CENTERS FOR MEDICARE & MEDICAID SERVICES
CENTER FOR MEDICARE & MEDICAID INNOVATION

Dementia Care Projects

Synthesis of Evaluation Results
1989 – 2020

Abstract

Background and Objective: Nearly half of older adults die with a diagnosis of Alzheimer's disease and/or a related dementia, either as the immediate cause of death or a co-morbidity. Dementia impairs memory, thought processes, and functioning. Persons with dementia need clinical and other care and services to manage this condition and often long-term services and supports as the disease progresses. This study synthesized evaluation results from CMS-funded work on dementia care to increase our understanding of the components used (e.g., setting, workforce, intensity) and to inform future CMS models and programs. These projects sought to improve the quality of life of persons with dementia and their unpaid caregivers by providing support to reduce medical emergencies and delay or avoid long-term care facility use.

Methods: Five CMS projects were included in this synthesis.[1] Participants (dementia clinics, academic medical systems) delivered care to enrolled Medicare fee-for-service beneficiaries with a dementia diagnosis and their unpaid caregivers. We examined the following claims-based outcomes: Total Medicare spending (Parts A & B), service use (e.g., emergency department visits, inpatient admissions, long-term care facility use). We also examined care experience assessed through surveys and interviews. Results and themes were summarized across projects to highlight their similarities and differences.

Results: Care settings varied according to each project's unique focus. Workforce innovations helped address gaps in care for persons with dementia, yet engagement among primary care providers and the dementia care team remained low. Service intensity may have been too low and the follow-up period too brief to observe an effect. Participating sites struggled to reach and enroll their target population. Across projects, we found no significant Medicare savings nor impacts on Medicare service use. One project (ADC-UCLA) showed significant reductions in long-term care facility use, enabling beneficiaries to remain in the community longer. Access to dementia care resources improved beneficiaries' and caregivers' experience of care. Caregivers reported increased efficacy in their caregiving abilities and lower stress.

Discussion: Use of dedicated staff with expertise in dementia care led to better care experience across projects, but did not result in Medicare savings. Low engagement with primary care providers limited care coordination and enrollment in these projects. Increased intensity (e.g., more home and community-based services including respite care) could, potentially, strengthen the intervention effects. Longer follow-up periods may be needed to see results, given the trajectory of dementia. New approaches are needed to reach populations that are socially or otherwise isolated.

Conclusions: Innovative approaches to dementia care delivery are important given the severe impact of dementia on the lives of those affected, the burdens placed on society, and the rising incidence of dementia as the population ages. Broader use of dementia care services and longer follow-up periods may improve outcomes (e.g., Medicare spending, hospitalization) that showed non-significant reductions in this analysis.

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[1] This synthesis included results from four Health Care Innovation Awards (HCIA): Dementia Care Ecosystem (Ecosystem), Maximizing Independence (MIND) at Home, Alzheimer's and Dementia Care (ADC-UCLA), and Aging Brain Care (ABC); and the Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE).

Introduction

Nearly half of older adults die with a diagnosis of Alzheimer's disease and/or a related dementia, either as the immediate cause of death or a co-morbidity (Davis et al., 2022). Dementia refers to conditions that impair memory, thought processes, and functioning (ASPE, 2021). Persons with dementia need clinical and other care and services to diagnose and manage this condition, and often long-term services and supports as the disease progresses.

The Centers for Medicare & Medicaid Services (CMS) funds the majority of dementia care services in the United States (U.S.). Section 1115A of the Social Security Act authorizes the Center for Medicare and Medicaid Innovation (Innovation Center) to test new payment and service delivery models that have the potential to reduce Medicare and Medicaid spending while maintaining or improving the quality of beneficiaries' care. The Innovation Center's strategic vision promotes high quality, affordable, person-centered care that coordinates care seamlessly and holistically across settings (CMS Innovation Center, 2021).

This study synthesized evaluation findings from five CMS projects focused on care for people living with dementia (see ***Table 1***). Results are intended to help CMS identify gaps and opportunities for new models and programs to improve care delivery and quality of life for persons living with dementia and their families/unpaid caregivers.

Background

In the U.S., 6.5 million Americans age 65 and older have dementia, including 40 percent of the population over age 85; by 2060, this figure is expected to reach 13.8 million (Alzheimer's Association, 2022; Rajan et al., 2021). Dementia ranks among the top 10 causes of death (Murphy et al., 2021).

Persons age 65 and older survive an average of four to eight years after a diagnosis of dementia, and as long as 20 years (Brodaty et al., 2012). Early stages of dementia often require assessments, disease management, and care planning to cope with memory loss and language difficulty. In later stages of the disease, commonly 24-hour supervision and help with activities of daily living and/or instrumental activities of daily living become necessary to address functional status and behavioral issues (e.g., agitation, aggression, and hallucinations). Persons with end-stage dementia may lose mobility and the ability to communicate, and become bedridden. The need for personal care services in later stages of the disease often leads to placement in assisted living memory care units or nursing homes.

