Dementia Care Management Program

Report to

Chairman of the House Appropriations Committee
Chairwoman of the Senate Finance and
Appropriations Committee

Virginia Department for Aging
and Rehabilitative Services

Commonwealth of Virginia
Richmond
November 1, 2024

COMMONWEALTH OF VIRGINIA
DEPARTMENT FOR AGING AND REHABILITATIVE SERVICES

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November 1, 2024

MEMORANDUM

TO: The Honorable L. Louise Lucas
Chair, Senate Finance and Appropriations Committee

The Honorable Luke E. Torian
Chairman, House Appropriations Committee

FROM: Kathryn A. Hayfield KAH
Commissioner, Department for Aging and Rehabilitative Services

SUBJECT: Annual Report on Dementia Case Management Program

Pursuant to Items 315 J and 315 M of the 2024 Appropriation Act, the Department for Aging and Rehabilitative Services (DARS) is pleased to submit the report on the status of the Dementia Care Management Programs delivered by the University of Virginia's (UVA) Memory and Aging Care Clinic in partnership with the Alzheimer's Association, and by the Martha W. Goodson Center of Riverside Health Services in partnership with the Peninsula Agency on Aging. This document provides a brief description of the UVA program's history and information about its services through the third year of funding from July 1, 2023, through June 30, 2024, and background about the Martha W. Goodson Center's program and expectations for its services going forward.

If you have any questions about the report, please do not hesitate to contact me.

KH/gw

Enclosure

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Report on Dementia Case Management

A Report to the Virginia General Assembly *November 1, 2024*

REPORT MANDATE

Item 315 J. of the 2024 Appropriations Act: *Out of this appropriation, $262,500 the first year and $262,500 the second year from the general fund shall be provided for an interdisciplinary plan of care and dementia care management for 88 individuals diagnosed with dementia. This service shall be provided through a partnership between the Memory and Aging Care Clinic at the University of Virginia and the Alzheimer's Association. The Department for Aging and Rehabilitative Services shall report the status and provide an update on the results of the dementia case management program to the Chairs of the House Appropriations and Senate Finance and Appropriations Committees by November 1 of each year.*

Item 315 M of the 2024 Appropriations Act: *Out of this appropriation, $200,000 the first year and $200,000 the second year from the general shall be provided for an interdisciplinary plan of care and dementia case management for 100 individuals diagnosed with dementia. This service shall be provided through a partnership between the Martha W. Goodson Center of Riverside Health Services and the Peninsula Agency on Aging. The Department for Aging and Rehabilitative Services shall report the status and provide an update on the results of the dementia case management program to the Chairs of the House Appropriations and Senate Finance and Appropriations Committees by November 1 of each year.*

BACKGROUND

During the 2020 Special Session, the General Assembly appropriated funding for a pilot program of dementia case management starting July 1, 2021. In the 2022 Special Session, the General Assembly appropriated additional funding starting July 1, 2022. This funding was appropriated to support the implementation of a program for dementia care management at the University of Virginia's Memory and Aging Care Clinic (UVA MACC) in partnership with the Alzheimer's Association. In the 2024 Special Session, the General Assembly appropriated funding for an additional program of dementia case management provided by the Martha W. Goodson Center of Riverside Health Services in partnership with the Peninsula Agency on Aging.

KEY ACCOMPLISHMENTS

- Dementia Care Managers (DCMs) support families using evidence-based programs.
- 123 persons living with dementia and their caregivers enrolled at UVA in the third year of the program.
- MOA with Riverside Martha W. Goodson Center initiated and program approved.

I. UNIVERSITY OF VIRGINIA MEMORY AND AGING CARE CLINIC in partnership with the ALZHEIMER'S ASSOCIATION

BRIEF HISTORY

Dementia Case Management began at UVA MACC in 2016 with support from a grant awarded to DARS by the federal Administration for Community Living under the Alzheimer's Disease Initiative—Specialized Supportive Services program. UVA MACC collaborated with the Jefferson Area Board for Aging (JABA), the Area Agency on Aging serving the Charlottesville region, to jointly hire and manage two dementia care managers serving a total caseload of 100 families. Over the nearly three years that the program operated through August 2018, the program served a total of 220 people living with dementia and their caregivers.

