

Spring 2023

Evaluation of a Care Management Program on Family Caregivers of Persons with Dementia

Victoria L. Jackson

California State University, Northern California Consortium Doctor of Nursing Practice

Follow this and additional works at: https://scholarworks.sjsu.edu/etd_doctoral



Part of the [Geriatric Nursing Commons](#)

Recommended Citation

Jackson, Victoria L., "Evaluation of a Care Management Program on Family Caregivers of Persons with Dementia" (2023). *Doctoral Projects*. 157.

DOI: <https://doi.org/10.31979/etd.7wj4-kbrp>

https://scholarworks.sjsu.edu/etd_doctoral/157

This Doctoral Project is brought to you for free and open access by the Master's Theses and Graduate Research at SJSU ScholarWorks. It has been accepted for inclusion in Doctoral Projects by an authorized administrator of SJSU ScholarWorks. For more information, please contact scholarworks@sjsu.edu.

Evaluation of a Care Management Program on Family Caregivers of Persons with Dementia

Victoria L. Jackson

A doctoral project completed in partial fulfillment of the
requirements for the degree of Doctor of Nursing Practice in the Valley
Foundation School of Nursing, San José State University

May 2023

Doctoral Project Team Members

Robin L. Whitney, PhD, RN

Associate Professor, San José State University

Doctoral Project Chair

Title and Affiliation

Denise Dawkins DNP, RN, CNL, CHSE

Associate Professor, San José State University

Doctoral Program Advisor

Title and Affiliation

Theresa Harvath, PhD, RN, FAAN, FGSA

Clinical Professor, University of Minnesota

Practice Mentor

Title and Affiliation

Eileen Partridge, DNP, APRN, AGPCNP-BC

Assistant Clinical Professor, UC Davis

Practice Mentor

Title and Affiliation

Dedication

This doctoral project is dedicated to my father, whose legacy of service lives on. While work can be tedious for most people, this was not the case for my father. With great enthusiasm, he looked for opportunities to improve not only himself but also others on his team. He looked to the future with a hope and a vision that the seeds of kindness he had sown would flourish. It was by watching him push past barriers, spread laughter, and stand with others in difficult times that I learned to do the same in my chosen field of nursing. I would not be where I am today without his love and guidance.

Acknowledgements

I would like to, first and foremost, acknowledge the mentorship and wise counsel of my doctoral project team members. I would also like to thank my family and friends who have supported me throughout this journey by reminding me of what truly matters. Special thanks to my mother, sister, and husband for taking care of my heart and soul during this process.

Evaluation of a Care Management Program on Family Caregivers of Persons with Dementia

Victoria Jackson, MS, RN, PHN, FNP-C, PA-C

Doctor of Nursing Practice Program

The Valley Foundation School of Nursing

San José State University

May 18, 2023

Abstract

Dementia due to Alzheimer's and other disease is a growing concern for healthcare providers as the number of individuals in the U.S. population ages. Persons with dementia (PWDs) rely on caregivers, primarily family caregivers (FCGs), for basic and instrumental activities of daily living as the disease progresses. There may be negative outcomes, such as depression, strain, and distress for FCGs of PWDs. Routine assessment and intervention by healthcare providers can address needs of FCGs of PWDs. There are multiple interventions that have demonstrated effectiveness in caring for PWDs and FCGs; one such intervention is care management. The University of California, Davis, Health (UCDH) Alzheimer's and Dementia Care (ADC) Program is a care management program serving PWDs and FCGs since July 2021. This project evaluates the program's effect on FCG outcomes, specifically depression, strain, and distress. Despite an increase in the severity of dementia and in the number of basic and instrumental activities of daily living requiring caregiving support, FCGs of PWDs experienced decreased levels of depression, strain, and distress following 12 to 18 months in the UCDH ADC Program. Other notable findings include PWDs experiencing reductions in severity of neuropsychiatric symptoms and remaining at home with FCGs. Encounters in the program were primarily unscheduled, non-billable encounters. Despite limitations, primarily small sample size and lack of sample diversity, this project contributes to literature supporting dementia care management for PWDs and FCGs. Future research should address these limitations to understand the experiences of a diverse population and to make dementia care management programs sustainable.

Keywords: dementia, family caregivers, care management, nurse practitioners

Contents

Background.....	5
Literature Review.....	7
Care Management.....	9
Gap in Practice.....	11
Theoretical Framework.....	12
Transactional Model of Stress and Coping.....	12
Assumptions, Constructs, and Their Relationships.....	13
Theory Application.....	15
Method.....	16
Design.....	16
Setting.....	17
Intervention.....	17
Participants.....	19
Measurements.....	20
Family Caregiver.....	20
Person with Dementia.....	23
Encounters.....	25
Procedures.....	25
Analysis.....	26
Institutional Review Board.....	26
Risks.....	27
Benefits.....	27
Costs.....	27
Payment.....	27
Confidentiality.....	27
Results.....	28
Persons with Dementia.....	29
Demographics.....	29
Health Characteristics at Initial and Annual Appointment.....	30
Family Caregivers.....	32
Demographics.....	32
Outcomes at Initial and Annual Appointment.....	33
Encounters.....	34
Discussion.....	36
Limitations.....	40
Conclusion.....	42

References 43
Tables..... 48
Appendix A..... 52

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 (Hudomiet et al., 2018). A 2023 report estimated 6.7 million people aged 65 and older are currently living with dementia due to Alzheimer's disease; furthermore, with the aging U.S. population, this number is expected to increase, because dementia risk increases with age (Alzheimer's Association, 2023). Dementia is characterized by progressively worsening neurological decline that results in the person with dementia (PWD) becoming dependent on a caregiver for basic and instrumental activities of daily living. Because of this, the caregiver, specifically family caregiver (FCG), is a critical member in the care of the PWD, providing care navigation within the health system and in the community (Ahuja et al., 2023). Specialized care from an interdisciplinary healthcare team with gerontological expertise and connections to community-based organizations will be required to provide high-quality care for the PWD and their FCG(s) (Ahuja et al., 2023).

Healthcare providers struggle with long-term supportive management of dementia; they tend to focus solely on caring for the PWD, while failing to recognize the FCG(s) involved (White et al., 2018). A FCG is a relative, partner, friend, or neighbor who provides assistance (e.g., basic and instrumental activities of daily living, emotional support, care coordination, and health management) to an older adult with a chronic or disabling condition (Family Caregiver Alliance, n.d.). In the United States in 2022, a FCG of a PWD provided an average of 30 hours of care per week, or 1,565 hours of care per year (Alzheimer's Association, 2023). Taken as a whole, 11.5 million Americans served as FCGs of PWDs, providing roughly 18 billion hours of

unpaid care worth \$339.5 billion (Alzheimer's Association, 2023). With the staggering number of FCGs providing contributions to not only PWDs but also society, it is imperative to consider the impact of dementia caregiving.

The unrelenting nature of dementia caregiving can cause deleterious effects to a FCG's psychosocial, behavioral, financial, and physiological well-being (Vitaliano et al., 2011). As dementia severity and functional impairments increase, so too do the caregiving requirements, which may lead to the FCG experiencing new or worsening negative outcomes, such as depression, social isolation, depletion of finances, interruptions in employment, and worsening physical health (Alzheimer's Association, 2023). FCGs of PWDs do not feel adequately supported because healthcare providers do not identify or assess FCGs. Additionally, they receive insufficient and untimely information regarding disease progression, future planning, and community-based resources (White et al., 2018).

To reduce the negative impacts of dementia caregiving, it is important to identify the needs of FCGs and to provide resources and support. In September 2005, the Family Caregiving Alliance convened at a conference to develop guidelines about caregiver assessment, which would help healthcare providers understand the caregiver experience and, therefore, provide education, counseling, and support. The report identified domains and related constructs that should be included in a caregiver assessment, including the following: the well-being of the caregiver (e.g., depression); the consequences of caregiving on the caregiver (e.g., perceived challenges like strain); and a caregiver's perception of the health of the care recipient (e.g., behavioral problems) (Family Caregiver Alliance, 2006). Following a caregiver assessment, the healthcare team can target interventions to meet the identified needs.

