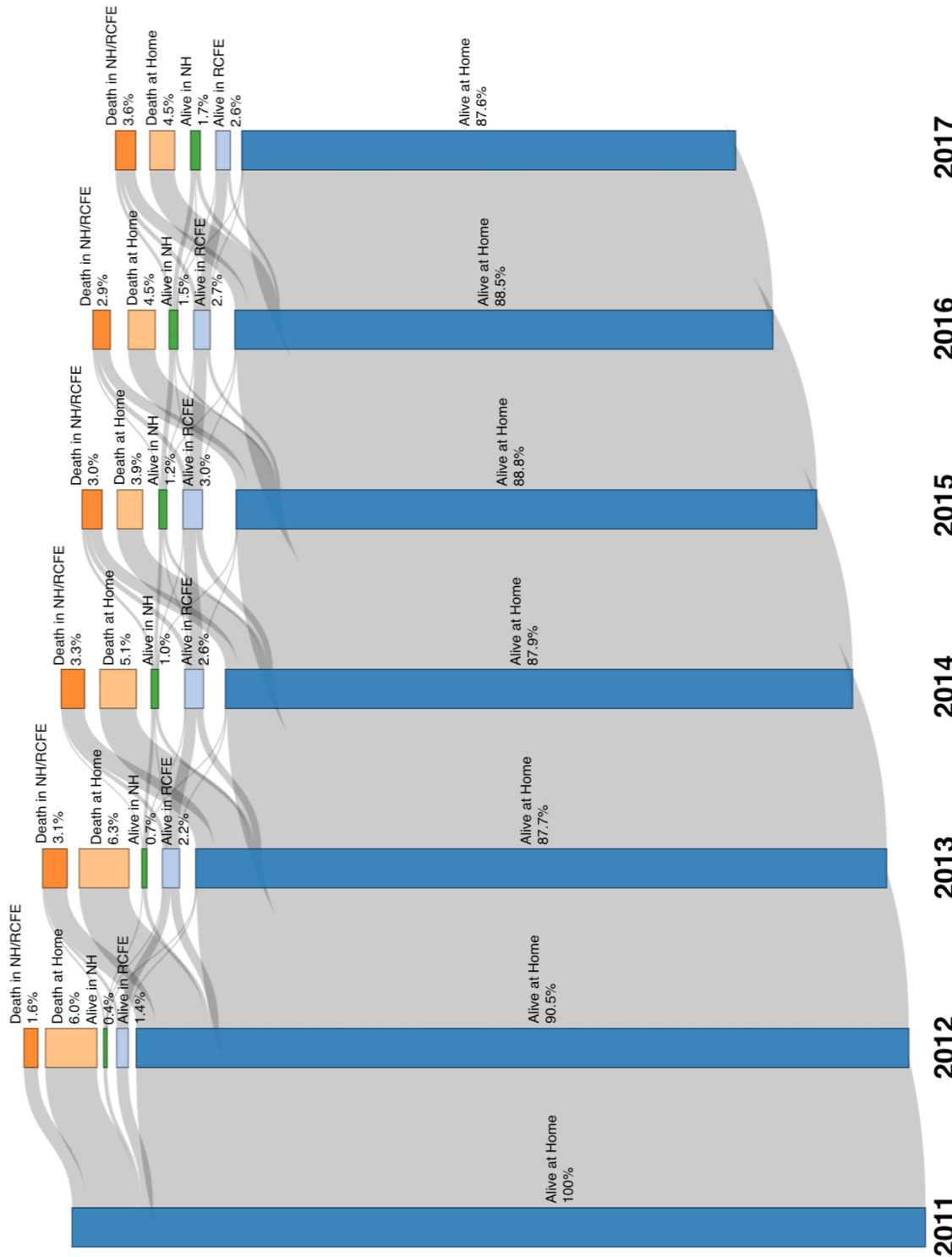
Figure 2.1 Sequence of residential transitions*, institutionalization, and death in a longitudinal, nationally representative study of older adults from 2011-2017

*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

Chapter 2 Appendix: Cognitive impairment subanalysis

Introduction

The decision to institutionalize a person with dementia (PWD) is based on characteristics of the PWD, caregiver, and the social, cultural, and economic circumstances.[1,2] With disease progression, older adults with dementia require increased help with basic ADLs and instrumental activities of daily living, such as household chores, preparing meals, paying bills, shopping, or using transportation.[3] PWD typically rely on unpaid caregivers, such as family members, friends, or other unpaid, informal caregivers for help with self-care activities and household activities.[4] Social relationships derived from participation and engagement in social activities may provide an additional, informal source of support.

Previous studies that examined the role of social support primarily focused on the support and resources available to the caregiver.[5] A systematic review of social support interventions for PWD found two studies limited in their small sample size and heterogeneous characteristics.[6] In these two studies, sources of socioemotional support (i.e. opportunities for venting and personal emotional expressions of empathy, caring, reassurance and trust) included individual counseling within cognitive behavioral therapy and social support group interventions. Non-intervention sources of socioemotional support for the PWD have not been studied in the literature. Thus, the purposes of this subanalysis is to examine the interactive effects of social support, including participation in social activities, and cognitive impairment (NHATS participants with probable dementia vs. NHATS participants with no dementia) on institutionalization.

Methods

Additional details on study sample and design

The National Health and Aging Trends Study (NHATS) is a nationally representative survey, designed to study the functioning of U.S. adults age 65 and older.[7,8] Annual in-person interviews were conducted with participants or proxy respondents if participants were unable to respond in order to document changes over time. Interviews collected information on the participants' physical health and cognitive capacity; how activities of daily living (ADLs) were carried out; physical, social, and technological aspects of the living environment; and participation in social and civic life activities. NHATS public use data files consist of a Tracker file that includes all persons ever sampled for NHATS; a Sample Persons file (responses from community-dwelling survey participants and staff persons for institutionalized survey participants [Facility Questionnaire]), and an Other Persons file (responses from proxy respondents). In addition, a Last Month of Life interview captured end-of-life details on place, quality of end-of-life care, and daily activities for decedents since the prior interview from proxy respondents.

At baseline in Round 1, 8,245 participants were enrolled in NHATS. For this longitudinal analysis, study participants were excluded from our study sample group (n=3,533) if during Rounds 1 through 7, they "dropped out" (i.e. were too ill to participate or physically/mentally unable to participate and without a proxy; unavailable, refused, were unable to be located; or did not complete the Sample Persons, Other Persons, or Facility Questionnaire) or had missing data on outcome, social support predictors, or covariates. Thus, our study sample consisted of 4,712 community-dwelling participants "living independently" at baseline in 2011. We examined

residential transitions, institutionalization, and death of these community-dwelling participants through 2017. Death was determined using the Tracker file (rXstatus variable).

We determined residential status for each NHATS round using the Tracker file and the Sample Persons file. The rXstatus variable in the Tracker file determined if the residence was in a NH. In addition, staff persons for institutionalized survey participants and proxy respondents could describe the residence as a nursing home (hhXkindplace, fqXfacdescr, fqXdfacarea, and fqXassdnrsng variables). We did not specifically distinguish between short- versus long-term nursing home placement but continued to assess the residential status for every participant for each subsequent NHATS round until participant death or censoring in 2017 (Round 7).

For RCFEs, participants described the residence as (i) a group home, board and care, supervised housing, assisted living facility or a continuing care retirement community (htXplacedesc and hhXplacekind variables) or (ii) a multi-unit building with assisted living or nursing home units that offered meals for residents, help with medication administration, bathing, or dressing (reXresistrct, htXdiffareun, htXmeals, and htXhelpmedbd variables). Home settings included personal private residences, retirement communities or senior housing communities, mobile homes, and religious group quarters (hhXplacedesc, hhXplacekind, and reXresistrct variables). Participants did not receive any meals, assistance with medication administration, bathing, or dressing (htXretiresen, htXmeals, and htXhelpmedbd variables) for retirement communities and senior housing communities that were considered to be home settings.

Statistical analysis for cognitive impairment subanalysis

For the purposes of this analysis, we specifically compared participants classified with probable dementia versus participants classified with no dementia. We examined differences

between participants with probable dementia and participants with no dementia at baseline via descriptive statistics (χ^2 tests of independence). In addition, we used stratified analyses to assess the effect of cognitive impairment on the relationship between social support and institutionalization while adjusting for covariates from the main model. First, we adjusted for potential confounders for the relationship between social support and risk of institutionalization (Model 1 - adjusted sub hazard ratio from the main model). Next, we included an interaction term between degree of cognitive impairment and each individual social support variable in order to determine if the risk of institutionalization was higher among participants with probable dementia compared with participants with no dementia (Model 2).

Results

Differences in baseline characteristics between older adults with probable dementia and no dementia

In 2011, 692 NHATS participants had probable dementia and were living at home while 3,406 NHATS participants had no dementia and were living at home. These two groups were different in their baseline characteristics. Baseline characteristics of the probable dementia group was mean age of 84 years (SD 7.0), 61% female, 68% white, 36% needed help with three or more ADLs, 73% had two or more coexisting conditions, and 27% were receiving financial assistance from Medicaid. In comparison, baseline characteristics of the no dementia group was mean age of 77 years (SD 7.5), 57% female, 84% white, 3% needed helped help with three or more ADLs, 63% had two or more coexisting conditions, and 9% were receiving financial assistance from Medicaid (Table 2.3).

For the social support variables, more participants with probable dementia had a deceased spouse or experienced death of their spouse in the last year compared to participants with no

dementia (62% vs. 43%), had zero people in their social network (11% vs. 6%), and lived alone (32% vs. 29%). As expected, participants with probable dementia were less likely to participate in social events than participants with no dementia (church attendance 43% vs. 58%; club meetings, classes, or organized activities (16% vs. 42%); going to the movie, dinner, or gambling (53% vs. 83%); and visiting family or friends (75% vs. 90%)).

Differences in transition patterns

Transition patterns were significantly different between participants with probable dementia and participants with no dementia (Figure 2.2). By 2017, 114 (16%) of participants with probable dementia at baseline remained at home, 312 (45%) died at home, 34 (5%) were institutionalized and living, and 232 (34%) were institutionalized and died. In comparison, 2,345 (69%) of participants with no dementia at baseline remained at home, 676 (20%) died at home, 2% (n=81) were institutionalized and living, and 9% (n=304) were institutionalized and died. Of those who were alive in each year, participants with probable dementia were more likely to transition from one setting to another year-to-year than participants with no dementia (average 8.4% vs. 2.7%). Three percent of participants with probable dementia on average per year transitioned to an RCFE (vs. 0.6% of participants with no dementia) and 6% transitioned to a NH (vs. 1%). Using population estimates, 2.2 million older adults with probable dementia were living at home in 2011. On average, 124,000 of these individuals transitioned to institutional settings per year and 132,000 individuals died at home per year. In contrast, 16.8 million older adults had no dementia and were living at home in 2011.

Predictors of institutionalization for participants with probable dementia and no dementia

The lack of social support (deceased spouse, no social network, living alone, and lack of participation in social activities) were strong predictors of transitioning out of the home and into

an institution for persons with no dementia (Table 2.4). The relationship between social support

and institutionalization was not as predictive in participants with probable dementia. In

participants with no dementia, those with a deceased spouse, no social network, and who lived

alone had a higher probability of institutionalization compared to those with a living spouse,

three or more people in their social network, and who lived with other people (adjusted sHR=1.5,

95% CI 1.2-1.9; adjusted sHR=1.8, 95% CI 1.2-2.9; and adjusted sHR = 2.2, 95% CI 1.8-2.8,

respectively). Similar to the main model, participation in certain social activities was a strong

predictor of delaying the transition out of the home and into an institution. In participants with no

dementia, those who went to club meetings, classes or organized meetings; enjoyed going out for

a movie, dinner, or gambling; or visited family or friends had a lower probability of transition

compared to participants who did not go to club meetings, classes or organized meetings; did not

go out to the movies, dinner, or the casino; or did not visit family or friends (adjusted sHR=0.8,

95% CI 0.6-1.0; adjusted sHR=0.6, 95% CI 0.4-0.8; and adjusted sHR = 0.5, 95% CI 0.4-0.7,

respectively).

Interactions existed between cognitive impairment and lack of social support

(experiencing death of spouse and lack of participation in social activities) that predicted

transitions out of the home and into an institution (Table 2.5). While lack of social network and

living alone at baseline increased the probability of institutionalization in the main model, this

probability of institutionalization did not vary between participants with probable dementia and

no dementia (adjusted sHR for interaction = 1.2, 95% CI 0.4-2.9; adjusted sHR for interaction =

0.8, 95% CI 0.5-1.1). Death of spouse was not predictive of risk of institutionalization in the

main model but a significant interaction existed between cognitive impairment and death of a

spouse. The negative interaction effect (adjusted sHR = 0.5, 95% CI 0.4-0.8) revealed that the

effect of spouse death was bigger if participants had no dementia. Participants with no dementia with death of a spouse had a higher probability of institutionalization compared to participants with no dementia who had a living spouse (adjusted sHR = 1.5, 95% CI 1.2-1.9, results not shown).

Interactions also existed between cognitive impairment and certain social activities (going to the movies, dinner, or casino or visiting family or friends [adjusted sHR =1.8, 95% CI 1.3-2.9; adjusted sHR = 2.2, 95% CI 1.4-3.5]). Participants with dementia who went to the movies, dinner, or casino, or visited family or friends had a lower probability of institutionalization compared to participants with no dementia who did not go to the movies, dinner, or casino, or visited family or friends (adjusted sHR = 0.6, 95% CI 0.4-0.8; adjusted sHR = 0.5, 95% CI 0.4-0.7, results not shown).

Discussion

This subanalysis compared residential transitions between participants with dementia and participants with no dementia and examined if the relationship between social support and institutionalization was different between NHATS participants with probable dementia and NHATS participants with no dementia. In examining residential transitions, we found that (i) participants with dementia who moved into institutional settings often died quickly and (ii) more participants with dementia who reside at home ended up dying at home than in an institution.

We found that in this nationally representative survey of U.S. adults ages 65 years and older, certain aspects of social support, specifically death of a spouse and lack of participation in social activities, and their role in predicting institutionalization, were significantly different between participants with probable dementia and no dementia. This relationship controlled for differences in age, gender, race/ethnicity, functional disability, multimorbidity, and Medicaid

enrollment. Interestingly, the role of social support were strong predictors for institutionalization in participants with no dementia. Participants with no dementia who experienced death of a spouse (i.e. lost a potential source of social support) were 50% more likely to be institutionalized than participants who had a living spouse. Participants with no dementia who enjoyed going to the movies, dinner, gambling, or visiting family and friends had a 40% and 50% risk reduction, respectively, in being institutionalized compared to those participants with no dementia who did not enjoy going to the movies, dinner, gambling, or visiting family and friends.

Participation and engagement in social activities, social relationships, and social support can have protective effects on cognitive functioning and reduce cognitive decline.[9] However, for participants with probable dementia, we found that participation in social activities and social support did not have protective effects on the risk of institutionalization. This finding is consistent with a meta-analysis that examined predictors of institutionalization for PWD.[1] This meta-analysis included living alone and presence of spouse caregiver (two sources of instrumental support, i.e. providing assistance with daily tasks). Both sources of instrumental support were not predictive of institutionalization. This finding suggests efforts to delay transition out of the home for PWD should rather focus on alternative, consistent predictors such as behavioral symptoms, depression, and functional impairment.[1] Thus, screening for social isolation, targeted interventions that seek to enhance social support and increase social connectedness, and interdisciplinary team engagement may be more suitable and beneficial for older adults with no dementia than for PWD.

