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Journal

Alzheimer's & Dementia: Translational Research & Clinical Interventions, 6(1)

ISSN

2352-8737

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Publication Date

2020

DOI

10.1002/trc2.12010

Peer reviewed

RESEARCH ARTICLE

Using care navigation to address caregiver burden in dementia: A qualitative case study analysis

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Funding information

U.S. Department of Health and Human Services, Grant/Award Number: 1C1CMS331346; Centers for Medicare & Medicaid Services; National Institute on Aging, Grant/Award Number: 1R01AG056715-01

Abstract

Introduction: Many caregivers of people with dementia experience burden and resulting health effects due to the intensive nature of caregiving. Phone- and web-based care navigation is an innovative model of care that may be useful in addressing caregiver burden in dementia.

Methods: Qualitative methods (interviews, focus groups, and case study analysis) were used to identify care navigator approaches used to address caregiver burden in dementia as part of a dementia care navigation program.

Results: Care navigators targeted caregiver burden by focusing on strategies to reduce caregiver guilt and frustration, manage patient-related behavior, address caregiver depression, and improve the relationship between the caregiver and person with dementia. The case studies presented demonstrate the ways that care navigators identified patient and caregiver needs and tailored their approaches to meet the specific social, cultural, economic, and geographic contexts of the dyads with which they worked.

Discussion: Findings provide insights into strategies used to address caregiver burden through care navigation. Care navigators who speak the same language as the caregivers with whom they work and who have an in-depth understanding of the symptoms of different dementia syndromes may be particularly effective.

KEYWORDS

care navigation, caregiver burden, case study analysis, dementia, personalized care, qualitative research

1 | INTRODUCTION

More than 15 million family members or friends care for individuals with Alzheimer's disease (AD) and related dementias in the United States, which involves providing emotional, physical, and practical

support.¹⁻³ Caregivers assist with daily physical and behavioral care and care management, maintain medication regimens, coordinate with providers, compensate for functional deficits, and address end-of-life issues and advance care decision-making.³ Many caregivers experience burden and resulting health effects due to the intensive nature of

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caregiving.³⁻⁷ These health effects include depression, stress, frustration, self-reported health decline, decrease in self-care and increase in poor health behaviors (drugs/alcohol, no exercise, poor sleep), and an increase in disease (impaired immune system function, elevated blood pressure, increase in cardiac disease) and mortality.^{2,5,8-17} Caregiver burden, which has been studied extensively in the literature, may also be a factor leading to premature institutionalization of individuals with dementia.^{3,5,18-20}

Researchers have sought to gain a clear understanding of the mechanisms of and approaches to studying caregiver burden, both in general and specifically in dementia. The literature on caregiver burden has identified key risk factors for and determinants of caregiver burden in general, as well as impacts on health and well-being.^{21,22} Some of the risk factors for caregiver burden include female sex, low education, hours spent caregiving, social isolation, and financial stressors.⁷ There has also been extensive work on how to measure caregiver burden. One of the most commonly used measures of caregiver burden, both generally and in dementia, is the Zarit Burden Interview (ZBI), which examines the impact of caregiving on people's health, relationships, and finances.^{10,23}

In the literature on caregiver burden in dementia, in particular, studies have demonstrated that burden may be determined by the degree of severity of the person with dementia's (PWD) neuropsychiatric and behavioral symptoms, the type of dementia, how competent the caregiver feels and the caregiver's health-related quality of life.^{6,11,24} In the area of implementation, there are also studies of programs that are testing and reporting findings from interventions designed to improve the health and well-being of caregivers of people with dementia.^{3,5,18-20,25-27} Many of these intervention-focused studies suggest that tailored multicomponent approaches, such as the Resources for Enhancing Alzheimer Caregiver Health, or REACH program, provide effective ways to help support caregivers.²⁸⁻³³ Yet, one study found that only one fourth of family and unpaid caregivers across community-dwelling older adults with disabilities, including dementia, use supportive services.¹⁸

In this article, we discuss one such dementia care model that has the potential to extend the reach of dementia supportive services to the most isolated and burdened caregivers. The Care Ecosystem program was designed to support people with dementia and their caregivers and was tested through a randomized clinical trial.³⁴ The program's care model is implemented by Care Team Navigators (CTNs), unlicensed trained dementia specialists who work directly through the phone and internet with caregivers and patients, enrolled as dyads. CTNs are trained and supervised by an expert clinical team comprising an advanced practice nurse, a social worker, and a pharmacist, all of whom have dementia expertise. CTNs carry caseloads of 50 to 80 dyads and communicate monthly or more frequently with caregivers to provide education, resources, and emotional support. CTNs also coordinate with and triage cases to the clinical support team and the person with dementia's other providers as needed. In recently published results from the randomized clinical trial designed to study the Care Ecosystem, at 12 months, caregiver burden was found to decrease significantly more among caregivers in the Care