Literature Review

Interventions targeted to meet the identified needs of FCGs can lead to improvements in quality of life. Studies reveal numerous interventions that are effective for FCGs of PWDs (Gitlin et al., 2015; Brodaty & Arasaratnam, 2012). In the dementia caregiving literature, interventions are typically categorized by their dominant component; some interventions involve multiple components. Examples of interventions for FCGs of PWDs include psychoeducation; psychotherapy, including cognitive-behavioral therapy; case management or care management (often used interchangeably); support (e.g., peer support groups, family support); respite (e.g., adult day programs, respite care facilities); training for the PWD; and multicomponent interventions. Systematic reviews and meta-analyses are helpful to understanding the effectiveness of various interventions for FCGs and PWDs.

Peacock and Forbes (2003) conducted a systematic review of the literature from 1992 to April 2002 to examine the effectiveness of interventions for FCGs of community-dwelling PWDs. The researchers focused on 11 strong studies out of a total of 36 relevant studies; the study interventions included case management and psychotherapy among others (Peacock & Forbes, 2003). They found no significant effect on levels of FCG depression or strain with case management; however, case management doubled the likelihood of FCG utilization of community services (Peacock & Forbes, 2003). With psychotherapy interventions, there was delayed institutionalization of PWDs (Peacock & Forbes, 2003). A major limitation of this systematic review was the number of articles retrieved; furthermore, most of the studies included in the systematic review included individuals with established connections within the formal system (Peacock & Forbes, 2003).

To examine the effects of various interventions on PWDs and FCGs, Pinquart and Sörensen (2006) conducted a meta-analysis of 127 studies between 1982 and 2005. The studies included interventions such as psychoeducation, cognitive-behavioral therapy, case management, general support, respite, training of the PWD, multicomponent interventions, and miscellaneous interventions (Pinquart & Sörensen, 2006). Pinquart and Sörensen (2006) reported that, on average, interventions had statistically significant reductions in FCG burden and depression as well as improvements in FCG subjective well-being and ability/knowledge. For PWDs, while there was no statistically significant effect on institutionalization, the interventions had a statistically significant effect on reducing symptoms in the PWD (Pinquart & Sörensen, 2006). In brief, case management had a significant moderate positive effect on burden but no significant effect on depression; and multicomponent interventions had a significant and moderate effect on delaying institutionalization of the PWD (Pinquart & Sörensen, 2006).

Walter and Pinquart (2020) sought to update the meta-analysis by Pinquart and Sörensen (2006). They added an additional 154 articles and excluded one article from the meta-analysis by Pinquart and Sörensen (2006) for a total of 280 articles and 332 interventions, hereafter referred to as “studies.” Like the meta-analysis by Pinquart and Sörensen (2006), on average, the interventions had small effects on FCG burden, depression, and subjective well-being, as well as symptoms in the PWD (Walter & Pinquart, 2020). In brief, Walter and Pinquart (2020) found significant small positive effects of case management on burden and anxiety; and significant small positive effects of multicomponent interventions on burden and depression.

Bayly et al. (2021) conducted a systematic review and meta-analysis to understand the effects of early-stage intervention on FCGs of community-dwelling PWDs or persons with mild cognitive impairment. Out of the 22 studies they included in their research, the researchers found

a small positive effect on FCGs' well-being (i.e., anxiety and caring-related distress) and ability to provide care (Bayly et al., 2021).

Care Management

As mentioned above, care management, sometimes called case 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 (Agency for Healthcare Research and Quality, 2018). 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 coordinating with the interdisciplinary healthcare team; and assisting with healthcare system navigation and finding community resources (Bodenheimer & Berry-Millett, 2009). Because care management requires a high degree of clinical expertise, the role of a care manager calls for a healthcare professional with clinical training, usually registered nurses, who work within an interdisciplinary healthcare team (Bodenheimer & Berry-Millett, 2009).

There are several studies evaluating the effectiveness of care management interventions on FCGs of PWDs. Backhouse et al. (2017) conducted a systematic review and meta-analysis of 14 randomized controlled trials involving a total of 10,372 participants to evaluate the effectiveness of care coordination in community-based settings for PWDs and FCGs. They found that care coordination, a component of care management, reduced caregiver burden (Backhouse et al., 2017).

There are several randomized studies evaluating the effectiveness of nurse-led care management interventions on outcomes for FCGs of PWDs. Callahan et al. (2014) conducted a randomized controlled trial with 153 PWDs and their FCGs at two primary care practices in Indianapolis, Indiana, to evaluate the effectiveness of a twelve-month care management program led by advanced practice nurses. The advanced practice nurses initiated behavioral intervention protocols that first focused on non-pharmacological treatments. If these failed, the advanced practice nurses initiated pharmacological treatment after collaborating with the primary care physician (Callahan et al., 2014). Other aspects of the care management program included interdisciplinary team meetings, a longitudinal tracking system, and voluntary group sessions for FCGs and PWDs (Callahan et al., 2014). FCGs who were randomized to receive the care management program ($n = 84$) experienced reductions in distress as measured with the Neuropsychiatric Inventory Questionnaire after 12 months in the program and in depression as measured with the Patient Health Questionnaire-9 after 18 months in the program (Callahan et al., 2014).

Other studies have examined the effects of care management programs compared to usual care. Mavandadi et al. (2017) performed a randomized study involving 75 FCGs of older veterans with dementia and their FCGs from primary care practices in Philadelphia, Pennsylvania, to examine the effects of a care management program compared to usual care. The program, which lasted for three months, involved dementia care management by a nurse who, through telephone contact, performed assessments of veterans' symptoms, provided support to FCGs, and assisted with connection to health system- and community-based programs (Mavandadi et al., 2017). The care manager then reported findings and recommendations to the healthcare team to facilitate treatment (Mavandadi et al., 2017). The program also involved

educational modules for FCGs on dementia caregiving (Mavandadi et al., 2017). The researchers assessed FCGs at baseline and at 3-month and 6-month follow up (Mavandadi et al., 2017). The findings of the study showed that FCGs who received the care management program experienced, over time, greater reductions in distress from PWDs' neuropsychiatric symptoms and greater improvements in coping and caregiving mastery compared to FCGs who received usual care (Mavandadi et al., 2017).

Situated within an urban academic medical center, the University of California, Los Angeles (UCLA), Alzheimer's and Dementia Care (ADC) Program is led by nurse practitioners who provide dementia care management in collaboration with primary care and specialty physicians (Reuben et al., 2019). Reuben et al. (2019) examined baseline and one-year results for PWDs and their FCGs enrolled in the UCLA ADC Program using an observational study design. Using the Neuropsychiatric Inventory Questionnaire, Modified Caregiver Strain Index, Patient Health Questionnaire-9, the researchers found reductions in FCG distress, strain, and depression, respectively (Reuben et al., 2019).

Gap in Practice

The University of California, Davis, Health (UCDH), ADC Program at the Healthy Aging Clinic is a dissemination site of the UCLA ADC Program through a grant from The John A. Hartford Foundation. Since July 2021, UCDH ADC Program has provided dementia care management led by nurse practitioners in collaboration with primary care and specialty physicians. The UCDH ADC Program had not yet been evaluated for its effectiveness in caring for FCGs. FCGs' assessment data can act as the critical first step in optimizing health outcomes for FCGs. Using assessment results, a healthcare provider can perform a program evaluation. Program evaluation is recommended by the Program Performance and Evaluation Office at the

Centers for Disease Control and Prevention (n.d.). Furthermore, program evaluation can help a healthcare provider understand the correlation between clinical initiatives and FCG health outcomes, thus having an impact on future quality improvement projects and initiatives within the clinic as well as the broader healthcare system (Adams & Neville, 2020).

Despite the evidence and recommendations for use as part of healthcare delivery, program evaluation is not routinely implemented in practice. In 2021, the Healthy Aging Clinic focused on the rollout of the UCDH ADC Program; however, there were no planned program evaluations. Several barriers to routine program evaluation include lack of training, time, staffing, and reimbursement (White et al., 2018). This project addressed the gap by evaluating the UCDH ADC Program and its impact on FCGs' outcomes in terms of depression, strain, and distress.

Theoretical Framework

Transactional Model of Stress and Coping

Dementia care management may be helpful in addressing the stress and coping processes in FCGs of PWDs. In 1984, psychologists Dr. Richard Lazarus and Dr. Susan Folkman published a book titled *Stress, Appraisal, and Coping* in which they describe the Transactional Model of Stress and Coping (TMSC) (Lazarus & Folkman, 1984). The TMSC is widely accepted and influential in the field of stress among FCGs of dependent older adults (Losada-Baltar, 2017). To understand the TMSC, one must first understand three themes in Lazarus and Folkman's metatheoretical approach to stress and emotion. The three themes are transaction and relationship, process, and emotion as a system.