Our study used participants' baseline cognitive status and available sources of instrumental and socioemotional support and examined the longitudinal effect on institutionalization. This study did not include in the model the progressive nature of dementia as

a time-dependent variable. Yet, approximately 15% of our sample was classified as having no dementia at baseline but in subsequent rounds was classified as having probable dementia. Further studies should examine the progressive time-dependent influence of cognitive impairment and possibly include other time-dependent factors, such as functional impairment and multimorbidity.

References

1. Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. *Med Care*. 2009;47(2):191-198. doi:10.1097/MLR.0b013e31818457ce

2. Toot S, Swinson T, Devine M, Challis D, Orrell M. Causes of nursing home placement for older people with dementia: A systematic review and meta-analysis. *Int Psychogeriatr*. 2017;29(2):195-208. doi:10.1017/S1041610216001654

3. Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2018;14(3):367-429. doi:10.1016/j.jalz.2018.02.001

4. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The Disproportionate Impact Of Dementia On Family And Unpaid Caregiving To Older Adults. *Health Aff Proj Hope*. 2015;34(10):1642-1649. doi:10.1377/hlthaff.2015.0536

5. Dam AEH, de Vugt ME, Klinkenberg IPM, Verhey FRJ, van Boxtel MPJ. A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas*. 2016;85:117-130. doi:10.1016/j.maturitas.2015.12.008

6. Leung P, Orrell M, Orgeta V. Social support group interventions in people with dementia and mild cognitive impairment: A systematic review of the literature. *Int J Geriatr Psychiatry*. 2015;30(1):1-9. doi:10.1002/gps.4166

7. Kasper JD, Freedman VA. *National Health and Aging Trends Study User Guide: Rounds 1-7 Final Release*. Baltimore: Johns Hopkins University School of Public Health; 2018. http://www.nhats.org.

8. Montaquila J, Freedman VA, Spillman BC, Kasper JD. *National Health and Aging Trends Study (NHATS) Development of Round 1 Survey Weights*. Baltimore: Johns Hopkins University School of Public Health; 2012. www.NHATS.org.

9. Kelly ME, Duff H, Kelly S, et al. The impact of social activities, social networks, social support and social relationships on the cognitive functioning of healthy older adults: A systematic review. *Syst Rev*. 2017;6(1):259. doi:10.1186/s13643-017-0632-2

Table 2.3. Baseline characteristics of participants, by probable or no dementia

Characteristics	Probable n=692 (%)	None n=3,406 (%)	p-value
Age (years), mean (SD)	84 (7.0)	77 (7.5)	
<80	167 (40.6)	2,171 (78.0)	<0.0001
≥80	525 (59.4)	1,235 (22.0)	
Female	426 (60.5)	1,997 (56.9)	0.0002
Race/ethnicity			
White	338 (67.6)	2,579 (83.6)	
Black	212 (12.4)	609 (7.2)	<0.0001
Hispanic	60 (12.1)	132 (5.3)	
Other	32 (7.9)	86 (3.8)	
Functional disability (needs help with)			
0 ADL	222 (41.4)	2,915 (88.8)	
1-2 ADLs	164 (23.0)	336 (7.8)	<0.0001
3+ ADLs	305 (35.6)	155 (3.4)	
Multimorbidity (multiple coexisting conditions)[†]			
0-1	174 (26.8)	1,066 (36.7)	<0.0001
2+	518 (73.2)	2,338 (63.3)	
Has Medicaid[†]	193 (27.3)	382 (9.0)	<0.0001
Spouse is deceased or experienced spouse death in last year (2011-2017)	392 (61.6)	1,408 (43.0)	<0.0001
Social network[†]			
0	33 (11.4)	211 (6.1)	
1-2	281 (68.9)	2,120 (63.5)	<0.0001
3+	68 (19.7)	1,027 (30.4)	
Lives alone[†]	204 (32.1)	1,162 (28.7)	0.0004
Participation in social events (in last month)[†]			
Church attendance	289 (43.3)	2,091 (58.6)	
Club meetings, classes, or organized activities	112 (16.3)	1,462 (41.7)	
Enjoyment activities (movie, dinner, gambling)	338 (52.9)	2,715 (83.0)	<0.0001
Visited family or friends	506 (74.9)	3,018 (90.0)	

* Based on weighted population estimates

† With some missing values: multimorbidity (probable n=0; none n=2), Medicaid (probable n=41; none n=53), social network (probable n=310; none n=48), live alone (probable n=2; none n=13), church attendance (probable n=3; none n=0), club meetings, classes, or organized activities (probable n=3; none n=1), enjoyment activities (probable n=1; none n=2), visited family or friends (probable n=3; none n=0)

Table 2.4. Association between social support predictors and time to institutionalization by cognitive impairment groups (probable and no dementia)

| | Adjusted sub Hazard Ratio [95% Confidence Interval] | | | |
Social support	Probable dementia	p-value	No dementia	p-value
Spouse is deceased or experienced spouse death in last year (2011-2017) (yes vs. no [reference])	0.8 [0.6, 1.1]	0.18	1.5 [1.2, 1.9]	0.002
Social network (0 vs. 3+ [reference])	2.1 [0.9, 4.7]	0.08	1.8 [1.2, 2.9]	0.01
Lives alone (yes vs. no [reference])	1.7 [1.2, 2.4]	0.002	2.2 [1.8, 2.8]	<0.0001
Church attendance (yes vs. no [reference])	1.0 [0.8, 1.4]	0.78	0.9 [0.7, 1.1]	0.28
Club meetings, classes, or organized meetings (yes vs. no [reference])	1.2 [0.8, 1.8]	0.37	0.8 [0.6, 1.0]	0.05
Enjoyment activities (movie, dinner, gambling) (yes vs. no [reference])	1.0 [0.8, 1.4]	0.83	0.6 [0.4, 0.8]	<0.0001
Visited family or friends (yes vs. no [reference])	1.2 [0.8, 1.7]	0.35	0.5 [0.4, 0.7]	<0.0001

Table 2.5 Association between social support predictors and time to institutionalization by cognitive impairment (interaction)

Social support	Adjusted sub Hazard Ratio [95% Confidence Interval] for probable vs. no dementia group	p-value
Spouse death (2011-2017] (yes vs. no [reference])		
Model 1	1.1 [0.9, 1.4]	0.18
Model 2	0.5 [0.4, 0.8]	0.002
Social network (0 vs. 3+ [reference])		
Model 1	1.8 [1.2, 2.5]	0.27
Model 2	1.2 [0.4, 2.9]	0.77
Live alone (yes vs. no [reference])		
Model 1	1.9 [1.6, 2.2]	<0.0001
Model 2	0.8 [0.5, 1.1]	0.17
Church attendance (yes vs. no [reference])		
Model 1	0.9 [0.8, 1.1]	0.35
Model 2	0.9 [0.7, 1.1]	0.28
Club meetings, organized activities (yes vs. no [reference])		
Model 1	0.9 [0.7, 1.0]	0.13
Model 2	1.5 [1.0, 2.4]	0.07
Enjoyment activities (movie, dinner, gambling) (yes vs. no [reference])		
Model 1	0.7 [0.6, 0.9]	0.001
Model 2	1.8 [1.3, 2.9]	0.004
Visited family or friends (yes vs. no [reference])		
Model 1	0.7 [0.6, 0.9]	0.006
Model 2	2.2 [1.4, 3.5]	0.001

Figure 2.2 Sequence of residential transitions*, institutionalization, and death between (a) older adults with probable dementia and (b) no dementia in a longitudinal, nationally representative study of older adults from 2011-2017

(a) Older adults with probable dementia
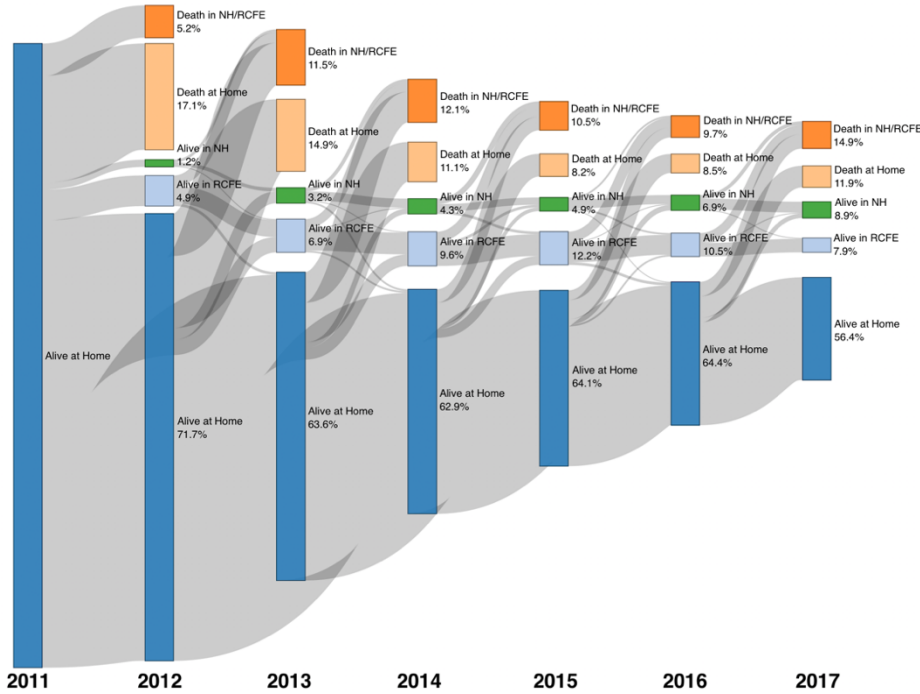
(b) Older adults with no dementia
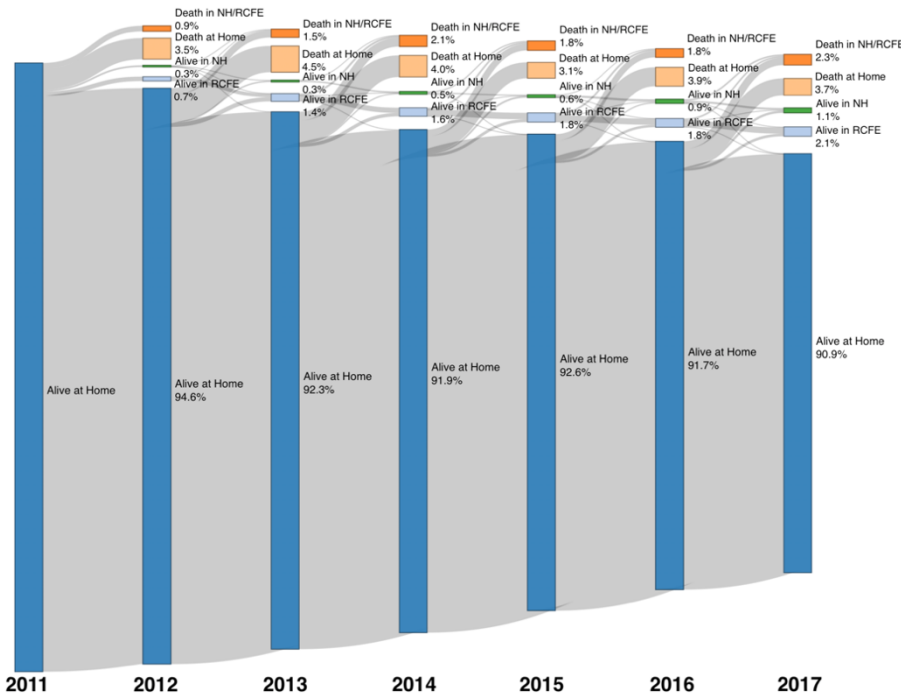
*Percentages in the figure refer to the percent of participants who transitioned to each residential setting from respective residential settings in the previous year

NH Nursing home; **RCFE** Residential care facility for the elderly

Chapter 3: Home health and hospice service use at the end-of-life among community-dwelling older adults with dementia

Introduction

Dementia is a progressive, neurodegenerative condition that may manifest with a wide range of symptoms including impaired memory and difficulty with other tasks such as language, motor activity, object recognition, and disturbed executive function. The public health impact of the various forms of dementia, including Alzheimer's disease, is a result of both their increasing prevalence and the long duration of illness that is spent in a state of disability and dependence prior to death.[1] These characteristics have profound financial implications for healthcare and insurance systems, with annual U.S. cost estimates attributed to dementia ranging from $157 billion to $215 billion.[2]

Nursing home placement often occurs as the disease progresses and a higher level of care than can be provided in the home is needed. In the early 2000s, almost two-thirds of dementia-related deaths occurred in the nursing home.[3] However, this proportion has decreased by approximately 20% in the past fifteen years with a corresponding increase in the proportion of persons with dementia (PWD) dying at home.[1,4] This shift reflects most older adults' preference to age-in-place at home.[5] In 2015, about two-thirds of PWD were living in community settings and not in acute care, post-acute care, or a nursing home.[6] Community living has been supported by the Supreme Court's *Olmstead* decision that mandated states to provide community-based services for people with disabilities and section 1915c of the Social Security Act, which expanded long term care (LTC) options for eligible individuals.[7,8]

In order to live and die in the home, PWD rely heavily on informal, unpaid caregivers (CGs), social support, and formal services (e.g. home and community-based services, home

health, and hospice care agencies). Social support and formal services provide social care services, medications and symptom management, and appropriate equipment and home adaptations.[9] Previous studies of formal service use by PWD have focused on the impact of hospice care in the nursing home setting on symptom management, satisfaction, and quality of life.[10,11] Studies of hospice care delivered in the home setting found that PWD who received hospice care were more likely to have adequate pain control, were satisfied with the care provided, and die in their location of choice (i.e. they are less likely to die in hospital and more likely to die at home).[11,12] Home health service use by PWD has been less explored in the literature. One study that examined longitudinal home health service use found home health service utilization increased 25% over four years and use was associated with being female, worse function, presence of depressive symptoms, and not living with a spouse.[13]

Additional quality metrics at the end-of-life include ensuring that a person's physical, emotional, and spiritual needs are met; the person's personal choices are honored; and the person and their families are supported.[14,15] These metrics strive to meet the national "Triple Aim" of better care experience, healthier populations, and more affordable care.[16] In order to meet PWD needs, the appropriate and necessary services and support need to be available and accessible. Thus, the purpose of this paper is to examine formal service use, specifically home health and hospice services, in the last year of life for community-dwelling PWD who died at home. We hope to identify characteristics of PWD that could benefit from formal services and support and the long-term care service elements that potentially preserve the PWD's ability to stay and die in the home. This paper will describe patterns of formal service use and precipitating causes for the services, which have not been described before. In order to understand the unique contribution of dementia to the use of home health and hospice service use, we will use participants with no

dementia as a comparison group and also describe their patterns of formal service use and precipitating causes.