The project reported on several measurable outcomes highlighting the benefits of care management. Among both people living with dementia and caregivers, these included: decreased depression, improved quality of life, reduced problematic behavioral symptoms and lower severity of dementia symptoms, and reduced health care utilization. In addition, caregivers reported a reduction in caregiver burden. Overwhelmingly, both people living with dementia and their caregivers felt the program was beneficial, helping prepare them for the future, improving clinical care and treatment, improving access to community resources and reducing stress.

These results help explain why dementia case management has maintained a high profile in Virginia's Dementia State Plan since the first plan in 2011. The Alzheimer's Disease and Related Disorders Commission has consistently advocated for state funding to support dementia case management with an ultimate goal of having these services available across the Commonwealth. Since the DARS-supported grant projects ended in 2018, UVA's dementia care managers have continued to serve families with the support of additional grant funding from the Administration for Community Living and the Department of Defense. Under the former funding project, UVA successfully incorporated the evidence-based Benjamin Rose Institute Care Consultation (BRICC) program. Through the Covid-19 pandemic, dementia care management continued to be provided

DARS AND DEMENTIA

DARS' mission is to improve the employment, quality of life, security, and independence of older Virginians, Virginians with disabilities, and their families.

Under the Code of Virginia § 51.5-152, DARS has several powers and duties with respect to Alzheimer's disease and related disorders (ADRD). These include evaluating the needs of individuals with ADRD and their caregivers, and identifying the services, resources, and policies that may be needed to address such needs for individuals and their caregivers, and recommending policies, legislation and funding necessary to implement the state plan for meeting the needs of individuals with ADRD and their caregivers.

The most recent plan, the *Virginia Dementia State Plan 2024-2027: Building a Dementia-Capable Virginia*, was developed by the Alzheimer's Disease and Related Disorders Commission in consultation with stakeholders and citizens and includes six main goals, including a new goal highlighting brain health and dementia risk reduction. Goal Four is to provide access to quality coordinated care for individuals living with dementia in the most integrated setting.

The Dementia Services Director, housed within the Division for Community Living at DARS, supports the Alzheimer's Disease and Related Disorders Commission, disseminates information on systems, services and related activities, and coordinates services and activities of state and local agencies, service providers, advocacy groups, first responders and law enforcement, as well as other entities throughout the state that engage with people with ADRD and their caregivers, specifically the Alzheimer's Association, Area Agencies on Aging and Adult Protective Services.

virtually, with similar outcomes in terms of depression, quality of life, symptom management and health care utilization.

DESCRIPTION

The *Innovative Supportive Care Model for Dementia* aims to fill a gap in care through implementation of a non-pharmacological dementia care coordination program for caregivers of community-dwelling persons living with dementia. The program is delivered both in person and via a novel telehealth technology approach. The project examines the program's efficacy in 1) reducing caregiver burden, 2) reducing symptoms of depression, 3) improving caregivers' ability to cope effectively with the behavioral symptoms of dementia, and 4) improving the quality of life in caregivers of persons living with dementia.

IMPLEMENTATION

Partnership with the Alzheimer's Association

As directed in the budget language, UVA MACC continues to partner with the Alzheimer's Association to carry out the project. This is accomplished under a Memorandum of Understanding (MOU) that covers the DCM's time and effort.

The Association's DCM has worked on the project since 2021. Her onboarding included extensive training on care coordination; the BRI platform, used to document DCM interactions with individuals living with dementia and their caregivers; REDCap, used to collect data on program efficacy; and EPIC, the health system's electronic medical record system, as well as helping her integrate into the UVA system and the MACC clinic. The existing DCMs invested significant amounts of time to support her training. The successful training effort has allowed her to be a solid member of the dementia care management team, whose experience allows her to help onboard and support new DCMs as they are hired.

The Association is responsible for invoicing UVA and paying this DCM directly as a contractor. The Association offices and staff are available to provide resources to assist clinic patients and their caregivers. The DCM maintains relationships with personnel at the Association and communicates regularly with them regarding initiatives and services available.

Spanish-language services

A bilingual, bicultural DCM was hired in 2022, enabling the program to enroll Spanish-speaking participants. Unfortunately, she left the role in 2024, and the remaining DCMs were able to absorb the participants she had served without any interruption to their services. The clinic is currently working to hire another DCM to fill this position. The team is currently in the process of translating program materials, measures and surveys into Spanish to increase access for Spanish-speaking families in the future.