First is the theme of transaction and relationship. The TMSC operates with the belief that the individual and the environment are not separate entities; neither the person nor the

environment alone creates stress or emotion; instead, the individual and the environment interact to form a new condition or state (Lazarus & Folkman, 1984). To describe the dynamic interplay between the individual and the environment, Lazarus and Folkman (1984) use the term *transaction*. Both the original text and this paper will use transaction and relationship interchangeably; however, the former emphasizes the bidirectional influences of the variables while the latter emphasizes the unity between the two.

Next is the theme of process. The TMSC operates with the belief that, to change an undesirable or distressing situation, an individual experiences stress and/or negative emotions. That is because coping is a process that requires the individual to describe the coping thoughts and actions that have taken place or are currently taking place; to observe the context in which it is happening; and to measure coping over different time periods or contexts (Lazarus & Folkman, 1984).

Last is the theme of emotion as a system. The TMSC operates with the belief that the transaction and process occurring between the person and the environment shape the emotion; furthermore, emotion is also influenced by variables and processes (e.g., environmental or person antecedents, mediating processes, short-run outcomes, long-run adaptational outcomes) (Lazarus & Folkman, 1984).

After having reviewed Lazarus and Folkman's metatheoretical approach to stress and emotion, one can begin a thorough examination of the assumptions, constructs, and their relationships.

Assumptions, Constructs, and Their Relationships

The two basic constructs in the TMSC are cognitive appraisal and coping. Lazarus and Folkman (1984) describe cognitive appraisal as the thought process involved when one evaluates

the significance of a transaction on one's well-being. There are three types of cognitive appraisal: primary appraisal, secondary appraisal, and reappraisal (Lazarus & Folkman, 1984).

The first type of cognitive appraisal is primary appraisal, which is a cognitive process by which one ascribes meaning to a transaction through identification of what is personally at stake. A transaction may be viewed as *irrelevant*, *benign-positive*, or *stressful*. Transactions that are viewed as *stressful* can be further described as one that has already created damage (*harm/loss*); one that has anticipated harm/loss (*threat*); or one that offers the potential for mastery or gain (*challenge*). Only stressful transactions result in the need for further cognitive and coping processes (Lazarus & Folkman, 1984).

Next, secondary appraisal is a cognitive process by which one evaluates what can be done to mitigate a stressful transaction. It includes assessment of one's available coping options; an analysis of the likelihood that the coping option(s) will be successful and the likelihood that one can effectively apply the coping option(s); and an evaluation of the consequences of using the coping option(s) (Lazarus & Folkman, 1984).

Reappraisal is a changed appraisal of a transaction based on new information from the environment and/or person, and it occurs after the coping process. The only difference between an appraisal and a reappraisal is that the latter follows the former in the same encounter and modifies it (Lazarus & Folkman, 1984).

Coping, as defined by Lazarus and Folkman (1984), is neither a trait nor an automatized adaptive behavior. Furthermore, it is not defined by an outcome, and it does not equate mastery. Instead, coping is defined by Lazarus and Folkman (1984) as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person". Problem-focused coping (PFC) is directed at

managing the problem causing the distress whereas emotion-focused coping (EFC) is directed at regulating emotional responses to the problem. PFC and EFC may facilitate and impede each other in the coping process because they often occur concurrently (Lazarus & Folkman, 1984).

Cognitive appraisal and coping processes influence adaptational outcomes. The short-term and long-term adaptational outcomes include social functioning, morale, and somatic health (Lazarus & Folkman, 1984).

A central assumption of TMSC is that primary appraisal and secondary appraisal influence each other. However, although the terms *primary appraisal* and *secondary appraisal* suggest an order of importance or temporality, this is not necessarily true because they are equally important cognitive processes involved in stress and coping; one does not exert more influence than the other (Lazarus & Folkman, 1984). In addition, an individual does not have to perform primary appraisal before performing secondary appraisal. For example, they may view themselves capable of handling a situation (secondary appraisal) without first examining their stake in the situation (primary appraisal) (Lazarus & Folkman, 1984).

The TMSC also assumes a relationship between appraisal and coping. The interaction between primary appraisals of what is at stake and secondary appraisals of the coping option(s) results in the enactment and evaluation of coping activities (Lazarus & Folkman, 1984). For example, an individual may view their loved one's well-being at stake (primary appraisal), and this leads to their specific decision to seek social support (coping) (Lazarus & Folkman, 1984).

Theory Application

The TMSC can be applied in many situations, including the situation of a FCG of a PWD. An example of the TMSC is as follows: John, a PWD, requires more assistance with activities of daily living. Sarah, his spousal FCG, performs a cognitive appraisal of the situation

and views it as stressful because it is a source of potential harm/loss for her physical, psychological, emotional, and social well-being. She also performs a secondary appraisal by evaluating her coping resources, such as the healthcare team with whom she and John work as well as the presence of support from other family members and from those in her dementia support group. She also reviews situational variables like possible formal caregiver support, adult day programs, and caregiver education programs. After this, she enacts problem- and emotion-focused coping strategies. Then, she evaluates the new situation and reappraises it as stressful. Before, the situation was threatening harm/loss, but now it is a challenge that offers an opportunity for reward, satisfaction, and growth. Sarah continues this process of appraisal and coping to influence adaptational outcomes throughout her caregiving journey.

The TMSC offers a theoretical framework to understand the effectiveness of various interventions provided by the UCDH ADC Program on FCGs' primary appraisal, secondary appraisal, and reappraisal. The programs also include interventions aimed at supporting FCGs' coping resources and situational variables, so the TMSC can help evaluate effectiveness on FCGs depression, strain, and distress.

Method

Design

This was a quasi-experimental research project utilizing 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 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 management, mobility, dietetics, pharmacology, and family caregiving. Also housed within the clinic is the UCDH Alzheimer's Disease Research Center, a nationally-recognized center funded by the National Institute on Aging at the National Institutes of Health.

The Healthy Aging Clinic is comprised of one clinic practice manager, one interim clinic medical director, two geriatricians, four cognitive neurologists, three neuropsychologists, three neuropsychology postdoctoral fellows, four advanced practice providers, one dietitian, one social worker, two pharmacists, one registered nurse, one licensed vocational nurse, two medical assistants, and two medical receptionists, and one referral coordinator.

Intervention

The UCDH ADC Program serves PWDs and their FCGs. 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, a "Pre-Visit Questionnaire" (see Appendix A) is completed by the PWD and/or their FCG(s), and a "Caregiver Packet" is completed by each

FCG present. The “Pre-Visit Questionnaire” gathers information about PWDs and resource needs of the dyad; the “Caregiver Packet” contains the Patient Health Questionnaire-9, Modified Caregiver Strain Index, Cornell Scale for Depression in Dementia, and Neuropsychiatric Inventory Questionnaire to assess both the PWD and the FCG. 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 the current financial and living situation, including safety concerns (e.g., home environment, driving, firearms); identifies 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 one-week follow-up telephone, video, or in-person 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. There are roughly 35-40 appointments per week in the UCDH ADC Program.

Participants

The participants in this project 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. Study exclusion criteria include the following: any PWD who presented 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 permanently relocating outside of California; and any PWD and/or FCG(s)

deciding to unenroll in the program. Additionally, they were excluded if the PWD went to hospice or died.

Measurements

Family Caregiver

Demographics and Outcomes. 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; and Neuropsychiatric Inventory Questionnaire, distress subscore. More information about the FCG variables and their operational definitions are listed in Table 1.

Patient Health Questionnaire-9. The Patient Health Questionnaire-9 (PHQ-9) is an instrument based on criteria for depression from the Diagnostic and Statistical Manual, fifth edition. The PHQ-9 is a 9-item, self-administered questionnaire used to screen for depressive symptoms and assess depression severity over the last two weeks. Scoring is 0 points for each “not at all” response, 1 point for each “several days” response, 2 points for each “more than half the days” response, and 3 points for each “nearly every day” response. Scoring ranges from 0 to 27. Major depressive disorder is suggested if 5 or more of the 9 depressive symptoms are checked as “more than half the days” and if one of those is depressed mood (item 1) or anhedonia (item 2). Other depressive symptom is suggested if 2 to 4 of the 9 depressive

symptoms are checked as “more than half the days” and if one of those items is depressed mood (item 1) or anhedonia (item 2). A total score of 0–4 suggests none to minimal depression. A total score of 5–9 suggests mild depression. A total score of 10–14 suggests moderate depression. A total score of 15–19 suggests moderately severe depression. A total score of 20–27 suggests severe depression.