RESEARCH IN CONTEXT

1. Systematic review: The authors reviewed the literature using traditional (eg, PubMed) sources and meeting abstracts and presentations. There are several recent publications that describe models for supporting people with dementia and their caregivers. These studies are cited in our manuscript.
2. Interpretation: Our findings led to an in-depth understanding of how unlicensed but expertly trained care navigators, supported by a small clinical team, can use phone- and web-based care navigation to provide needs assessments and targeted work to address caregiver burden among caregivers of people with dementia.
3. Future directions: This article provides insights into strategies used to address caregiver burden using care navigation. We specifically noted the importance of care navigators who speak the same language as those they work with in diverse populations, as well as having an in-depth understanding of the symptoms and disease management required of different dementia syndromes. Future work will focus on how to integrate new models, such as care navigation, into healthcare payment systems and health policies to support people with dementia and their caregivers.

Ecosystem intervention group than among caregivers receiving usual care.³⁴

To further contextualize these findings, in this study, we conducted qualitative research to understand and report specific approaches used by CTNs to address caregiver burden. We also provide an in-depth analysis of three exemplary cases to illustrate how caregiver-focused education, communication, and care strategies were incorporated into the implementation of this model of dementia care as a way to extend the reach of caregiver support in dementia.

2 | METHODS

2.1 | Study design and setting

We conducted this study using qualitative methods (interviews, focus groups, and observations) and qualitative case study analysis to understand approaches used by Care Team Navigators to address caregiver burden among caregivers of people with dementia (Figure 1). This study took place within the Care Ecosystem program at the University of California, San Francisco and the University of Nebraska Medical Center.

The Care Ecosystem program was designed to incorporate best-practice findings from prior successful dementia support interventions.^{35,36} These approaches include a multicomponent focus

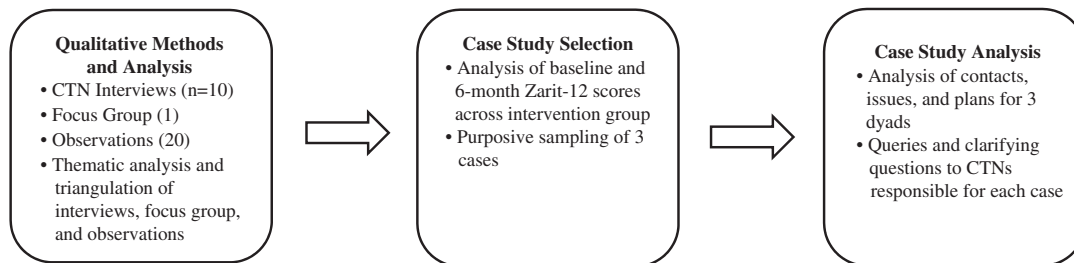


FIGURE 1 Methods



FIGURE 2 The Care Ecosystem care model

on caregiver well-being, psychoeducation, counseling and support groups, behavior management interventions, respite models, and psychotherapeutic approaches.⁸⁻¹⁰ In order to have the most extensive reach in both urban and rural areas, the Care Ecosystem was implemented as a telephone and web-based program for people with dementia and their caregivers, enrolled as dyads. Dyads are assigned a CTN, an unlicensed, trained dementia care specialist, who is supported by an expert clinical team (Figure 2). CTNs received 40 or more hours of didactic and observational training, as well as ongoing supervision. CTNs provide consistent support and education, tailored resources and referrals, motivational guidance, and problem-solving assistance. Each dyad enrolled in the Care Ecosystem received interventions focused on medication management, decision-making, behavioral symptoms and other symptom management, and caregiver well-being and education. The study and a detailed description of the key aspects of CTN training and role have been described in prior publications.³⁸⁻⁴⁰ The University of California, San Francisco Human Subjects Review Board approved this qualitative study.

2.2 | Data collection

2.2.1 | Qualitative data

All CTNs employed by the Care Ecosystem program at the time of this qualitative study were included after consenting to participate

($n = 10$). The first author (A.B., a medical anthropologist) conducted semi-structured interviews with all CTNs.⁴¹ We developed our interview guide based on the research questions of our study and a review of literature on caregiving in dementia and care navigation. The guide focused on the following domains: (1) care navigator background and skills; (2) care navigator role (activities in practice, unexpected responsibilities, rewarding and difficult experiences, strategies for job success); (3) triage (reasons for coordinating care, scope and boundaries of role); (4) addressing caregiver burden and caregiver self-efficacy. The first and second author (A.B. and J.M.) conducted a 1-hour focus group with a subset of CTNs ($n = 7$) to confirm and expand on themes identified in interviews related to caregiver burden. The first author also conducted 20 observations at all-staff meetings and clinical support team debriefings with CTNs to understand the process of navigating care for caregivers of people with dementia.