How the program works

Persons with Alzheimer's disease or related dementias (ADRD) and their families are approached in the MACC at UVA by members of their health care team (neurologist, neuropsychologist, or nurse practitioner) or program personnel. A brief description of the care provision program is provided and if the families are interested, their contact information is shared with the program coordinator. The program coordinator calls the families to discuss the program in detail and identify a primary caregiver to meet regularly with their assigned DCM.

Once a willing caregiver is identified and the PWD is willing to participate, a comprehensive set of questionnaires are sent to the caregiver from the REDCap platform. The questionnaires provide the DCMs essential information on how to provide the most effective care, and include measures assessing depression, anxiety, quality of life, healthcare utilization, dementia-related behaviors and caregiver reactions, and others. Caregivers are additionally asked to complete measures of caregiver stress and burden, dementia knowledge and preparedness for caregiving.

After questionnaires are completed, the program coordinator emails the caregiver an introduction to their DCM and further details regarding the program and telehealth platform used. The DCMs have ongoing contact with caregivers and the patient over a 12-month period by phone, email, videoconferencing, and in person. The job and care provided by DCMs are multifaceted, emphasizing a person-centered approach for both the individuals living with dementia and their caregivers, while examining their needs through the lens of their emotional, physical, and spiritual wellbeing.

At the end of the 12-month period, a second set of questionnaires is sent to the caregiver comprising the same questionnaires as at baseline with the addition of a satisfaction with care survey. In response to caregiver concerns about losing care coordination after 12 months, DCMs review the caregiver's participation at the end of the 12-month period. If the caregiver has participated monthly and utilized the program appropriately, they are invited to remain in the program for another year. This process of evaluation is repeated annually.

How the DCM helps

One of the primary goals of the DCM program involves coordinating care around their dementia diagnosis, with an emphasis on providing person focused support, education and guidance as they navigate the healthcare and community systems that are available to them. An equally important but less often discussed piece of DCMs' impact involves providing validation and emotional support at a time in life where things can be particularly overwhelming. DCMs validate the PWDs and care partners' emotional experience, while also providing disease-specific education and helping them to identify supports and strategies that would be beneficial for their unique needs. DCMs have the flexibility to meet the PWD and CG where they are both physically and emotionally, allowing for rapport, safety and trust established early on in the relationship.

Most of the DCM program's interventions can be organized into seven main categories: 1) care coordination, 2) education on diagnosis and dementia progression, 3) guidance and education on community resources, 4) guidance and education on financial resources, 5) guidance and support for long term care planning, 6) emotional support, and 7) behavioral symptom management and safety strategies (see Table 3 in Appendix A for examples of each).

While the goals and anticipated outcomes of care are unique for each individual living with dementia and primary caregiver, DCMs can broadly anticipate helping to prepare individuals for the challenges associated with living with dementia, reduce the need for unplanned medical treatment, decrease the emotional and physical burden of living with dementia, and improve emotional outcomes for individuals and caregivers.

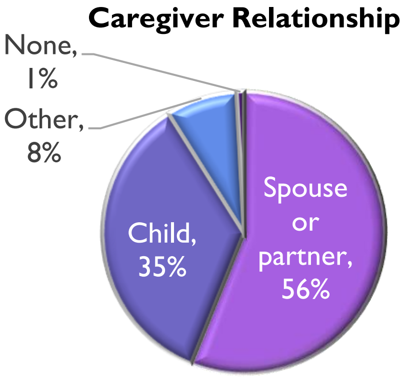
DCMs use a variety of means to maintain contact with the participants including phone, email, videoconferencing and in-person visits. Typically, DCMS will also accompany participants while they are in the MACC for follow-up care visits, providing another set of ears in often emotional and sometimes overwhelming appointments. Clinic visits usually entail meeting with several members of the care team that can include neurologists, neuropsychologists, nurse practitioners, social workers and others.

Program enrollment

Through early June 2024, the program had enrolled 123 individuals living with dementia and their primary caregivers, with new enrollment for the latest year at 32. Demographic information about the participants is in Table 1. Caregivers are often younger than the person living with dementia and generally female. By relationship, 56% of caregivers were the spouse or partner of the person living with dementia, followed by 35%

Table 1: Participant Demographics SFY 2024

	Individual Living with Dementia	Primary Caregiver
Female	50%	71%
Black/African-American	9%	7%
Hispanic/Latino	4%	6%
Veterans	10%	12%
Age Range		
Under 60	8%	34%
60+	92%	66%
Lives alone	8%	n/a
Rural	70%	70%



who were adult children, typically daughters.