Medicare and Medicaid spending for dementia in 2022 is projected to reach $206 billion, or 64 percent of the total cost[2] of caring for persons with dementia (Alzheimer's Association, 2022). Partners or other family members bear much of the rest of the expense through hours of unpaid care or by paying out of pocket for home health aides and residential facilities (Hurd et al., 2013; Kelley et al., 2015). Hospice care offers support at the end of life, yet qualifying for the Medicare hospice benefit is frequently complicated by the long and unpredictable trajectory of dementia (Gianattasio et al., 2022; Harrison et al., 2022).

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[2] Total payments of $321 billion are projected to be made in 2022 for health care, long-term care, and hospice services for persons age 65 and older with dementia (Alzheimer's Association, 2022). Medicare payments for beneficiaries with dementia are nearly three times as high as payments for those without dementia, and Medicaid payments are 22 times as high (Alzheimer's Association, 2022).

Collaborative models of dementia care provide comprehensive, interdisciplinary care to persons with dementia and their families. Dementia care components vary by setting (e.g., telehealth, clinic-based, in-home), workforce (e.g., nurse care managers, non-clinical navigators), and intensity (e.g., number of visits or phone calls). These models may help improve beneficiary well-being, reduce caregiver burden, and delay or avoid long-term care facility use. Yet, the evidence for Medicare savings (or cost neutrality) and reductions in Medicare service use are less clear. To increase our understanding of which settings, workforce structures, and intensity levels work and do not work, this synthesis assessed the relative effectiveness of CMS dementia care projects to date.

Dementia Care Projects

We examined findings from all four dementia care projects funded through the Innovation Center's Health Care Innovation Awards, and a multi-site Medicare demonstration (see ***Table 1***). Each project sought to improve the quality of life of persons with dementia and their unpaid caregivers (enrolled dyads) by providing support to reduce avoidable Medicare service use and long-term care facility use. Projects varied by setting, workforce, and intensity (see ***Table 2***). An overview of each project appears in the appendix.

Table 1. Five CMS Dementia Care Projects in this Synthesis

Project	**Sponsor/site(s)**	**Years**	**Data Source**
HCIA* Dementia Care Ecosystem (Ecosystem)	University of California, San Francisco (UCSF), University of Nebraska Medical Center (UNMC)	2015–2017	Final evaluation report
HCIA* Maximizing Independence (MIND) at Home	Johns Hopkins University (JHU)	2015–2017	Final evaluation report
HCIA* Alzheimer's and Dementia Care (ADC)	University of California, Los Angeles (UCLA)	2012–2015	Final evaluation report
HCIA* Aging Brain Care (ABC)	Indiana University (Indiana)	2012– 2015	Final evaluation report
Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE)+	8 sites: IL, TN, OR, NY; OH, FL MN, WV	1989–1994	Final evaluation report^

* HCIA = Health Care Innovation Awards round one or two

\+ Demonstration conducted prior to the creation of the CMS Innovation Center

^ See Newcomer, Miller, Clay, and Fox (1999). Evaluation report is not available online due to its age.

Research Questions

This synthesis addressed the following research questions:

1. How did the components of each project foster better health care for persons with dementia and their unpaid caregivers?
2. What effect did these projects have on Medicare spending and service use?
3. What effect did these projects have on beneficiary and caregiver experience of care?

Methods

For each project, we looked at claims-based outcomes available across projects: Total Medicare spending, service use (e.g., emergency department [ED] visits, inpatient admissions, long-term care facility use. We also examined care experience assessed through surveys and interviews. Each project had a similar theory of action: Offering Medicare beneficiaries with dementia and their caregivers personalized support could reduce the incidence of emergencies, prevent ED visits and hospitalizations, and delay or avoid long-term care facility use. These outcomes together could result in Medicare savings and improve quality of life for beneficiaries and their caregivers.

We summarized results and themes across projects to highlight similarities and differences. Observed differences in design components, outcomes, and care experience were integrated into key findings and lessons learned.

Measures

We examined final regression-adjusted impact estimates, where available, using data from intervention and comparison beneficiaries, for the following outcomes:

- Total Medicare spending (Parts A & B)[3]
- ED visits per 1,000 persons
- Inpatient admissions per 1,000 persons
- Long-term care placement (nursing home > 90 days)
- Beneficiary and caregiver experience of care (from focus groups and interviews)

Data Sources

Data for this synthesis were drawn from the independent evaluation reports for each dementia care project. Sources of data included interviews with participants during site visits; focus groups with enrolled beneficiaries, caregivers and medical partners; surveys; and Medicare claims data.

Results

Results appear below for each research question (RQ).

RQ1. How did the components of each project foster better health care for persons with dementia and their unpaid caregivers?

Key findings

- Care settings varied according to each project's unique focus.
- Workforce innovations helped address gaps in care for persons with dementia, yet engagement among primary care providers and the dementia care team remained low.
- Service intensity may have been too low and the follow-up period too brief to observe an effect on key outcomes (e.g., Medicare spending, service use).
- Participating sites struggled to reach and enroll their target population.

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[3] These evaluations did not measure or simulate savings related to deferred long-term care facility admission.

