

**MODELS OF GERIATRIC CARE, QUALITY  
IMPROVEMENT, AND PROGRAM DISSEMINATION****Dissemination of a successful dementia care program:  
Lessons from early adopters**

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**Abstract**

**Background:** Evidence-based models for providing effective and comprehensive care for Alzheimer's disease and related dementias exist but have yet to be successfully implemented at scale. The Alzheimer's and Dementia Care Program (ADC Program) is an effective comprehensive dementia care model that is being disseminated across the United States. This qualitative study examines barriers and facilitators to implementing the model among early adopting sites.

**Methods:** This study included semi-structured interviews with a total of 21 clinical site leaders and Dementia Care Specialists from a total of 11 sites across the US. Interviews were audio recorded, transcribed, and coded using Dedoose qualitative analysis software. Coding scheme development and data interpretation were informed by Rogers' Diffusion of Innovations framework.

**Results:** Key themes are organized in line with Rogers' framework. These include: the innovation-decision process, implementation and characteristics of the innovation, and sustainability.

**Conclusions:** Across the three overarching themes presented in this manuscript, the importance of engagement from site leaders, the multifaceted nature of the dementia care specialist role, and the value of technical assistance from qualified experts are apparent. However, for this work to continue to be successful, there needs to be more appropriate payment to cover needed services and a mechanism for supporting comprehensive dementia care over time.

**KEYWORDS**

advanced practice providers, Alzheimer's disease, caregiver burden, collaborative care, dementia

## INTRODUCTION

Alzheimer's disease and related dementias (ADRD) are prevalent disorders with devastating consequences for those living with the disease and the people who care for them as it progresses. Effective management of ADRD requires significant time, specialized skills, and integration with community-based resources—resources that many primary care providers (PCP) do not have.<sup>1</sup> Evidence-based models designed to address this need by providing comprehensive care for persons living with dementia (PLWD) and supporting their care partners exist but have yet to be successfully implemented at scale.<sup>2</sup>

The ADC Program is a health-systems based model in which advanced practice providers with extensive training in dementia care, known as Dementia Care Specialists (DCSs), co-manage care with the PCP. DCSs provide comprehensive care addressing medical, behavioral, and social aspects of dementia through the development of care plans tailored to the needs and goals of each patient living with dementia and their care partner. In this co-management model, the PCP is responsible for the patient's primary care needs but shares responsibility for the dementia-related aspects of care with the DCS, including reviewing and providing input on the dementia care plan. The care plan is then implemented by a team, led by the DCS, including family, other health professionals, and community-based organizations. Extensive research on the model has demonstrated its clinical benefits for PLWD, their care partners, and its ability to reduce health care costs.<sup>1,3-6</sup>

To increase the availability of the ADC Program, The John A. Hartford Foundation (JAHF) awarded a grant to UCLA to support implementation at 8–10 sites across the country.<sup>7</sup> Around the same time, the Patient Centered Outcomes Research Institute (PCORI) and the National Institute on Aging funded awards to UCLA to conduct a pragmatic randomized trial (the D-CARE study) that included ADC as an intervention.<sup>8</sup> Importantly, neither D-CARE nor JAHF dissemination sites received funds to the support implementation of the program. D-CARE sites received funds to support data collection related to the trial, not to support program implementation. JAHF dissemination sites did not receive any funding.

This study aimed to assess barriers and facilitators to implementing an innovative comprehensive dementia care program and guide the development of tools and resources that will facilitate the implementation process for future adopters. In this paper, we present results from interviews conducted with clinical site leaders and DCSs from 11 D-CARE and JAHF dissemination sites across the US. The purpose of these interviews was to document

### Key points

- The Alzheimer's and Dementia Care Program (ADC Program) is an effective comprehensive dementia care model that is being disseminated across the United States.
- The Diffusion of Innovations framework is useful in helping to categorize and describe strategies for program dissemination, site-level barriers and facilitators to implementation, and considerations for sustainability.
- Results from this study underscore the importance of highly engaged clinical champions, well-trained and supported dementia care specialists, and the need for payment reform to support program sustainability.

