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Featured Article

Evaluation of a care management program on family caregivers of persons with dementia



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ABSTRACT

As the U.S. population ages, dementia due to Alzheimer's or other disease is concerning for healthcare providers. Family caregivers (FCGs) of persons with dementia (PWDs) may experience negative outcomes. The University of California, Davis, Health (UCDH) Alzheimer's and Dementia Care (ADC) Program provides care management for PWDs and their FCGs. This pilot study evaluates the program's effect on FCG depression, strain, and distress. Despite an increase in dementia severity in PWDs, FCGs experienced decreased levels of depression, strain, and distress following 12 to 18 months in the UCDH ADC Program. Other findings include PWDs experiencing reductions in severity of neuropsychiatric symptoms and remaining at home with FCGs. Despite limitations, such as a relatively small sample size and lack of sample diversity, this pilot study demonstrated positive outcomes to both PWDs and their FCGs and contributes to the literature supporting dementia care management programs. Future projects should address these limitations to understand the experiences of a diverse population and to make dementia care management programs sustainable.

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Background

With the growing population of older adults in the United States, dementia due to Alzheimer's or other disease is a topic of concern for many healthcare providers. The Aging, Demographics and Memory Study (ADAMS) estimates that 11% of people aged 65 and older in the United States have dementia.¹ With an increase in dementia severity comes an increase in the support needed from caregivers, primarily family caregivers (FCGs), who provide care navigation within the health system and in the community.² A FCG is a relative, partner, friend, or neighbor who provides assistance to an older adult with a chronic or disabling condition.³ In the United States in 2022, a FCG of a person with dementia (PWD) provided an average of 30h of care per week, or 1565h of care per year.⁴ The unrelenting nature of dementia caregiving can cause deleterious effects to a FCG's psychosocial, behavioral, financial, and physiological well-being.⁵ To reduce

the negative impacts of dementia caregiving, it is important to identify the needs of FCGs and to provide them with resources and support.

Interventions targeted to meet the needs of FCGs of PWDs can lead to improvements in quality of life. Care management is an intervention with promising outcomes for FCGs of PWDs. Care management is a strategy utilized in healthcare delivery systems to improve the care experience, decrease healthcare costs, and improve population health for individuals with chronic conditions.⁶ Components of care management include the following: identifying and assessing an individual's risks and needs; developing a personalized care plan with the individual and family; educating and coaching on disease self-management (e.g., coping, crisis management); tracking progress of care goals; care coordination with the interdisciplinary healthcare team; and assisting with healthcare system navigation and finding community resources.⁷ Because care management requires a high degree of clinical expertise, the role of care manager calls for a healthcare professional with clinical training who works within an interdisciplinary healthcare team.⁷ Components of care management that have been implemented in studies include interdisciplinary collaboration among healthcare professionals, telephonic assessment and support to both PWDs and FCGs, education to FCGs, and referrals to health system- and community-based programs.^{8–10} Several studies have found positive outcomes, including reduced depression, strain, and distress as well as improved coping and caregiving

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mastery, for FCGs of PWDs with care management programs led by nursing personnel.⁸⁻¹⁰

Dementia care management programs have gained popularity within the last decade, as there has been a growing national interest in evidence-based, value-oriented care for both PWDs and their FCGs. In 2011, the National Alzheimer's Project Act was signed into law, which led to the creation of the National Plan to Address Alzheimer's Disease.¹¹ One goal is to enhance dementia care quality and efficiency through interdisciplinary teams skilled in dementia care as well as through implementation and evaluation of dementia care programs to support PWDs and their FCGs.¹¹ Additionally, the plan seeks to expand support for both PWDs and their FCGs through education, training, and resources; and to ensure the health and well-being of FCGs through routine assessments and referrals to supportive services.¹¹ In 2018, the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Act made it a priority for the nation to develop a national family caregiving strategy to recognize and support FCGs. Findings and recommendations from two councils and various stakeholders led to the 2022 National Strategy to Support Family Caregivers.¹² With the July 2023 announcement from the Centers for Medicare and Medicaid Services regarding the Guiding an Improved Dementia Experience (GUIDE) Model, many are shifting attention to dementia care management. "The GUIDE Model will focus on dementia care management and aims to improve quality of life for people living with dementia, reduce strain on their unpaid caregivers, and enable people living with dementia to remain in their homes and communities. It will achieve these goals through a comprehensive package of care coordination and care management, caregiver education and support, and respite services."¹³ Dementia care management is becoming an essential part of delivering care to PWDs and FCGs.