Services provided

Care coordination is provided in a variety of settings, including during participants' visits to the clinic and DCM visits to the participants' homes, and through phone calls, emails and telehealth visits. Home visits are an important component of the program as they typically provide a wealth of information to help the DCM support the participant more effectively, as well as providing an important opportunity to develop rapport.

Table 2. SFY 2024 DCM Outputs

Total Service Hours	2,979
Direct	1,578
Indirect	1,401
Total Contacts (#)	3,541

At a minimum, DCMs contact each participant once a month, with an average of three contacts per month. DCMs record the time spent assisting participants as direct hours and indirect hours (see Table 2). Direct hours are actual time spent with the participants including at clinic visits, in-person home visits, phone calls, telehealth visits, and emails. Indirect hours are time spent working on tasks for the participants such as leaving or answering voicemails, time spent locating resources, time spent communicating with providers about specific patient needs, travel to and from visits, and time spent documenting interactions with participants.

Program Outcomes

From the time of enrollment to 12-months, there was a significant increase in caregiving preparedness and a significant decrease in caregiver reaction to symptoms of dementia in the individual living with dementia. Additionally, there was a notable decline in the PWD's activities of daily living. There were no significant differences on other measures analyzed (see Table 4, Appendix B).

Caregiving preparedness, as measured by the Preparedness for Caregiving Scale, reflects perceived readiness for multiple domains of caregiving, including providing physical care, emotional support, resource identification and utilization, and coping with the stress of caregiving. DCMs provide dementia care partners with support for social/emotional adjustment, health system navigation, and resource identification, among other components.

Therefore, it is not surprising that care partners demonstrated significant improvement on caregiving preparedness as a result of the program, given the ability of trained dementia care coordinators to help address the majority of aspects of caregiving preparedness.

Caregiver reaction to symptoms, assessed using the Revised Memory and Behavior Problem Checklist, reflect both the frequency of behavior problems in persons with dementia and the caregivers' reaction to those behaviors. Consequently, caregivers who feel more prepared to provide care exhibit less reactivity to dementia related behaviors, which may also be occurring less frequently due to the caregiver's increased knowledge and preparedness, an example of a virtuous circle enabled by the care management program.

Care partners' improvement in caregiving preparedness also dovetails with self-reported satisfaction with the program (see Table 5, Appendix B). Specifically, care partners were given a satisfaction survey about their participation in the program. Analysis of responses to the survey administered at the 12-month evaluation revealed that caregivers highly valued the role of the DCMs. Over 90% of care partners agreed DCMs had a positive impact on their mood, were emotionally supportive, and were an important part of the healthcare team. Overall, 92.5% of caregivers found having a DCM to be beneficial. It is possible that having access to supportive and responsive DCMs yields improvements in feeling "well prepared", and becoming less reactive to the behavioral symptoms of dementia, allowing them to better meet the care-recipients' physical, emotional, health, and functional needs and to better manage the stress of caregiving.

There has also been a reduction in the need for in-person appointments at MACC and emergency room visits as DCMs are able to problem solve, answer questions, help caregivers navigate the health system, and help caregivers implement behavioral intervention strategies.

DCMs have also been able to facilitate positive changes for participating caregivers that support the person living with dementia to stay in the home for longer than may otherwise have been the case. Examples of such changes include the following:

- Creating a safe environment (i.e. making suggestions to make the home safer and help with fall prevention) while finding community volunteers and grants to make the home more accessible (i.e. installing ramps and shower bars, fixing mold issues, helping with roof repair, finding and delivering durable medical equipment)
- Connecting families with local individuals and home health agencies to provide respite care
- Addressing cognitive changes with the treatment team as needed rather than participants waiting for the standard yearly follow up visit
- Providing education and emotional support
- Connecting families to community-based services for free durable medical equipment or other adaptive devices (e.g. tub chairs, disposable briefs, wedges to make shifting someone in the bed easier on a caregiver's back, etc.)
- Helping connect caregivers to support groups, therapists, or other mental health support to combat caregiver fatigue/burnout
- Ensuring caregivers are aware of their local community support agencies, including their Area Agency on Aging, Department of Social Services, Senior Centers, etc.