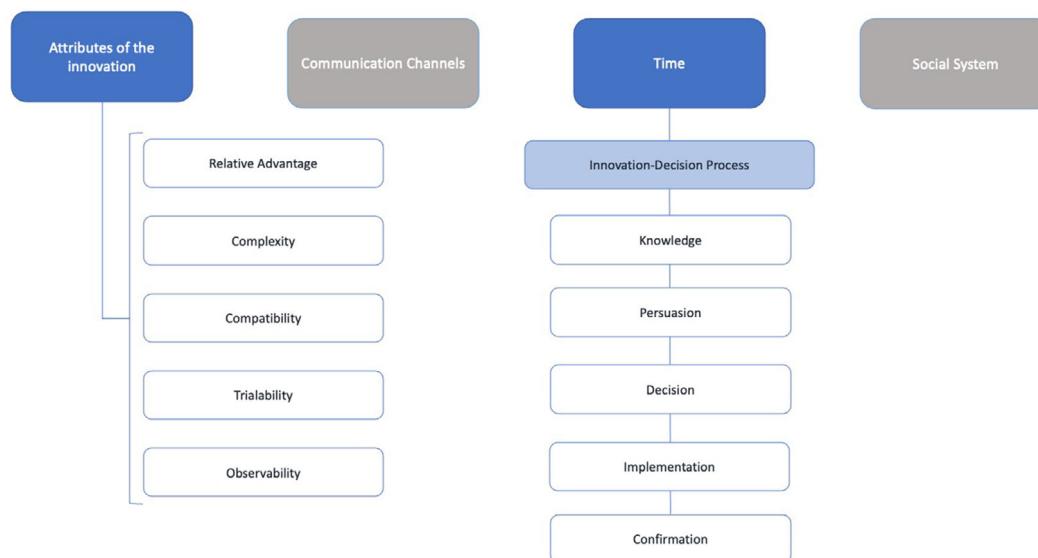
### Why does this paper matter?

These findings will be used to inform ongoing efforts to disseminate the ADC Program across the United States, advocate for policy change to support needed services for persons living with dementia and their care partners, and can help inform similar efforts by clinical sites, researchers, and innovators who are interested in developing, testing, and disseminating health-system-based innovations for dementia care.

the experiences of these early adopters, including their motivation and process for adopting, the opportunities and challenges they experienced during the implementation process, the implications of the COVID-19 pandemic on implementation, and considerations for long-term sustainability of the program.

## METHODS

Participants were recruited based on their role at an organization participating in the D-CARE study or the JAHF-funded dissemination project that had already begun seeing ADC participants. Semi-structured interviews were conducted virtually with clinical site leaders, typically medical directors, responsible for overseeing model implementation and DCSs between August 2020 and December 2021. JAHF Dissemination site leaders and DCS were interviewed a median of 89 and 135 days after the first patient was seen, respectively. The D-CARE site leaders and DCSs were interviewed a median of 392 and



**FIGURE 1** Conceptual framework: Diffusions of innovations. This study includes aspects of the four main elements of the diffusion of an innovation described in Rogers'<sup>10</sup> Framework: (1) an innovation, (2) communicated through channels, (3) over time, (4) within a social system. Themes from the data show particular relevance to the elements shown in blue: (1) Attributes of the ADC innovation and (2) Time, including what motivates sites to adopt the ADC program as described through the Innovation-Decision process

388 days after the first patient was seen, respectively. D-CARE site leaders had been interviewed twice previously and these interviews also informed the results presented here.