However, a major barrier to the implementation of a dementia care management program within a health system is the wide array of options from which to choose.¹⁴ Differences among dementia care management programs create a unique challenge for healthcare professionals, organizational leadership, and other stakeholders looking to implement these programs. Additional guidance on program implementation and outcome evaluation is necessary to help healthcare teams decide which program will be best for their health system.

Purpose

The purpose of this pilot study was to evaluate a dementia care management program, specifically the Alzheimer's and Dementia Care (ADC) Program, disseminated from the University of California, Los Angeles, (UCLA) to the University of California, Davis, Health (UCDH). The aim of this pilot study was to evaluate the UCDH ADC Program and its impact on FCGs' outcomes in terms of depression, strain, and distress.

Theoretical model and application

RE-AIM is a model that was first developed in 1999 by Drs. Russell E. Glasgow, Thomas M. Vogt, and Shawn M. Boles to evaluate the public health impact of health promotion interventions by assessing and reporting on individual- and/or system-level issues within five dimensions: reach (R), effectiveness (E), adoption (A) implementation (I), and maintenance (M). Because the model draws attention to essential program elements, including external validity, it is useful both for translating research into practice in a timely and equitable manner and for guiding planning and implementing population-based programs.¹⁵

RE-AIM guided the ADC Program implementation within UCDH. The individual-level measures for PWDs and FCGs within

the program address the reach and effectiveness dimensions of the RE-AIM model. The project specifically focused on effectiveness of the program by assessing both positive and negative outcomes as well as other outcomes such as behavioral outcomes and participant-centered outcomes (e.g., functional level, mental health, quality of life, participant satisfaction). The pilot study design was also chosen based on the RE-AIM model, which reports that experimental or quasi-experimental methods with a prospective or pre-posttest design may be used to test effectiveness.¹⁶ The ADC Program's adoption, implementation, and maintenance as part of the dissemination work of the UCLA team are beyond the scope of this paper.

Methods

Study design

We evaluated this program using a one-group, pretest-posttest design with assessments of FCGs of PWDs in the UCDH ADC Program. Assessments were gathered following the initial appointment and an appointment 12 to 18 months after the initial appointment, hereafter called the annual appointment, to examine the impact of the program on FCG depression, strain, and distress.

Setting

The UCDH ADC Program at the Healthy Aging Clinic is a dissemination site of the UCLA ADC Program. The project took place at the Healthy Aging Clinic, an ambulatory care clinic within UCDH located in Sacramento, California. The interdisciplinary clinic serves individuals 65 and older and their FCGs from various regions across the state. The clinic offers expertise in geriatric medicine, cognitive neurology, neurocognitive testing, dementia care, mobility, dietetics, pharmacology, family caregiving, and case management.

Program description

The UCDH ADC Program consists of UCDH physicians (e.g., primary care physicians, cognitive neurologists, geriatricians), two nurse practitioners, one registered nurse, two medical assistants, and one licensed vocational nurse. Other ancillary staff include one referral coordinator and two medical receptionists.

After a UCDH physician refers a PWD and their FCG(s) to the UCDH ADC Program, the PWD and their FCG(s) are scheduled for a 90-minute, in-person, initial appointment with a nurse practitioner. Prior to the initial appointment, the PWD and/or their FCG(s) are asked to complete a "Pre-Visit Questionnaire" (Appendix A) and "Caregiver Packet". The "Pre-Visit Questionnaire" assesses information about the PWD; the "Caregiver Packet" contains questionnaires to assess both the FCG and PWD (i.e., Patient Health Questionnaire-9, Modified Caregiver Strain Index, Cornell Scale for Depression, Neuropsychiatric Inventory Questionnaire). The medical assistant provides the "Pre-Visit Questionnaire" and "Caregiver Packet" via mail, electronic mail, fax, or electronic health message, also called MyChart message. The completed "Pre-Visit Questionnaire" and "Caregiver Packet" are provided to the nurse practitioner prior to the start of the appointment.

During the initial appointment, the nurse practitioner gathers a cognitive-focused history and physical assessment; evaluates for neuropsychiatric symptoms; reviews current and prior medical treatment; performs medication reconciliation; assesses functional status, including decision-making capacity; assesses current financial and living situation, including safety concerns (e.g., home environment, driving, firearms); identifies family and other caregivers, specifically focusing on FCG knowledge, social support, and needs; assists with

reviewing, creating, or revising advance care planning documents; and prompts a discussion on “what matters.”