2.2.2 | Case study data

To obtain an in-depth understanding of the specific strategies CTNs used, we qualitatively examined three cases selected from the first 96 participants in the Care Ecosystem to identify characteristics, major concerns, and interventions and follow-up conducted by CTNs that addressed caregiver burden. Inclusion criteria for all dyads enrolled in the larger clinical trial and details of the findings from the trial are described in detail in a previous publication.³⁴ Specifically, a total of 780 dyads were enrolled, with 512 dyads receiving the Care Ecosystem intervention for 12 months. A person with dementia was included if he or she had a dementia diagnosis; was older than 45 years; was enrolled in or was eligible for Medicare or Medicaid; was a resident of California, Nebraska, or Iowa; and had an identified caregiver who also agreed to enroll in the study. All participants (the PWD and the caregiver) had to be fluent in English, Spanish, or Cantonese. People with dementia living in a nursing home at the time of enrollment were excluded from the study.³⁴

For our case study analysis, cases were selected because the caregiver showed among the greatest improvement in caregiver burden between the time of enrollment and 6 months into the study in the California cohort, and because these cases were exemplary of strategies used by CTNs to address caregiver burden. Caregiver burden is measured in the Care Ecosystem at baseline, 6 months, and 12 months using a modified 12-item version of the ZBI, a validated tool used to

assess caregiver burden.⁴² We analyzed baseline Zarit-12 scores of the first 96 California enrollees and used purposive sampling, which involves selecting examples that were information-rich in order to conduct in-depth analysis of key issues faced and strategies used by CTNs to address caregiver burden.⁴³ Among the first 96 participants enrolled in the California arm of the Care Ecosystem intervention, average caregiver burden was “high” (mean $18.6 \pm$ standard deviation [SD] 8.4). Caregivers for the three dyads we present had Zarit burden scores 0.5 to 1.5 SD above the mean, and all reported high baseline burden (defined as a score >17).⁴² After 6 months in the intervention, caregiver burden for the first 96 participants decreased by 0.36 points. Caregiver burden scores for the three cases chosen declined by 11 to 15 points. Cases were also selected because they illustrate how specific strategies identified by CTNs in interviews and focus groups manifested in real-life care navigation scenarios.

2.3 | Analysis

2.3.1 | Qualitative data analysis

In our analysis of the interviews, focus group, and observations, we used an approach called data triangulation, which enables a researcher to use multiple data sources to confirm the rigor of qualitative research findings.^{44,45} First, interview and focus group recordings were transcribed and analyzed through an iterative process using the software ATLAS.Ti.^{46,47} The first author (A.B.) coded the transcripts to identify common approaches and strategies to addressing caregiver burden in the responses.⁴⁸ The second author (J.M.) reviewed all codes, and any discrepancies in coding were discussed until agreement was reached. We confirmed that there was agreement between approaches identified in interviews and focus groups, and organized our resulting codes according to themes within five overarching domains from the literature on caregiver burden: (1) feelings of guilt and frustration; (2) behavioral and psychological symptoms of dementia (BPSD); (3) the PWD's functional abilities; (4) caregivers' feelings of competence, and (5) caregivers' satisfaction with their relationship with the PWD.^{6,10,49} The first author reviewed observation notes to assess and triangulate these data in relationship to interview and focus group findings.

2.3.2 | Case study analysis

To analyze each case, we reviewed the Care Ecosystem Dashboard to identify the following dyad characteristics: the PWD's type and stage of dementia, caregiver characteristics, living situation, and concerns that contributed to caregiver burden. We reviewed all contacts and CTN notes about issues identified by caregivers and plans to address these issues. In notes, CTNs describe reasons for contact, what was covered, and follow-up. We conducted follow-up interviews with CTNs responsible for each case. We compiled these data into case summaries. To protect dyad anonymity, we altered identifying information in the cases.

TABLE 1 Care Team Navigator characteristics (n = 10)

Age, mean, median (SD)	28, 24 (9)
Gender, female (%)	70%
Race (%)	
White	6
Asian	2
Black or African American	1
Other or mixed	1
Ethnicity (%)	
Hispanic or Latino	1
Not Hispanic or Latino	9
NA	0
Education	
<12 years	0
12 years	0
13 to 15 years	0
≥ 16 years	10
Languages spoken in CTN role	
English	10
Spanish	1
Cantonese	1

3 | RESULTS

3.1 | Participant characteristics

Demographic information about the CTNs are presented in Table 1. Demographic information about the three dyads are presented in Table 2.