Methods

Data source and study cohort

The National Health and Aging Trends Study (NHATS) is a nationally representative ongoing, longitudinal survey of U.S. adults age 65 years and older that started in 2011 and which has been linked to Medicare claims.[17] Annual in-person interviews with survey participants or proxy respondents provide detailed information on participant's physical and cognitive capacity; functional ability; economic status; social, physical, and technological environment; and participation in valued activities. Proxy respondents were used when survey participants were unable to complete the survey.[18]

In 2011, 8,245 participants were enrolled in NHATS. For this study, we only included participants who died in the home setting between 2011 and 2014 and who were classified as having probable dementia or no dementia in the survey assessment prior to death. We used the 2011 to 2014 time period because Medicare Part A and Part B claims data (home health and hospice claim files) were only available for these four years matched to NHATS participants. We excluded participants with any breaks in their Medicare Part A and Part B fee-for-service coverage and participants who passed away in any setting other than the home (e.g. hospital, in transit, or nursing home). We obtained dates of death from Medicare enrollment files. Home settings included private residences; retirement communities or senior housing communities; mobile homes, and religious group quarters. We determined residential status at time of death for each NHATS round using the Tracker file (that includes all persons ever sampled for NHATS) and the Sample Persons file (responses from community-dwelling survey participants and staff

persons for institutionalized survey participants [Facility Questionnaire]). Dementia classification was determined via a derived variable that reflected three levels of cognitive impairment – probable dementia, possible dementia, or no dementia – based upon a combination of information that included self-reported physician diagnosis of dementia, a score on the AD8 Dementia Screening Interview from proxy respondents, and a cognition battery on memory, orientation, and executive function.[19] We chose to focus our analysis on participants with probable dementia and participants with no dementia and thus, excluded participants with possible dementia. As a result, our study sample consisted of 454 community-dwelling participants (226 participants with probable dementia and 228 participants with no dementia) who died at home between 2011 and 2014 and who had continuous fee-for-service Medicare claims in the one year prior to death.

Measures

We determined patterns of home health and hospice use by grouping participants based on the type of claims in the one year prior to death: (i) both home health and hospice claims; (ii) home health claims only; (iii) hospice claims only; (iv) no home health or hospice claims. We compared patterns of home health and hospice use between participants with probable dementia (referred to as "dementia" going forward) and participants with no dementia. We examined the primary diagnosis for each home health and hospice claim and categorized the primary diagnoses using ICD-9 coding algorithms (Deyo's [Charlson comorbidities], Elixhauser comorbidities, and previously published literature on coding of dementia, rehabilitation needs, and chronic nonhealing wounds).[20–23]

Beneficiaries usually receive either home health or hospice services. Home health care is paid for by Medicare in 60-day episodes while the hospice benefit period is 90-days.[24] In order to

compare home health and hospice service use for this study, we used the number of days that the participant received either home health or hospice services (formal service use). In determining the number of days of formal service use, we also assessed the number of days between death and when home health or hospice service was initiated (service initiation). We compared the length of formal service use (average and median in days); initiation of hospice use within three days or one week prior to death in participants who used hospice (yes/no); and number of total transitions (i.e. switches) between home health and hospice use. We relied on the median length of formal service use for our interpretations as the distributions of formal service use was not normally distributed and right-skewed. We chose to examine initiation of hospice use within three days and one week prior to death as the domain of care of imminently dying has been identified as a gap where more objective quality measures are needed. Yet, official quality measures for this domain have not yet been officially endorsed by the National Quality Forum, the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association.[14,25]

Other variables. Sociodemographic characteristics included age (<80 or ≥80 years), gender (male/female), race/ethnicity (white, black, Hispanic, and other), education (did not finish high school, high school graduate, associate degree/some college; bachelor's degree, advanced degree), income, functional disability, multimorbidity, Medicaid enrollment (yes/no in the year prior to death), and self-reported hospitalization (yes/no). Individual income was an average of values provided in 2011 and 2013. Functional disability, multimorbidity, Medicaid enrollment, and hospitalization were assessed in the survey assessment prior to death. Functional disability was a derived variable of requiring assistance with activities of daily living (ADLs) (zero to 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 the 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. All of the sociodemographic measures were from NHATS.

Statistical analyses

We used standard descriptive statistics to summarize the baseline characteristics of the

participants with dementia or no dementia who died at home. We used chi-squared tests of

association (Fisher's exact test if there were less than five observations in a group) for

categorical variables and two-sample t-tests for continuous variables, in order to make inferences

about observed associations between sociodemographic characteristics in participants classified

with dementia and participants classified with no dementia.[26]

Results

Participant characteristics

454 NHATS participants died at home between 2011 and 2014. Baseline characteristics

of the total sample included a mean age of 84.6 years (standard deviation [SD] 7.8), 54% female,

70% white, 18% having finished college, 64% needing help with three or more ADLs, 84%

having two or more coexisting conditions, 20% enrolled in Medicaid, and 48% having at least

one hospitalization in the one year prior to death (Table 3.1).

Of the 454 NHATS participants, 226 participants were classified with dementia and 228

participants were classified with no dementia. The two groups were different in most of their

baseline characteristics, except for multimorbidity and hospitalization. Participants with

dementia were older than participants with no dementia (mean 87.1 years [SD 7.0] vs. 82.1 years

[SD 7.8]), predominantly female (61% vs. 48%), were less white (60% were white vs. 80%), did not finish high school (48% vs. 25%), had more folks with income less than $14,000 (42% vs. 30%), required more assistance with three or more ADLs (80% vs. 49%), and received financial assistance from Medicaid (27% vs. 14%) (Table 3.1).

Formal service use

Home health and hospice service use was different between participants with dementia and participants with no dementia (Figure 3.1). More participants with dementia utilized home health and hospice services in all three claim combination groups than participants with no dementia: (i) presence of both home health and hospice claims (31% vs. 22%); (ii) home health claims only (24% vs. 21%); and (iii) hospice claims only (24% vs. 16%) (p<.0001 for all combination groups). Analogously, a greater proportion of participants with no dementia did not utilize any home health and hospice services compared with participants with dementia (41% vs. 21%).

Length of service use, service initiation, and primary diagnosis related to service initiation for participants with only one home health or hospice claim. 58% of participants with dementia and 63% of participants with no dementia had only one claim for home health care during the last year of life. 22% of participants with dementia had two home health care episodes (vs. 31% of participants with no dementia) and 15% had three home health care episodes (vs. 6% of participants with no dementia). For one single claim of continuous care, the average number of home health formal service use was 118 days (SD 107, median 80) and 86 days (SD 94, median 60) for participants with dementia and participants with no dementia, respectively (Table 3.2). Home health services were initiated on average 222 days (median 169) prior to death for

participants with dementia. In comparison, home health services were initiated on average 170 days (median 134) prior to death for participants with no dementia.

Table 3.3 lists the top primary diagnoses found for participants with home health or hospice claims. In participants with dementia, the most common primary and secondary diagnoses for home health claims were wounds/pressure ulcers, which also included diabetic foot ulcers, surgical wounds and infections, and arterial/venous ulcers (n=14, 16% for both primary and secondary diagnoses). The second most common primary diagnosis was congestive heart failure (n=10, 12%), which was the most common primary diagnosis in participants with no dementia (n=13, 19%). In participants with no dementia, the second most common primary diagnosis was continued care after an initial treatment or surgery (n=7, 10%). All participants with home health claims, regardless of cognitive impairment, had multiple, additional diagnoses associated with each episode. In comparison, over half of the participants with hospice claims did not have any additional diagnosis (n=38, 69% in participants with dementia and n=25, 66% in participants with no dementia). The most common secondary diagnosis for participants with no dementia was gait abnormality (n=9, 13%). Uncomplicated hypertension was the most common tertiary diagnosis for both participants with dementia and participants with no dementia (n=13, 15% and n=7, 10%, respectively).

Ninety-eight percent of both participants with dementia and no dementia had only one hospice claim (episode) in the last year of life. The average number of days receiving hospice care for one single, continuous claim (episode) was 99 days (SD 132, median 13.5) and 38 days (SD 71, median 12) for participants with dementia and no dementia, respectively (Table 3.2). Hospice services were initiated on average about four months prior to death (median 13) for

participants with dementia. In contrast, for participants with no dementia, hospice services were initiated on average about a month and a half prior to death (median 10).

The top three primary diagnoses for hospice claims in participants with dementia were dementia (n=18, 33%), malignancies, including lymphoma and leukemia (n=10, 19%), and debility and failure to thrive (n=7, 15%). The top three primary diagnoses for people with no dementia were malignancies (n=17, 46%), chronic pulmonary disease (n=4, 11%), and congestive heart failure and cerebrovascular disease (n=3, both 8%). Most participants with hospice claims did not have any additional diagnoses related to their claims (n=37, 69% for participants with dementia and n=24, 65% for participants with no dementia).

Transitions (i.e. switches) between home health and hospice use – length of service use and primary diagnosis related to service initiation for participants with multiple home health or hospice claims. 58% of participants with dementia had two claims (vs. 66% of participants with no dementia), 25% had three claims (vs. 30% of participants with no dementia), 13% had four claims (vs. 4% of participants with no dementia), and 4% had five or more claims (vs. 0% in participants with no dementia). The percentages of total claims were not different between participants with dementia and participants with no dementia, likely due to small numbers, but are reported here for descriptive purposes. The majority of the participants had multiple home health service claims while only four participants (3%) had more than one hospice claim. For participants with both home health and hospice service claims and with dementia, the average number of days for all combined episodes was 172 days (SD 122), median 145 days; 127 days (SD 109), median 79 days for home health service use specifically; and 51 days (SD 78), median 12 days for hospice service use specifically. In contrast, participants with no dementia received on average for all combined episodes 90 days (SD 75), median 64 days; 73 days (SD 72), median

46 days for home health service use specifically; and 17 days (SD 23), median 8 days for hospice service use specifically.

Only five of the total participants (4%) with both home health and hospice service claims regardless of cognitive impairment received home health as their final service prior to death (Table 3.3). Primary diagnoses for these five participants ranged from debility and failure to thrive (n=2, 2% in both participants with dementia and participants with no dementia) to neurological deficiency, malignancy, and chronic pulmonary disease. In participants who received hospice service prior to death, the most common primary diagnosis was malignancy in both participants with dementia (n=10, 14%) and participants with no dementia (n=18, 36%). The second most common diagnoses in participants with dementia were dementia, debility and failure to thrive, and congestive heart failure (n=7 for all three diagnoses, 10%). The second most common diagnosis in participants with no dementia was congestive heart failure (n=13, 26%).

Discussion

We found that home health and hospice service use was different between people who died at home with dementia and without dementia. Participants with dementia who received only one type of formal service use (either home health or hospice) in the last year of life had few (one claim/episode) but long interactions (in number of days) with formal services. The median number of formal service days (length of stay) for any home health and hospice service episode for these participants was around 80 days and 12 days, respectively. In addition, home health and hospice services were initiated around 170 days and 12 days, respectively (median) prior to death.

The median number of formal service days was similar between participants who received one type of formal service use and participants who received both home health and

hospice services (median of 79 home health days and 12 hospice days). When home health and hospice service days were combined, participants who received both services spent almost half a year (median of 145 days) utilizing formal services. For hospice services specifically, 38% of all hospice service users received hospice services for seven or fewer days. These findings indicate that hospice was initiated within the last two weeks of life for half of our study population and from a quality improvement perspective, participants with dementia could potentially have benefitted from earlier initiation of hospice services. These findings agree with a 2014 examination of hospice length of stay done by the Alzheimer's Association.[1]

Current Centers for Medicare and Medicaid Services (CMS) guidelines for hospice eligibility for people with dementia include Stage 7C or beyond on the Functional Assessment Scale (FAST) for Alzheimer's Type Dementia and one or more of the following conditions: aspiration pneumonia, pyelonephritis, septicemia, multiple pressure ulcers, recurrent fever, any other significant clinical condition that suggests a limited prognosis, and inability to maintain sufficient fluid and calorie intake in the past six months.[27,28] Our review of Medicare claims and the primary diagnosis for service initiation confirmed that participants with dementia had a variety of significant clinical conditions, pressure ulcers, and coexisting conditions that may make them eligible for earlier initiation of hospice services. Combined with our finding that only 12% of participants with hospice claims had dementia listed as their primary diagnosis, our study confirmed that the clinical profile of these participants is complicated with multiple coexisting conditions and complex medical needs. Home health and hospice claims showed that participants required help with wound care, had multiple coexisting conditions such as congestive heart failure, diabetes, and malignancies (cancer), and were frail. This health profile was different

from participants without dementia, whose needs were related to malignancies, chronic pulmonary disease, congestive heart failure, and post-surgical care.

We acknowledge some limitations of our study, many of which are related to reliance on administrative claims. For this study, we did not examine Medicare claims for palliative care services; services related to symptom management, such as reducing pain and discomfort. Palliative care may be initiated earlier than hospice care and may alter patterns of formal service use. Another limitation is that we analyzed only home health and hospice claims of participants. Future work could examine all claims (inpatient, outpatient) in order to obtain a more detailed picture of study participants' use of formal services. In addition, family and unpaid caregivers provide substantial assistance to PWD.[29] Information on informal caregivers in the linked National Study of Caregiving study could provide a more complete picture of services and support that community-dwelling PWD utilize at the end-of-life.

Efforts to identify prognostic indicators for mortality in PWD have had mixed success and in turn, guidelines to determine hospice eligibility have not accurately or reliably predicted 6-month life expectancy.[30–32] This examination of home health and hospice service use has shown that the health profile of community-dwelling older adults with dementia who die at home is complicated, different from people without dementia, and requires consideration of complex medical needs. The criteria for hospice eligibility in community settings may need to be reexamined in order to better reflect the complicated picture of PWD who die at home. Thus, ensuring adequate and appropriate support is available to both PWD and their families, personal needs are met, and a better care experience is achieved.

References

1. Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2018;14(3):367-429. doi:10.1016/j.jalz.2018.02.001

2. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med*. 2013;368(14):1326-1334. doi:10.1056/NEJMsa1204629

3. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc*. 2005;53(2):299-305. doi:10.1111/j.1532-5415.2005.53118.x

4. Taylor CA, Greenlund SF, McGuire LC, Lu H, Croft JB. Deaths from Alzheimer's Disease — United States, 1999–2014. *MMWR Morb Mortal Wkly Rep*. 2017;66:521-526. doi:10.15585/mmwr.mm6620a1

5. Barrett L. *Home and Community Preferences of the 45+ Population 2014*. AARP Research Center; 2014. https://www.aarp.org/content/dam/aarp/research/surveys_statistics/il/2015/home-community-preferences.doi.10.26419%252Fres.00105.001.pdf.

6. Harris-Kojetin L, Sengupta M, Lendon J, Rome V, Valverde R, Caffrey C. *Long-Term Care Providers and Services Users in the United States, 2015-2016*. Hyattsville, MD: National Center for Health Statistics; 2019. https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf.

7. U.S. Department of Health and Human Services. Serving people with disabilities in the most integrated setting: Community living and Olmstead. https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html. Published June 28, 2018. Accessed July 17, 2019.

8. State of California, Department of Developmental Services. *The HCBS Waiver Primer and Policy Manual*. Sacramento; 2008. https://www.dds.ca.gov/waiver/docs/WaiverManual2008.pdf. Accessed July 17, 2019.