Table 2. Components of Five CMS Dementia Care Projects

Project	Focus	Setting	Workforce	Intensity	Duration[#]
HCIA Ecosystem-UCSF-UNMC	Care planning, support	Telehealth[^]	Non-clinical navigators; IDT	Varied by disease acuity, monthly phone contact or every 3-4 months	12 months
HCIA MIND-JHU	Barriers to care, navigation	Home	Non-clinical memory care coordinators; IDT	Home visit every 2 months, weekly phone contact	18 months
HCIA ADC-UCLA	Partnership with community-based services	Clinic	Nurse practitioners; IDT	Annual clinic visit, quarterly phone contact	25 months[X]
HCIA ABC-Indiana	Barriers to care, navigation	Home	Lay health workers; IDT	Quarterly home visit, monthly phone contact	32 months[X]
MADDE	Direct payments to beneficiaries to help cover care needs	Home	Nurse case managers; IDT	In-home assessment, updated every 6 months by phone	36 months

HCIA = Health Care Innovation Awards round one or two
MADDE = Medicare Alzheimer's Disease Demonstration and Evaluation
[#] Exposure to the intervention and evaluation follow-up period. [X] Average number of months enrolled in the project.
[^] Care team navigators primarily engaged beneficiaries and caregivers by telephone and occasionally in person.
IDT = Interdisciplinary care team, consisting of a program director (e.g., geriatrician/neurologist), nurses, occupational therapists, social workers, pharmacists.

Care settings varied according to each project's unique focus. Each project offered support to persons with dementia and their unpaid caregivers (enrolled dyads) to prevent unnecessary ED and hospital use, and delay or avoid long-term care facility use. Projects varied in their focus on barriers to care and partnership with community-based services (see ***Table 2***) and by care setting (e.g., telehealth, home, or clinic). Projects also varied in the services they provided directly and the referrals they made to community-based resources. For example, some projects offered lists of care providers while others assisted enrollees in setting up services and provided vouchers to help pay for care, depending on the unique needs of the dyads.

Ecosystem-UCSF-UNMC provided telehealth, primarily to enrollees with mild dementia. Navigators offered phone-based assistance with care planning, referrals to community-based resources, and emotional support. MIND-JHU and ABC-Indiana focused on underserved populations and offered frequent calls and home visits to help dyads navigate unmet needs. ADC-UCLA, by contrast, required dyads to travel to a medical office for structured assessments to identify cognitive and functional needs and caregivers' needs for education, counseling, and/or respite care. Both ADC-UCLA and MADDE offered referrals to community-based services supported through contracts or vouchers for dyads to spend on their care (e.g., adult day health care), up to a specified amount.[4]

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[4] MADDE enrollees were eligible for up to $699 per month in community care benefits (amounts varied by site) for adult day care, skilled nursing and rehabilitation therapies not otherwise reimbursed by Medicare,

Workforce innovations helped address gaps in care for persons with dementia, yet engagement among primary care providers and the dementia care team remained low. Across projects, clinical and non-clinical workers with specialized training in dementia care intended to supplement the beneficiaries' usual source of primary care (see ***Table 2***). Nurse practitioners (ADC-UCLA) co-managed enrollees' care and advised primary care providers on dementia medications and potential drug interactions. Nurse case managers (MADDE) developed care plans and shared them with the beneficiaries' primary care provider but without explicit coordination. Non-clinical navigators (Ecosystem-UCSF-UNMC), memory care coordinators (MIND-JHU), and care coordination assistants (ABC-Indiana) communicated directly with enrolled dyads under the supervision of licensed clinical staff on the dementia care team. However, close engagement among primary care providers and the dementia care team remained low outside of the academic medical systems aligned with these projects.

Service intensity may have been too low and the follow-up period too brief to observe an effect on key outcomes (e.g., Medicare spending, service use). Medicare fee for service beneficiaries who met the inclusion criteria[5] were enrolled in the project and followed by the evaluation for an average of 12 – 36 months (see ***Table 2***). Intensity of services—the type and frequency of contact or "touches"—varied across projects. In Ecosystem-UCSF-UNMC, for example, enrollees with mild dementia (a majority of the intervention group) received a lite version of the project which delivered fewer and less frequent services, in response to enrollees' preferences and needs. Ecosystem-UCSF-UNMC dyads graduated from the program after 12 months, which may have been too brief to produce an intervention effect.

In ADC-UCLA and ABC-Indiana, evaluation follow-up ended when the period of performance for their Health Care Innovation Awards ended. For beneficiaries who enrolled near the end of the period of performance, exposure to the project may have been too short, and evaluation follow-up too brief, to detect an effect. In MADDE, by contrast, individuals entered the demonstration during a two-year enrollment period and were then followed by the evaluation for three years.

Table 3. Characteristics of Beneficiaries Enrolled in Five CMS Dementia Care Projects

Project	Number#	Dementia Stage	Demographics^	Market
HCIA Ecosystem-UCSF-UNMC	358	Mild (69%), Moderate or Severe (29%)	Age ≥85 (26%), Female (55%), Black (3%), White (87%), Dual (15%)	Urban, Suburban, Rural
HCIA MIND-JHU	249	Mild (36%) Moderate (46%) Severe (16%)	Age 81 (mean), Female (74%), Black (60%), White (31%), Dual (70%)	Urban, Suburban

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homemaker/personal care, housekeeping, chores, home repairs and maintenance, companion services, care while caregiver attends support groups, home-delivered meals, non-emergency transportation, assistive equipment, medical supplies, consumable goods, safety modifications to home. Enrolled dyads paid a 20 percent copayment for demonstration subsidized services. For ADC-UCLA, the amount varied according to individual needs.