3.2 | Qualitative results

CTNs reported that once they were assigned a dyad they engaged in an in-depth intake process to understand and prioritize the dyad's needs. Through regular check-ins, CTNs continued to assess and address dyad needs. Through our qualitative methods, we identified strategies CTNs used to address aspects of caregiver burden that included feelings of guilt and frustration, behavioral and psychological symptoms of dementia (or BPSDs), the PWD's functional abilities, the caregivers' feelings of competence, and caregivers' satisfaction with their relationship with the PWD.^{6,10,49} These strategies, represented in Table 3, include normalizing the caregiver's experiences and preparing them for the future; identifying triggers of behaviors and approaches to address these behaviors; providing information and support for caregiver depression and grief; educating about disease progression; and identifying strategies for caregivers to better communicate with the person with dementia. In the following section we demonstrate how these strategies were used by CTNs in specific cases.

TABLE 2 Person with dementia and caregiver characteristics

	Case 1	Case 2	Case 3
Person with dementia			
Gender	Male	Female	Female
Age	70	83	68
Race/ethnicity	Asian	Hispanic and Caucasian	Caucasian
Annual household income	\$50,000-99,999	\$25,000-49,999	\$50,000-99,999
Stage ^a	Advanced	Mild	Advanced
Diagnosis	Vascular dementia	Lewy body dementia	Frontotemporal dementia
Common symptoms			
Medicare enrollment	Medicare only	Medicare only	Medicare only
Time in study (days)	460	540	657
Caregiver			
Gender	Female	Female	Male
Age	64	48	65
Race/ethnicity	Chinese	Caucasian	Caucasian
Relationship to PWD	Spouse	Child	Spouse
Preferred language	Cantonese	English	English
Zarit-12 burden scores			
Baseline	31	24	23
6-Month	20	9	10

^aWe assessed dementia stage using the Quick Dementia Rating System (QDRS), a 10-item questionnaire that is completed by the caregiver.⁵¹

3.3 | Case study results

3.3.1 | Case 1

Background

The person with dementia is a 70-year-old male monolingual Cantonese speaker with vascular dementia who emigrated from China 30 years ago with his wife, who is his caregiver. He had a stroke in 2012 and at that time was given a general diagnosis of dementia. The PWD's caregiver and wife is 64-years-old and a monolingual Cantonese speaker. At baseline, the caregiver's burden score was 31.

Major concerns

At the time of enrollment the caregiver reported stress and frustration as the sole caregiver for her husband. She was responsible for all household activities, including cleaning, meals, and managing her husband's functional and behavioral symptoms. She worked during the day but came home at lunchtime because of the PWD's incontinence. The caregiver told her CTN that she put multiple diapers on the PWD to last until lunchtime, and that the cost of incontinence supplies was a financial burden. The caregiver also expressed frustration that she did not understand the disease, identifying language as a major barrier preventing her from fully engaging during medical visits. The caregiver's CTN found that much of her burden was due to frustration navigating the healthcare system without speaking English. The caregiver also reported feeling socially isolated as her responsibilities increased.

In summary, the key aspects of burden identified by the caregiver included frustration with finances and difficulty communicating with providers; lack of independence due to caregiving responsibility; mood issues related to social isolation; and difficulties managing disease symptoms, such as incontinence.

CTN interventions and follow-up

When enrolled in the Care Ecosystem, this dyad was matched with a Cantonese-speaking CTN who could offer support and resources in their native language. To ease stress around medical visits, the CTN, with support from the Care Ecosystem clinical nurse specialist, connected the dyad with a new neurologist who was in a more accessible location and had access to a Cantonese-speaking translator. To make this change, the CTN identified a physician covered by the dyad's insurance, obtained a referral letter from the PWD's primary care provider, set up an appointment with the new neurologist and an interpreter, and helped the caregiver transfer the PWD's medical history. Neurological evaluation and an MRI clarified a diagnosis of vascular dementia. As a result, the PWD began seeing a stroke specialist, and was put on appropriate medications to help address his symptoms. The CTN continued to clarify clinician feedback in Cantonese following appointments. The CTN also worked with the Care Ecosystem's social worker to help the dyad apply for respite grants from the Alzheimer's Association and Self-Help for the Elderly. These grants allowed the caregiver to hire in-home care assistance and obtain a case manager. The caregiver reported less frustration and increased independence. The CTN also assisted the caregiver in finding affordable adult diapers and created