## Conceptual framework

This study was guided by Rogers' theory of Diffusion of Innovations.<sup>9</sup> This framework helps to describe the mechanisms by and speed at which innovations are adopted and brought to scale. The theory conceptualizes the spread of new ideas as a social process facilitated by several elements including: (1) attributes of the innovation, (2) communication channels, (3) time, and (4) the social system. Perceived attributes of an innovation are further categorized in terms of their relative advantage, complexity, compatibility, trialability, and observability. This study includes aspects of the four primary elements described in the Framework,<sup>9</sup> but emerging themes from the data showed particular relevance to elements (1) Attributes of the ADC innovation and (3) Time, including what motivates sites to adopt the ADC program as described through the Innovation-Decision process (Figure 1).

## Interview protocol and coding scheme

A semi-structured interview guide was designed to elicit information about processes and motivators for deciding

to adopt the ADC Program; beginning and maintaining program implementation; sites' relationships with key stakeholders including PCPs, community-based organizations, and the UCLA technical assistance team; and the implications of the COVID-19 pandemic on the institution, program, and patients and caregivers. Interview guides were tailored to the type of site (D-CARE or JAHF dissemination site), and participant role (clinical site leader or DCS).

Interviews ranged from 30 to 60 min in length, were conducted virtually using videoconferencing, audio recorded, and transcribed verbatim for coding. To conduct thematic analyses,<sup>11</sup> interviews were coded in Dedoose qualitative analysis software by two researchers using a coding scheme developed through an iterative process and in discussion with the dissemination team. Each interview transcript was assigned a primary coder to review and code the interview and a secondary coder to review and supplement the coding performed by the primary coder. Disagreements about code application were tracked and discussed until resolved by the coders. Codes were then interpreted and organized into themes.

## Participants

Twenty-one participants from 11 sites (7 JAHF, 4 D-CARE) were recruited. We recruited and interviewed six site leaders and seven DCSs from the JAHF dissemination sites, and three site leaders and five DCSs from the D-CARE sites

TABLE 1 Themes and key points

Theme	Diffusion process steps	Key points
1. Knowledge to Decision	Knowledge	Site leaders heard about the program from: <ul style="list-style-type: none"> <li>• Scientific meetings and publications</li> <li>• Word of mouth from respected experts and thought leader</li> </ul>
	Persuasion	<ul style="list-style-type: none"> <li>• Motivators include: <ul style="list-style-type: none"> <li>◦ Potential to fill need in community</li> <li>◦ Inclusion in national initiative</li> <li>◦ Standardization of practice</li> </ul> </li> <li>• Early conversations and technical assistance from dissemination team were important</li> </ul>
	Decision	<ul style="list-style-type: none"> <li>• Sites included diverse groups of stakeholders to guide decision</li> <li>• Earliest adopters reported little pushback from organizational leadership at this stage</li> </ul>
2. Implementation	Implementation	<p>Key points aligned with Rogers' Characteristics of Innovations:</p> <ul style="list-style-type: none"> <li>• <i>Compatibility and Relative advantage</i>: ADC program aligned with needs of organization, PLWD, and community. Program offered mechanism for standardizing practice.</li> <li>• <i>Complexity</i>: Challenges included defining DCS role and managing multiple roles, co-managing patients with PCPs, and data collection.</li> <li>• <i>Trialability</i>: Sites were able to adapt the model to fit local needs and resources.</li> <li>• <i>Observability</i>: Participants were able to observe the benefits of the program for primary care providers, PLWD and care partners. DCS described the work as rewarding.</li> </ul>
3. Sustainability	Confirmation	<ul style="list-style-type: none"> <li>• Sites described the need to plan for sustainability. Sites expressed interest in using the return-on-investment calculator, which they had not used at the persuasion or decision stages.</li> </ul>

Abbreviations: DCS, dementia care specialist; PCP, primary care provider; PLWD, persons living with dementia.

for the 2020/2021 interviews. Data from interviews conducted with all four D-CARE site leaders in 2018 and 2019 were also referenced to help interpret results.