9. Mogan C, Lloyd-Williams M, Harrison Dening K, Dowrick C. The facilitators and challenges of dying at home with dementia: A narrative synthesis. *Palliat Med*. 2018;32(6):1042-1054. doi:10.1177/0269216318760442

10. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc*. 2010;58(12):2284-2291. doi:10.1111/j.1532-5415.2010.03185.x

11. Mitchell SL, Kiely DK, Miller SC, Connor SR, Spence C, Teno JM. Hospice care for patients with dementia. *J Pain Symptom Manage*. 2007;34(1):7-16. doi:10.1016/j.jpainsymman.2007.01.003

12. Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Patients dying with dementia: Experience at the end of life and impact of hospice care. *J Pain Symptom Manage*. 2008;35(5):499-507. doi:10.1016/j.jpainsymman.2007.06.011

13. Zhu CW, Torgan R, Scarmeas N, et al. Home health and informal care utilization and costs over time in Alzheimer's disease. *Home Health Care Serv Q*. 2008;27(1):1-20. doi:10.1300/J027v27n01_01

14. National Quality Forum. *Performance Measurement Coordination Strategy for Hospice and Palliative Care*. Washington, D.C.; 2012. https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&ved=2ahUKEwi Mv8Ce_OfjAhVHxlQKHWLzC1sQFjABegQIBhAC&url=http%3A%2F%2Fwww.qualityf

orum.org%2FPublications%2F2012%2F06%2FMAP_Hospice_and_Palliative_Care_Final_

Report.aspx&usg=AOvVaw3c8gpUsFy3E0zR0BzFLc4S.

15. National Quality Forum. *Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Dementia, Including Alzheimer's Disease.*; 2014.

http://www.qualityforum.org/priority_setting_for_healthcare_performance_measurement_al zheimers_disease.aspx. Accessed February 1, 2018.

16. Berwick DM, Nolan TW, Whittington J. The triple aim: Care, health, and cost. *Health Aff Proj Hope*. 2008;27(3):759-769. doi:10.1377/hlthaff.27.3.759

17. Montaquila J, Freedman VA, Edwards B, Kasper JD. *National Health and Aging Trends Study Round 1 Sample Design and Selection.* Baltimore: Johns Hopkins University School of Public Health; 2012.

https://www.nhats.org/scripts/sampling/NHATS_Round1_Sample_Design_05_10_12.pdf. Accessed May 25, 2017.

18. Kasper JD, Freedman VA. *National Health and Aging Trends Study User Guide: Rounds 1-7 Final Release*. Baltimore: Johns Hopkins University School of Public Health; 2018. http://www.nhats.org.

19. Kasper JD, Freedman VA, Spillman BC. *Classification of Persons by Dementia Status in the National Health and Aging Trends Study*. Baltimore: Johns Hopkins University School of Public Health; 2013.

https://www.nhats.org/scripts/documents/DementiaTechnicalPaperJuly_2_4_2013_10_23_1 5.pdf. Accessed May 25, 2017.

20. Quan H, Sundararajan V, Halfon P, et al. Coding algorithms for defining comorbidities in ICD-9-CM and ICD-10 administrative data. *Med Care*. 2005;43(11):1130-1139.

21. Lin P-J, Kaufer DI, Maciejewski ML, Ganguly R, Paul JE, Biddle AK. An examination of Alzheimer's disease case definitions using Medicare claims and survey data. *Alzheimers Dement J Alzheimers Assoc*. 2010;6(4):334-341. doi:10.1016/j.jalz.2009.09.001

22. Buchanan JL, Rumpel JD, Hoenig H. Charges for outpatient rehabilitation: Growth and differences in provider types. *Arch Phys Med Rehabil*. 1996;77(4):320-328.

23. Nussbaum SR, Carter MJ, Fife CE, et al. An Economic Evaluation of the Impact, Cost, and Medicare Policy Implications of Chronic Nonhealing Wounds. *Value Health*. 2018;21(1):27-32. doi:10.1016/j.jval.2017.07.007

24. Medicare Payment Advisory Committee. *March 2019 Report to the Congress: Medicare Payment Policy*. Washington, D.C.; 2019:1-497. http://www.medpac.gov/docs/default-source/reports/mar19_medpac_entirereport_sec_rev.pdf?sfvrsn=0.

25. Dy SM, Kiley KB, Ast K, et al. Measuring what matters: Top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *J Pain Symptom Manage*. 2015;49(4):773-781. doi:10.1016/j.jpainsymman.2015.01.012

26. Vittinghoff E, Glidden DV, Shiboski SC, McCulloch CE. *Regression Methods in Biostatistics: Linear, Logistic, Survival, and Repeated Measures Models*. Springer Science & Business Media; 2012.

27. The National Hospice Organization. Medical guidelines for determining prognosis in selected non-cancer diseases. *Hosp J*. 1996;11(2):47-63. doi:10.1080/0742-969X.1996.11882820

28. Jayes RL, Arnold RM, Fromme EK. Does this dementia patient meet the prognosis eligibility requirements for hospice enrollment? *J Pain Symptom Manage*. 2012;44(5):750-756. doi:10.1016/j.jpainsymman.2012.08.004

29. Wolff JL, Spillman BC, Freedman VA, Kasper JD. A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Intern Med*. 2016;176(3):372-379. doi:10.1001/jamainternmed.2015.7664

30. Schonwetter RS, Han B, Small BJ, Martin B, Tope K, Haley WE. Predictors of six-month survival among patients with dementia: An evaluation of hospice Medicare guidelines. *Am J Hosp Palliat Care*. 2003;20(2):105-113. doi:10.1177/104990910302000208

31. Brown MA, Sampson EL, Jones L, Barron AM. Prognostic indicators of 6-month mortality in elderly people with advanced dementia: A systematic review. *Palliat Med*. 2013;27(5):389-400. doi:10.1177/0269216312465649

32. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med*. 2004;19(10):1057-1063. doi:10.1111/j.1525-1497.2004.30329.x

Table 3.1 Participant characteristics

| | Total sample n=454 (%) | Cognitive Impairment | | p-value for probable dementia vs. no dementia |
		Probable dementia n=226 (%)	No dementia n=228 (%)	
Age (years), mean (SD)	84.6 (7.8)	87.1 (7.0)	82.1 (7.8)	
<80	222 (48.9)	77 (34.1)	145 (63.6)	<.001
80+	232 (51.1)	149 (65.9)	83 (36.4)	
Female	246 (54.2)	138 (61.0)	108 (47.4)	.003
Race/ethnicity				
White	319 (70.3)	136 (60.2)	183 (80.3)	
Black	100 (22.0)	71 (31.4)	29 (12.7)	<.001
Hispanic	21 (4.6)	14 (6.2)	7 (3.1)	
Other	14 (3.1)	5 (2.2)	9 (4.0)	
Education	n=447	n=223	n=224	
Did not finish HS	162 (36.2)	106 (47.5)	56 (25.0)	
HS graduate	113 (25.3)	55 (24.7)	58 (25.9)	
Associate's/Some college	93 (20.8)	33 (14.8)	60 (26.8)	<.001
Bachelor's degree	49 (11.0)	19 (8.5)	30 (13.4)	
Advanced degree	30 (6.7)	10 (4.5)	20 (8.9)	
Income	n=271	n=128	n=143	
<$14,000	97 (35.8)	54 (42.2)	43 (30.0)	
$14,000-$21,999	60 (22.1)	30 (23.4)	30 (20.1)	
$22,000-$35,999	50 (18.4)	25 (19.5)	25 (17.5)	.02
$36,000-$48,999	18 (6.6)	7 (5.5)	11 (7.7)	
≥$49,000	46 (17.0)	12 (9.4)	34 (23.8)	
Functional disability, need assist				
0-2 ADLs	163 (35.9)	46 (20.3)	117 (51.3)	<.001
3+ ADLs	291 (64.1)	180 (79.7)	111 (48.7)	
Multimorbidity				
0-1 conditions	75 (16.5)	40 (17.7)	35 (15.4)	.50
2+ conditions	379 (83.5)	186 (82.3)	193 (84.6)	
Medicaid enrollment* (yes)	n=441 91 (20.6)	n=221 60 (27.2)	n=220 31 (14.1)	.001
Hospitalization in the one year prior to death (yes)	n=448 215 (48.0)	n=224 115 (51.3)	n=224 100 (44.6)	.16

Table 3.2 Characteristics of home health and hospice service use in the last year of life by cognitive impairment and formal service use

	HH & Hospice			HH only			Hospice only		
	Prob dem n=69	No dem n=50	p-value	Prob dem n=55	No dem n=48	p-value	Prob dem n=54	No dem n=37	p-value
Formal service use (in days)	*All claims*								
	178 (122)	90 (75)	<.001						
	145	63							
	HH								
Mean (SD)	127 (109)	73 (72)	<.001	118 (107)	86 (94)	.11			
Median	79	46		80	60				
	Hospice								
	51 (78)	17 (23)	<.001				99 (132)	38 (71)	.01
	12	8					13.5	12	
Service initiation (in days), for each individual claim	*All claims*								
	n=183	n=119							
	184 (219)	102 (117)	<.001						
	103	53							
	HH								
	n=109	n=69		n=86	n=69				
Mean (SD)	265 (234)	159 (120)	<.001	222 (195)	170 (148)	.07			
Median	193	130		169	134				
	Hospice								
	n=74	n=50					n=55	n=38	
	66 (122)	22 (42)	.02				123 (188)	46 (116)	.03
	12	8					13	10	
Hospice initiation (in days), n (%)									
Within last 3d of life	22 (32)	16 (32)	.98				8 (15)	8 (22)	.40
Within last 7d of life	29 (42)	25 (50)	.39				19 (35)	15 (41)	.60

Table 3.3 Primary diagnoses* for home health and hospice service use in the last year of life

1 claim in the last year of life

HH claim only

Prob dem (n=32)	No dem (n=30)
Individual wounds 16%	CHF 19%
CHF 12%	Post-operative care 10%
Diabetes without complication 6%	Chronic pulmonary disease 9%
Rehabilitation needs 6%	Malignancies (cancer) 6%
Muscle weakness, osteoarthritis, joint pain 6%	Wounds 6%
Injury 5%	Infection 6%
	Injury 6%

Hospice claim only

Prob dem (n=53)	No dem (n=36)
Dementia 33%	Malignancy (cancer) 46%
Malignancy (cancer) 19%	Chronic pulmonary disease 11%
Debility/failure to thrive 15%	CHF 8%
Cerebrovascular disease 13%	Cerebrovascular disease 8%
	Dementia 5%
	Debility and failure to thrive 5%

2 claims in the last year of life

Hospice (i) – HH at EOL (ii)

Prob dem (n=2)	No dem (n=1)
Other neurological deficiency	Debility/FTT
Debility/FTT	

HH (i) – Hospice at EOL (ii)

Prob dem (n=38)	No dem (n=32)
Malignancy (cancer) 26%	Malignancy (cancer) 44%
Dementia 18%	CHF 28%
Debility/FTT 13%	Debility/FTT 6%
	Cerebrovascular disease 6%
	Chronic pulmonary disease 6%

3 claims in the last year of life

HH (i) – Hospice (ii) – HH at EOL (iii)

No dem (n=1)
Malignancy (cancer)

Hospice (i) – HH at EOL (ii-iii)

Prob dem (n=1)
Chronic pulmonary disease

HH (i) – Hospice at EOL (ii-iii)

Prob dem (n=1)
Renal disease

Hospice (i) – HH (ii) – Hospice at EOL (iii)

Prob dem (n=1)
Debility/FTT

HH (i-ii) – Hospice at EOL (iii)

Prob dem (n=14)	No dem (n=14)
CHF 43%	Malignancy (cancer) 29%
Dementia 14%	CHF 21%
Chronic pulmonary disease 14%	Chronic pulmonary disease 14%

4 claims in the last year of life

HH (i-iii) – Hospice at EOL (iv)

Prob dem (n=6)	No dem (n=2)
CHF	CHF
Cerebrovascular disease	Debility/FTT
Dementia	
Neurological disorder	
Debility/FTT	
Respiratory disease	

HH (i-ii) – Hospice claim at EOL (iii-iv)

Prob dem (n=2)
CHF
Dementia

HH (i) – Hospice (ii) – HH (iii) – Hospice at EOL (iv)

Prob dem (n=1)
Debility/FTT

5-6 claims in the last year of life

HH (i-iv/v) – Hospice claim at EOL (v/vi)

Prob dem (n=3)
Debility/FTT
Renal disease

* For participants with multiple HH and hospice claims, primary diagnosis listed in the table is for the last claim prior to or at death

CHF Congestive heart failure **EOL** End of life; **FTT** Failure to thrive; **HH** Home health

Figure 3.1 Sample derivation
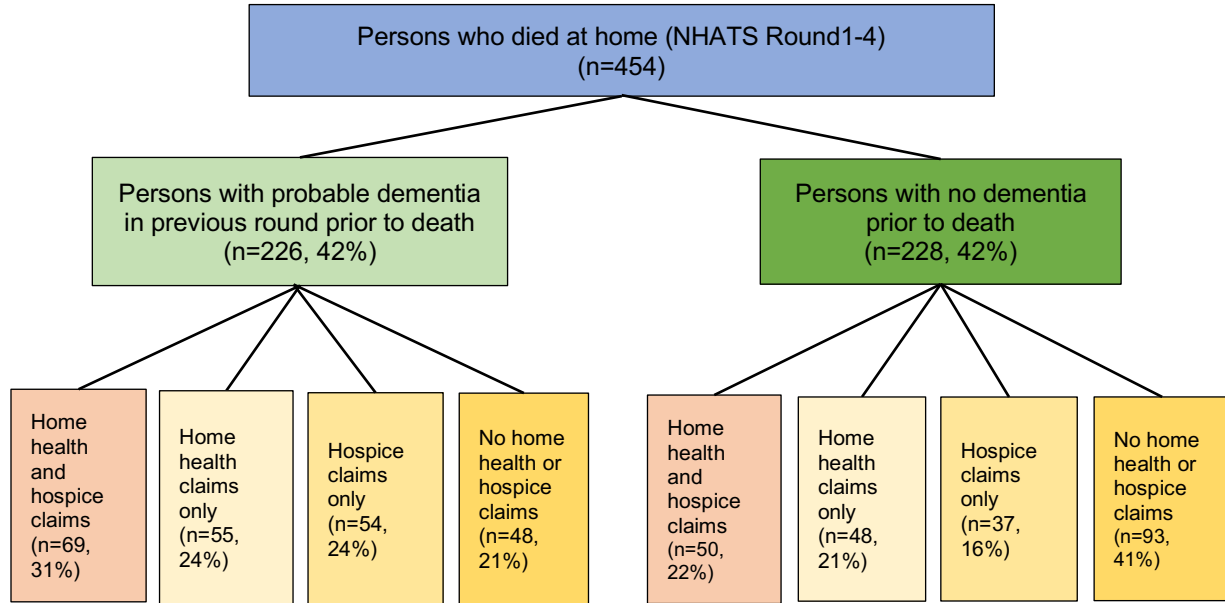
Chapter 4: Care coordination for people with dementia and their informal caregivers: Key components, workforce implications, and implementation considerations going forward

Anna Oh, Wendy Max, Caroline Stephens, Alexander Smith, Christine Ritchie

Abstract

Existing researchers advocate for the redesign of existing delivery systems of care for people with dementia and reimbursement systems to meet the unique care needs of community-dwelling PWDs and their informal, unpaid caregivers. This article reviews the way in which best practices are being executed in seven redesigned dementia care coordination programs, identifies facilitators and barriers to delivering dementia care using an implementation framework, and discusses implementation considerations as health systems initiate partnerships with community-based resources and primary care practices. This review lends support to the wide dissemination of these collaborative dementia care coordination programs by discussing lessons learned from existing programs and steps needed going forward.