Lessons from the third year

The DCMs and team have learned from caregivers that they are concerned about losing care coordination after 12 months. Caregivers and individuals living with dementia are so satisfied with the program that they have requested services to be extended beyond a year. The program team has continued discussing the dilemma of whether it is of greater impact to limit the program to 12 months to provide services to more people, or to extend services to current participants and limit the number of additional participants who can be provided the service. DCMs have observed that caregivers experience unpredictable fluctuations between crises, where they heavily utilize the service, and periods when they require fewer services.

These fluctuations impact the DCM's service times and make it difficult to set optimal caseloads. To address this, the project team is exploring creative solutions, such as introducing a Care Navigator, to manage CGs in periods of lower need and potentially extend services to more people.

During the onboarding process for the newest DCM, the team recognized the importance of new team members being actively engaged in the clinic and ancillary activities, such as support groups. In-person experience in the clinic prepares DCMs to answer caregiver questions about the process and what they can expect. This engagement ensures that new team members are well-prepared to provide high-quality support to caregivers.

An additional lesson learned is that enrolling Spanish-speaking participants has challenges beyond the DCM speaking Spanish. Many of the Spanish-speaking participants were not born in the United States. They have less familiarity with the health care system and cultural factors that enable service provision. The bilingual DCM found that more phone calls and home visits were required to help people understand the program and how to access and use available resources. Additionally, she found that participants needed hands on support with filling out the questionnaires. This may have been related to reading ability, education level, and/or familiarity with filling out questionnaires.

Despite having strong family support, Spanish-speaking participants frequently have fewer external resources and often present with more complex needs that require more services before formal evaluation can begin and more time on the part of the DCM to provide the services that most benefit the caregivers. Work will continue to better understand how to improve service delivery to this population.

Program reception

Reception of the Care Coordination program has been overwhelmingly positive within UVA MACC and with associated partners. The team has found that the great majority of caregivers receiving clinic care are interested in care coordination. As such, the team has had to be strategic in how the program is advertised to prevent the waitlist from being flooded with people desiring services. Demand for services continues to far outreach the current availability of DCMs.

Dementia care coordination remains a highly desired service in the UVA MACC. The rate-limiting factor to providing this service to all interested patients and families is the lack of available DCMs.

II. RIVERSIDE MARTHA W. GOODSON CENTER in partnership with PENINSULA AGENCY ON AGING

BRIEF HISTORY

Dementia Case Management began at Riverside in 2018, through the former Center for Excellence in Aging and Geriatric Health, now through the Riverside Martha W. Goodson Center (MWGC) and the Riverside Neurology Memory Care Clinic. The development of this program, referred to initially as dementia care coordination, was funded in part by a grant awarded to Riverside by the federal Administration for Community Living under the Alzheimer's Disease Program Initiative. One full-time and one part-time dementia care coordinators were hired to support this project through the fall of 2021. These dementia care coordinators served 117 patients living with dementia and their families during the grant period utilizing the Benjamin Rose Institute on Aging Care Consultation (BRICC) program.

Measurable outcomes among these families included a substantial drop of emergency room visits (from 35% to 29% of enrolled participants) at program completion. Hospitalization rates remained the same at 18.4%. Overall quality of life for participants living with dementia was largely maintained, dipping from 1.56 to 1.50. Caregivers reported increased ability to manage day-to-day caregiving and handle new problems. Negative indicators, such as being angry or feeling overwhelmed, also improved. Both persons living with dementia and their families consistently reported satisfaction with the program and highlighted benefits such as having things explained in an understandable way, listening to what the caregiver has to say, including both the person living with dementia and their caregiver in planning, and helping to connect with resources and services.

In the spring of 2021, Riverside received a donation that facilitated the continuation of this program after the federal funding ended, with the program renamed as Memory Care Navigation. The first Memory Care Navigator was hired by the MWGC in the fall of 2021, and since then two additional Memory Care Navigators have been hired. This team of Memory Care Navigators utilizes BRICC where appropriate, and they serve a caseload of more than 300 families. As part of the program, both extensive services (e.g., at least 6 months of case management) and limited services (e.g., generally 1-2 touchpoints) are tracked. In 2022, 112 families received extensive services, and this rose to 276 in 2023 and 337 to date in 2024. The team of Memory Care Navigators is also supported by a Geriatric Care Specialist and a Community Health Care Navigator. The MWGC has connected with the UVA MACC to learn about their approach and workflow in offering dementia case management.