Based on the identified issues, the nurse practitioner develops a personalized written care plan that includes medical, behavioral, and social recommendations and resources. The nurse practitioner then routes and discusses the care plan and recommendations with the referring physician via a message in the electronic health record. The referring physician reviews, revises, and approves the care plan before coordinating with the nurse practitioner to enact the final care plan.

The nurse practitioner also shares the personalized written care plan with the registered nurse. Specifically, the nurse practitioner discusses the social needs of the PWD and their FCG(s) with the registered nurse either in-person or via a message in the electronic health record. The registered nurse then assists with navigation of health system resources, provides referrals to community-based organizations, provides counseling and support, and assists with proactive outreach.

The nurse practitioner performs a follow up telephone, video, or in-person appointment within one week of the initial appointment to review the final care plan. Follow-up appointments are scheduled every four months at minimum; the PWD and/or their FCG(s) have the option of choosing telephone, video, or in-person follow-up appointments. PWDs and FCGs may contact the program staff via unscheduled telephone calls, MyChart messages, or other encounters (e.g., automated medication refill requests). Close follow-up appointments by either the nurse practitioner or the registered nurse, as often as every week, may be necessary depending on the PWD and/or their FCG(s) needs. After 12 months in the program, the PWD and their FCG(s) are required to be seen in-person for a 60-minute appointment with a nurse practitioner; the nurse practitioner conducts the same assessment as the one performed during the initial appointment.

Sample

The participants in this pilot study included adults 18 years or older who provided informal care to a spouse/partner, relative, or non-relative (e.g., friend, neighbor) with dementia, who completed an initial appointment from July 1, 2021, to December 31, 2021, and who completed an annual appointment by December 31, 2022, with the UCDH ADC Program at the Healthy Aging Clinic in Sacramento, California. Exclusion criteria include the following: any PWD who presented only with formal caregiver(s) at the initial appointment; any FCGs of a PWD who incorrectly used the “Caregiver Packet” (i.e., multiple FCGs completing one “Caregiver Packet”); any PWD who permanently relocated outside of California; and any PWD and/or FCG(s) who decided to unenroll in the program. Additionally, they were excluded if the PWD went to hospice or died.

Human subjects protection

The study was reviewed by the University of California, Davis, Institutional Review Board (IRB). The study was determined to be research not involving human subjects; IRB review was not required.

Measurements

Measures for both PWDs and FCGs were gathered as part of routine care within the UCDH ADC Program.

Family caregiver

Information about the FCG was obtained at the initial appointment and at the annual appointment with the UCDH ADC Program.

From the initial appointment, the researcher obtained information on the name, sex, and relationship of the FCG to the PWD. In addition, the researcher gathered information on whether multiple caregivers were involved in the care of the PWD and on whether the FCG had an appointment with the Family Caregiving Institute, a program offering psychoeducation and psychotherapy from a specialist in family caregiving. At both the initial appointment and the annual appointment, the following were collected: Patient Health Questionnaire-9 score; Modified Caregiver Strain Index Score; Neuropsychiatric Inventory Questionnaire, Distress Subscore.

Patient Health Questionnaire-9. The Patient Health Questionnaire-9 (PHQ-9) is a validated, 9-item, self-administered questionnaire used to screen for depressive symptoms and assess depression severity over the last two weeks. Scoring ranges from 0 to 27. A total score of 0–4 indicates none to minimal depression. A total score of 5–9 indicates mild depression. A total score of 10–14 indicates moderate depression. A total score of 15–19 indicates moderately severe depression. A total score of 20–27 indicates severe depression.¹⁷

Modified Caregiver Strain Index. The Modified Caregiver Strain Index (MCSI) is an instrument to screen for caregiver strain in long-term FCGs. The MCSI is a validated, 13-item, self-administered questionnaire that measures caregiver strain in the following domains: financial, physical, psychological, social, and personal. Scoring ranges from 0 to 26. A higher score indicates a higher level of caregiver strain.¹⁸