Kroenke et al. (2001) tested the reliability and validity of the PHQ-9 in a sample of 6,000 adult patients in 8 primary care clinics and 7 obstetrics-gynecology clinics. The internal reliability using Cronbach’s α was 0.89 in the primary care group and 0.86 in the obstetrics-gynecology group (Kroenke et al., 2001). The researchers also assessed the criterion validity of the PHQ-9 against a psychiatric interview by a mental health professional in a sample of 580 patients and found that “a PHQ-9 score ≥ 10 had a sensitivity of 88% and specificity of 88% for diagnosing major depression” (Kroenke et al., 2001).

Modified Caregiver Strain Index. The Modified Caregiver Strain Index (MCSI) is an instrument to screen for caregiver strain in long-term family caregivers. The MCSI is a 13-item, self-administered questionnaire that measures caregiver strain in the following domains: financial, physical, psychological, social, and personal. Scoring is 2 points for each “yes” response, 1 point for each “sometimes” response, and 0 points for each “no” response. Scoring ranges from 0 to 26, with a higher score indicating a higher level of caregiver strain.

Thornton & Travis (2003) modified the Caregiver Strain Index, which was originally developed in 1983, and developed the MCSI. They tested its reliability in a sample of 158 family caregivers who performed activities related to medication administration for persons 53 years of age and older living in a community-based setting. In this sample, the internal reliability

coefficient for the MCSI was 0.90. The test-retest reliability coefficient was 0.88 based on two-week retest data for one-third of the caregiving sample ($n = 53$) (Thornton & Travis, 2003).

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 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. Each of the 12 neuropsychiatric symptom domains is assessed by a screening question. For each screening question, the caregiver circles either "yes" or "no". The caregiver is instructed to proceed to the next question if the answer to the screening question is "no". If the caregiver answers "yes" to the screening question, the caregiver is then asked to rate symptom severity (how it affects the patient) and distress (how it affects the caregiver) in the last 4 weeks. Details on rating and scoring of symptom severity is provided in the subsequent paragraphs under "Persons with Dementia."

The caregiver rates caregiver distress on a 0 to 5-point scale: 0 = Not distressing at all; 1 = Minimal (slightly distressing, not a problem to cope with); 2 = Mild (not very distressing, generally easy to cope with); 3 = Moderate (fairly distressing, not always easy to cope with); 4 = Severe (very distressing, difficult to cope with); 5 = Extreme or Very Severe (extremely distressing, unable to cope with). The total NPI-Q distress score is the sum of all individual

distress scores and ranges from 0 to 60, with a higher number indicating a higher level of caregiver distress.

Kaufer et al. (2000) developed the NPI-Q based on the Neuropsychiatric Inventory (NPI), which was originally designed as a scripted interview with a caregiver. In the study, Kaufer et al. (2000) recruited community-dwelling persons with Alzheimer's disease and their caregivers from the University of Pittsburgh Alzheimer's Disease Research Center Memory Disorders or Treatment Clinics. Both the NPI and the NPI-Q were administered to 60 caregivers. The study also assessed the test-retest reliability of the NPI-Q in 15 caregivers by asking caregivers to complete a blank NPI-Q within a few hours of initial questionnaire administration. Using Pearson correlational analyses, the test-retest correlations between the total symptom and distress score on the NPI-Q were 0.80 and 0.94, respectively ($P < 0.0001$ for both). The interscale correlation between NPI-Q total score and NPI total score was 0.91 ($P < 0.0001$) (Kaufer et al., 2000).

Person with Dementia

Demographics and Health Characteristics. 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 (see Table 2). 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 ADLs (IADLs) requiring caregiver support (definition of BADLs and IADLs listed in Table 3); 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. More information about the PWD variables and their operational definitions are listed in Table 2.

Functional Assessment Staging Tool. The Functional Assessment Staging Tool (FAST) is designed to evaluate for change in functional performance 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. A clinician determines FAST level based on information obtained by a knowledgeable informant, such as a family caregiver.

Sclan & Reisberg (1992) studied the reliability of the FAST in a sample consisting of 16 subjects from the NYU Aging and Dementia Research Center. Researchers calculated two intraclass correlation coefficients (ICCs). Rater consistency (fixed effect ICC) was 0.86 ($p < 0.01$), and rater agreement (random effect ICC) was 0.87 ($p < 0.01$).

Neuropsychiatric Inventory Questionnaire, Severity Subscore. As mentioned above, the NPI-Q evaluates for the presence and severity of neuropsychiatric symptoms in persons with Alzheimer's disease. The NPI-Q is a 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. Each of the 12 neuropsychiatric symptom domains is assessed by a screening question. For each screening question, the caregiver circles either "yes" or "no". The caregiver is instructed to proceed to the next question if the answer to the screening question is "no". If the caregiver answers "yes" to the screening question, the caregiver is then asked to rate symptom severity (how it affects the patient) and distress (how it affects the caregiver) in the last

4 weeks. The caregiver rates symptom severity on a three-point scale: 1 = Mild (noticeable, but not a significant change); 2 = Moderate (significant, but not a dramatic change); 3 = Severe (very marked or prominent, a dramatic change). The total NPI-Q severity score is the sum of all individual symptom scores and ranges from 0 to 36, with a higher number indicating more severe neuropsychiatric symptoms in the PWD. The caregiver distress rating and scoring as well as the validity and reliability of the tool overall are provided in detail above, under “Family Caregiver.”

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 project, 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. More information about encounters and its operational definition is listed in Table 4.

Procedures

Planning and Training

To ensure clinical staff support and engagement, the researcher provided an announcement at a meeting to the UCDH ADC Program leadership team consisting of the clinic practice manager, the interim clinic medical director, and a nurse practitioner. In the announcement, the researcher provided a brief background on the purpose and the methods for

the project. Then, to prepare for implementation and data collection, the researcher met with a clinical nurse scientist from the UCDH Center for Nursing Science to obtain training on data collection from the electronic health record, Epic.

Implementation and Data Collection

This project had two phases. The first phase involved the researcher obtaining a list of PWDs seen in the UCDH ADC Program from July 1, 2021, to December 31, 2021. Then, the researcher created a Microsoft Excel spreadsheet to house the data. The researcher then performed chart abstraction from the electronic health record and documented data on PWDs and FCGs from their initial appointment between July 1, 2021, to December 31, 2021. The second phase involved chart abstraction and collection of data on PWDs and FCGs following their annual appointment from July 1, 2022, to December 31, 2022. The researcher documented data from the annual appointment into the Microsoft Excel spreadsheet.

Analysis

Descriptive statistics were used to analyze the demographics of PWDs and FCGs. The impact of the UCDH ADC Program on FCGs of PWDs was assessed by using a paired t-test to compare mean PHQ-9 score, MCSI score, 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.

Institutional Review Board

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.

Risks

There were limited risks associated with the project. The project posed the risk of loss of confidentiality. This study abided by all applicable law, regulations, and standard operating procedures governing the protection of human subjects and protected health information. Specifically, subjects were protected by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) while receiving care in the UCDH ADC Program.

Benefits

Subjects did not receive any benefit from the proposed project, but others may benefit from the knowledge obtained. Understanding the program's effectiveness may guide strategic planning and initiatives as well as refine current processes.

Costs

There were no additional costs to subjects for care or participation in the project above and beyond insurance co-pays for care in the UCDH ADC Program.

Payment

There was no payment to subjects who participated in the project.