IMPLEMENTATION

Memorandum of Agreement (MOA)

DARS staff, including the Dementia Services Director, negotiated an MOA with Riverside Martha W. Goodson Center ("Center") to provide dementia case management services to 100 families. The MOA was fully executed in September 2024, with services commencing immediately thereafter. The MOA requires the Center to coordinate an evidence-informed or evidence-based, integrated care system for people living with dementia and their caregivers in collaboration with the Peninsula Agency on Aging (PAA). The Center has negotiated a subcontract with PAA to provide outreach and other services, as well as to provide space for Dementia Care Managers to meet with participating families.

The Center has hired a new DCM to provide services. Ten individuals and their caregivers are expected to be enrolled by the end of

September, with a further 25 to be enrolled by the end of December 2024. Enrollment of 100 individuals and their caregivers is expected to be achieved by June 30, 2025.

Program Implementation Plan approved

Under the MOA, the Center was required to submit a Program Implementation Plan to DARS prior to providing services. The plan was received, reviewed, and approved by the DARS Dementia Services Director and the Director of Aging Services. The plan provides for the use of evidence based or evidence-informed tools such as the Care Ecosystem or the BRICC which is also used at UVA.

The DCM (known as a Memory Care Navigator at the Center) will perform the following core functions for families during the six months of core enrollment.

Assessment: Identification of persons living with memory loss for case management; comprehensive collection of patient information and medical status; and continued evaluation of an established plan of care.

Planning: Collaboration with the patient, family/caregiver, primary provider, specialty providers, pharmacist, community partners and other members of the health care team for developing an effective plan of care.

Facilitation: Care coordination and communication in partnership with the person living with memory loss and their family/caregiver. Develop and help facilitate community classes and presentations on topics related to dementia, Alzheimer's Disease, caregiver stress, and other related resources.

Advocacy: Assistance, support, referral services to community partners for the person living with memory loss and the family/caregiver to ensure identified education, and appropriate timely care is received.

APPENDIX A

Table 3. Action types and examples of DCM interventions

Action Step Types	***Examples***
Behavioral management strategies	E.g., for sundowning, hallucinations; using dry erase boards for scheduling; dementia clocks.
Safety strategies	E.g., grab bars in the shower, removing rugs from the home; reviewing how to call 911 in the event of an emergency; reviewing personal safety equipment (e.g., medical alert device); contacting Adult Protective Services about concerns of abuse or neglect.
Strategies for both behavior management AND safety	Discussing strategies for managing/reducing the likelihood of wandering (e.g., alarms on doors); camera systems for in-home safety and monitoring; strategies for discouraging persons with dementia from driving.
Strategies for activities of daily living	Discussing automatic pillboxes/pillboxes with alarms; educating about incontinence care; putting water bottles on the counter as a visual reminder to hydrate throughout the day.
Administration/case management	Initial chart review; scheduling visits; consulting with other providers (e.g., on the team) with whom the individual is already established; completing paperwork.
Referrals to other providers	E.g., to speech therapy, physical therapy, psychotherapy, palliative care, hospice.
Providing education about navigating diagnosis and disease progression	Reviewing the diagnosis of Alzheimer's disease and what might be expected for Mild Cognitive Impairment or the relevant stage of dementia; educating about the difference between depression and apathy, or about anosagnosia.
Guidance and education on community resources	Discussing Silver Sneakers program, directing a care partner to the local area agency on aging; connecting them with Meals on Wheels or another specific community resource; sharing information about the Alzheimer's Association 24/7 Hotline.
Guidance and education on financial resources or benefits	Discussing Medicare/Medicaid benefits, long-term care insurance, VA benefits, or FMLA benefits; making the care partner aware of grants; assisting with affordable housing vouchers or respite care vouchers.
Guidance and support for long-term care planning	Discussing options for assisted living versus in-home help; providing guidance about questions to ask home health agencies or facilities.