Introduction

In the U.S. alone, an estimated 5.7 million Americans have Alzheimer's disease (AD) and 5.5 million of these people are 65 years and older.[1] In 2011, an estimated 3.6 million older adults with dementia were living in residential, community settings. Thirty percent of these adults received help from three or more informal, unpaid caregivers (CGs), which included family members, neighbors, and community members.[2] These estimates come from the National Health and Aging Trends Study, a nationally representative survey of Medicare beneficiaries. As AD and its associated symptoms of impaired memory, difficulty with language, motor activity, object recognition, and disturbed executive function intensify, the person with dementia (PWD) grows increasingly reliant on informal CGs to step in and make treatment and economic decisions. In addition, the PWD relies on formal, paid long-term care services, which includes adult day centers, home health, and hospice among others, for assistance with daily activities and health maintenance.[3]

Annual estimates of the monetary costs of dementia in the U.S. range from $159 billion to $215 billion.[4] Thus, the Centers for Medicare and Medicaid Services has supported innovative demonstration projects to assist PWDs and their CGs in community settings, reduce costs, and improve healthcare quality.[5,6] Care coordination, the deliberate planning and organization of patient care activities among the PWD, CG, and a multidisciplinary care team, facilitates the delivery of healthcare services and is the main intervention in these demonstration projects.[7,8]

Randomized controlled trials of dementia care coordination programs have shown delayed transitions out of the home into nursing homes, decreased unmet needs in both the PWD and informal CGs, and improved quality of care.[9–18] While a cure for AD and related dementias remains elusive, current researchers advocate for the redesign of existing delivery systems of

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care for PWDs and reimbursement systems to meet the unique care needs of community-dwelling PWDs and their informal CGs.[19–21]

A proposed model of collaborative dementia care includes, at a minimum, continuous monitoring and assessment; an ongoing care plan; medication management; psychosocial interventions; self-management by the informal CG; treatment of conditions related to dementia; and care coordination. Accompanying activities include but are not limited to making a formal diagnosis of dementia; discussing goals of care, tracking outcomes, and adjusting goals as needed; considering cognition enhancing drugs; assessing for psychoactive side effects of prescription and nonprescription medications; providing referrals to relevant community support services; teaching informal CGs how to identify and manage problem behaviors in the PWD; and managing a PWD's coexisting conditions concurrently with the specific signs and symptoms of their dementia.

Researchers have previously identified facilitators (enhancing attributes of a program or environment) and barriers (obstructing attributes) to the delivery of collaborative dementia care.[19–21] Facilitators include strong, existing evidence-based knowledge of best-practice dementia care; desire of providers and health care systems to provide high-quality dementia care that supports and improves PWD and informal CG outcomes; increasingly complicated needs of PWDs; and incremental changes to billing codes that support chronic care management. Barriers include the high cost of necessary practice redesign, limited evidence of cost-effectiveness, financial sustainability, and competition with other worthy quality improvement efforts.

Implementation research attempts to solve problems related to implementation through a scientific inquiry into the questions and processes of implementation.[22] Implementation research can guide collaborative dementia care (i.e. care coordination) program development, execution,

evaluation, modification, and dissemination. Practically, implementation research and its

frameworks can help primary care practices incorporate care coordination for PWDs into their

current practices by identifying either an existing program as a consulting service or the

appropriate key individuals, components, and activities that best fit their specific practice

environment.

The Consolidated Framework for Implementation Research (CFIR) is one such

framework that uses standardized language to define unique components of a program or

intervention and the environment in which the program or intervention resides, guide

assessments of program or intervention implementation and evaluation, and identify key

audiences, stakeholders, and implementation processes.[23,24] CFIR consolidated nineteen different

theories related to dissemination, innovation, organizational change, implementation, knowledge

translation, and research uptake of program or intervention implementation.[24] CFIR is organized

across five major domains: program or intervention characteristics, inner setting, outer setting,

characteristics of the individuals involved, and the process by which the program or intervention

implementation is accomplished (Table 4.1). CFIR's five domains acknowledge the multi-level

interactions that influence the implementation process and implementation effectiveness.[24]

The first domain in CFIR, program characteristics, is related to the characteristics of the

care coordination program. Programs have core components that need to be adapted to each

unique environment in order to achieve a good fit and accomplish implementation. The second

and third domains in CFIR, inner and outer settings, depend on the implementation context. The

inner setting traditionally refers to the structural characteristics, networks, and cultural climate

(perception and fit of the norms, values, assumptions of the implementing organization with the

norms, values, and assumptions of the involved individuals within the program). The outer

setting includes the economic, political, and social context within which the program and implementing organization resides. The fourth domain refers to the individuals involved with the program and their knowledge, beliefs, skills, and mindsets. The fifth and last domain is the implementation process, i.e. the active change process and individuals required to accomplish implementation.

Methods

A previously published Cochrane systematic review initially identified four U.S.-based dementia care coordination programs.[8] Two programs were implemented in the 1990s while the other two programs were implemented in the 2000s. This review identified three additional dementia care coordination programs: two which were implemented in the late 2000s and one in the mid 2010s. Results for these additional programs were published after the publication of the Cochrane review, using the Cochrane review's inclusion criteria and definition of care coordination ("any…intervention delivered in the community predominantly focuses on the planning and coordination of care required to meet the identified needs of the person with dementia"). Inclusion criteria for this review included English language publications of randomized controlled trials where the intervention is a case management (care coordination) program in the U.S.; program enrolling both patients with Alzheimer's disease or related dementias living in the community and their informal CGs; and program's use of a care coordinator. Programs were excluded if the intervention focused solely on informal CGs, no care coordinator was present, or if patients with Alzheimer's disease or related dementia were a subgroup of a larger study population of Medicare beneficiaries with chronic illnesses (e.g. Medicare Coordinated Care Demonstration projects). Next, we searched PubMed from database inception through February 2019 for peer-reviewed publications for each program based on the

name of each program's primary investigator. Ninety-three articles were found and reviewed.

Due to the heterogeneity of the programs, we used a narrative literature review approach for this

article to describe the unique environments, processes, and implementation outcomes (intentional

actions to deliver care coordination) of the seven programs. We used CFIR to examine dementia

care coordination programs in a way not done before. Using CFIR, we identify implementation-

related constructs particular to ongoing and completed dementia care coordination programs.[23,24]

We summarize from these constructs how essential practices (i.e. core components) identified in

previous studies were executed in seven dementia care coordination programs. Next, we identify

facilitators and barriers to delivering dementia care in these programs and provide

implementation considerations as health systems initiate linkages with community-based

resources. Exhibit 1 summarizes the characteristics of the seven dementia care coordination

models.

Key individuals, core components and activities of observed dementia care coordination

programs

The effort to redesign delivery systems of dementia care is motivated by the desire to

help the PWD and informal CG, improve the quality of dementia care based on evidence-based

management guidelines, and support the crucial link between health care systems and

community resources.[19,21,25,26] Our review of dementia care coordination programs found three

main components essential to the delivery of collaborative dementia care: (i) a team-based,

coordinated approach to care; (ii) an on-going long-term assessment, monitoring, and

management of PWD and informal CG needs (a dyadic approach); (iii) critical partnerships

between other providers, healthcare systems and community-based resources.

Care coordinator and the multidisciplinary, collaborative care coordination team

Care coordinators and the multidisciplinary, collaborative care coordination team are core components of the program. They provided the dyad with emotional support, self-management tools, and access to psychosocial interventions. In addition, they supported the PWD/informal CG dyad directly by coordinating care in a complex healthcare system.

Care coordinators included either an individual or a combination of nurses, social workers, advanced practice nurses, and lay health workers. Programs chose the type of care coordinator based on their clinical background and skills, program purpose, and functional features of the program: using nurses for medical-related needs; social workers for non-medical, case management needs; nurse practitioners for their ability to start, prescribe, adjust, and titrate medications; and non-clinical lay health workers for monitoring and follow-up of less-complicated PWD/informal CG dyads.[27–30] Programs developed specific protocols that enhanced the care coordinator's existing knowledge of dementia care and guided care coordinators in their roles and responsibilities.[30,31] For non-clinical staff, programs developed didactic training modules comprised of lectures, assigned readings, and clinical observations, and required ongoing, rigorous training and weekly check-ins with the care coordination team.[14,29,32] Some of the programs employed their own care coordinators while other programs utilized care coordinators in partnering with community organizations, like the local-chapter of the Alzheimer's Association, Home Care Group, or Jewish Community Services.[5,11–14,16,31,33–35]

The multidisciplinary, collaborative care coordination team consisted of the care coordinator, nurses, social workers, medical assistants, non-clinical lay health workers, community agency care managers, geriatricians, geriatric psychiatrists, and social psychologists. Through frequent communication (i.e. weekly or biweekly in-person meetings or conference

calls), the care team exchanged information both within the team and with specialty and primary care providers; assessed and addressed each dyad's unique care needs; and facilitated the optimal delivery and availability of integrated health care activities.[15–17,29,30,36,37] Some of the care programs provided their own psychosocial interventions such as individualized mental health and counseling services, support groups, and education and training for PWDs and informal CGs.[16–18,31,38,39] All seven programs had their care coordinators or a member of the collaborative care team available as needed, with 24-hour access available in three programs.[12,14,16,31]

Continuous monitoring and assessment and ongoing care plan

Care coordination programs continuously monitored and assessed the needs of the PWD and the informal CG either in-person or by telephone. PWD needs were related to cognitive, functional, behavioral, and psychological changes while CG needs were related to education, support, and CG health.[25] The frequency of assessments ranged from bi-weekly or monthly to every three months, six months, or annually.[9–18] This monitoring and assessment of the PWD included identifying treatable causes of cognitive impairment or excess disability; problem behaviors which include but are not restricted to aggression, agitation, confusion, repetitive behavior, psychosis, and sleep disturbances; adverse effects of medications and potential need for cognition enhancing drugs; vascular risk factors; need for formal referrals to specialty memory care practices; and effects from coexisting condition management.[9,12–17,30,31,40] For the informal CG, programs monitored and assessed CG stress, burden, burnout, and overall quality of life.[10–12,15,29,37,40–44]

Additional unique or core activities included assessments of PWDs and informal CGs in the home through specific home safety assessments and the use of information technology (IT) software to continuously monitor dyad goals and progress.[5,12,17,29,35,45,46] Five programs

developed their own specific software; and one program has made their licensed software available for sale and distribution to other health systems.

Monitoring and assessment of the PWD and informal CG informed the development and implementation of the ongoing care plan. Over half of the programs used unmet needs as a specific outcome for either both the PWD and informal CG or solely for the informal CG for care plan development.[11–13,29,41,42] For the PWD, unmet needs included help with daily living functional tasks, legal and financial issues, safety, alternative living arrangements, treatment of neuropsychiatric and/or cognitive symptoms, and medication use. For the informal CG, unmet needs included education for understanding dementia, help with care tasks, emotional support, resource referrals, and organizing family care or alternative living arrangements.

Four programs used quality indicators for dementia care processes in order to develop the care plan.[12,16,28,29,47,48] These quality indicators are divided into three main domains: assessment and screening; counseling; and treatment. Quality indicators for the assessment and screening domain include screening for cognitive status, functional assessment, dementia staging, related conditions such as depression, delirium, and other neuropsychiatric symptoms; laboratory testing for other causes of mental status change. The counseling domain includes discussion of dementia diagnosis, prognosis, behavioral interventions for dementia-related problems, safety (i.e. driving), and advanced care planning (designation of a surrogate decision maker and life-sustaining care preferences, including artificial nutrition). The treatment domain includes pharmacological treatments for dementia, stroke prophylaxis for vascular or mixed dementia, risks/benefits discussion about any new medications, and discontinuation of any medications associated with adverse effects.

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Next, a majority of the care plans included the creation of action steps that responded to the identified PWD and informal CG needs. Programs would specify tasks to be completed, schedule regular follow-ups in order to monitor progress, resolve tasks, or add new tasks as coordination needs changed.[10,14,27] One program specifically helped manage care transitions for the PWD, facilitating transfers to nursing homes or alternative housing as coordination needs changed with continuous monitoring and assessment.[27]

Partnerships with primary care providers, healthcare systems, and community organizations

The last core component of a dementia care coordination program are the critical partnerships between the program and other providers, healthcare systems, and community-based resources. Dementia care coordination programs are specialized, systems-level, team-based initiatives aimed at improving the quality of dementia care. Dementia care coordination programs complement primary care by supporting the management of the PWD's coexisting conditions and risk factors and promoting access to psychosocial interventions.[10,12,14,15,17,29–31] These programs could be useful particularly in rural areas where primary care is the usual source of care and rural residents lack access to specialized dementia care.[29] In addition, these programs can also help introduce discussions on goals of care, assist with advanced care planning, and evaluate for treatable causes of cognitive impairment or excess disability.[5,12,29,42,43]

Programs obtained referrals from primary care offices and health care systems. In turn, programs shared care plans and provided targeted support (i.e. medication management) to assist primary care providers in caring for PWDs and supporting CGs.[12,14,29–31] Programs established partnerships with community-based resources such as the Alzheimer's Association (support groups), home health and social service agencies (in-home help, meals, transportation), and case management groups (overall resources).[9,10,17,30,31,33]

Facilitators and barriers to delivering and evaluating care coordination for PWD and informal CGs

The application of CFIR to examine the implementation of care coordination programs and the delivery of dementia care confirmed existing facilitators and barriers and identified additional facilitators and barriers (Figure 4.2). We identified determinants to implementation (facilitators and barriers, i.e. the enhancing and obstructing attributes of the program or environment) within each CFIR domain and construct in order to describe how care coordination programs were developed and collaborative dementia care was delivered. Several of the identified facilitators and barriers overlapped CFIR domains.

Program characteristics

The delivery of care coordination for PWDs and informal CGs was facilitated by characteristics of the implementing organization, use of pilot randomized controlled trials (RCTs), and IT software. All seven programs were based in large, mature medical centers with experienced research investigators (implementing organizations); six of the programs were internally developed. These organizations ensured that strong, existing evidence-based knowledge of best-practice dementia care was present in their particular program. Each program was unique in its geographic area.

Implementing organizations used pilot RCTs to develop and validate study instruments for needs assessments and monitoring of dementia symptoms (e.g. Johns Hopkins Dementia Care Needs Assessment, Healthy Aging Brain Care Monitor).[49,50] Pilot RCTs also validated process-of-care quality indicators (e.g. Assessing Care of Vulnerable Elders).[12,51,52] These pilot RCTs informed the adaptation, refinement, and transformation of three dementia care coordination programs over time.[6,10,14–17,30]

Medication management was crucial to the management of both disease and related and unrelated side effects. Almost all of the programs provided medication management as a coordination activity, managed either by nurse practitioners or by pharmacists.[13,15,28,29,42,53] Medication management involved reviewing medication regimens, reconciling discrepancies, and monitoring for outcome and side effects. Side effects may occur as a direct result of inappropriate use of psychoactive medications, which can directly affect the presence of behavioral and psychological symptoms of dementia and impact PWD safety.