## RESULTS

The term Innovation-Decision is part of the third element of the diffusion process (i.e., time), as described in the Diffusion of Innovations framework (Figure 1). The Innovation-Decision Process is “the process through which an individual (or other decision-making unit) passes from first knowledge of an innovation to the formation of attitude toward the innovation, to a decision to adopt or reject, to implementation and use of the new ideas, and to confirmation of the decision.”<sup>9</sup> This process includes five steps: (1) knowledge, (2) persuasion, (3) decision, (4) implementation, and (5) confirmation.<sup>9</sup> Theme 1 presents sites' progression from step 1 (knowledge) through step 3 (decision). Theme 2: Implementation Process and Theme 3: Sustainability relate to steps 4 (implementation) and 5 (confirmation) respectively. Results are described in detail in the following sections and summarized in Table 1.

### Theme 1. Knowledge, persuasion, decision

The companion paper in this issue describes the dissemination team's pre-adoption efforts to increase knowledge about the program through marketing efforts.<sup>7</sup>

#### Knowledge

Site leaders reported that they first heard about the program through two main sources: (1) scientific publications and presentations and (2) word of mouth. Many of the sites in the dissemination initiative reported hearing about the program from American Geriatrics Society publications and presentations. The D-CARE sites reported hearing about the program from opinion leaders within their organizations or from ADC Program developer, David Reuben, MD, directly. Dr. Reuben's status as a well-respected geriatrician and dementia care expert was noted repeatedly in the interviews and speaks to the importance of opinion leadership in the dissemination process.

## Persuasion

Site leaders reported being motivated to implement the ADC program because they recognized a need for improved dementia care in their communities, a desire to participate in a national initiative, and the ability to market dementia care under a recognized name. Multiple sites also described that they were already implementing some of the elements of the ADC Program but needed a mechanism for standardizing their practice, which the ADC Program offered. All JAHF sites participated in a readiness assessment which asked them to provide information about their goals for the program and indicators of success, telephone meetings with the UCLA dissemination team leaders, and were offered a meeting with a business planning specialist to discuss return on investment. Interviewees reported having informal conversations with key stakeholders like PCP and patients to gauge interest in the program.

## Decision

Once site leaders were persuaded to adopt, they typically needed to seek approval from organizational leadership to move from the persuasion stage to the decision stage. Site leaders reported involving stakeholders from multiple departments (e.g., geriatrics, primary care, neurology, population health, information technology, and division or organizational leadership) to prepare for and receive approval. Once they had made it to this point, participants described very little to no barriers to approval from leadership to implement the model.

## Theme 2. Implementation and characteristics of the ADC program innovation

The Diffusion of Innovations framework describes five characteristics of innovations that influence success and rates of adoption: (1) Relative advantage, (2) Compatibility, (3) Complexity, (4) Trialability, and (5) Observability. Here we present key findings related to these five characteristics.

### Compatibility and relative advantage

Participants reported that the ADC Program aligned with the needs of their organization, patients, and the community and built upon their existing approaches to dementia care. As illustrated in the quote below, participants expressed that the ADC Program's extensive initial visit was an improvement upon typical practice:

It's nice...to talk about all the things that people actually want to talk about, to troubleshoot specific behaviors or talk about resources that they can look at online...The duration of the initial appointments really allows for almost a terminal illness-type of conversation ... that's really helpful. So, I think the structure of the dementia care program is really nice in that it allows for those conversations that typically you wouldn't get to have as in-depth in a 20-minute appointment. (DCS)

Participants reported that the ADC Program formalized and standardized some aspects of care that they were already providing. In the quote below, a site leader describes how the ADC Program offered a way for the organization to make formal use of the interests and expertise of an existing advanced practice provider.