(table continued on next page)

Providing emotional support	**"Above and beyond" active listening and typical counseling skills, such as validating and discussing anticipatory grief, ambiguous loss, or guilt about transitioning the individual to an assisted living facility.**
Guidance and education about research/clinical trials	Providing information about local research opportunities/clinical trials; helping to coordinate brain donation/autopsy for research purposes.
Guidance and education about legal resources	Discussing the importance of updating wills and advance directives, designating an agent under power of attorney; connecting the participants with an elder law attorney.
Rapport-building	Initial establishment of rapport; could also occur after an issue or conflict between the DCM and the participants (either the individual living with dementia or the caregiver), for example if the care partner is frustrated with the DCM about a conversation or

	resource. On-going maintenance of rapport and provision of empathic care.
Lifestyle, quality of life, and enrichment/engagement resources	Memory scrapbooking for the purpose of enrichment and reflection on the individual's life; encouraging increased use of respite to improve quality of life; discussing the benefits of a specific enrichment activity (e.g., arts/crafts).

APPENDIX B

Table 4. Care Coordination 12-Month Efficacy Results

Construct	**Baseline** (n=57) Mean (SD)	**12-Months** (n=57) Mean (SD)	**p-value**
Caregiver Preparedness	15.53 (5.30)	17.98 (6.03)	**.028**
Reaction to individual's dementia symptoms	16.77 (12.43)	12.33 (9.22)	**.043**
Individual's Activities of Daily Living (bathing, toileting etc.)	5.14 (1.46)	4.28 (2.07)	**.013**

Table 5. Satisfaction with Care Responses (n=53)

Survey Statement	**Agree* (%)**
I consider my Care Coordinator to be an important part of my loved one's healthcare team.	90.6%
My Care Coordinator assisted me in making informed decisions for my loved one's care	86.8%
Having a Care Coordinator helped me adjust to my loved one's diagnosis	84.9%
My Care Coordinator provided me with access to community resources for myself and/or my loved one	86.8%
I have more support from family/friends due to my Care Coordinator	58.5%
I learned valuable information about memory loss and dementia from my Care Coordinator	86.8%
My Care Coordinator provided valuable information about legal issues (Health insurance, Power of Attorney, Medical Directive, etc.).	60.4%
I am better prepared for the future because of my Care Coordinator	77.4%
My Care Coordinator had a positive impact on my mood.	92.5%
My Care Coordinator was emotionally supportive.	94.3%
I learned valuable coping skills from my Care Coordinator.	75.5%
I have less stress because of my Care Coordinator	79.2%

I have been able to take time more for myself by utilizing resources provided by my Care Coordinator (i.e., respite care, adult day care, etc.)	52.8%
My Care Coordinator responded to my needs in a timely manner and met my needs as quickly as possible.	86.8%
Overall, having a Care Coordinator was beneficial and I am happy with their services.	92.5%

* The Satisfaction with Care survey used a Likert scale from 1 (Strongly Agree) to 5 (Strongly Disagree). For analysis, the scale was collapsed into two categories: Agree and Neutral/Disagree.

APPENDIX C

Testimonials provided to program staff directly or through the satisfaction surveys.

> *AB with UVA Care Was Wonderful helping my Family!! I don't know what we would of done if we didn't have her helping US! THANK YOU ALL AT UVA!!!!!*
>
> *Thank you so much for providing this opportunity. We are deeply appreciative!*
>
> *Thank you for the help and we appreciate everything that DG has helped us with. My family appreciates her so much!*
>
> *Our care coordinator has simply been invaluable this past year. I have learned so much and felt so supported. Thank you for the opportunity to participate! I truly hope the benefit of providing this service is found so it becomes an option for everyone caring a loved one with dementia.*
>
> *I've gained so much from this program! And from talking with and learning from EF throughout this process.*
>
> *This is a very difficult journey. AF has been a tremendous support, resource, and conduit to resources. She is knowledgeable, accessible, and empathetic. We certainly would have had a lot more difficulty navigating this last year without her and UVA neurology. Thank you!*
>
> *I am grateful to UVA neurology, our care coordinator, and for participation in this program and the help and hope it can provide. We have made progress through this difficult journey. Support and information is definitely needed and helpful for a growing number of people going through this. Thank you.*
>
> *I am so grateful to have KA as my "sounding board" for the past 12 months. She was incredibly helpful in finding resources I was unaware of. That is invaluable! Living on a fixed income and not able to afford any services has been a huge challenge for me. Because of COVID, the answer was always "no." Now I hope to move forward armed with resources and knowledge of how to "work" the system. At least it is a good start. Thank you.*