TABLE 3 Strategies Care Team Navigators used to address caregiver burden

Area of burden	Case study	CTN strategies
Guilt and frustration	1, 2, 3	<ul style="list-style-type: none"> • Normalizing caregiver experience • Preparing caregiver for what is coming next in order to address expectations • Positive reinforcement (eg, discussing positive aspects of the caregiving relationship) • Reframing expectations • Providing emotional support • Referring to clinical team for assessments and short-term supportive counseling
Behavior management	2, 3	<ul style="list-style-type: none"> • Identifying triggers, such as physical, emotional, interpersonal, or environmental causes of behaviors, eg, through behavior logs • Iterating with caregiver on approaches that realistically match PWD's functional and cognitive skills • Referring to clinical team to optimize medications and non-pharmacological strategies for responding to behaviors
Caregiver depression	2, 3	<ul style="list-style-type: none"> • Providing information about depression and grief • Referring to support groups and therapists • Helping caregiver find meaningful activities to engage in outside of caregiving • Helping to build social connections • Referring to clinical team for depression or suicide risk assessment and short-term supportive counseling
Responding to person with dementia's neuropsychiatric symptoms	1, 2, 3	<ul style="list-style-type: none"> • Educating around disease progression and specific types of dementia • Naming the problem • Working with caregivers to try to understand the root of symptoms, eg, apathy and lack of motivation • Educating around medications and obtaining pharmacy review of medications and consultations; decreasing stigma around medications
Caregiver satisfaction with relationship with person with dementia	3	<ul style="list-style-type: none"> • Identifying strategies for communication and meaningful connection with the person with dementia • Educating around modifying messaging (eg, strategic timing and limiting of information; therapeutic lying) • Helping caregiver adjust to new role in the person with dementia's life

a toileting schedule, which helped to decrease incontinence episodes. To address the caregiver's desire for social support and knowledge, her CTN found a Cantonese-speaking support group that meets monthly as well as a Cantonese Savvy Caregiver class through the Alzheimer's Association. As a result, the caregiver made friends with whom she could share her experiences in her native language.

3.3.2 | Case 2

Background

The person with dementia is an 83-year-old woman with a diagnosis of Lewy body dementia (LBD), who lives with her primary caregiver, her 48-year-old daughter. The caregiver's baseline caregiver burden score was 24.

Major concerns

The PWD experienced problems with movement, judgment, and attention. The caregiver worked full time and was a parent to two young children. She felt guilty that she was not doing enough and worried

about her mother's functional decline. She reported that her mother had poor balance and mobility, suffering three falls in 6 months. The PWD walked with a shuffling gait and a cane, although she often forgot to use it. The caregiver had not implemented any fall prevention strategies and was distressed with worries about her mother's falls. The PWD also had outbursts of anger, typically directed toward the caregiver. The caregiver identified a high level of depression and stress, and scored high enough on the Patient Health Questionnaire-9 (PHQ-9), a depression screen administered at baseline, to be considered at risk of suicide. The caregiver, however, felt she was too busy to seek help for her depression.

In summary, the caregiver experienced guilt and frustration due to the stress of her role and reported difficulties managing the PWD's neuropsychiatric and behavioral symptoms. The caregiver also reported depression, a key area of caregiver burden.

CTN intervention and follow-up

The CTN assigned to the case first focused intensively on the caregiver's depression by triaging with the Care Ecosystem social worker. Together, they identified online, phone, and Skype-based support

groups and counselors so the caregiver could seek treatment for depression without leaving home. The CTN offered consistent emotional support around the caregiver's feelings of guilt. To address the PWD's movement issues, which contributed to the caregiver's stress, the CTN connected her with a physical therapist to work on fall prevention, as well as a personal trainer to help with mobility. As a result, the PWD was able to walk the short distance to a community group. In coordination with the clinical team pharmacist, the CTN also facilitated the increase of an antidepressant targeting the PWD's angry outbursts. The caregiver felt her mother seemed calmer. Finally, the CTN identified respite options for the caregiver including in-home care, a mobile manicurist who cuts hair and nails in people's homes, and a day program and senior swing dancing group to provide socialization and physical movement opportunities for the PWD.

3.3.3 | Case 3

Background

The person with dementia is a 68-year-old woman with advanced frontotemporal dementia (FTD). The PWD's primary caregiver is her husband, who is 65 and had a baseline caregiver burden score of 23.

Major concerns

The caregiver works out of the home full time. The PWD's main behavioral symptoms, typical for people with FTD, include compulsive behaviors, agitation, physical aggression, and disinhibited behavior toward strangers. Although the PWD was prescribed medications to help control these behaviors, the caregiver had difficulty helping her comply, leading to erratic medication dosing and increasingly difficult behaviors. Furthermore, although the caregiver hired paid caregivers to supervise in the home while he was at work, the PWD often objected to their presence, and when upset, would become violent. The caregiver expressed preoccupation with the physical risk that the PWD posed to herself and others. The caregiver reported feeling socially isolated and had no support from a social network or family. After work he resorted to drinking alcohol at home due to stress. After enrollment in the Care Ecosystem, the PWD was placed in a long-term care facility due to her behavioral issues. Although this was safer for her, the caregiver told his CTN that he felt guilty for this decision. Furthermore, he visited the PWD after work, but would sometimes fall asleep because of exhaustion, thereby increasing his feelings of guilt.

In summary, the aspects of burden the caregiver reported include guilt and frustration. He also reported depression and alcohol use due to stress. Finally, due to the specific characteristics of the disease, the caregiver reported difficulties in his relationship with the PWD, particularly around her personality changes and violent actions.