Confidentiality

To protect the privacy of subjects who participated in the project and to maintain the confidentiality of the identifiable data throughout the project, the researcher stripped data of personally identifiable information and assigned a code to each subject. Data was stored in a password-protected Microsoft Excel file and saved to a secured cloud service, Microsoft OneDrive. The researcher maintained a key that linked the personally identifiable information to the data set. The key was stored in a password-protected Microsoft Excel file and saved to a

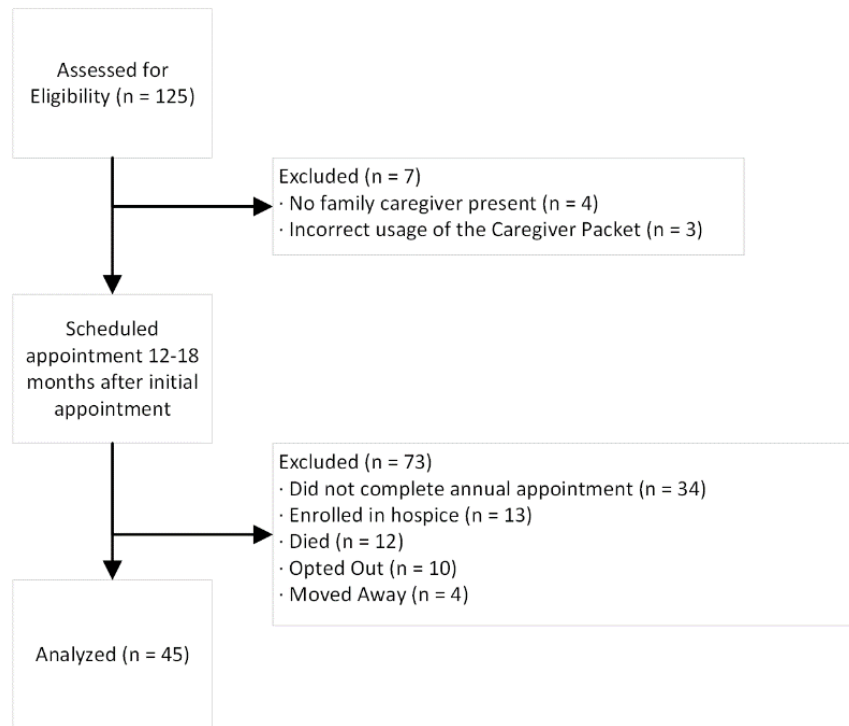
personal home drive on the encrypted UCDH network drive. Identifiers will be kept until July 1, 2023. The linking key will be destroyed on July 1, 2023.

Results

There were 125 PWDs who had an initial appointment in the UCDH ADC Program between July 1, 2021, and December 31, 2021. Four were excluded from analyses because there was no FCG present during the initial appointment. Three were excluded from analyses because the FCG(s) who were present incorrectly completed the “Caregiver Packet”. Annual appointments were not made for 39 PWDs who were unenrolled from the program due to patient enrollment in hospice (n = 13), patient death (n = 12), patient and/or FCG decision to opt out of the program (n = 10), and patient relocation out of the program service area (n = 4). For the final analyses, 34 PWDs were excluded because of failure to schedule an annual appointment. The final analyses were run on 45 PWDs and their FCGs who completed an initial and an annual appointment (see Figure 1).

Figure 1

Enrollment Status in ADC Program between 07/01/2021-12/31/2021.

**Persons with Dementia*****Demographics***

As shown in Table 5, 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%), followed by mixed disease (31.11%), vascular disease (15.56%), Lewy body dementia (6.67%), and Parkinson's disease (2.22%). 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.

Table 5*Demographics of Persons with Dementia (n = 45)*

Variable	M	SD
Age, years	81.02	8.81
Sex	n	%
Female	33	73.33
Male	12	26.67
Race		
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		
Not Hispanic or Latino	40	88.89
Hispanic or Latino	4	8.80
Decline to State	1	2.22
Primary Language		
English	42	93.33
Spanish	0	0.00
Other	3	6.67
Marital Status		
Widowed	19	42.22
Married	16	35.56
Single	7	15.56
Divorced	3	6.67
Type of Dementia		
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, percentages may not equal 100%. *M* = mean. *SD* = standard deviation.

Health Characteristics at Initial and Annual Appointment

Table 6 lists the health characteristics of the 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. At the initial appointment, the average FAST was 5.07 ($SD = 0.99$); and at the annual appointment, the average FAST was 5.51 ($SD = 0.97$).

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 the initial appointment, 32 PWDs required assistance with anywhere from 6 to 14 BADLs and IADLs, with the majority requiring assistance with 9 to 11 BADLs and IADLs (26.67%). At the annual appointment, 38 persons with dementia required assistance with anywhere from 6 to 14 BADLs and IADLs, with the majority requiring assistance with 12 to 14 BADLs and IADLs (40%).

At both the initial and the 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).

Table 6*Health Characteristics of Persons with Dementia at Initial and Annual Appointment (n=45)*

Variable	Initial Appointment	Annual Appointment
Functional Assessment Staging Tool, <i>M (SD)</i>	5.07 (0.99)	5.51 (0.97)
Number of BADLs/IADLs Requiring Caregiver Support	n (%)	n (%)
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		
Yes	3 (6.67)	2 (4.44)
No	42 (93.33)	43 (95.56)
Living Situation		
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, percentages may not equal 100%. *M* = mean. *SD* = standard deviation.

Family Caregivers

Demographics

The majority of FCGs were female (77.78%). The relationship of the FCG to the PWD was primarily child or child-in-law (55.56%), followed by spouse or partner (33.33%), grandchild or grandchild-in-law (4.44%), sibling or sibling-in-law (4.44%), and other relative (2.22%). There were no non-relatives (e.g., friends, neighbors). Almost all FCGs received support from multiple caregivers (93.33%) as well as from the Family Caregiving Institute (57.78%) (see Table 7).

Table 7*Demographics of Family Caregivers (n=45)*

Variable	<i>n</i>	%
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, percentages may not equal 100%.

Outcomes at Initial and Annual Appointment

A two-tailed paired samples t-test was performed on PHQ-9, MCSI, and NPI-Q. For all the tests, statistical significance was set at $p < .05$.

PHQ-9. There were 23 FCGs who completed the PHQ-9 at the initial and the annual appointment. Although there was no statistically significant difference in caregiver depression from the initial to the annual appointment ($t[22] = 1.74, p = .096$), the mean PHQ-9 score decreased from 3.87 ($SD = 3.63$) to 2.57 ($SD = 2.19$). However, this difference was not statistically significant (see Table 8).

MCSI. There were 29 FCGs who completed the MCSI at the initial and the annual appointment. Although there was no statistically significant difference in caregiver strain from

the initial to the annual appointment ($t[28] = 1.52, p = .141$), the mean MCSI score decreased from 9.41 ($SD = 5.90$) to 7.79 ($SD = 4.62$) (see Table 8).

NPI-Q. There were 16 FCGs who completed the NPI-Q at the initial and the annual appointment. The average severity of neuropsychiatric symptoms in the PWD, as reported by the FCG, decreased from the initial appointment ($M = 10.06, SD = 9.05$) to the annual appointment ($M = 9.69, SD = 5.83$). However, there was no statistically significant difference in the mean severity of neuropsychiatric symptoms in the PWD from the initial appointment to the annual appointment ($t[15] = 0.21, p = .837$). The average level of distress that a FCG reported as a result of the PWD's neuropsychiatric symptoms decreased from the initial appointment ($M = 11.38, SD = 11.99$) to the annual appointment ($M = 9.75, SD = 6.78$). However, there was no statistically significant difference in the mean caregiver distress ($t[15] = 0.72, p = .480$) (see Table 8).

Table 8

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.

Encounters

From the initial to the annual appointment, most dyads had an average of 21.31 encounters; the maximum, an outlier, was 82 encounters for one dyad (see Table 9).

Table 9

Average Number of Encounters per Dyad by Type from Initial Appointment to Annual

Appointment (n = 45)

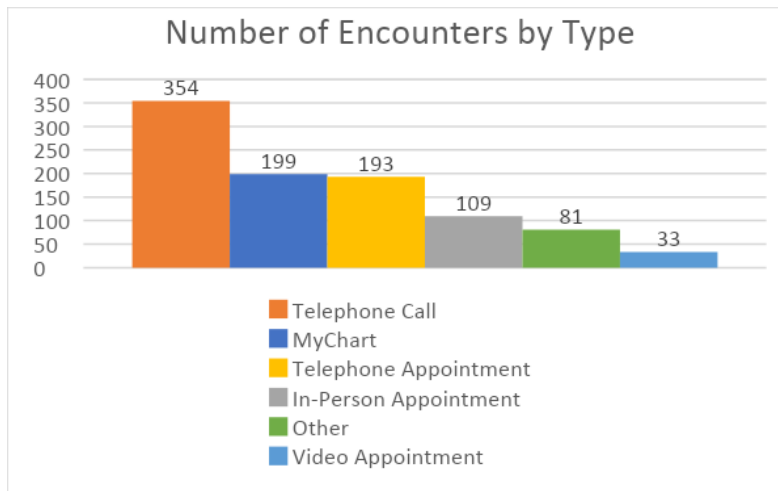
Variable	<i>M</i>	<i>SD</i>
Encounter Type		
Telephone Call	7.87	5.36
MyChart Message	4.42	3.83
Telephone Appointment	4.29	2.25
In-Person Appointment	2.42	0.66
Video Appointment	0.73	1.18
Other	1.80	1.80
Total	21.31	11.91

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

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 (see Figure 2).