Each program also developed their own IT software. Four of the programs have trademarked their software and reached out to insurance providers in order to encourage support for value-based or bundled payments for adequate reimbursement and program sustainability.[5,17,21,29] Primary care practices considering practice redesign of their clinical practices in order to incorporate dementia care coordination may consider and budget for the use of trademarked software from existing programs. Additional advantages of this software include ensuring fidelity of implementation to planned courses of action and informing process measures to monitor implementation and program outcomes.

Over half of the programs utilized their experience and expertise in order to acquire financial support from the Centers for Medicare and Medicaid Innovation (CMMI) Health Care Innovation Awards. Working with CMMI encouraged program transparency and flexibility to make timely adjustments and modifications based on incoming data. Adjustments and modifications included the addition of lay health workers as care coordinator assistants, introduction of a self-efficacy survey for informal CGs, and modifications to inclusion criteria in order to aid and enhance recruitment.[5,35] Two programs in particular experienced difficulties with attracting PWDs to be part of the program (participant recruitment).[6,29,35] These

adjustments, modifications, and overall heterogeneity and complexity of the programs presented challenges for evaluators who were trying to compare the different care coordination programs.

An additional barrier is that initial cost evaluations have shown small or null benefits and savings, which may be attributed to high start-up and maintenance costs.[5,6,9,18,46,54]. Program costs include salary, benefits, training of personnel, payments for services to community-based organizations, and other non-personnel expenses such as equipment and IT software maintenance. One program estimated start-up costs of around $70,000 and annual fixed costs of almost $25,000 (in 2002 US dollars [USD]) regardless of number of PWD/CG dyads enrolled.[54] When adjusted for inflation to 2019 USD, start-up costs and annual fixed costs would be approximately $100,000 and $35,000, respectively.[55] To encourage other programs, two programs have offered their expertise in the form of consulting services and access to their IT software for primary care practices considering practice redesign.[56,57] Implementing organizations have also adjusted or modified their programs to focus on a high-risk subset of their sample. Three programs made their care coordinator available via 24-hour telephone support (for emergencies) and installed an alert in the IT software if the PWD went to the emergency room. This targeted modification had a potential effect on utilization outcomes, reducing readmissions and poor outcomes during hospitalization, as has been seen in the Transitional Care Model for hospitalized, cognitively impaired older adults.[58]

Additional research is needed into new payment mechanisms, such as a per-beneficiary-per-month payment for comprehensive dementia care management services and incremental changes to billing codes for chronic care management.[20] Meanwhile, ongoing research could focus on how capitation should be split between the dementia care coordination program, referring primary care providers and primary care practices, and community organizations.[9,31]

Inner and outer setting

The seven dementia care coordination programs span almost thirty years. Yet, the context in which implementation takes place (i.e. theoretical basis, circumstances, or unique factors around a program or intervention implementation) has overall remained the same. In CFIR, the inner setting includes the structural, political, and cultural context through which implementation occurs (e.g. features within the implementing organization) while the outer setting includes the overall economic, political, and social context within which the program and implementing organization resides.[24]

Collaborative dementia care and care coordination brought about significant changes from existing practice. New teams and the care coordinator role were created, new processes were instituted both with formal assessments and partnerships with community organizations. Yet, changes were possible due to the expertise and established maturity of the implementing organizations and the organization's enduring commitment to the program. The implementing organizations used their own validated study instruments and IT software to identify and track PWD needs.[27,45] All of the programs were designed to complement primary care. Most programs were developed with the purpose of establishing partnerships with community organizations, supporting the PWD and the informal CG and improving the overall quality of dementia care (Table 4.2).

The main barrier to improving the delivery of dementia care in the programs was the lack of workforce evaluation and dissemination efforts, which provide insight into the implementation climate, culture, and processes. Only one program documented evidence in the peer-reviewed literature of interviews with staff of the care coordination team, feedback to the team, and efforts to address workforce stress and burnout.[29] CMMI interviews of PWDs, informal CGs, and

program staff in the demonstration projects (a gray paper) revealed that the overall culture was positive and dedicated.[5,6,35] PWDs and CGs were grateful to have assistance and were in need of education, counseling, and support.

Another facilitator was the presence of strong communication both internally within the team and externally with community organizations. External ties with community organizations helped three of the programs find their care coordinators and all of the programs their resources for psychosocial interventions.[12,14,30] Initially, several home health organizations did not want to collaborate with one of the care coordination program due to concerns about service duplication.[59] Financial reimbursement via vouchers for home-and-community-based-services and alignment of study objectives with perceived unmet community needs (i.e. shared desire to provide high-quality dementia care that supports PWDs and informal CGs) achieved buy-in from these organizations.

Interest from policymakers and the availability of short-term financial support facilitated the creation and ongoing support of the care coordination programs. Funding mechanisms were available when policymakers were interested in lowering costs and utilization: first, with Section 9342 of the Omnibus Budget Reconciliation Act of 1986 and most recently, with the Affordable Care Act and the creation of the CMS Innovation Center and the Patient-Centered Outcomes Research Institute.[5,9,35] However, additional research is needed into new payment mechanisms as this financial support is temporary and programs work towards long-term sustainability.

Characteristics of the individuals involved

The characteristics of the individuals domain examines the interplay between individuals and the organization within which they work and how that interplay influences individual or

organizational behavior change.[24] This domain essentially examines the knowledge, beliefs, self-efficacy, mindset, perceptions, and commitment of the individuals toward the organization.

The delivery of collaborative dementia care involves multiple individuals: both the PWD and the informal CG (individually and as a dyad), all members of the care coordination team, referring primary care providers, and members of the community organizations involved in supporting the PWD and informal CG. More than half of the programs focused the purpose of their programs on the PWD and informal CG dyad: supporting the dyad; reducing informal CG burden; maximizing PWD function, dignity, and independence; reducing unmet needs of the dyad; and improving dyad health and social support.[9,12,14,29–31,41] Yet, quantitative and qualitative feedback from the dyad was not always available in the published literature from the implementing organization. Dyad and team member interviews were included as part of evaluations of CMMI demonstration projects. PWDs and informal CGs were grateful to have assistance and placed high value on the program, which was not always reflected in the quantitative, published results. Lay health workers had prominent roles in CMMI demonstration projects: coordinating communication and long-term service activities, addressing social and non-clinical needs of participants, and providing education to PWDs and informal CGs. These prominent roles and the dyad's gratitude increased the lay health worker's commitment to the program.[5]

Three programs assessed the knowledge, beliefs, and mindset of the referring providers with focus groups and surveys.[29,47,60,61] Providers helped with participant recruitment and were actively included in care plan development. In one program, providers viewed the program as useful and valuable because it saved time and explored issues that had not yet been clinically addressed.[47] Yet in another program, providers participating for nine months did not have any

different attitudes or perceptions about collaborative care or dementia knowledge than providers not participating in the program.[61]

The lack of surveys to assess self-efficacy and mindset (e.g. burnout, stress) for both the dyad and the care coordination team is a significant barrier to our understanding of the programs. Over half of the programs neither included nor assessed for self-efficacy in PWDs and informal CGs.[6,11,45] Only one program surveyed the care coordinator and other members of the care coordination team.[29] A knowledge gap was present as self-efficacy is desired and needed among the dyad but was not included as part of the assessment. Additionally, workforce surveys can provide insight into the personal attributes of the individuals, individual stage of change, and individual identification with the implementing organization.

Process

The four essential activities to examine the implementation process common across programs are planning, engaging, executing, and reflecting and evaluating.[24]

One facilitator of successful programs was the extensive planning and engaging that programs undertook. Planning included development and testing of assessment tools and preliminary implementation with RCTs. For engaging, programs focused on achieving community support and buy-in through networking with large organizations, community outreach, and community involvement. Programs identified community liaisons ("champions") who helped lead recruitment efforts.[30,59] Programs created advisory boards or steering committees, comprised of community members, PWDs, and informal CGs.[12,29,59] One program created a dissemination team to assist with sustainability efforts.[21] Internally, programs dedicated formal weekly meeting times for care coordinators and the care coordination team to discuss challenging cases and other issues that arose with program implementation.

However, the total time required to set-up and execute the care coordination program was extensive and served as a barrier to assessing program impact. One of the programs was funded for only twelve months but the median time for a formal reassessment to occur was seven months (range four to sixteen months). When program funding is restricted to short time periods (e.g. three years), the dyad may not receive the full extent of services needed to have a meaningful impact. Longer follow-up periods for program evaluation are needed. In addition, most programs used either the health IT system or care coordinators (providing feedback on why formal reassessment were not done) to measure fidelity of implementation to planned courses of action. However, a formal checklist did not exist. A formal checklist would describe the quality of program implementation and execution. This checklist could include degree of fidelity of implementation to planned courses of action as defined by dyad needs, timeliness of task completion, and degree of engagement of persons involved in the implementation process.[24]

Future implications

The goal in describing the core components of the program and facilitators and barriers to delivering dementia care within these care coordination programs is to provide examples for other primary care practices and academic medical centers that are looking to enhance and expand on existing dementia care practices. Core components identified in our review include a team-based coordinated approach to care; on-going long-term assessment, monitoring, and management of dyad needs; and indispensable partnerships with other providers, healthcare systems, and community-based resources.

We used the CFIR model to identify facilitators and barriers to delivering dementia care coordination. We found that characteristics of the implementing organization and relationships with community resources were paramount. Characteristics of the implementing organization

determined functioning features of the program, composition of the multidisciplinary, collaborative care coordination team, study instruments, health IT software, and approach in how relationships with the community and community organizations were developed. We also found that implementing organizations have relied on short-term financial support in order to develop, launch, and operate dementia care coordination programs but now are focusing on long-term sustainability through alternative payment mechanisms and reimbursement. Last, we found a knowledge gap regarding workforce outcomes in these programs.

The PWD have complicated medical, behavioral, social, and functional needs. Management of these needs requires specialized knowledge, time, and substantial support. Dementia care coordination programs can complement primary care in order to increase the quality of dementia care and improve PWD and informal CG outcomes. As primary care practices consider practice redesign and incorporation of collaborative dementia care into their existing practices, we hope that implementation research can guide this process in order to ensure that quality dementia care is delivered.

References

1. Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2018;14(3):367-429. doi:10.1016/j.jalz.2018.02.001

2. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The Disproportionate Impact Of Dementia On Family And Unpaid Caregiving To Older Adults. *Health Aff Proj Hope*. 2015;34(10):1642-1649. doi:10.1377/hlthaff.2015.0536

3. Harris-Kojetin L, Sengupta M, Park-Lee E, et al. *Long-Term Care Providers and Services Users in the United States: Data from the National Study of Long-Term Care Providers, 2013-2014*. Hyattsville, MD: National Center for Health Statistics; 2016. https://www.cdc.gov/nchs/data/series/sr_03/sr03_038.pdf.

4. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med*. 2013;368(14):1326-1334. doi:10.1056/NEJMsa1204629

5. NORC at the University of Chicago. *HCIA Disease-Specific Evaluation - Third Annual Report*.; 2017. https://downloads.cms.gov/files/cmmi/hcia-diseasespecific-thirdannualrpt.pdf. Accessed August 27, 2017.

6. Mathematica Policy Research. *Evaluation of the Round Two Health Care Innovation Awards (HCIA R2): Second Annual Report*.; 2017. https://downloads.cms.gov/files/cmmi/hcia2-yrtwoannualrpt.pdf. Accessed December 10, 2017.

7. McDonald KM, Schultz EM, Albin L, et al. *Care Coordination Atlas Version 4*. Rockville, MD: Agency for Healthcare Research and Quality; 2014. https://www.ahrq.gov/sites/default/files/publications/files/ccm_atlas.pdf. Accessed March 3, 2017.

8. Reilly S, Miranda-Castillo C, Malouf R, et al. Case management approaches to home support for people with dementia. *Cochrane Database Syst Rev*. 2015;1:CD008345. doi:10.1002/14651858.CD008345.pub2

9. Fox P, Newcomer R, Yordi C, Arnsberger P. Lessons learned from the Medicare Alzheimer Disease Demonstration. *Alzheimer Dis Assoc Disord*. 2000;14(2):87-93.

10. Bass DM, Clark PA, Looman WJ, McCarthy CA, Eckert S. The Cleveland Alzheimer's managed care demonstration: outcomes after 12 months of implementation. *The Gerontologist*. 2003;43(1):73-85.

11. Bass DM, Judge KS, Snow AL, et al. Caregiver outcomes of partners in dementia care: effect of a care coordination program for veterans with dementia and their family members and friends. *J Am Geriatr Soc*. 2013;61(8):1377-1386. doi:10.1111/jgs.12362

12. Vickrey BG, Mittman BS, Connor KI, et al. The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Ann Intern Med*. 2006;145(10):713-726.

13. Bass DM, Judge KS, Snow AL, et al. A controlled trial of Partners in Dementia Care: veteran outcomes after six and twelve months. *Alzheimers Res Ther*. 2014;6(1):9. doi:10.1186/alzrt242

14. Callahan CM, Boustani MA, Weiner M, et al. Implementing dementia care models in primary care settings: The Aging Brain Care Medical Home. *Aging Ment Health*. 2011;15(1):5-12. doi:10.1080/13607861003801052

15. Callahan CM, Boustani MA, Unverzagt FW, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA*. 2006;295(18):2148-2157. doi:10.1001/jama.295.18.2148

16. Boustani MA, Sachs GA, Alder CA, et al. Implementing innovative models of dementia care: The Healthy Aging Brain Center. *Aging Ment Health*. 2011;15(1):13-22. doi:10.1080/13607863.2010.496445

17. Samus QM, Johnston D, Black BS, et al. A multidimensional home-based care coordination intervention for elders with memory disorders: the maximizing independence at home (MIND) pilot randomized trial. *Am J Geriatr Psychiatry Off J Am Assoc Geriatr Psychiatry*. 2014;22(4):398-414. doi:10.1016/j.jagp.2013.12.175

18. Jennings LA, Laffan AM, Schlissel AC, et al. Health Care Utilization and Cost Outcomes of a Comprehensive Dementia Care Program for Medicare Beneficiaries. *JAMA Intern Med*. 2019;179(2):161-166. doi:10.1001/jamainternmed.2018.5579

19. Callahan CM, Sachs GA, Lamantia MA, Unroe KT, Arling G, Boustani MA. Redesigning systems of care for older adults with Alzheimer's disease. *Health Aff Proj Hope*. 2014;33(4):626-632. doi:10.1377/hlthaff.2013.1260

20. Boustani M, Alder CA, Solid CA, Reuben D. An Alternative Payment Model To Support Widespread Use Of Collaborative Dementia Care Models. *Health Aff Proj Hope*. 2019;38(1):54-59. doi:10.1377/hlthaff.2018.05154

21. Haggerty KL, Stoeckle RJ, Spragens L, Jennings L, Carmody J. Primary care innovations can improve Alzheimer's and dementia care for patients, family caregivers, and providers. *Health Aff Blog*. March 2019. https://www.healthaffairs.org/do/10.1377/hblog20190327.432411/full/. Accessed April 3, 2019.

22. Peters DH, Adam T, Alonge O, Agyepong IA, Tran N. Implementation research: what it is and how to do it. *BMJ*. 2013;347:f6753.

23. Kirk MA, Kelley C, Yankey N, Birken SA, Abadie B, Damschroder L. A systematic review of the use of the Consolidated Framework for Implementation Research. *Implement Sci IS*. 2016;11:72. doi:10.1186/s13012-016-0437-z

24. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci*. 2009;4:50. doi:10.1186/1748-5908-4-50

25. National Quality Forum. *Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Dementia, Including Alzheimer's Disease*.; 2014. http://www.qualityforum.org/priority_setting_for_healthcare_performance_measurement_al zheimers_disease.aspx. Accessed February 1, 2018.