CTN interventions and follow-up

The dyad's CTN triaged the case to the Care Ecosystem Nurse Coordinator due to the risk of neglect regarding medication noncompliance. A report was filed with adult protective services that led to more effective protocols around medications. The CTN supported this pro-

cess by helping the caregiver understand connections between medications and behaviors, and provided education, in coordination with the Care Ecosystem pharmacist, about the importance of complying with medication recommendations. Furthermore, the CTN helped the caregiver locate a long-term care facility near home as he was making the difficult decision about whether he could keep the PWD at home. In response to the caregiver's guilt surrounding this transition, his CTN offered emotional support by calling regularly and giving him the opportunity to express his feelings. The CTN also sent educational handouts and communicated information about depression, grief, and local support groups. During calls, the CTN affirmed the caregiver's strengths. The CTN encouraged the caregiver to join a support group and see a therapist. Finally, the CTN helped to promote the caregiver's health by encouraging exercise (he resumed golfing with friends) and regular check-ups with his doctor. A referral to Alcoholics Anonymous was also made to address his alcohol use.

4 | DISCUSSION

In this article we present themes that emerged from our qualitative study that demonstrate specific approaches to addressing caregiver burden in a dementia care navigation program that was administered through the phone and internet. CTNs reported strategies focused on alleviating stress; reducing guilt and frustration; addressing the PWD's challenging behavioral symptoms; enhancing caregivers' feelings of competence and the PWD's independence; and supporting a meaningful and harmonious relationship between the caregiver and the PWD. The three illustrative cases demonstrate some of these strategies in practice with caregivers who entered the program with high burden scores, as measured by the ZBI-12. We found that interventions to address caregiver burden were tailored to and incorporated an understanding of both the PWD and the caregivers' needs. CTNs had continuous engagement with dyads through the provision of support and information, and by coaching caregivers and focusing on behaviors and care coordination. Through this approach, they were able to address many components of burden simultaneously.

In the literature, there is extensive work on interventions for caregivers of people with dementia.²⁵⁻²⁷ Studies identify the importance of intervention dosing, timing, tailoring, and individualization, all of which have shown great promise. Furthermore, multicomponent approaches, such as the Care Ecosystem program, can provide effective interventions to address caregiver burden that are more than a sum of their parts (eg, the Resources for Enhancing Alzheimer Caregiver Health, or REACH and REACH II studies, as well as the NYU Caregiver Counseling and Support Intervention).²⁸⁻³³ The REACH II protocol, for example, involves a multicomponent caregiver intervention that is based on an individualized assessment of caregiver needs. The Care Ecosystem takes a similar approach, with interventions tailored to the needs of the caregiver and the PWD based on an assessment of caregiver quality of life, depression, burden, self-efficacy, social support, and challenging behaviors. The REACH model also addresses the needs of culturally

diverse caregivers of people with dementia. Similarly, the Care Ecosystem program employs bilingual CTNs to work with diverse populations. As was demonstrated in Case 1, the language concordance played a key role in the intervention.

The Care Ecosystem is unique in that it trained CTNs, who were primarily recent college graduates, to address the health and well-being of both the person with dementia and a caregiver through expert dementia instruction and supervision. CTNs worked closely with the clinical supervisory team and the PWD's other providers to help coordinate care and facilitate recommendations for medication changes, patient evaluation, safety protocols, behavior changes, and other patient-focused interventions that also impacted caregiver well-being. Furthermore, the cases presented demonstrate particular disease-specific differences in supporting caregivers and managing caregiver burden. For example, the caregiver of the person with FTD dealt with issues related to their interpersonal relationship due to personality change and violent behavioral symptoms. These disease-specific differences require attention by people who are expertly trained in different dementia syndromes, such as the CTN, and who can tailor their interventions to address the specific manifestation of the different diseases. To support CTNs in this comprehensive dyadic and disease-specific focus, they received in-depth training in both caregiver support and in specific dementia syndromes and their associated behaviors. CTNs were knowledgeable and could tailor their approaches to the presenting symptoms and medical concerns that impacted caregivers.

Finally, as a health systems intervention, CTNs did not replace licensed clinicians; however, they were supported by a clinical team and had the time and training to focus on caregiver education—helping to identify resources and build community connections—and the time to work on implementing creative support techniques. They thus provided extensive dementia-specific care in a sustainable way in a health care environment where primary care providers and neurologists do not have the time or resources to take on all of these aspects of care management, particularly the focus on the caregiver. Furthermore, although the telephone and web-based care delivery model relied primarily on caregiver report of the situation rather than an in-person visit, it did enable the Care Ecosystem to be more accessible and sustainable, and have a broader reach. In the literature, no difference in quality was found between dementia care management interventions delivered by phone or in person.⁵⁰

4.1 | Limitations

In this study we examined demonstrated procedures of care navigation, but we were not able to study factors that may affect caregiver burden that are outside of the scope of the Care Ecosystem. This study had a small sample size due to the qualitative and case study analysis methods. Although these case studies provide an in-depth examination of three PWD/caregiver dyads, their experiences may not be representative of the general population. Furthermore, another question

that requires more study is the role that CTNs play in reducing caregiver burden as compared to a caregiver's growing familiarity with the caregiving role.