Figure 2

Total Number of Encounters by Type from July 1, 2021, to December 31, 2022



Discussion

In this evaluation of a dementia care management program within the Healthy Aging Clinic at UCDH, 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. The outcomes from this DNP project are similar to those reported by the UCLA ADC Program, which is the model site for the UCDH ADC Program. Reuben et al. (2019) conducted a study of the first 1,091 dyads in the UCLA ADC Program using the same instruments (i.e., PHQ-9, MCSI, and NPI-Q), and they found that, in a sample size of 469 FCGs of PWDs, there were improvements, though not statistically significant, in the mean levels of depression and strain. Unlike this DNP project, there was a statistically significant reduction in distress (Reuben et al., 2019). One possible explanation for the lack of statistically significant reduction in distress for FCGs of PWDs in the UCDH ADC Program is the timing of the program's start date occurring during the COVID-19 pandemic. With this difference in mind, this project's results are still promising because it signifies that the UCDH ADC Program has the potential for success like the UCLA ADC Program.

Our findings suggest that the UCDH ADC program benefits not only FCGs but also PWDs. For PWDs, it is expected that their stage of dementia, and therefore the dependence on caregivers, increases over time. However, our program found that, despite an increase in the mean FAST and in the number of daily activities requiring caregiver support, there was a decrease in neuropsychiatric symptoms of dementia. Furthermore, all but one of the PWDs remained living in the same household as their FCG at the annual visit; essentially, there was no institutionalization of the PWDs in the sample. This suggests that interventions during

involvement in the UCDH ADC Program were helpful for both FCGs and PWDs. This may have been due to FCG distress management because one study found that higher levels of distress in FCGs are correlated with institutionalization of PWDs (Stall et al., 2019). Regardless of the reason, promoting aging in place is a goal of the program and an important part of maintaining a good quality of life for both PWDs and FCGs (Jennings et al., 2017). Thus, it is recommended that programs supporting PWDs and their FCGs promote aging in place and implement interventions to meet the aim.

Another measure in the project was the number of encounters by type per dyad. Lane et al. (2021) found that PWDs had roughly 8 to 13 appointments with their primary care physicians in one year. Comparatively, dyads in the UCDH ADC Program had an average of 7.44 appointments within a 12-to-18-month timespan. However, most encounters during this time period 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 (Centers for Medicare and Medicaid Services, 2023). 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, building time into the advanced practice provider's schedule for unscheduled encounters (e.g., telephone calls, MyChart messages) is essential to allow the advanced practice provider to respond to the complex and unpredictable needs of PWDs and FCGs. Additionally, regular 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 services 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, and this is reflective of the difference in prevalence of dementia between men and women in the United States (Alzheimer's Association, 2023). 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. Data obtained from a 2014 sample of Medicare beneficiaries aged 65 and older showed that Black and Hispanic older adults have a higher prevalence of dementia (14.7% and 12.9%, respectively) compared with non-Hispanic White (11.3%), American Indian and Alaska Natives (10.5%), and Asian and Pacific Islander (10.1%) older adults (Matthews et al., 2019). 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. For example, barriers to seeking care for cognitive complaints include stigma and cultural misunderstandings surrounding normal aging versus neurocognitive disorders (Jacobson et al., 2022; Jennings et al., 2017).

The sample of family caregivers in the project was representative of data in the United States, which is that most dementia caregivers are a child or spouse of the PWD (Friedman et al., 2015). 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; in the United States population, less than 5% are non-relative family caregivers (Friedman et al., 2015). 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 for my project, 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 care) can help to not only identify any difference in caregiver outcomes but also understand how these factors impact caregiver outcomes in the long term.

Limitations

Our findings should be interpreted cautiously in light of potentially confounding variables that may have influenced our outcomes. While data suggests that dyads did not receive HBPC services during the 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 caregivers during the 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 (Peacock & Forbes, 2003; Pinquart & Sörensen, 2006; Walter & Pinquart 2020). In other words, dyads may have received additional support (e.g., monitoring of disease progression, caregiver education and counseling) that was 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 project is that the sample of both PWDs and FCGs was not representative of the national population. This sample bias impacts the generalizability of the results. In addition, there may have been attrition bias affecting the results of the project. Out of 125 dyads, nearly 60% did not complete an annual appointment for various reasons, the most common being failure to schedule an annual appointment. Inclusion of dyads whose reasons for attrition was due to failure to schedule an annual appointment may generate findings different than that obtained in this sample. For example, a FCG may not have been able to complete an annual appointment with the PWD due to difficulties managing the neuropsychiatric symptoms of dementia. Likewise, a dyad who opted out may have done so due to competing personal and professional responsibilities. With the differing sample sizes for each caregiver outcome measure (i.e., PHQ-9, MCSI, NPI-Q) suggesting that FCGs did not complete all three questionnaires, there may have been non-response bias. Thus, the FCG levels of depression, strain, and/or distress and the PWD characteristics (e.g., stage of dementia, severity of behaviors and psychological symptoms of dementia) may be different and unaccounted for in the project because of lack of data.

Lastly, a major limitation of the project was 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.

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 the lack of assessment and intervention by healthcare providers. A care management program at UCDH was established in July 2021 to provide care for PWDs and their FCGs. In addition to assessing PWDs, nurse practitioners in the program assessed depression, strain, and distress 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 the severity of neuropsychiatric symptoms, though not statistically significant, and they remained at home during the 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.

References

- Adams, J., & Neville, S. (2020). Program evaluation for health professionals: What it is, what it isn't and how to do it. *International Journal of Qualitative Methods, 19*
<https://doi.org/10.1177/1609406920964345>
- Agency for Healthcare Research and Quality. (2018). *Care management: Implications for medical practice, health policy, and health services research*.
<https://www.ahrq.gov/ncepcr/care/coordination/mgmt.html>
- Ahuja, R., McDermott, M., & Ty, D. (2023). *Guiding the care journey: Building dementia workforce and system capacity through care navigation*. Milken Institute.
<https://milkeninstitute.org/report/guiding-care-journey-dementia-workforce-system-capacity>
- Alzheimer's Association. (2023, February). 2023 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 19*(4), 1598–1695. <https://doi.org/10.1002/alz.13016>
- Backhouse, A., Ukoumunne, O. C., Richards, D. A., McCabe, R., Watkins, R., & Dickens, C. (2017). The effectiveness of community-based coordinating interventions in dementia care: A meta-analysis and subgroup analysis of intervention components. *BMC Health Services Research, 17*, 1-10. <https://doi.org/10.1186/s12913-017-2677-2>
- Bayly, M., Morgan, D., Elliot, V., Kosteniuk, J., Chow, A. F., Peacock, S., & O'Connell, M. E. (2021). Does early-stage intervention improve caregiver well-being or their ability to provide care to persons with mild dementia or mild cognitive impairment? A systematic review and meta-analysis. *Psychology and Aging, 36*(7), 834-854. <https://doi.org/10.1037/pag0000642>
- Bodenheimer, T. & Berry-Millett, R. (2009). *Care management of patients with complex health care needs*. Robert Wood Johnson Foundation.
<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.621.9056&rep=rep1&type=pdf>

- Brodaty, H., & Arasaratnam, C. (2012). Meta-analysis of nonpharmacological interventions for neuropsychiatric symptoms of dementia. *The American Journal of Psychiatry; Am J Psychiatry*, 169(9), 946-953. <https://doi.org/10.1176/appi.ajp.2012.11101529>
- Callahan, C. M., Sachs, G. A., LaMantia, M. A., Unroe, K. T., Arling, G., & Boustani, M. A. (2014). Redesigning systems of care for older adults with Alzheimer's disease. *Health Affairs*, 33(4), 626-632. <https://doi.org/10.1377/hlthaff.2013.1260>
- Centers for Disease Control and Prevention. (n.d.) *Program evaluation*. <https://www.cdc.gov/eval/index.htm>
- Centers for Medicare and Medicaid Services. (2023). Physicians and other clinicians: CMS flexibilities to fight COVID-19. <https://www.cms.gov/files/document/physicians-and-other-clinicians-cms-flexibilities-fight-covid-19.pdf>
- Family Caregiver Alliance. (2006). *Caregiver assessment: Principles, guidelines and strategies for change*. Report from a National Consensus Development Conference Vol 1. https://www.caregiver.org/uploads/legacy/pdfs/v1_consensus.pdf
- Family Caregiver Alliance. (n.d.). *Definitions*. <https://www.caregiver.org/resource/definitions-0/>
- Gitlin, L. N., Marx, K., Stanley, I. H., & Hodgson, N. (2015). Translating evidence-based dementia caregiving interventions into practice: State-of-the-science and next steps. *The Gerontologist; Gerontologist*, 55(2), 210-226. <https://doi.org/10.1093/geront/gnu123>
- Hudomiet, P., Hurd, M. D., & Rohwedder, S. (2018). Dementia prevalence in the United States in 2000 and 2012: Estimates based on a nationally representative study. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences; J Gerontol B Psychol Sci Soc Sci*, 73, S10-S19. <https://doi.org/10.1093/geronb/gbx169>