[5] Inclusion criteria and eligibility requirements for each project are outlined in the appendix (see ***Table A.2***)

HCIA ADC-UCLA	1,083	2.9 years[X]	Age ≥85 (42%) Female (65%), Black (9%), White (72%), Dual (15%)	Urban, Suburban
HCIA ABC-Indiana	473	2.6 years[X]	Age ≥85 (29%), Female (66%), Black (29%), White (71%), Dual (32%)	Urban, Suburban, Rural
MADDE[+]	4,151	Mild (28%) Moderate (37%) Severe (29%)	Age ≥85 (22%), Female (62%), Black (10%), White (86%), Dual (8%)	Urban, Suburban, Rural

HCIA = Health Care Innovation Awards round one or two

MADDE = Medicare Alzheimer's Disease Demonstration and Evaluation

[+] Demonstration conducted prior to the creation of the CMS Innovation Center

[#] Number of fee-for-service Medicare beneficiaries included in the intervention group in the impact analysis, with a dementia diagnosis.

[^] Dual refers to enrollment in both Medicare and Medicaid.

[X] Mean duration of dementia diagnosis in Medicare claims data

Participating sites struggled to reach and enroll their target population. Disease status (e.g., dementia stage) and demographics varied across sites (see ***Table 3***). Most projects enrolled fewer dyads than projected and beneficiary characteristics differed from the diverse population initially targeted.

In Ecosystem-UCSF-UNMC, enrollees had mild dementia (69%) and were disproportionately white (87%). Enrolled dyads likely had access to more services at baseline and less need for the resources offered by the program than anticipated. MIND-JHU and ABC-Indiana enrolled high rates of non-white beneficiaries and those dually eligible for both Medicare and Medicaid. Still, MIND-JHU did not enroll enough beneficiaries with sufficient exposure to the project to detect impacts.

ADC-UCLA enrolled a large proportion of beneficiaries who were older (42% age 85 and over). This project produced the only statistically significant outcome, a reduction in long-term care facility use.

RQ2. What effect did these projects have on Medicare spending and service use?

Key findings

- No significant impacts on Medicare expenditures.
- No significant impacts on ED visits and hospitalizations.
- Significant reduction in long-term care facility use in one project (ADC-UCLA).

Table 4. Impacts of Five CMS Dementia Care Projects

Project	**Total Medicare Spending**	**ED Visits**	**Inpatient Admissions**	**Long-term Care Facility Use**[^]
HCIA Ecosystem[R]	-5%	-9%	-10%	--
HCIA MIND-JHU	--	--	--	--
HCIA ADC-UCLA	-$365[‡]	6[§]	12[§]	**-34%**
HCIA ABC-Indiana	$8[‡]	4[§]	3[§]	No change
MADDE[R]	-$167	$38[B]	-$435[A]	No change

Table Key: Bolded estimates are statistically significant at least at the $p<0.05$ level. [X] significant at the $p<0.10$ level.
Green shading indicates statistically significant results in a favorable direction. Red/orange shading indicates statistically significant results in an unfavorable direction. Cells with gray shading indicate non-significant results.
HCIA = Health Care Innovation Awards round one or two
MADDE = Medicare Alzheimer's Disease Demonstration and Evaluation
[R] Randomized design
[‡] per person per quarter, available only as a point estimate (with confidence interval) not as a % difference
[§] per 1,000 persons, available only as a point estimate (with confidence interval) not as a % difference
[^] Time to event analyses were used to estimate the likelihood (hazard ratio) of long-term placement occurring. See appendix for more information.
[A] Annualized effect on Part A spending, across all MADDE sites; [B] Annualized effect on Part B spending, across all MADDE sites.
ED = emergency department

No significant impacts on Medicare expenditures. Three projects (Ecosystem-UCSF-UNMC, ADC-UCLA, and MADDE[6]) showed non-significant reductions in total Medicare spending (Parts A & B) relative to the comparison group (see ***Table 4***). No Medicare savings were found in ABC-Indiana. For MIND-JHU, it was not possible to evaluate impacts on Medicare expenditures due to the small number of beneficiaries enrolled and an inability to construct an adequate comparison group.

No significant impacts on ED visits and hospitalizations. One project (Ecosystem-UCSF-UNMC) showed non-significant reductions in ED visits and inpatient admissions relative to the comparison group (see ***Table 4***). No decreases were found in ADC-UCLA or ABC-Indiana. MADDE reported expenditures, not service use. MIND-JHU did not have enough enrollment for an impact analysis.

Significant reduction in long-term care placement in one project. ADC-UCLA enrollees were 34 percent less likely to be admitted to a long-term care facility relative to the comparison group[7] (see ***Table 4***). No differences were found in ABC-Indiana. Ecosystem-UCSF-UNMC did not measure long-term care placement as an outcome. MIND-JHU did not have enough enrollment for an impact analysis.

RQ3. What effect did these projects have on beneficiary and caregiver experience of care?

Key findings

- Access to dementia care resources improved beneficiaries' and caregivers' experience of care.
- Caregivers reported increased efficacy in their caregiving abilities and lower stress.