4.2 | Conclusions

Given the varied determinants and manifestations of caregiver burden, there is a need for creative, accessible, and sustainable interventions to address the complex and interconnected issues that emerge. Furthermore, due to the growing population of people who will be diagnosed with dementia, there will be an increasing number of family caregivers. We already know that most caregivers do not access supportive services. A significant challenge for the health care system is to find care models, such as those that use unlicensed providers through phone- and web-based platforms, that can address the burdens and issues of access that caregivers face in a timely and cost-effective manner. Our findings from the Care Ecosystem demonstrate that there is an important role for active, highly engaged non-clinician specialists to address the complex and interconnected issues that comprise caregiver burden while tailoring their approaches to the specific social, cultural, and demographic needs of those they work with. Findings from this qualitative study can be used to shape the approach of providers and community support services that work with caregivers of people with dementia.

Note: All patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

ACKNOWLEDGMENTS

This publication was made possible by Grant Number 1C1CMS331346 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services and Grant Number 1R01AG056715-01 from the National Institute on Aging (NIA), and by the Global Brain Health Institute. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript. The contents of this publication are solely the responsibility of the authors and do not necessarily represent the official views of the U. S. Department of Health and Human Services or any of its agencies.

REFERENCES

1. 2018 ALZHEIMER'S DISEASE FACTS AND FIGURES Includes a Special Report on the Financial and Personal Benefits of Early Diagnosis. <https://alz.org/media/HomeOffice/Facts and Figures/facts-and-figures.pdf>. Accessed August 1, 2018.
2. Schulz R, Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry*. 2004;12(3):240-249.
3. Merrilees J. The impact of dementia on family caregivers: what is research teaching us. *Curr Neurol Neurosci Rep*. 2016;16(10):88.
4. Butcher HK, Holkup PA, Buckwalter KC. The experience of caring for a family member with Alzheimer's disease. *West J Nurs Res*. 2001;23(1):33-55.