- Jacobson, M., Joe, E., & Zissimopoulos, J. (2022). Barriers to seeking care for memory problems: A vignette study. *Alzheimer's & Dementia*, 8(1), e12238. <https://doi.org/10.1002/trc2.12238>
- Jennings, L. A., Palimaru, A., Corona, M. G., Cagigas, X. E., Ramirez, K. D., Zhao, T., Hays, R. D., Wenger, N. S., & Reuben, D. B. (2017). Patient and caregiver goals for dementia care. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, 26(3), 685–693. <https://doi.org/10.1007/s11136-016-1471-7>
- Kaufers, D. I., Cummings, J. L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., Lopez, O. L., & DeKosky, S. T. (2000). Validation of the NPI-Q: A brief clinical form of the neuropsychiatric inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences; J Neuropsychiatry Clin Neurosci*, 12(2), 233-239. <https://doi.org/10.1176/jnp.12.2.233>
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine: JGIM; J Gen Intern Med*, 16(9), 606-613. <https://doi.org/10.1046/j.1525-1497.2001.016009606.x>
- Lane, N. E., Ling, V., Glazier, R. H., & Stukel, T. A. (2021). Primary care physician volume and quality of care for older adults with dementia: A retrospective cohort study. *BMC family practice*, 22(1), 51. <https://doi.org/10.1186/s12875-021-01398-9>
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company.
- Matthews, K. A., Xu, W., Gaglioti, A. H., Holt, J. B., Croft, J. B., Mack, D., & McGuire, L. C. (2019). Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged ≥ 65 years. *Alzheimer's & dementia : the journal of the Alzheimer's Association*, 15(1), 17–24. <https://doi.org/10.1016/j.jalz.2018.06.3063>
- Mavandadi, S., Wright, E. M., Graydon, M. M., Oslin, D. W., & Wray, L. O. (2017). A randomized pilot trial of a telephone-based collaborative care management program for caregivers of

individuals with dementia. *Psychological Services, 14*(1), 102-

111. <https://doi.org/10.1037/ser0000118>

Peacock, S. C. & Forbes, D. A. (2003). Interventions for caregivers of persons with dementia: A systematic review. *Canadian Journal of Nursing Research, 35*(4), 88–107.

Pinquart, M. & Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics, 18*(4), 577–595. <https://doi.org/10.1017/S1041610206003462>

Reuben, D. B., Tan, Z. S., Romero, T., Wenger, N. S., Keeler, E., & Jennings, L. A. (2019). Patient and caregiver benefit from a comprehensive dementia care program: 1-Year results from the UCLA Alzheimer's and dementia care program. *Journal of the American Geriatrics Society, 67*(11), 2267-2273. <https://doi.org/10.1111/jgs.16085>

Scian, S. G., & Reisberg, B. (1992). Functional assessment staging (FAST) in Alzheimer's disease: Reliability, validity, and ordinality. *International Psychogeriatrics, 4*(3), 55-69. <https://doi.org/10.1017/S1041610292001157>

Stall, N. M., Kim, S. J., Hardacre, K. A., Shah, P. S., Straus, S. E., Bronskill, S. E., Lix, L. M., Bell, C. M., & Rochon, P. A. (2019). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. *Journal of the American Geriatrics Society, 67*(3), 609–617. <https://doi.org/10.1111/jgs.15690>

Thornton, M., & Travis, S. S. (2003). Analysis of the reliability of the modified caregiver strain index. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 58*(2), S127-S132. <https://doi.org/10.1093/geronb/58.2.S127>

Vitaliano, P. P., Murphy, M., Young, H. M., Echeverria, D., & Borson, S. (2011). Does caring for a spouse with dementia promote cognitive decline? A hypothesis and proposed

mechanisms. *Journal of the American Geriatrics Society (JAGS)*, 59(5), 900-908. <https://doi.org/10.1111/j.1532-5415.2011.03368.x>

Walter, E. & Pinquart, M. (2020). How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. *The Gerontologist*, 60(8), e609–e619.

<https://doi.org/10.1093/geront/gnz118>

White, C. L., Overbaugh, K. J., Pickering, C. E. Z., Piernik-Yoder, B., James, D., Patel, D. I., Puga, F., Ford, L., & Cleveland, J. (2018). Advancing care for family caregivers of persons with dementia through caregiver and community partnerships. *Research Involvement and Engagement*, 4(1), 1. <https://doi.org/10.1186/s40900-018-0084-4>

Tables

Table 1

Family Caregiver Variables and Operational Definitions

Variable Name	Operational Definition
Name	Name of family caregiver
Sex	Male Female
Relationship to the Person with Dementia	Spouse/Partner Child/Child-in-law Grandchild/Grandchild-in-law Sibling/Sibling-in-law Other relative Non-relative (e.g., friend, neighbor)
Multiple Caregivers Involved	Yes No
Appointment with the Family Caregiving Institute	Yes No
Patient Health Questionnaire-9 (PHQ-9) Score	Total Patient Health Questionnaire-9 (PHQ-9) Score
Modified Caregiver Strain Index (MCSI) Score	Total Modified Caregiver Strain Index (MCSI) Score
Neuropsychiatric Inventory Questionnaire (NPI-Q) Distress Subscore	Total Neuropsychiatric Inventory Questionnaire (NPI-Q) Distress Subscore

Table 2*Person with Dementia Variables and Operational Definitions*

Variable Name	Operational Definition
Name	Name of person with dementia
Medical record number	University of California, Davis, Health medical record number
Age	Age at initial appointment, measured in years
Sex	Male Female
Race	African American or Black American Indian or Alaska Native Asian Decline to State Native Hawaiian or Other Pacific Islander Other Unable to Respond Unavailable or Unknown White
Ethnicity	Declined to State Hispanic or Latino Not Hispanic or Latino
Primary Language	English Spanish Other
Marital Status	Single Married Separated Divorced Widowed
Type of Dementia	Alzheimer's disease Frontotemporal dementia Lewy body dementia Mixed disease Parkinson's disease Vascular disease
Functional Assessment	1
Staging Tool	2 3 4

	5
	6
	7
Number of BADLs and IADLs requiring caregiver support (Table 3)	0-2 3-5 6-8 9-11 12-14
Enrollment in home-based palliative care	Yes No
Living Situation	Same household as the family caregiver Different household as the person with dementia
Neuropsychiatric Inventory Questionnaire (NPI-Q) Severity Subscore	Total NPI-Q Severity Subscore

Table 3

Definitions of Basic Activities of Daily Living (BADLs) and Instrumental Activities of Daily Living (IADLs)

Basic Activities of Daily Living (BADLs)	Instrumental Activities of Daily Living (IADLs)
Bathing	Ability to use telephone
Dressing	Shopping
Toileting	Food preparation
Transferring	Housekeeping
Continence	Laundry
Feeding	Mode of transportation
	Responsibility for own medications
	Ability to handle finances

Table 4

Encounters Variable and Operational Definition

Variable Name	Operational Definition
Encounters	<p>Number of communications received by the UCDH ADC Program staff about the PWD and/or the FCG(s).</p> <p>Types of encounters include:</p> <ul style="list-style-type: none"> ● In-person appointment ● Telephone appointment ● Video appointment ● MyChart message ● Telephone call ● Other encounter

5. Medications: Have you ever been prescribed dementia medications?

Yes No

If yes, check all that apply:

Donepezil (ARICEPT) Memantine (NAMENDA) AXONA

Rivastigmine (EXELON) Galantamine (RAZADYNE)

6. Hospitalizations/Skilled Nursing Visits:

Please list all your hospitalizations and skilled nursing visits (including neuropsychiatric) outside the UC Davis Health System for the last 2 years.