Neuropsychiatric Inventory Questionnaire, Distress Subscore. The Neuropsychiatric Inventory Questionnaire (NPI-Q) is an instrument completed by caregivers to evaluate the presence and severity of neuropsychiatric symptoms in persons with Alzheimer’s disease and to evaluate the presence and severity of caregiver distress associated with the symptom(s). The NPI-Q is a validated, 12-item, self-administered questionnaire that covers 12 neuropsychiatric symptom domains: delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviors, nighttime behavioral disturbances, and appetite/eating disturbances. The total NPI-Q distress subscore ranges from 0 to 60; a higher number indicates more distress in the FCG. Information about the NPI-Q severity subscore is listed in the section on the PWD.¹⁹

Person with dementia

The researcher obtained information about the PWD at the initial appointment and at the annual appointment with the UCDH ADC Program. At the initial appointment, the researcher obtained sociodemographic information (i.e., name, medical record number, age, sex, race, ethnicity, primary language, and marital status) and the type of dementia for the PWD. At both the initial appointment and the annual appointment, the following were collected: Functional Assessment Staging Tool; number of basic activities of daily living (BADLs) and instrumental activities of living (IADLs) requiring caregiver support; enrollment in home-based palliative care (HBPC), which is a program offering support and education for chronic conditions; living situation in relation to the FCG; and Neuropsychiatric Inventory Questionnaire, Severity Subscore.

Functional Assessment Staging Tool. The Functional Assessment Staging Tool (FAST) is designed to evaluate for change in functional performance and BADLs and IADLs in persons with Alzheimer’s disease. The FAST is comprised of functional levels ranging from 1 to 7, with a higher number indicating more functional impairment in the PWD.²⁰

Neuropsychiatric Inventory Questionnaire, Distress Subscore. As mentioned above, the Neuropsychiatric Inventory Questionnaire (NPI-Q) is an instrument completed by caregivers to evaluate for the presence and severity of neuropsychiatric symptoms in persons with

Alzheimer's disease and to evaluate the presence and severity of caregiver distress associated with the symptom(s). The total NPI-Q severity subscore ranges from 0 to 36; a higher number indicates more severe neuropsychiatric symptoms in the PWD.¹⁹

Encounters

To understand the dyad's utilization of the program's services, the researcher counted the total number of encounters between the initial appointment and the annual appointment in the UCDH ADC Program and further characterized them by encounter type. For this pilot study, an encounter was defined as any type of communication received by the UCDH ADC Program staff about the PWD and/or the FCG(s). Examples of encounter types included scheduled appointments (i.e., telephone, video, and in-person appointments) and unscheduled encounters (i.e., telephone calls, MyChart messages, and other encounters). Additionally, the researcher calculated the sum of all program encounters from July 1, 2021, (program start date) to December 31, 2022 (project end date), and further characterized them by encounter type.

Statistical analysis

Descriptive statistics were used to describe the demographics of PWDs and FCGs. The impact of the UCDH ADC Program was assessed by using a paired *t*-test to compare mean PHQ-9, MCSI, and NPI-Q Distress Subscore at the initial appointment to the same scores at the annual appointment. The threshold for statistical significance was set as a *p*-value < 0.05. Intellectus Statistics was used to analyze the data.

Results

There were 125 PWDs who had an initial appointment in the UCDH ADC Program between July 1, 2021, and December 31, 2021. Dyads were excluded from final analyses for various reasons (Fig. 1).

The final analyses were run on 45 PWDs and their FCGs who completed an initial and annual appointment (Fig. 1).

Persons with dementia

Demographics

As shown in Table 1, most PWDs were female (73.33 %), White (60.00 %), Not Hispanic or Latino (88.89 %), and reported English as their primary language (93.33 %). Most PWDs were widowed (42.22 %) or married (35.56 %). The most common cause of dementia was Alzheimer's disease (44.44 %). The average age of the PWD was 81.02 years (*SD* = 8.81 *SE_M* = 1.31); the youngest person was 61 years old, and the oldest person was 97 years old.

Health characteristics at initial and annual appointment

Table 2 lists the health characteristics of PWDs at the initial appointment and the annual appointment. The stages of dementia ranged from mild (FAST 4) to severe (FAST 7) at both the initial and the annual appointment. Overall, the average stage of dementia (i.e., moderate stage) remained unchanged from the initial to the annual appointment. The number of BADLs and IADLs requiring caregiver support increased from the initial to the annual appointment. At both initial and annual appointment, most PWDs were not enrolled in HBPC (93.33 % and 95.56 %, respectively). In most cases, at both the initial and the annual appointment, the PWD lived in the same household as the FCG that was analyzed (64.44 % and 62.22 %, respectively).