26. Reuben DB, Gupta R, Skootsky SA. How a population-based approach can improve dementia care. *Health Aff Blog*. May 2019. https://www.healthaffairs.org/do/10.1377/hblog20190506.543619/full/. Accessed June 9, 2019.

27. Yordi C, DuNah R, Bostrom A, Fox P, Wilkinson A, Newcomer R. Caregiver supports: outcomes from the Medicare Alzheimer's disease demonstration. *Health Care Financ Rev*. 1997;19(2):97-117.

28. Jennings LA, Tan Z, Wenger NS, et al. Quality of Care Provided by a Comprehensive Dementia Care Comanagement Program. *J Am Geriatr Soc*. 2016;64(8):1724-1730. doi:10.1111/jgs.14251

29. Possin KL, Merrilees J, Bonasera SJ, et al. Development of an adaptive, personalized, and scalable dementia care program: Early findings from the Care Ecosystem. *PLoS Med*. 2017;14(3):e1002260. doi:10.1371/journal.pmed.1002260

30. Judge KS, Bass DM, Snow AL, et al. Partners in dementia care: a care coordination intervention for individuals with dementia and their family caregivers. *The Gerontologist*. 2011;51(2):261-272. doi:10.1093/geront/gnq097

31. Reuben DB, Evertson LC, Wenger NS, et al. The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: preliminary data. *J Am Geriatr Soc*. 2013;61(12):2214-2218. doi:10.1111/jgs.12562

32. Austrom MG, Carvell CA, Alder CA, Gao S, Boustani M, LaMantia M. Workforce development to provide person-centered care. *Aging Ment Health*. 2016;20(8):781-792. doi:10.1080/13607863.2015.1119802

33. Judge KS, Bass DM, Kunik ME. *Partnership Supports Patients with Dementia and Their Caregivers through Care Coordinator Team, Leading to Improved Psychosocial Outcomes*. Rockville, MD: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, AHRQ Health Care Innovations Exchange; 2014. https://innovations.ahrq.gov/profiles/partnership-supports-patients-dementia-and-their-caregivers-through-care-coordinator-team. Accessed October 10, 2017.

34. Arnsberger P, Fox P, Zhang X. Case manager-defined roles in the Medicare Alzheimer's Disease Demonstration: relationship to client and caregiver outcomes. *Care Manag J J Case Manag J Long Term Home Health Care*. 1999;1(1):29-37.

35. Mathematica Policy Research. *Evaluation of the Round Two Health Care Innovation Awards (HCIA R2): First Annual Report*.; 2016.

https://downloads.cms.gov/files/cmmi/hcia2-yroneevalrpt.pdf. Accessed December 10, 2017.

36. Chodosh J, Colaiaco BA, Connor KI, et al. Dementia Care Management in an Underserved Community: The Comparative Effectiveness of Two Different Approaches. *J Aging Health*. 2015;27(5):864-893. doi:10.1177/0898264315569454

37. Tanner JA, Black BS, Johnston D, et al. A randomized controlled trial of a community-based dementia care coordination intervention: effects of MIND at Home on caregiver outcomes. *Am J Geriatr Psychiatry Off J Am Assoc Geriatr Psychiatry*. 2015;23(4):391-402. doi:10.1016/j.jagp.2014.08.002

38. Yaffe K, Fox P, Newcomer R, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA*. 2002;287(16):2090-2097.

39. French DD, LaMantia MA, Livin LR, Herceg D, Alder CA, Boustani MA. Healthy Aging Brain Center improved care coordination and produced net savings. *Health Aff Proj Hope*. 2014;33(4):613-618. doi:10.1377/hlthaff.2013.1221

40. Jennings LA, Palimaru A, Corona MG, et al. Patient and caregiver goals for dementia care. *Qual Life Res Int J Qual Life Asp Treat Care Rehabil*. 2017;26(3):685-693. doi:10.1007/s11136-016-1471-7

41. Newcomer R, Yordi C, DuNah R, Fox P, Wilkinson A. Effects of the Medicare Alzheimer's Disease Demonstration on caregiver burden and depression. *Health Serv Res*. 1999;34(3):669-689.

42. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *J Am Geriatr Soc*. 2013;61(12):2087-2095.

43. Jennings LA, Reuben DB, Evertson LC, et al. Unmet needs of caregivers of individuals referred to a dementia care program. *J Am Geriatr Soc*. 2015;63(2):282-289. doi:10.1111/jgs.13251

44. LaMantia MA, Alder CA, Callahan CM, et al. The Aging Brain Care Medical Home: Preliminary Data. *J Am Geriatr Soc*. 2015;63(6):1209-1213. doi:10.1111/jgs.13447

45. Connor K, McNeese-Smith D, van Servellen G, et al. Insight into dementia care management using social-behavioral theory and mixed methods. *Nurs Res*. 2009;58(5):348-358. doi:10.1097/NNR.0b013e3181b49910

46. Morgan RO, Bass DM, Judge KS, et al. A break-even analysis for dementia care collaboration: Partners in Dementia Care. *J Gen Intern Med*. 2015;30(6):804-809. doi:10.1007/s11606-015-3205-x

47. Tan ZS, Jennings L, Reuben D. Coordinated care management for dementia in a large academic health system. *Health Aff Proj Hope*. 2014;33(4):619-625. doi:10.1377/hlthaff.2013.1294

48. Chodosh J, Pearson ML, Connor KI, et al. A dementia care management intervention: which components improve quality? *Am J Manag Care*. 2012;18(2):85-94.

49. Monahan PO, Boustani MA, Alder C, et al. Practical clinical tool to monitor dementia symptoms: the HABC-Monitor. *Clin Interv Aging*. 2012;7:143-157. doi:10.2147/CIA.S30663

50. Johnston D, Samus QM, Morrison A, et al. Identification of community-residing individuals with dementia and their unmet needs for care. *Int J Geriatr Psychiatry*. 2011;26(3):292-298. doi:10.1002/gps.2527

51. Wenger NS, Roth CP, Shekelle P, ACOVE Investigators. Introduction to the assessing care of vulnerable elders-3 quality indicator measurement set. *J Am Geriatr Soc*. 2007;55 Suppl 2:S247-252. doi:10.1111/j.1532-5415.2007.01328.x

52. Reuben DB, Roth CP, Frank JC, et al. Assessing care of vulnerable elders--Alzheimer's disease: a pilot study of a practice redesign intervention to improve the quality of dementia care. *J Am Geriatr Soc*. 2010;58(2):324-329. doi:10.1111/j.1532-5415.2009.02678.x

53. Chodosh J, Mittman BS, Connor KI, et al. Caring for patients with dementia: how good is the quality of care? Results from three health systems. *J Am Geriatr Soc*. 2007;55(8):1260-1268. doi:10.1111/j.1532-5415.2007.01249.x

54. Duru OK, Ettner SL, Vassar SD, Chodosh J, Vickrey BG. Cost evaluation of a coordinated care management intervention for dementia. *Am J Manag Care*. 2009;15(8):521-528.

55. U.S. Bureau of Labor Statistics. *Consumer Price Index Inflation Calculator*. https://data.bls.gov/cgi-bin/cpicalc.pl. Accessed July 2, 2019.

56. Regenstrief Institute. Applied Solutions. https://www.regenstrief.org/applied-solutions/. Published 2019. Accessed July 4, 2019.

57. Benjamin Rose Institute on Aging. BRI Care Consultation Evidence-Based Program. http://www.benrose.org/BRICareConsultation/index.cfm. Published 2018. Accessed July 4, 2019.

58. Naylor MD, Hirschman KB, Hanlon AL, et al. Comparison of evidence-based interventions on outcomes of hospitalized, cognitively impaired older adults. *J Comp Eff Res*. 2014;3(3):245-257. doi:10.2217/cer.14.14

59. Samus QM, Amjad H, Johnston D, Black BS, Bartels SJ, Lyketsos CG. A Multipronged, Adaptive Approach for the Recruitment of Diverse Community-Residing Elders with

Memory Impairment: The MIND at Home Experience. *Am J Geriatr Psychiatry Off J Am Assoc Geriatr Psychiatry*. 2015;23(7):698-708. doi:10.1016/j.jagp.2015.01.005

60. Harris DP, Chodosh J, Vassar SD, Vickrey BG, Shapiro MF. Primary care providers' views of challenges and rewards of dementia care relative to other conditions. *J Am Geriatr Soc*. 2009;57(12):2209-2216. doi:10.1111/j.1532-5415.2009.02572.x

61. Chodosh J, Berry E, Lee M, et al. Effect of a dementia care management intervention on primary care provider knowledge, attitudes, and perceptions of quality of care. *J Am Geriatr Soc*. 2006;54(2):311-317. doi:10.1111/j.1532-5415.2005.00564.x

Table 4.1 Consolidated Framework for Implementation Research domains and constructs (Damschroder et al., 2009)

I. Program/ Intervention Characteristics	II. Inner Setting	III. Outer Setting	IV. Individual Characteristics	V. Implementation Process
• Intervention source • Evidence strength and quality • Relative advantage • Adaptability • Trialability • Complexity • Design quality • Cost	• Structural characteristics • Networks and communications • Culture • Implementation climate • Implementation readiness	• Patient needs and resources • Cosmopolitanism • Peer pressure • External policy and incentives	• Knowledge and beliefs about the intervention • Self-efficacy • Individual stage of change • Individual identification with organization • Other personal attributes	• Planning • Engaging • Executing • Reflecting and evaluating

Table 4.2 Characteristics of current dementia care coordination programs

Program purpose, defining attributes of the program, who delivered care coordination, and primary outcomes identified by the literature review of seven dementia care coordination programs. Program purpose was focused on the PWD and CGs. The defining attribute for five out of the seven programs was partnerships with CBOs. Majority of the programs (5 out of 7) delivered care coordination via a multidisciplinary collaborative care team. Primary outcomes were almost evenly split, with four programs focusing on the informal caregiver (e.g. stress, depression, burden, unmet needs) and the remaining three programs focusing on the system/utilization (e.g. adherence to dementia guideline recommendations, hospitalizations, ED visits, cost of care)

Program	Program purpose	Defining attributes	Care coordination delivery	Outcomes
A	Provide info to PWD/CG	Partnership with CBOs	Social worker; Nurse	Informal CG
B	Reduce CG burden	Partnership with CBOs; Alternative reimbursement	Social worker; Nurse	Informal CG
C	Enhance CG self-managing skills and coping behaviors; ACP for PWD	Clinical program in health system	Team	System/utilization
D	Reduce CG unmet needs; improve PWD and CG health	Guideline-concordant care; Partnership with CBOs	Team	Informal CG
E	Delay transition from home; reduce PWD/CG unmet needs and improve QOL	Partnership with CBOs	Team	System/utilization
F	Maximize PWD function; minimize CG burnout; reduce costs	Partnership with CBOs	Team	System/utilization
G	Provide complementary CG support and education; address PWD and CG unmet needs; ensure decisions are consistent with patient values, align with government initiatives	Medication management	Team	Informal CG

ACP Advanced care planning; **CBO** Community-based organization; **CG** Caregiver; **CMS** Centers for Medicare and Medicaid Services; **ED** Emergency department; **PWD** Person with dementia; **QOL** Quality of life

Outer Setting

Characteristics of dementia care coordination programs (observed)

Core Components

- Team-based, coordinated approach to care
- On-going long-term assessment, monitoring, & management of dyadic needs
- Strong networks between other providers,

- Political, geographical environment (B)
- Current reimbursement (B)

- Unique PWD needs and available resources (F)
- Affordable Care Act – CMMI demonstration awards (F)

Individuals Involved (F/B)

- PWD/informal CG
- Care coordinator
- Primary care providers
- Community organizations

- Multidisciplinary collaborative care team
- Healthcare systems

Inner Setting

- Structural characteristics (F)
- Strong commitment to collaborative dementia care (F)
- Networks developed with external organizations (F)

- Information on workforce outcomes, implementation climate, culture (B)

Characteristics of dementia care coordination programs (proposed)

Core Components

- Continuous monitoring, assessment, & ongoing-care plan
- Psychosocial interventions, medication management, treatment of depression, BPSD, coexisting conditions
- Dyad self-management
- Coordination of care

- Plans for sustainability (F/B)
- Community liaisons, advisory boards, steering committees (F)

- Information on whether PWD/CG dyads received full extent of services, set-up and execution time, fidelity (B)
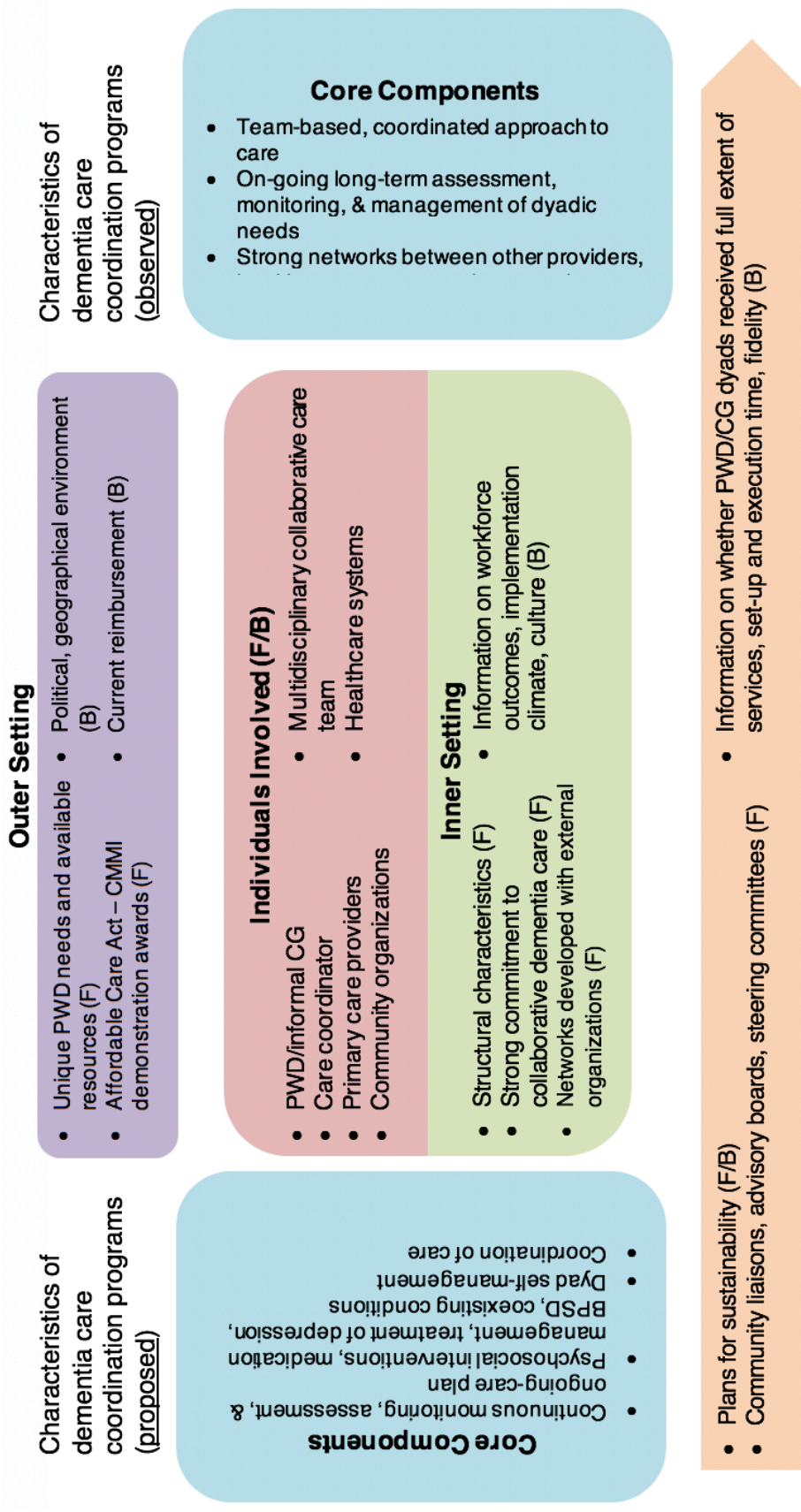
Process

Figure 4.1 Core components of dementia care coordination programs, facilitators (F) and barriers (B) to delivering collaborative dementia care via the Consolidated Framework for Implementation Research

BPSD Behavioral and psychological symptoms of dementia, **CG** Caregiver, **PWD** Person with dementia

Chapter 5: Conclusions and Implications for Clinical Practice, Policy, and Future Research

This dissertation research examined the role and influence of social support and formal service use in community-dwelling PWD – prior to moving out of the home and into an institution and at the end-of-life. In addition, this dissertation research examined how dementia care coordination programs can provide additional support to community-dwelling PWD and implementation considerations as health care professionals and health systems continue to improve the quality of dementia care.