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[6] MADDE showed non-significant reductions in total Medicare expenditures overall; yet two of the eight sites reached or approached statistical significance in savings (Newcomer, Miller, Clay, and Fox, 1999).

[7] During the period of performance, fewer ADC-UCLA enrollees were admitted to a long-term care facility relative to the comparison group (13% and 22%, respectively).

Access to dementia care resources improved beneficiaries' and caregivers' experience of care. Resources across all five projects included access to caregiver education by dedicated dementia staff and referrals to community-based services. Additionally, ADC-UCLA contracted with community partners and, like MADDE, offered vouchers to enrollees to pay for the services they needed most. MADDE enrollees were more than twice as likely as the comparison group to use one or more of these four services: homemaker/chore, personal care, companion services, and adult day care (Yordi, Fox, and Spitalny, 1999). Caregiver training and support group participation also increased. Perceived unmet need for client ADL/IADL task assistance decreased for those in the MADDE intervention group.

Ecosystem-UCSF-UNMC showed no meaningful differences in dementia-specific quality-of-life,[8] relative to the comparison group. MADDE produced no significant reductions in caregiver burden and depression. Self-reported data across the other projects showed positive trends over time in measures of caregiver burden, depression, and satisfaction with care; yet, follow-up data from both the intervention and comparison groups were not consistently available to calculate impacts for these measures.

Caregivers reported increased efficacy in their caregiving abilities and lower stress. Learning what behaviors to expect in persons with dementia, and advice on how to respond, boosted caregivers' confidence in their skills and improved their relationship with the care recipient. Factors that contributed to reduced stress included: 1) regular or 24/7 access to dementia care staff to receive guidance, and 2) access to information, counseling, and emotional and instrumental support.

Caregivers appreciated around-the-clock access to dementia care specialists, relationships with their care team navigator (Ecosystem-UCSF-UNMC) or coordinator (MIND-JUH, ADC-UCLA), and help communicating with other health care providers (ABC-Indiana). Access to community-based services (e.g., support groups and respite services like adult day health care) alleviated isolation and helped caregivers cope with stress (ADC-UCLA and MADDE).

Discussion

Findings from all five projects have important implications for the development of future models and programs at CMS.

Lessons Learned

- Use of dedicated staff with expertise in dementia care led to better care experience across projects, but did not result in significant Medicare savings.
- Low engagement among primary care providers and the dementia care team limited care coordination and enrollment in these projects.
- Increased intensity (e.g., more home and community-based services including respite care) could, potentially, strengthen the effects of dementia care projects.
- Longer follow-up periods may be needed to see results, given the trajectory of dementia.
- New approaches are needed to reach populations that are socially or otherwise isolated.

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[8] Ecosystem-UCSF-UNMC administered the 13-item Quality of Life–Alzheimer's Dementia instrument that measures caregiver perceptions of the beneficiary's quality of life on a 4-point scale (1 indicates poor, 4 indicates excellent). An impact estimate of 0.1 is not clinically meaningful or statistically significant.

Use of dedicated staff with expertise in dementia care led to better care experience across projects, but did not result in significant Medicare savings. Primary care physicians often lack the training and time to manage the complex needs of persons with dementia and their caregivers (Weiss et al., 2020; Warshaw & Bragg, 2014). These dementia care projects used clinical and non-clinical staff with specialized training in dementia to fill this gap in care delivery, leading to better care experience for beneficiaries and their caregivers.

Caregivers often need help accessing community-based resources, which vary by state and may not be well-integrated into the local health care system (McGhan et al., 2022). Improved access to adult day health care and respite care, via vouchers and contracted services, likely contributed to significant reductions in long-term care placement (ADC-UCLA) (see ***Table 4***). These outcomes may have been driven in part by the availability of home- and community-based services in the area surrounding the project.[9] Reductions in long-term care placement likely increased the quality of life for beneficiaries who remained in the community longer (Anthony et al., 2019).

Telehealth (Ecosystem-UCSF-UNMC) enabled dyads to receive support remotely, which helped those who might be harder to reach in person (e.g., at a distance or with transportation issues). Home visits helped enrollees and caregivers from urban (MIND-JHU) and rural (ABC-Indiana) areas with otherwise limited access to dementia care specialists. An impact analysis could not be conducted (MIND-JHU) due to low enrollment, but caregivers reported high satisfaction with their care.

Low engagement among primary care providers and the dementia care team limited care coordination and enrollment in dementia care projects. Although they intended to share individual dementia care plans and discuss medication and service needs, sites reported low engagement with enrollees' primary care providers outside of academic medical systems that shared electronic health records. At Ecosystem-UCSF-UNMC, for example, multiple attempts by staff and program leadership to contact external providers—such as by fax, email, and phone—were unsuccessful. Care team navigators instead worked with caregivers to empower them to engage directly with the providers of the person with dementia.

Better integration with primary care could build on effective approaches that tailor workforce structures to the target population to address unmet social and medical needs. For example, non-clinical memory care coordinators developed close relationships with dyads to build trust and reduce barriers to care (MIND-JHU). Lay health workers assisted beneficiaries and unpaid caregivers in navigating the health care system by relaying questions to providers and scheduling appointments (ABC-Indiana). Greater involvement of primary care providers could also increase the reach of these projects, through referrals and higher enrollment.