Family caregivers

Demographics

The majority of FCGs were female (77.78 %). The relationship between the PWD and the FCG was primarily child or child-in-law

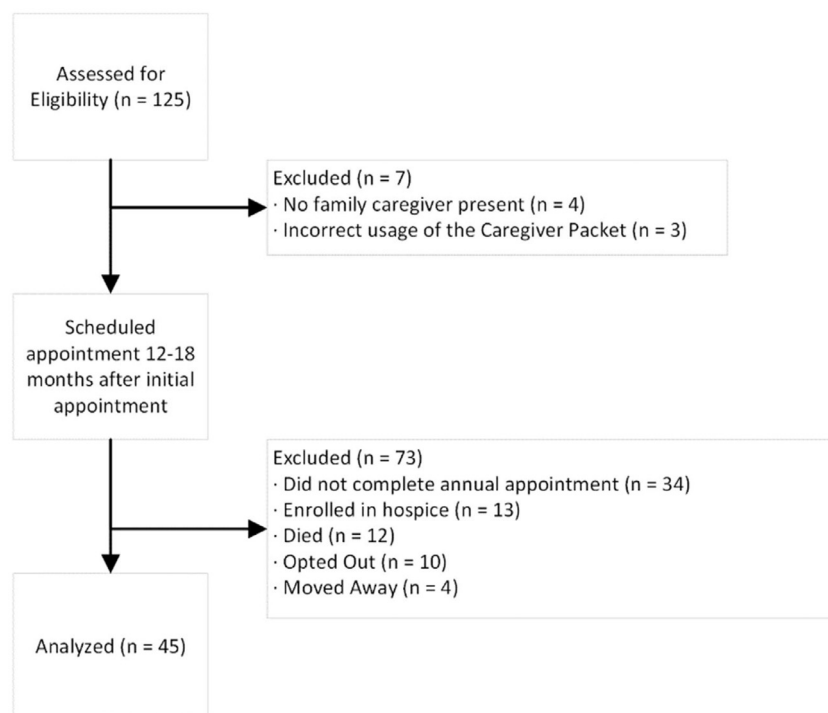


Fig. 1. Enrollment status in UCDH ADC program between 07/01/2021–12/31/2021.

Table 1
Demographics of Persons with Dementia (n = 45)

Variable		
Age, years (<i>M, SD</i>)	81.02	8.81
Sex (<i>n, %</i>)		
Female	33	73.33
Male	12	26.67
Race (<i>n, %</i>)		
White	27	60.00
Asian	10	22.22
African American or Black	5	11.11
Other	2	4.44
Unavailable or Unknown	1	2.22
Ethnicity (<i>n, %</i>)		
Not Hispanic or Latino	40	88.89
Hispanic or Latino	4	8.80
Decline to State	1	2.22
Primary Language (<i>n, %</i>)		
English	42	93.33
Spanish	0	0.00
Other	3	6.67
Marital Status (<i>n, %</i>)		
Widowed	19	42.22
Married	16	35.56
Single	7	15.56
Divorced	3	6.67
Type of Dementia (<i>n, %</i>)		
Alzheimer's disease	20	44.44
Mixed disease	14	31.11
Vascular disease	7	15.56
Lewy body dementia	3	6.67
Parkinson's disease	1	2.22

Note. Due to rounding errors, percentages may not equal 100%. *M* = mean. *SD* = standard deviation.

(55.56 %). Almost all FCGs received support from multiple caregivers (e.g., multiple family caregivers, paid caregivers) (93.33 %) as well as from the Family Caregiving Institute (57.78 %) (Table 3).

Outcomes at initial and annual appointment

There was a reduction in caregiver PHQ-9 score from the initial (*M* = 3.87, *SD* = 3.63) to the annual appointment (*M* = 2.57, *SD* = 2.19). However, this difference was not statistically significant (*t*[22] = 1.74, *p* = .096). Similarly, caregiver strain improved from initial (*M* = 9.41, *SD* = 5.90) to annual appointment (*M* = 7.79, *SD* = 4.62), but this reduction was also not statistically significant (*t*[28] = 1.52, *p* = .141).