Which Hospital/Skilled Nursing Facility?	Reason for Hospitalization or Skilled Nursing Facility Visit	Year

Please check “Yes” or “No” for the following questions.

	Yes	No
7. Patient Family History:		
a. Have any members of your family had memory problems?		
8. Driving:		
a. Do you have a valid Driver’s License?		
b. If Yes, are you currently driving?		
9. Safety:		
a. Are there any firearms in your home?		
b. Do you have a history of wandering or getting lost while outside of the home?		

10. Daily Activities:

(Please check the most appropriate box for each task.)

	No Help Needed	Help Needed	Who Helps?
Feeding	<input type="checkbox"/>	<input type="checkbox"/>	
Getting from bed to chair	<input type="checkbox"/>	<input type="checkbox"/>	
Getting to the toilet	<input type="checkbox"/>	<input type="checkbox"/>	
Getting dressed	<input type="checkbox"/>	<input type="checkbox"/>	
Bathing or showering	<input type="checkbox"/>	<input type="checkbox"/>	
Walking across the room (includes using a cane or walker)	<input type="checkbox"/>	<input type="checkbox"/>	
Using the telephone	<input type="checkbox"/>	<input type="checkbox"/>	
Taking your medicines	<input type="checkbox"/>	<input type="checkbox"/>	
Preparing meals	<input type="checkbox"/>	<input type="checkbox"/>	
Managing money (like keeping track of expenses or paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	
Moderately strenuous housework such as doing the laundry	<input type="checkbox"/>	<input type="checkbox"/>	
Shopping for personal items like toiletries, medications, or groceries	<input type="checkbox"/>	<input type="checkbox"/>	
Driving	<input type="checkbox"/>	<input type="checkbox"/>	
Climbing a flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	
Getting to places beyond walking distance (ie: by bus, taxi, or car)	<input type="checkbox"/>	<input type="checkbox"/>	

Daily Activities Continued:

Do you use a mobility aid?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
<i>If yes, which ones do you use?</i>	<input type="checkbox"/> Cane <input type="checkbox"/> Walker <input type="checkbox"/> Wheelchair <input type="checkbox"/> Electric Scooter		
Are you afraid of falling?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Have you had a fall in the past year?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	

11. During the LAST 3 MONTHS have you had any of the following symptoms or problems? (Please check all that apply)

<p>A. General Problems:</p> <p><input type="checkbox"/> Weight Loss <input type="checkbox"/> Weight Gain</p> <p><input type="checkbox"/> Change of Appetite <input type="checkbox"/> Wandering</p> <hr/> <p>B. Ear, Nose, Mouth, Throat:</p> <p><input type="checkbox"/> Trouble hearing</p> <p><input type="checkbox"/> Swallowing problems</p> <p>Special diet? _____</p> <p>Consistency? _____</p> <p><input type="checkbox"/> Teeth Problems</p> <hr/> <p>C. Eyes:</p> <p><input type="checkbox"/> Trouble seeing</p> <hr/> <p>D. Skin Problems:</p> <p><input type="checkbox"/> Rash</p> <p><input type="checkbox"/> Ulcers</p> <hr/> <p>E. Lung Problems:</p> <p><input type="checkbox"/> Cough when eating</p> <p><input type="checkbox"/> Difficulty breathing or shortness of breath</p> <hr/> <p>F. Heart Problems:</p> <p><input type="checkbox"/> Chest pain or tightness</p> <p><input type="checkbox"/> Lightheadedness</p> <p><input type="checkbox"/> Irregular heartbeat</p> <p><input type="checkbox"/> Rapid heartbeat</p>	<p>G. Digestive Problems:</p> <p><input type="checkbox"/> Abdominal pain</p> <p><input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> Frequent indigestion or heartburn</p> <p><input type="checkbox"/> Frequent nausea or vomiting</p> <p><input type="checkbox"/> Persistent constipation</p> <p><input type="checkbox"/> Frequent diarrhea</p> <p><input type="checkbox"/> Bleeding from rectum</p> <p><input type="checkbox"/> Black bowel movement</p> <hr/> <p>H. Brain and Nervous System Problems:</p> <p><input type="checkbox"/> Frequent headaches <input type="checkbox"/> Frequent dizzy spells</p> <p><input type="checkbox"/> Passing out or fainting <input type="checkbox"/> Tremor or shaking</p> <p><input type="checkbox"/> Paralysis, leg, or arm weakness</p> <p><input type="checkbox"/> Numbness or loss of feeling</p> <hr/> <p>I. Kidney and Urinary Tract Problems:</p> <p><input type="checkbox"/> Frequent urination</p> <p><input type="checkbox"/> Painful urination</p> <p><input type="checkbox"/> Difficulty starting or stopping urination</p> <p><input type="checkbox"/> Frequent urine infections</p> <p><input type="checkbox"/> Urination at night</p> <p> If yes, how many times a night: _____</p> <p><input type="checkbox"/> Loss of urine or getting wet</p>
---	---

12. Access to Resources & Services:

Please check the appropriate box for each service to indicate the service you are currently receiving and what services if any, you would be interested in receiving.

Day-to-Day Services

Currently Receiving	Interested in Receiving	
<input type="checkbox"/>	<input type="checkbox"/>	Transportation (ie: Subsidies, public, door-to-door services)
<input type="checkbox"/>	<input type="checkbox"/>	Nutrition Services (meal deliver, shopping, meal preparation)
<input type="checkbox"/>	<input type="checkbox"/>	Adult Day Care Services
<input type="checkbox"/>	<input type="checkbox"/>	Access to Communication (ie: TTY, instruments for the hearing impaired)
<input type="checkbox"/>	<input type="checkbox"/>	Home Health Care
<input type="checkbox"/>	<input type="checkbox"/>	Home Safety Modification (ie: Bathroom bars, commodes, etc.)

Social Services:

<input type="checkbox"/>	<input type="checkbox"/>	Social Work Services
<input type="checkbox"/>	<input type="checkbox"/>	Housing Services (ie: Subsidized housing, discrimination, landlord disputes, homelessness)
<input type="checkbox"/>	<input type="checkbox"/>	Care Coordination
<input type="checkbox"/>	<input type="checkbox"/>	Legal Advocacy

Financial Services:

<input type="checkbox"/>	<input type="checkbox"/>	Savings
<input type="checkbox"/>	<input type="checkbox"/>	Social Security Disability Insurance (SSDI)
<input type="checkbox"/>	<input type="checkbox"/>	Social Security Retirement Benefits
<input type="checkbox"/>	<input type="checkbox"/>	Medicare
<input type="checkbox"/>	<input type="checkbox"/>	Retirement Income/Pension
<input type="checkbox"/>	<input type="checkbox"/>	Medi-Cal
<input type="checkbox"/>	<input type="checkbox"/>	In-Home Supportive Services (IHSS; Medi-Cal ONLY Program)
<input type="checkbox"/>	<input type="checkbox"/>	Long Term Care Insurance
<input type="checkbox"/>	<input type="checkbox"/>	Supplemental Security Income
<input type="checkbox"/>	<input type="checkbox"/>	Other Income (ie: trust, annuity)
<input type="checkbox"/>	<input type="checkbox"/>	VA Benefits

Other Concerns:

A. Property: Do you currently own or rent any property or business? Yes No

B. Financial Concerns: Do you have any concerns regarding patient finances (ie: Paying for caregiver)?

Yes, current concerns

No concerns now, but maybe in the future

No concerns at all

C. Legal Concerns: Do you have any legal concerns (ie: Conservatorship, advanced directives, etc.)?

Yes, current concerns

No concerns now, but maybe in the future

No concerns at all

::FOR CAREGIVERS:: Caregiver Services:

Currently Receiving	Interested in Receiving	
<input type="checkbox"/>	<input type="checkbox"/>	Respite or break from caregiving
<input type="checkbox"/>	<input type="checkbox"/>	Caregiver Support Group
<input type="checkbox"/>	<input type="checkbox"/>	Consultation or help in planning for board and care or assisted living placement
<input type="checkbox"/>	<input type="checkbox"/>	Hospice Care
<input type="checkbox"/>	<input type="checkbox"/>	Private In-Home Care (privately paid caregiver)
<input type="checkbox"/>	<input type="checkbox"/>	In-Home Supportive Services (IHSS; Medi-Cal ONLY Program)

13. Please list specific health concerns that you would like the care manager to know about before your visit.

Please be sure to include any information not already reported in this form.

1)

2)

3)

THANK YOU FOR COMPLETING THIS FORM! 😊