[The DCS] was a great person to start the program...with her interest in neurocognitively impaired patients and the psych aspect of geriatrics, this was a way to utilize her talent, and this was a perfect fit... She fit right into that nurse practitioner role, and she was the first who really helped us start the program. (Dissemination site leader)

Finally, sites expressed the importance of collecting data to demonstrate the relative advantage of implementing the ADC Program for the organization, PLWD, and care partners. In the quote below, a DCS explains their belief that the data being collected for the D-CARE study will provide further evidence of the value of providing comprehensive dementia care to patients and care partners:

I know that I've already been seeing [the value] of including that family member or caregiver...With geriatrics, the more frail they get... there is a family member or a caregiver of somebody that you also help manage...You troubleshoot with them and you come up with ideas of how to keep them at home ... I really do believe [the study] is going to give justification for that. (DCS)

### Complexity: Perceived difficulty of using and understanding the innovation

Along with characteristics of the ADC Program that facilitated implementation, sites also encountered and

overcame challenges. Defining the DCS role within each setting was a complexity that was repeatedly described as a challenge. One aspect of this was related to the DCSs filling multiple roles within and outside of ADC Program implementation. Participants reported that DCSs played important roles in program start-up including developing templates for electronic health records, materials for marketing and communicating about the program, and presenting the program to key stakeholders (e.g., referring PCP, community-based organizations). However, in addition to their DCS role, they were also often responsible for providing clinical care such as primary care, hospital service, specialty clinics (e.g., memory, falls, mobility), assisted living and nursing home care, and teaching, at least during program start-up. Participants noted that multiple roles and underestimates of the DCS workload were a challenge. However, some DCSs reported that this challenge was mitigated by feelings of support from their organization and the technical assistance provided by the dissemination team which helped them advocate for more autonomy over schedules and the ability to dedicate time for note writing and case management activities.

...It's been nice in a pilot phase that we've been given some autonomy. I've been able to kind of formulate my own schedule... The early morning hours we're using for any type of care coordination,...outstanding follow-up, and I do a lot of my patient prep. And so I'm able to then prepare. And then you run through a very busy clinic day that's pretty nonstop, but I was able to have enough time set aside to feel like I've adequately prepared for each patient. And I think that really is that extra mile for everyone, because it makes someone feel very cared for if they come in and you already know a lot of their health information. (DCS)

The concept of co-managing patients with PCP also presented challenges. While most DCSs reported that they have positive relationships with referring PCP, some expressed frustration about needing approval from a physician for aspects of care they could otherwise provide on their own as Advanced Practice Providers, difficulty communicating with PCP about care plans, and that not hearing back from the providers about proposed changes (to medications, for example) prevented them from providing efficient care. Notably, co-management is a concept that can be interpreted differently depending upon the type of provider and their competing priorities. For example, geriatricians, geriatric psychiatrists, and

neurologists with more expertise in dementia than generalists may be more active in management.

As described by a DCS in the quote below, the DCS role requires navigating PCP' varying levels of familiarity and expertise with dementia and their understanding of the concept of co-management:

So, the co-management role, I think... there needs to be clearer lines of what that expectation is. And my geriatric group, they do dementia very well and they understand diagnosis and treatment and the psychosocial issues and all that. But the family practice providers are very different...it's just a portion of their panel... the co-management role, you know, it's a different animal. It's a different beast...some people don't even understand what it is. (DCS)

A third challenge described by participants was the data collection requirements for participating in the D-CARE and JAHF-funded dissemination initiatives. While DCSs and site leaders recognized the value in collecting data to improve program delivery and track outcomes, efforts to standardize data collection across sites presented challenges that they would not face if implementing the program outside of these initiatives. DCSs reported that while the initial burden of learning was substantial, the development of data collection and management tools (e.g., templates and modifications to the electronic health system to facilitate case management, redcap databases to facilitate the data transmission to central project management), and their increased experience using the tools helped to decrease burden over time.