Table 2
Health Characteristics of Persons with Dementia at Initial and Annual Appointment (n=45)

Variable	Initial Appointment	Annual Appointment
Functional Assessment Staging Tool, <i>M</i> (<i>SD</i>)	5.07 (0.99)	5.51 (0.97)
Number of BADLs/IADLs Requiring Caregiver Support, <i>n</i> (%)		
0-2	3 (6.67)	1 (2.22)
3-5	8 (17.78)	5 (11.11)
6-8	10 (22.22)	13 (28.89)
9-11	12 (26.67)	7 (15.56)
12-14	10 (22.22)	18 (40.00)
Missing	2 (4.44)	1 (2.22)
Enrollment in Home-Based Palliative Care, <i>n</i> (%)		
Yes	3 (6.67)	2 (4.44)
No	42 (93.33)	43 (95.56)
Living Situation, <i>n</i> (%)		
Same household as the family caregiver	29 (64.44)	28 (62.22)
Different household as the family caregiver	16 (35.56)	17 (37.78)

Note. Due to rounding errors, percentages may not equal 100%. *M* = mean. *SD* = standard deviation.

Table 3
Demographics of Family Caregivers (n=45)

Variable	n	%
Sex		
Female	35	77.78
Male	10	22.22
Relationship to the Person with Dementia		
Child/Child-In-Law	25	55.56
Spouse/Partner	15	33.33
Grandchild/Grandchild-In-Law	2	4.44
Sibling/Sibling-In-Law	2	4.44
Other Relative	1	2.22
Non-relative (e.g., friend, neighbor)	0	0.00
Multiple Caregivers Involved		
Yes	42	93.33
No	3	6.67
Appointment with the Family Caregiving Institute		
Yes	26	57.78
No	19	42.22

Note. Due to rounding errors, percentages may not equal 100%.

While average severity of neuropsychiatric symptoms in the PWD remained similar between the initial (*M* = 10.06, *SD* = 9.05) and the annual appointment (*M* = 9.69, *SD* = 5.83), FCG distress related to these symptoms decreased from the initial appointment (*M* = 11.38, *SD* = 11.99) to the annual appointment (*M* = 9.75, *SD* = 6.78). Again, this reduction was not statistically significant (*t*[15] = 0.72, *p* = .480) (Table 4).

Encounters

From the initial to the annual appointment, dyads had an average of 21.31 total encounters (Table 5). The sum of the encounters for all dyads was calculated; total number of encounters by type was analyzed from July 1, 2021, (program start date) to December 31, 2022, (project end date). The most common types of encounters in the UCDH ADC Program were telephone calls and MyChart messages. Overall, the most common type of scheduled encounter was telephone appointment, followed by in-person appointment and video appointment (Fig. 2).

Discussion

In this evaluation of a dementia care management program, we found meaningful, though not statistically significant, improvements in caregiver depression, strain, and distress after 12 to 18 months. Notably, these outcomes improved despite a worsening in the stage of dementia and an increase in the amount of support needed with BADLs and IADLs for the PWD. Additionally, we found desirable outcomes for PWDs. Despite an increase in dementia severity, there was a decrease in severity of neuropsychiatric symptoms and essentially no institutionalization of the PWDs in the sample. This suggests that

Table 4
Caregiver assessment outcomes at initial and annual appointment.

Assessment	Initial		Annual		<i>n</i>	<i>t</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
PHQ-9 score	3.87	3.63	2.57	2.19	23	1.74	.096
MCSI score	9.41	5.90	7.79	4.62	29	1.52	.141
NPI-Q severity subscore	10.06	9.05	9.69	5.83	16	0.21	.837
NPI-Q distress subscore	11.38	11.99	9.75	6.78	16	0.72	.480

Note. Two-tailed paired samples *t*-test. *M* = mean. *SD* = standard deviation. PHQ = Patient Health Questionnaire-9. MCSI = Modified Caregiver Strain Index. NPI-Q = Neuropsychiatric Inventory Questionnaire.

Table 5

Average Number of Encounters per Dyad by Type from Initial Appointment to Annual Appointment (n = 45)

Variable	M	SD
Encounter Type		
Telephone Call	7.87	5.36
MyChart Message	4.42	3.83
Telephone Appointment	4.29	2.25
In-Person Appointment	2.42	0.66
Video Appointment	0.73	1.18
Other	1.80	1.80
Total	21.31	11.91

Note. Due to rounding errors, percentages may not equal 100%.

interventions during involvement in the UCDH ADC Program were helpful for both FCGs and PWDs.