5. Eters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract.* 2008;20(8):423-428.
6. Chiao C-Y, Wu H-S, Hsiao C-Y. Caregiver burden for informal caregivers of patients with dementia: a systematic review. *Int Nurs Rev.* 2015;62(3):340-350.
7. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS, S J. Caregiver burden. *JAMA.* 2014;311(10):1052.
8. Christakis NA, Allison PD. Mortality after the Hospitalization of a Spouse. *N Engl J Med.* 2006;354(7):719-730.
9. Fredman L, Cauley JA, Hochberg M, Ensrud KE, Doros G. Study of Osteoporotic Fractures. Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: results of caregiver-study of osteoporotic fractures. *J Am Geriatr Soc.* 2010;58(5):937-943.
10. Springate BA, Tremont G. Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *Am J Geriatr Psychiatry.* 2014;22(3):294-300.
11. Svendsboe E, Terum T, Testad I, et al. Caregiver burden in family carers of people with dementia with Lewy bodies and Alzheimer's disease. *Int J Geriatr Psychiatry.* 2016;31:1075-1083.
12. Hoffman GJ, Lee J, Mendez-Luck CA. Health behaviors among baby boomer informal caregivers. *Gerontologist.* 2012;52(2):219-230.
13. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist.* 1995;35(6):771-791.
14. Pinquart M, Sörensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci.* 2003;58(2):P112-P128.
15. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull.* 2003;129(6):946-972.
16. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA.* 1999;282(23):2215-2219.
17. Gallagher D, Rose J, Rivera P, Lovett S, Thompson LW. Prevalence of depression in family caregivers. *Gerontologist.* 1989;29(4):449-456.
18. Wolff JL, Spillman BC, Freedman VA, et al. A National profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Intern Med.* 2016;176(3):372.
19. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci.* 2009;11(2):217-228.
20. Schoenmakers B, Buntinx F, Delepeleire J. Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas.* 2010;66(2):191-200.
21. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden. *JAMA.* 2014;311(10):1052-1060.
22. Collins LG, Swartz K. Caregiver care. *Am Fam Physician.* 2008;83(11):1310-1217.
23. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist.* 1986;26(3):260-266.
24. van der Lee J, Bakker TJEM, Duivenvoorden HJ. Do determinants of burden and emotional distress in dementia caregivers change over time. *Aging Ment Heal J.* 2015;21(3):1-9.
25. Gitlin LN, Belle SH, Burgio LD, et al. Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. *Psychol Aging.* 2003;18(3):361-374.
26. Gitlin LN, Marx K, Stanley IH, Hodgson N. Translating evidence-based dementia caregiving interventions into practice: state-of-the-science and next steps. *Gerontologist.* 2015;55(2):210-226.
27. Czaja SJ, Lee CC, Perdomo D, et al. Community REACH: an implementation of an evidence-based caregiver program. *Gerontologist.* 2018;58(2):e130-e137.
28. Belle SH, Burgio L, Burns R, et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. *Ann Intern Med.* 2006;145(10):727-738.
29. Burgio LD, Collins IB, Schmid B, Wharton T, McCallum D, DeCoster J. Translating the REACH caregiver intervention for use by area agency on aging personnel: the REACH OUT Program. *Gerontologist.* 2009;49(1):103-116.
30. Elliott AF, Burgio LD, Decoster J. Enhancing caregiver health: findings from the resources for enhancing Alzheimer's caregiver health II intervention. *J Am Geriatr Soc.* 2010;58(1):30-37.
31. Mittelman MS, Roth DL, Clay OJ, Haley WE. Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention. *Am J Geriatr Psychiatry.* 2007;15(9):780-789.
32. Mittelman MS, Bartels SJ. Translating research into practice: case study of a community-based dementia caregiver intervention. *Health Aff.* 2014;33(4):587-595.
33. Mittelman MS. Psychosocial intervention for dementia caregivers: what can it accomplish. *Int Psychogeriatrics.* 2003;15(suppl 1):247-249.
34. Possin KL, Merrilees JJ, Dulaney S, et al. Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use. *JAMA Intern Med.* 2019;179(12):1658-1667.
35. Reuben DB, Evertson LC, Wenger NS, et al. The University of California at Los Angeles Alzheimer's and Dementia Care Program for comprehensive, coordinated, patient-centered care: preliminary data. *J Am Geriatr Soc.* 2013;61(12):2214-2218.
36. LaMantia MA, Alder CA, Callahan CM, et al. The aging brain care medical home: preliminary data. *J Am Geriatr Soc.* 2015;63(6):1209-1213.
37. Sörensen S, Duberstein P, Gill D, Pinquart M, Zarit S, Patterson M. Dementia care: mental health effects, intervention strategies, and clinical implications. *Lancet Neurol.* 2006;5(11):961-973.
38. Merrilees JJ, Bernstein A, Dulaney S, et al. The Care Ecosystem: promoting self-efficacy among dementia family caregivers. *Dementia.* 2018. <https://doi.org/10.1177/1471301218814121>.
39. Bernstein A, Harrison K, ... SD-J of, 2019 undefined. The role of care navigators working with people with dementia and their caregivers. *content.iospress.com.* <https://content.iospress.com/articles/journal-of-alzheimers-disease/jad180957>. Accessed October 8, 2019.
40. Possin KL, Merrilees J, Bonasera SJ, et al. Development of an adaptive, personalized, and scalable dementia care program: early findings from the Care Ecosystem. *PLoS Med.* 2017;14(3):e1002260.
41. Strauss A, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory.* London: Sage Publications; 1998.
42. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist.* 1980;20(6):649-655.
43. Patton MQ. *Qualitative Research & Evaluation Methods: Integrating Theory and Practice.* 4th ed. Saint Paul, MN: Sage; 2014.
44. Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. *BMJ.* 2008;337:a1020.
45. Kuper A, Lingard L, Levinson W. Critically appraising qualitative research. *BMJ.* 2008;337:a1035.
46. ATLAS.ti. Version 1.6.0 (484) for OSX [Computer software] (2013-2016) Berlin, Scientific Development, Software.
47. Miles MB, Huberman AM, Saldaña J. *Qualitative Data Analysis: A Methods Sourcebook.* 4th ed. Arizona: Sage; 2019.
48. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: *Analyzing Qualitative Data.* Abingdon, UK: Taylor & Francis; 173-194.

49. Jennings LA, Reuben DB, Evertson LC, et al. Unmet needs of caregivers of individuals referred to a dementia care program. *J Am Geriatr Soc*. 2015;63(2):282-289.
50. Chodosh J, Colaiaco BA, Connor KI, et al. Dementia Care Management in an Underserved Community. *J Aging Health*. 2015;27(5):864-893.
51. Galvin JE. The Quick Dementia Rating System (QDRS): a rapid dementia staging tool. *Alzheimers Dement*. 2015;1(2):249-259.

How to cite this article: Bernstein A, Merrilees J, Dulaney S, et al. Using care navigation to address caregiver burden in dementia: A qualitative case study analysis. *Alzheimer's Dement*. 2020;6:e12010. <https://doi.org/10.1002/trc2.12010>