Increased intensity (e.g., more home and community-based services including respite care) could, potentially, strengthen the effects of dementia care projects. Caregiving takes a tremendous toll on partners and caregivers, often leading to poor health outcomes and higher mortality among caregivers (Cheng, 2017; Richardson et al., 2013). More in-home support and access to respite services could help alleviate caregiver burden, improve the health of caregivers, and increase their quality of life.

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[9] California ranks high on a scorecard of the availability of long-term services and supports. California also holds multiple waivers that allow Medicaid beneficiaries to receive home and community-based services.

Caregivers who received respite care (ADC-UCLA, MADDE) reported that it reduced their stress and helped alleviate loneliness. MADDE enabled more individuals to purchase services,[10] but the amount of care (days of adult day care or hours of home care) did not differ from that paid for privately by those in the comparison group. For those with lower incomes, this effect may have been constrained by the 20 percent co-payment on demonstration services. Further measurement of caseload and number of touches would help us better understand the intensity needed to improve dementia care model outcomes.

Longer follow-up periods may be needed to see results, given the trajectory of dementia. Follow-up periods[11] across projects varied from 12 – 36 months, on average, which may be too brief to detect an effect, given the long dementia disease trajectory. For example, enrollees with mild dementia who received a lite version of Ecosystem-UCSF-UNMC for 12 months might have had too little exposure to the project to produce an effect.

When beneficiaries enrolled near the end of the project's period of performance, they may have received too little exposure to the intervention to produce an effect. If enrolled at early stages of dementia, years may pass before the disease progresses to the point of needing long-term care. With longer follow-up, outcomes (e.g., hospitalizations, Medicare spending) may have been significant for projects that in this analysis showed non-significant reductions.

New approaches are needed to reach populations that are socially isolated. Dementia disproportionately affects underserved populations, minority groups, and women (Rajan et al., 2021; Samper-Ternent et al., 2012). Social isolation and lack of access to primary care contributed to low enrollment even in projects that specifically targeted populations with high unmet medical and social needs. According to MIND-JHU coordinators, low enrollment occurred in part because of mistrust of research and the consent process in the targeted communities. Required involvement of a caregiver further limited recruitment among individuals who lacked this source of support.

Limitations

Results across projects are not directly comparable because:

- Implementation occurred at different points in time (MADDE from 1989 – 1994, other projects from 2012 – 2021).
- Enrolled populations varied according to the unique focus of each project and the states where the projects were implemented.
- Evaluation methods varied and increments differed (e.g., percentage change, rates per 1,000, quarterly or annualized effects).
- Evaluations included beneficiaries who met specified criteria, not the entirety of the population that enrolled in the project and received services.
- New beneficiaries entered the project at different intervals and varied in their exposure to the intervention (due to late referrals).
- Qualitative findings from interviews and focus groups only included those beneficiaries and their family members who were willing and able to participate. Severe symptoms and/or caregiver burden may have limited who volunteered for interviews and focus groups.

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[10] Dyads in MADDE were more than twice as likely to use home care or adult day care as those in the comparison group.

[11] The evaluation followed beneficiaries during their period of enrollment (duration) in each project (see ***Table 2***).

Despite these concerns, this synthesis allowed for broad patterns to be observed (see ***Table 4***) and lessons learned to be to drawn to help inform new models and programs at CMS.

Additional technical and methodological issues limited and strengthened the evaluation,[12] as follows:

- Low enrollment limited the generalizability of these results nationally.
- Dementia diagnosis, functional ability, and caregiver status are not consistently available in CMS administrative data used to construct the comparison group.
- Randomized study designs strengthened the evaluations of two of these projects.

Low enrollment limited the generalizability of these results nationally. Most of these projects fell short of their enrollment goals (see ***Table 3***). Only ADC-UCLA (n=1,083) and MADDE (n=4,151) enrolled sizable numbers, and these sites, too, struggled to recruit the populations they initially targeted. Low enrollment stemmed in part from the fact that dementia affects around 10 percent of the Medicare population over age 65 and the projects were voluntary. Not all providers and beneficiaries were required to participate and those that did were self-selected, a source of bias that further limited the generalizability of these results nationally.

To increase enrollment, MIND-JHU began recruiting individuals with no prior dementia diagnosis and screened for dementia. Screening likely identified persons with dementia at an earlier stage than would occur in the absence of the project. It was not possible to evaluate impacts in MIND-JHU due to the small number enrolled and an inability to replicate the eligibility criteria in claims data (to construct an adequate comparison group).

Dementia diagnosis, functional ability, and caregiver status are not consistently available in CMS administrative data used to construct the comparison group. Two projects (ADA-UCLA and ABC-Indiana) relied on CMS administrative data to construct matched comparison groups. Using claims to identify beneficiaries with dementia is problematic because many individuals do not receive a timely diagnosis (Amjad et al., 2018; Chen et al., 2019; Grodstein et al., 2022; McCarthy, 2022). They may not have discussed their cognitive issues with their health care providers,[13] or they may lack access to primary care. Selecting persons with higher disease acuity into the comparison group could bias the results if most enrollees in the project have mild or recently diagnosed dementia. The evaluators attempted to mitigate this issue by matching on length of dementia diagnosis, but this does not address the concern about missing diagnoses.