To understand program utilization, we measured the number of encounters by type per dyad. Most encounters were unscheduled, non-billable encounters for evaluation and management services (e.g., triaging symptoms and coordinating a treatment plan with the care team). Because the most common types of encounters were unscheduled, non-billable encounters, the utilization of these types of encounters for evaluation and management services results in lower reimbursement for the program. Most billable encounters during the project timespan were telephone appointments, which, with the flexibilities afforded by legislation associated with the COVID-19 public health emergency, were reimbursed by Medicare at the same rate as in-person appointments; however, these flexibilities will end in December 2024.²¹ Because PWDs make up nearly a quarter of Medicare beneficiaries, without any legislative action to continue reimbursement rates, revenue will be affected.

Furthermore, there was a relatively low number of billable encounter types (i.e., telephone, video, and in-person appointments), giving the appearance of low patient volume for the program. Both low reimbursement and low patient volume may impact the clinic's staffing and the organization's strategic planning for initiatives affecting PWDs and their FCGs. For healthcare organizations interested in implementing a dementia care management program led by advanced practice providers, regular review of workflows and billing practices may enhance program revenue and sustainability. Healthcare providers should consider advocating for alternative reimbursement models that include telehealth services as a way of supporting

dementia care management. In addition, future research on the program's effect in reducing emergency and hospital utilization as well as costly end-of-life care may help demonstrate the cost benefits of a care management program for PWDs and their FCGs.

Consistent with the national population of PWDs, our sample of PWDs was primarily women. However, the majority of PWDs in our sample identified as non-Hispanic White; less than 10 % as Hispanic or Latino; and none as American Indian or Alaska Native and Native Hawaiian or Other Pacific Islander. Therefore, the sample did not reflect the racial and ethnic differences in prevalence of dementia in the United States. The lack of diversity within the sample of PWDs may have been due to the racial and ethnic composition of the patient population within the health system as well as the lack of identification, and therefore physician referrals, of racially and ethnically diverse individuals.

It is unknown if the sample of FCGs in the project was representative of data in the United States. The project did not identify the age, race, and ethnicity of the FCG. Future studies may want to include this information to understand generational and cultural caregiving differences and provide targeted care interventions to meet these needs. In addition, there was also limited diversity in the relationship of the FCG to the PWD. There was no representation from non-relatives such as friends and neighbors of PWDs. Furthermore, representation from grandchildren/grandchild-in-law, siblings/siblings-in-law, and other relatives (e.g., cousins) was low. The lack of representation from these groups of FCGs limits overall understanding of the caregiver experience and the effectiveness of the program in a heterogeneous group. With a more diverse sample, findings can help the organization tailor interventions that suit the needs of various FCGs. In addition, understanding if and why the program was less beneficial for a certain type of caregiver (e.g., sibling FCG) can guide future program interventions.

While there were multiple caregivers involved in most cases, it is important to note that this does not discriminate between FCGs and formal (trained) caregivers. FCGs with formal caregiver support may have experienced better outcomes (e.g., lower depression, strain, and distress) due to having a formal caregiver to help with BADLs and IADLs, for example. It would be important in future studies to make this distinction and to note the number of hours per week and the type of support provided by formal caregivers. In addition, gathering more information about the context of caregiving (e.g., duration of caregiving, number of care recipients for whom the FCG is providing

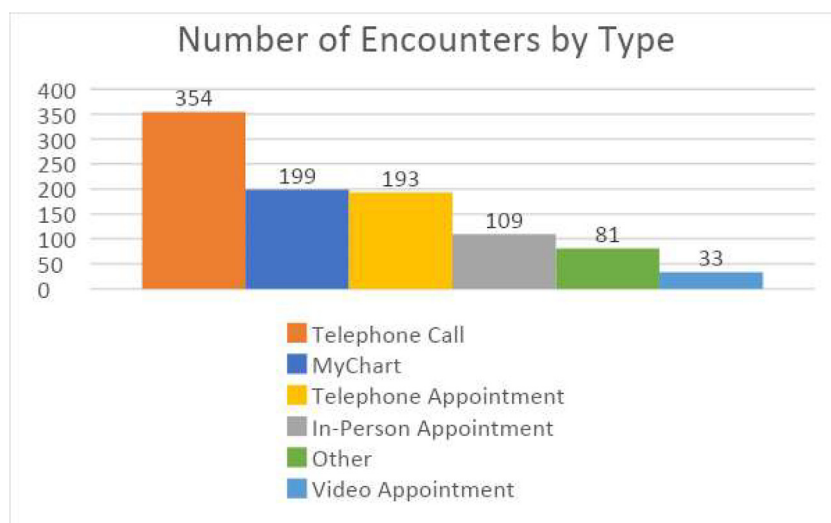


Fig. 2. Total number of encounters by Type from July 1, 2021, to December 31, 2022.