The role of social support

In Chapter 2, we examined the residential transitions of community-dwelling older adults in a nationally representative sample between 2011 and 2017. We estimated the risk of transition into an institutional setting, with death prior to institutionalization considered a competing risk and sources of social support as our primary predictors. We found that after adjusting for age, gender, race, cognitive status, functional disability, multimorbidity, and Medicaid enrollment, older adults were more likely to move out of the home into an institution if they had no social network or lived alone. Going out to the movies, dinner, or the casino or visiting family or friends lowered the risk of institutionalization. In a subanalysis, we compared the residential transitions of community-dwelling older adults with dementia and without dementia, and the distinct role of social support in institutionalization within these subgroups. We found that many older adults with dementia moved to an institution prior to death and that for these older adults, sources of social support may not be predictive of institutionalization.

The role of formal service use

In Chapter 3, we studied home health and hospice service use (formal services) in the last year of life for community-dwelling participants with dementia who died at home. Our study

confirmed the complicated clinical profile of these participants with dementia, which was different from participants without dementia. Participants with dementia had multiple coexisting conditions (heart failure, diabetes, and malignancies [cancer]), complex medical needs (help with wound care) and were frail. We found that participants with dementia who received only one type of formal service (either home health or hospice) in the last year of life had few (one claim/episode) but long interactions (in number of days) with formal services. In addition, hospice was initiated within the last two weeks of life for half of our study population.

The role of care coordination

Building upon our findings related to social support and formal care needs, we next examined and compared seven care coordination programs through a structured review of the literature in Chapter 4. We reviewed their characteristics in order to determine the core components of these programs, facilitators and barriers to delivering dementia care in these programs, and implementation considerations as health systems initiate linkages with community-based resources. Key core components of the programs included the care coordinator and the multidisciplinary, collaborative care coordination team; continuous monitoring and assessment and ongoing care planning; and partnerships with primary care providers, healthcare systems, and community organizations. Our primary finding was that characteristics of the implementing organization determined the functioning features of the program; creation of multidisciplinary, collaborative care coordination teams, study instruments, and health information technology software; and the approach to establishing relationships with community-based resources. In addition, implementing organizations relied on short-term financial support in order to develop, launch, and operate the dementia care coordination programs and are now focusing on long-term sustainability through alternative payment

mechanisms and advocacy for expanded reimbursement. Essential to implementation is a workforce with the appropriate training and skill mix. As primary care practices or existing care coordination programs continue to provide collaborative dementia care, we suggest particular attention to workforce outcomes such as satisfaction, stress, and burnout, a gap identified in our review.

Finally, this dissertation work found that common quality indicators for dementia care processes in care coordination programs covered three domains: assessment and screening, counseling, and treatment. Quality indicators for the assessment and screening domain included screening for cognitive status, functional assessment, dementia staging, and related conditions such as depression, delirium, and other neuropsychiatric symptoms, and laboratory testing for other causes of mental status change. The counseling domain included discussion of dementia diagnosis, prognosis, behavioral interventions for dementia-related problems, safety (i.e. driving), and advanced care planning. Last, the treatment domain included pharmacological treatments for dementia, stroke prophylaxis for vascular or mixed dementia, risks/benefits discussion about any new medications, and discontinuation of any medications associated with adverse effects.

Summary

In summary, findings from this dissertation research provide insight into the life of community-dwelling PWD (i) prior to moving out of the home and into an institution and (ii) prior to death at home. This dissertation first examined the influence of socioemotional support (sources of meaningful social connections) on risk for institutionalization. Next, we characterized the complicated clinical profiles of community-dwelling PWD who utilize home health and hospice services prior to death at home. Finally, we proposed implementation

considerations for primary care practices and academic medical centers to support the initiation and continued operations of collaborative dementia care as illustrated by the care coordination programs we examined.

Implications for Clinical Practice and Future Research

Recent data from the National Study of Long-Term Care Providers found that at least one-quarter of long-term care service use (nursing home [institution], hospice, residential care community, home health agency, and adult day services center) was used by people with a dementia diagnosis.[1] Nursing home use was most prevalent (used by 48% of PWD) followed by hospice services (45%), residential care communities (42%), home health agencies (32%), and adult day services (31%). Taking into account the broader picture of transitions between residence types and types of care, this dissertation research found that community-dwelling PWD are likely to move to a nursing home prior to death but sources of social support may not be predictive of this move. Living alone was predictive of institutionalization and may reflect the PWD's reliance on informal, unpaid CGs and formal services and support. Efforts to delay nursing home placement should rather focus on factors that predict this move, such as behavioral symptoms, depression, and functional impairment.[2]

This dissertation research also found that participants with dementia cycled between home health and hospice service use in the last year of life. For half of the participants, hospice services were initiated within the last two weeks of life. As a result, the participant with dementia may not have received the full benefits of hospice care. Hospice is restricted to terminally ill patients with a prognosis of six months or less who agree to forego "curative" care.[3] Efforts to prognosticate mortality in PWD have been unreliable as PWD survive an average of four to eight years after a dementia diagnosis and as long as twenty years.[4–7] Due to the gradual downhill

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course of disease progression, it may not have been clear that the participant with dementia was dying.[8] This suggests that the appropriate care may not have been provided to the PWD as the PWD approached death. Suggested approaches for providers include identifying whether the PWD has other coexisting conditions such as heart, lung, or kidney disease that allow them to qualify for hospice.[9]

Earlier introduction of palliative care, which can be delivered concurrently with curative therapies may reduce symptoms of distress and improve the overall quality of life for the PWD and the informal CG. Palliative care focuses on supporting and maximizing the best possible quality of life by assessing, preventing, and relieving symptoms of distress. While this dissertation focused on PWD outcomes, palliative care should be directed at the PWD and informal CG dyad, especially with disease progression. An additional benefit of palliative care is initiation of early conversations dedicated to advance care planning, which includes goals of care, treatment preferences, and advanced directives.[10] This dissertation research found that dementia care coordination programs are already introducing and facilitating these conversations as one of their program components.[11–15]

An additional clinical benefit of dementia care coordination programs is their unique, central position that includes interactions with community-based resources such as formal services and supports. Dementia care coordination programs can support the continued refinement of dementia quality measures and efforts aimed at quality improvement.

Quality indicators for dementia care processes in care coordination programs differ from the home health and hospice quality measures endorsed by the Centers for Medicare and Medicaid Services (CMS). CMS home health quality measures focus on outcome and process measures derived from OASIS (instrument/data collection tool used by home health agencies)

and claims data. Outcome measures include improvement measures (i.e. functional abilities, general health); measures of potentially avoidable events; utilization measures; and cost/resource measures. Process outcomes use a non-risk-adjusted calculation that evaluates home health agency use of specific processes of care (e.g. timeliness of home care admission or immunizations).[16] On the other hand, hospice quality measures endorsed by the National Quality Forum include treatment preferences, beliefs/values addressed, pain screening, pain assessment, dyspnea screening, dyspnea treatment, and patients treated with opioids who are given a bowel regimen.[17] Future work could focus on examining the home health and hospice quality measures, apply quality measures specifically to the unique PWD population, and modify existing measures as needed for the unique care needs of PWD. Last, the vast majority of services provided in the home are done by informal CGs.[18] Future research efforts must incorporate the informal CG and study the PWD and informal CG as a dyad.

Implications for Health Policy and Future Work

Recent policies have already started to prioritize noninstitutional settings.[18,19] In addition, there is a shift towards increasing access to community-based care. Yet, the current reimbursement system limits the potential benefits of care coordination and restricts access to many formal services (i.e. formal services are covered by Medicaid and are not covered by Medicare and private insurers).[8,10,18–20] Our review of dementia care coordination programs and study of social support and formal services found that long-term sustainability will rely on continued efforts to modify existing payment systems. Payment reform options include a per member per month payment for care management (care coordination) or applying a bundled payment for reimbursement of home health services.[10,18,20]

CMS initiated payment reform for hospice services in 2015 in order to take account changes in utilization since the original benefit was established in 1983.[21] The payment system for hospice services was developed around cancer disease trajectories. Yet, this reform did not address the barriers to care created by the hospice eligibility standards. Our review of Medicare claims and the primary diagnosis for hospice initiation supports efforts to evaluate and modify current guidelines for hospice eligibility. This dissertation work confirmed that that the clinical profile of PWD is complicated and that their needs are different from participants without dementia. Participants with dementia had multiple coexisting conditions (heart failure, diabetes, and malignancies [cancer]), complex medical needs (help with wound care) and were frail. Thus, hospice payment mechanisms need to be refined to consider the unique needs of PWD.

In addition, our review of dementia care coordination programs revealed that the workforce is an area of future study, which is consistent with the literature.[8,10,19] Efforts should not only focus on creating a skilled, dementia care interdisciplinary workforce but also focus on evaluating workforce stress and burnout as collaborative dementia care is implemented and roles change. In conclusion, the goal of supporting community-dwelling PWD to age-in-place can only be addressed by assuring that their social support and formal care needs are met. Care coordination programs have the potential to address many of their unique needs but require an enhanced and value-based payment system that recognizes the roles of informal, unpaid caregivers, providers and interdisciplinary healthcare team, and community resources and support.

References

1. Harris-Kojetin L, Sengupta M, Lendon J, Rome V, Valverde R, Caffrey C. *Long-Term Care Providers and Services Users in the United States, 2015-2016*. Hyattsville, MD: National Center for Health Statistics; 2019. https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf.

2. Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. *Med Care*. 2009;47(2):191-198. doi:10.1097/MLR.0b013e31818457ce

3. Centers for Medicare and Medicaid Services. *Medicare Hospice Benefits*. Baltimore, MD; 2019. https://www.medicare.gov/pubs/pdf/02154-medicare-hospice-benefits.pdf.

4. Brown MA, Sampson EL, Jones L, Barron AM. Prognostic indicators of 6-month mortality in elderly people with advanced dementia: A systematic review. *Palliat Med*. 2013;27(5):389-400. doi:10.1177/0269216312465649

5. Brodaty H, Seeher K, Gibson L. Dementia time to death: A systematic literature review on survival time and years of life lost in people with dementia. *Int Psychogeriatr*. 2012;24(7):1034-1045. doi:10.1017/S1041610211002924

6. Todd S, Barr S, Roberts M, Passmore AP. Survival in dementia and predictors of mortality: A review. *Int J Geriatr Psychiatry*. 2013;28(11):1109-1124. doi:10.1002/gps.3946

7. Tom SE, Hubbard RA, Crane PK, et al. Characterization of dementia and Alzheimer's disease in an older population: Updated incidence and life expectancy with and without dementia. *Am J Public Health*. 2015;105(2):408-413. doi:10.2105/AJPH.2014.301935

8. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med*. 2004;19(10):1057-1063. doi:10.1111/j.1525-1497.2004.30329.x

9. Jayes RL, Arnold RM, Fromme EK. Does this dementia patient meet the prognosis eligibility requirements for hospice enrollment? *J Pain Symptom Manage*. 2012;44(5):750-756. doi:10.1016/j.jpainsymman.2012.08.004

10. Unroe KT, Meier DE. Research priorities in geriatric palliative care: Policy initiatives. *J Palliat Med*. 2013;16(12):1503-1508. doi:10.1089/jpm.2013.9464

11. Vickrey BG, Mittman BS, Connor KI, et al. The effect of a disease management intervention on quality and outcomes of dementia care: A randomized, controlled trial. *Ann Intern Med*. 2006;145(10):713-726.

12. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the maximizing independence at home study. *J Am Geriatr Soc*. 2013;61(12):2087-2095.

13. Possin KL, Merrilees J, Bonasera SJ, et al. Development of an adaptive, personalized, and scalable dementia care program: Early findings from the Care Ecosystem. *PLoS Med*. 2017;14(3):e1002260. doi:10.1371/journal.pmed.1002260

14. NORC at the University of Chicago. *HCIA Disease-Specific Evaluation - Third Annual Report*.; 2017. https://downloads.cms.gov/files/cmmi/hcia-diseasespecific-thirdannualrpt.pdf. Accessed August 27, 2017.

15. Jennings LA, Turner M, Keebler C, et al. The Effect of a Comprehensive Dementia Care Management Program on End-of-Life Care. *J Am Geriatr Soc*. 2019;67(3):443-448. doi:10.1111/jgs.15769

16. Centers for Medicare and Medicaid Services. Home health quality measures. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HomeHealthQualityInits/Home-Health-Quality-Measures.html. Published July 11, 2019. Accessed August 1, 2019.

17. Centers for Medicare and Medicaid Services. Hospice quality public reporting. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Hospice-Quality-Public-Reporting.html. Published November 28, 2017. Accessed August 1, 2019.

18. Landers S, Madigan E, Leff B, et al. The Future of Home Health Care: A Strategic Framework for Optimizing Value. *Home Health Care Manag Pract*. 2016;28(4):262-278. doi:10.1177/1084822316666368

19. Samus QM, Black BS, Bovenkamp D, et al. Home is where the future is: The BrightFocus Foundation consensus panel on dementia care. *Alzheimers Dement J Alzheimers Assoc*. 2018;14(1):104-114. doi:10.1016/j.jalz.2017.10.006

20. Boustani M, Alder CA, Solid CA, Reuben D. An Alternative Payment Model To Support Widespread Use Of Collaborative Dementia Care Models. *Health Aff Proj Hope*. 2019;38(1):54-59. doi:10.1377/hlthaff.2018.05154

21. Stevenson DG, Huskamp H. Hospice payment reforms are a modest step forward, butt more changes are needed. *Health Aff Blog*. January 2016. https://www.healthaffairs.org/do/10.1377/hblog20160104.052496/full/.

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