Functional ability is important to evaluating the risk of long-term care facility use, a key outcome of these projects. Functional status in CMS administrative data is limited to the subset of beneficiaries with prior home health care, skilled nursing, or long-term care assessments.

These projects also required caregiver participation, which is not observable in CMS administrative data. Proximity and involvement of a caregiver is likely to affect outcomes, especially long-term care placement. ADC-UCLA lacked caregiver status for the comparison group, which limits the significant reduction observed in long-term care facility use (see ***Table 4***).

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[12] See evaluation reports linked to each project in ***Table 1*** for a full discussion of methods and limitations in the technical appendix of each report.

[13] Annual Medicare wellness visits offer an opportunity to assess cognitive functioning in every Medicare beneficiary, but many primary care providers do not cover this topic.

Randomized study designs strengthened the evaluations of two of these projects. Two projects employed a randomized design. Eligible dyads in Ecosystem-UCSF-UNMC and MADDE were randomly assigned to the intervention or comparison group at the time of enrollment. Those in the comparison group received usual care and completed surveys.[14] Randomization helped ensure that the intervention and comparison groups were alike in both observable factors (e.g., age, claims history) and unobservable factors (e.g., disease acuity, caregiver status).

Despite using a randomized design, Ecosystem-UCSF-UNMC was not sufficiently powered to detect small effects due to low enrollment. And in some MADDE sites, the intervention was not very different from usual care available to the comparison group (Newcomer, Miller, Clay, and Fox, 1999). These limitations made it difficult to detect an intervention effect (see ***Table 4***).

Conclusion

Care experience improved across projects and one project (ADC-UCLA) showed a significant decrease in the rate of long-term care facility use. These reductions enabled beneficiaries to remain in the community longer and enjoy better quality of life. Wider use of dementia care services and longer follow-up periods may improve outcomes (e.g., Medicare spending, hospitalizations) that showed non-significant reductions in this analysis.

New and innovative approaches to dementia care delivery are important given the severe impact of dementia on the lives of those affected, the burdens placed on society, and the rising incidence of dementia as the population ages. In the absence of effective treatments, the total cost of care for persons with dementia is expected to increase from $321 billion in 2022 to just under $1 trillion by 2050 (in 2022 dollars) (Alzheimer's Association, 2022). Lessons learned from this synthesis could be useful in addressing goals set forth in the National Alzheimer's Plan (ASPE, 2021; NASEM, 2021) for enhancing the quality and efficiency of dementia care for beneficiaries and their families and caregivers.

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[14] Attrition from the project occurred at similar rates for both groups.

Appendix

A summary of each dementia care project and a link to the evaluation report[15] used in this synthesis appear below, followed by an overview of each project and its payment approach (see ***Table A.1***), eligibility requirements (see ***Table A.2***), and a list of services (see ***Table A.3***).

Dementia Care Ecosystem (Ecosystem-UCSF-UNMC): Telephonic support and education to persons with dementia and their caregivers to reduce caregivers' burden, improve clients' and caregivers' satisfaction with dementia care, and enable caregivers to better support persons with dementia in the community, leading to lower costs. UCSF's care team navigators provided telephonic support to link clients with dementia and their caregivers with resources; supportive care and education; medication consultation; and support in planning future medical, financial, and legal decisions. Most contact occurred by phone. Frequency of contact varied from monthly to every three to four months depending on dementia acuity score.

Maximizing Independence at Home (MIND-JHU): Care management by trained non-clinical memory care coordinators who worked with an interdisciplinary team (psychiatrist, therapists, nurses) to identify unmet needs, improve health outcomes and prevent or delay institutionalization. Home visits every two months, on average, with regular (~weekly) contact. By addressing enrollees' unmet social and medical needs, supporting caregivers, and improving home safety, this project aimed to help participants stay in their homes longer and reduce costs of nursing home care. Additional support for caregivers could reduce ED visits and hospital admissions.

Alzheimer's and Dementia Care (ADC-UCLA): Co-management by nurse practitioners serving as dementia care managers to conduct formal assessments, establish care plans, and make referrals to community-based services as needed. Annual in-person clinic visits and quarterly phone check-in. Through comprehensive dementia care coordination and caregiver education and support, this project sought to reduce excess costs attributable to dementia and keep more individuals in community-based settings.

Aging Brain Care (ABC-Indiana): Care management by a team of lay health workers (plus nurses, social workers, and a supervising physician) who assessed and monitored needs through quarterly home visits with monthly contact between visits. Because depression and stress are important determinants of health care use, lower caregiver burden and stress could potentially result in fewer hospitalizations and reduced Medicare expenditures. Home visits enabled staff to identify and address barriers to care, safety issues, and concerns with care plan adherence.

Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE): Care management by nurse case managers plus up to $699 per month in community care benefits to address medical, mental health, and social support needs, reduce burden, and enhance caregiving skills. In-home assessments delivered, updated every 6 months by phone. Vouchers offered to intervention group to pay for community-based services to increase the use of these services, reduce caregiver burden and depression, and enable persons with dementia to remain in the community longer. Care management could reduce Medicare expenditures and service use.