care) can help to not only identify any difference in caregiver outcomes but also to understand how these factors impact caregiver outcomes in the long term.

Limitations

Findings should be interpreted cautiously in light of potentially confounding variables that may have influenced our outcomes. While data suggest that dyads did not receive HBPC services during the pilot study timeframe, it is important to note that this may not be an accurate representation since dyads may have enrolled following the initial appointment and may have been discharged prior to the annual appointment. Importantly, many individuals in our sample received services from the Family Caregiving Institute and additional support from multiple FCGs during the pilot study timeframe. While we examined whether these services were received at baseline, we did not examine the extent or duration of support from these programs, nor did we control for receipt of these services using multivariable models. Furthermore, we did not gather data on participation in external programs, such as adult day programs and support groups. Involvement in internal and external programs may have mediated levels of depression, strain, and distress in FCGs and delayed functional decline and institutionalization of PWDs.²²⁻²⁴ In other words, dyads may have received additional support (e.g., monitoring of disease progression, caregiver education and counseling) that were not accounted for in the project. Future studies may include quantitative measures of extent, duration, and timing of internal and external programs in relation to enrollment in the UCDH ADC Program to better understand how multicomponent interventions affect outcomes for FCGs and PWDs.

Another limitation of the pilot study is that the sample of both PWDs and FCGs was not representative of the national population, which impacts the generalizability of the results. In addition, participant attrition may have affected our results. Out of 125 dyads who completed initial appointments, nearly 60 % did not complete an annual appointment for various reasons, the most common being failure to schedule an annual appointment. This attrition may have influenced our results if those who completed annual appointments were substantially different from those who did complete appointments. For example, a FCG may not have been able to complete an annual appointment with the PWD due to difficulties managing the behavioral and psychological symptoms of dementia. Likewise, a dyad who opted out may have done so due to competing personal and professional responsibilities.

Additionally, we had a small sample size, which affects the power to determine statistical significance in the analyses. While there were multiple reasons why dyads were excluded from the final analyses, the most common reason was a lack of data available from the annual appointment. Future efforts to address this limitation may include utilizing telehealth to perform appointments and gather questionnaires; sending scheduling reminders through multiple modalities (e.g., mailed letters, telephone calls); and addressing barriers to attending appointments.

Finally, although we found positive outcomes for both FCGs and PWDs using the retrospective, one-group, pretest-posttest design, a randomized control trial would have been helpful in minimizing bias and in controlling for confounding factors. In the future, with appropriate staffing, budget, and timeframe, a randomized control trial should be considered to evaluate the effectiveness of the UCDH ADC Program.

Conclusion

The number of Americans with dementia is expected to increase as the number of older adults increases in the United States. FCGs

provide most of the care for PWDs as they cognitively and functionally decline. FCGs experience negative outcomes, which often go unnoticed due to lack of assessment and intervention by healthcare providers. A care management program at UCDH was established in July 2021 to provide care to PWDs and their FCGs. In addition to assessing PWDs, nurse practitioners in the program assessed depression, strain, and distress in FCGs of PWDs utilizing valid and reliable tools. Following 12 to 18 months in the care management program, FCGs of PWDs experienced decreased levels of depression, strain, and distress, though these were not statistically significant findings; this was despite an increase in the severity of dementia in the PWD and in the number of BADLs and IADLs requiring caregiver support. Furthermore, PWDs experienced reductions in severity of neuropsychiatric symptoms, though not statistically significant, and remained at home during the pilot study timeframe. Encounters between the program staff and the dyad were primarily unscheduled, non-billable encounters. Despite limitations, primarily small sample size and lack of sample diversity, this project demonstrated positive results. Future research can address these limitations to understand the experiences of a diverse population and to make dementia care management programs sustainable.

Declaration of Competing Interest

The authors declare no conflicts of interest.

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Supplementary materials

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