### Trialability: Ability to experiment with the program

The dissemination team recognized the need to balance fidelity to the program's core components with flexibility so that organizations could adapt aspects of the program to fit the structure, priorities, and needs of their organizations and communities. From the Diffusion of Innovations framework, this flexibility and trialability are critical to addressing some challenges and complexities involved in implementation. The adaptations described in this section illustrate implementation strategies that included slight deviations from the original model but still maintained fidelity to the core elements of the model (DCS role staffed by an advanced practice provider, staffing a dementia care assistant to help with administrative duties, provision of longitudinal dementia care, 24/7 coverage, access to electronic health records for

efficient care coordination, and linkages to community-based services).<sup>7</sup>

At some institutions, the concept of co-management with an advanced practice provider proved complicated and sites needed to modify protocols based on feedback from primary care. For example, the original ADC Program as implemented at UCLA requires that patients have an established dementia diagnosis to enroll in the program. One site modified this requirement because they found that PCP needed assistance both with patients diagnosed with dementia and those who came in with memory complaints or cognitive concerns but had not yet been diagnosed. Another site shifted the requirement that the PCP approve care plan changes and instead had care plans reviewed by the ADC Program site leader.

Connections to community-based resources is a core element of the ADC Program. At most sites, the DCS is responsible for identifying community-based resources and managing referrals. One site adapted the ADC Program model to include a social worker and found that strategy very successful.

[The DCS and social worker] work together and kind of divide and conquer with all patients and families...[The DCS] role is to do a very thorough evaluation and assessment, and provide a lot of diagnostic disclosure, anticipatory guidance, looking into medications. A lot of the medical aspects of things...And then the social worker...will do a lot of the caregiver/care partner support. So, they're also doing a caregiver evaluation, checking in, how are they doing, do they need assistance in connection with community resources? So, they're kind of handling a little bit more of that angle and just being that support for the care partner. (DCS)

In addition, some sites did not staff a formal dementia care assistant role and either relied on other administrative staff to assist with scheduling or included those duties among the DCSs responsibilities. Sites that were not able to provide 24/7 access to DCSs relied on their organizations' existing systems for providing on-call services for patients.

Finally, while not an aspect of the ADC Program itself, the COVID-19 pandemic presented unique challenges and required sites to adapt operations and care. Participants noted many challenges related to staffing and the effects of the pandemic on their institutions. For example, participants described DCS furloughs and staff being pulled from DCS roles to cover clinical care in

other departments during the first year of the COVID-19 pandemic. One site noted that their institution pulled funding for the DCS salary entirely requiring the site leader to find other means for supporting the role.

Interestingly, participants described mixed effects on patient engagement during the pandemic. DCSs described difficulty providing the same quality of services to patients during COVID-19 shutdowns when they were not able to go to patients' homes or see them in the clinic. For example, it was more difficult to look for safety issues, patient assessments were harder and took longer, and DCSs had a harder time developing a close relationship with new patients without being in-person. However, some patients embraced the shift to telemedicine. Many participants described telemedicine as increasing patient access while others noted that some patients were not able to use the technology. Importantly, participants described the loss of respite services during shutdowns as a huge challenge for many caregivers. Participants noted that some PLWD and their care partners were more engaged with the program and relied more heavily on their relationship with the DCS while they were isolated from natural social supports like family and friends and lacked access to community-based services, underscoring the importance of the personal role that DCSs play beyond the medical aspects of dementia care.

### Observability: Visibility of program's results to others

Related to observability, participants noted that the success of the program was illustrated by PCP, patient, and care partner perceptions. One site leader applauded the DCS's ability to communicate with PCP and noted that providers and their medical directors recognized the value of implementing the ADC Program:

I think the most important thing is that our nurse practitioner is awesome... She's very good at communicating with the practice... The medical directors of those practices are also champions, and they see the value, they hear about the value. And so they have also been really supportive. (Site leader)

DCS participants were asked to describe rewarding aspects of their work with patients and caregivers. Observing clinical improvements in patients and caregivers was a theme among the rewarding experiences. One DCS describes powerful feedback received from a caregiver:

I can recall [a caregiver] telling me that it was like a ray of sunshine and that I made such a difference to them and that when [the patient] started [a medication I prescribed] and it started working that it was like ...[she was] like a bucket of blackness and then it just, you know, it just dropped sunshine in that bucket and she was just so much better. (DCS)

### Theme 3. Planning for sustainability

The final theme from the interviews is about sustaining the program over time. The dissemination team recognized that sustaining the program would require a mechanism for supporting the DCS role in the long term, a difficult task under the current fee-for-service payment model.<sup>10,12</sup> To assist sites, the team developed guidance on billing code usage and a return-on-investment calculator to help sites model the investment required to implement the program.

Sites reported using existing departmental funds, research-related funds, and/or philanthropy to support project start-up and DCS salaries. Billing to cover a full time DCS salary was described as a challenge. Sites noted that reimbursement rates are insufficient for the services being provided, that some of the services that DCSs spend significant time providing cannot be billed (for example, care for the caregiver, telephone follow-up, referrals to community-based services, and data entry), and that while the temporary flexibility and increased reimbursement rates for telemedicine visits during the early stages of the COVID-19 pandemic helped they did not cover the loss in revenue from in-person visits. However, some sites have been able to improve their billing procedures through collaboration with the dissemination team, building on the experience and expertise of the founding site at UCLA, and by working closely with their local billing departments.

## DISCUSSION

This study utilized Rogers' Diffusion of Innovations framework<sup>9</sup> to investigate the experiences of early adopters of the ADC Program. The three overarching themes presented here included (1) Knowledge to Decision, (2) Implementation, and (3) Sustainability. The Diffusion of Innovations framework describes innovation spread as a social process. This is well illustrated across the three overarching themes and demonstrated by the importance of high initial and ongoing

engagement from site leaders, the multifaceted nature of the DCS role, and the critical value of the technical assistance provided by the dissemination team to help sites navigate both programmatic and clinical aspects of the program. Interestingly, while interviewees did not report use of the return-on-investment calculator as a factor in their innovation-decision process, it is likely that knowledge about existing published data on cost-savings associated with the ADC Program, availability of the return-on-investment calculator, and access to consultation with a business case expert weighed into their decision to adopt.

This study will help inform interested sites about the requirements, challenges, and opportunities related to implementing comprehensive dementia care. However, it is limited in that it focuses on only a small number of sites, all of which were operating under a fee-for-service model and may not be generalizable to all sites interested in this type of model implementation. In addition, sites implemented the ADC Program during the COVID-19 pandemic which presented unique staffing and healthcare system challenges. Despite these challenges, sites were ultimately able to implement the program. These findings also point to the need for continued work to support wider dissemination, including the need to educate PCPs about comprehensive dementia care, co-management, and role of the DCS. Moreover, there is an urgent need for the development of appropriate reimbursement mechanisms that support the critical but currently non-billable services that DCSs and partnering community-based organizations provide.<sup>12</sup>

### AUTHOR CONTRIBUTIONS

Kristin Lees Haggerty: Contributed to study concept and design, acquisition of subjects, data collection, analysis and interpretation of data, and preparation of manuscript. Randi Campetti: Acquisition of subjects, analysis and interpretation of data, preparation of manuscript. Rebecca Jackson Stoeckle: Interpretation of data, preparation of manuscript. Gary Epstein-Lubow: Interpretation of data, preparation of manuscript. Leslie Chang Evertson: Interpretation of data, preparation of manuscript. Lynn Spragens: Interpretation of data. Katherine Sy Serrano: Acquisition of subjects, Interpretation of data, preparation of manuscript. Lee A. Jennings: Interpretation of data, preparation of manuscript. David B. Reuben: Conceptualization of study design, Access to subjects, Interpretation of data, preparation of manuscript.

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## CONFLICT OF INTEREST

The author declares that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

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