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[15] Each report includes evaluation results, an assessment of implementation effectiveness, and a technical appendix.

Table A.1. Overview of Five CMS Dementia Care Projects in the Synthesis

Years	Project	Overview	Payment	Participants	Beneficiaries
2015 – 2017	HCIA Dementia Care Ecosystem^R (Ecosystem): University of California at San Francisco (UCSF), University of Nebraska Medical Center (UNMC)	***Telephonic*** care management and navigation for caregivers and beneficiaries with dementia, including medication consultation and support in planning future medical, financial, and legal decisions. Trained ***non-clinical care team navigators*** provided support and education, linked beneficiaries with resources, and triaged clinical questions to appropriate professionals.	FFS billing codes	Academic institutions in San Francisco and Omaha (Nebraska and parts of Iowa)	538 Medicare FFS beneficiaries: 358 assigned to intervention and 180 to comparison group (out of 780 enrolled)
2015 – 2017	HCIA Maximizing Independence at Home (MIND): Johns Hopkins University (JHU)	Care management by trained non-clinical memory care coordinators who worked with an interdisciplinary team (psychiatrist, therapists, nurses) to identify unmet needs, improve health outcomes and prevent or delay institutionalization. ***Home visits*** every 1-2 months, on average, with regular (weekly or monthly) phone contact as needed.	Per capita care management payment, clinical support capitated payment, and shared savings	Academic health system in Baltimore and surrounding counties	249 Medicare FFS beneficiaries included in final descriptive analysis due to low enrollment (out of 342 enrolled)
2012 – 2015	HCIA Alzheimer's and Dementia Care (ADC): University of California, Los Angeles (UCLA)	Co-management by nurse practitioners serving as dementia care managers to conduct formal assessments, establish care plans, and make referrals to community-based services as needed. Annual in-person ***clinic*** visits and quarterly phone check-in.	FFS billing codes	Academic health system in Los Angeles	1,083 Medicare FFS beneficiaries included in impact analysis (out of 1,574 enrolled)
2012 – 2015	HCIA Aging Brain Care (ABC): Indiana University	Care management by a team of lay health workers plus nurses, social workers, and a supervising physician. Care teams assessed and monitored needs through quarterly home visits and monthly phone contact.	FFS billing codes	Academic institution, 2 sites: Indianapolis (Eskenazi) and Lafayette (Arnett)	1,120 Medicare FFS beneficiaries included in impact analysis (out of 1,959 enrolled)

Years	Project	Overview	Payment	Participants	Beneficiaries
1989 – 1994	Medicare Alzheimer's Disease Demonstration and Evaluation+ R (MADDE)	Care management by nurse case managers plus up to $699 per month in community care benefits to address medical, mental health, and social support needs, and to reduce burden, and enhance caregiving skills. In-home assessments, updated every 6 months by phone.	PBPM based on the ratio of case manager to community benefit services used and regional adjustments; 20% copay	8 sites: Model A states: IL, TN, OR, NY. Model B states: OH, FL, MN, WV.	5,170 Medicare FFS beneficiaries: 4,151 assigned to intervention and 3,944 to control (out of 8,095 enrolled)

HCIA = Health Care Innovation Awards round one or two

+ Demonstration conducted prior to the creation of the CMS Innovation Center

R Randomized design; FFS = Fee for service, PBPM = Per beneficiary per month payment

The following matrices summarize the eligibility requirements and services offered across projects.

Table A.2. Eligibility Requirements Across Five CMS Dementia Care Projects

Criterion	HCIA Ecosystem-UCSF-UNMC	HCIA MIND-JHU	HCIA ADC-UCLA	HCIA ABC-Indiana	MADDE
Medicare FFS (Parts A and B)	x	x	x	x	x
Dementia diagnosis	x	x (screened)	x	x	x
Caregiver participation	x	x	x	x	x
Reside at home (not in a long-term care facility)	x	x	x	x	x
Dually eligible for Medicare and Medicaid		x^			
Receive care from affiliated hospital, health clinic				x	

HCIA = Health Care Innovation Awards round one or two

MADDE = Medicare Alzheimer's Disease Demonstration and Evaluation

FFS = fee for service, not in Medicare Advantage

^ MIND initially targeted dually eligible beneficiaries, but later expanded eligibility criteria to all Medicare beneficiaries to reach enrollment goals.

Table A.3. Services Offered Across Five CMS Dementia Care Projects

Service	HCIA Ecosystem-UCSF-UNMC	HCIA MIND-JHU	HCIA ADC-UCLA	HCIA ABC-Indiana	MADDE
Advance care planning	x	x	x	x	x
Care coordination	x	x	x	x	x
Care plan	x	x	x	x	x
Education	x	x	x	x	x
Emotional support	x	x	x	x	x
24/7 access to care team	x	x	x	x	x
Identify barriers to care (underserved)		x		x	
Interdisciplinary team (IDT)	x	x	x	x	x
Medication consult/interaction	x	x	x	x	x
Navigation by non-clinical or lay health worker	x	x		x	
Referrals to community-based services	x	x	x	x	x
Vouchers for community-based services			x		x

HCIA = Health Care Innovation Awards round one or two

MADDE = Medicare Alzheimer's Disease Demonstration and Evaluation

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