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RESEARCH ARTICLE

# Long-term effects of collaborative dementia care on quality of life and caregiver well-being

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## Abstract

**INTRODUCTION:** Collaborative dementia care models with care navigation, including the Care Ecosystem, improve outcomes for persons living with dementia (PLWDs) and their caregivers. The effects of continuous care over long periods have not been studied.

**METHODS:** In this randomized clinical trial with 456 PLWD-caregiver dyads with high caregiver burden, we evaluated the cumulative 5-year treatment effect on PLWD quality of life, health care utilization, caregiver depression, self-efficacy, and burden.

**RESULTS:** Five-year participation was associated with higher quality of life, lower caregiver depression, and higher caregiver self-efficacy (all  $p$ 's < 0.05) with a trend for lower burden ( $p = 0.07$ ). Treatment effects were most robust during the first 2 years. The effects on emergency department visits and hospitalizations were not significant.

**DISCUSSION:** The benefits of collaborative dementia care on PLWD quality of life and caregiver well-being are sustained for 5 years, and the dyads may experience the greatest benefit during the first 2 years.

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**KEYWORDS**

care management, care navigation, caregiver burden, collaborative care, dementia, quality of life

**Highlights**

- Collaborative dementia care with care navigation was evaluated over 5 years using a randomized clinical trial.
- The care was associated with better quality of life for the person with dementia and well-being for the caregiver.
- The most robust treatment effects were in the first 2 years.

## 1 | BACKGROUND

An estimated 6.9 million people in the United States are living with dementia in 2024, and this number is expected to double by 2050.<sup>1,2</sup> Persons living with dementia (PLWDs) experience declines in their quality of life with advancing disease and with long-term care placement,<sup>3</sup> and have complicated care needs related to high rates of comorbidities, potentially avoidable hospitalizations, frequent care transitions, and polypharmacy.<sup>4–8</sup> To support PLWDs in the community, family caregivers are the primary workforce, on average providing about 30 h of care per week.<sup>9</sup> Although many caregivers experience positive rewards and meaningful connection from caregiving,<sup>10–12</sup> caregivers also shoulder substantial burdens including high rates of extreme stress,<sup>13</sup> depression,<sup>14</sup> physical ill health,<sup>15,16</sup> and financial costs.<sup>17</sup> Caregiver distress and depression have been associated with adverse outcomes for the PLWD including accelerated placement in long-term care, emergency department use, and elder abuse,<sup>18–20</sup> and PLWDs are more likely to be hospitalized if their caregiver is overwhelmed or new to the caregiving role.<sup>21,22</sup>

Collaborative care models for dementia that feature care navigation mitigate the burdens of dementia.<sup>23</sup> These models use multidisciplinary teams that integrate medical and psychosocial approaches to the care of the PLWD while also addressing caregiver needs related to dementia care.<sup>24</sup> Care navigators address 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. They provide individualized, strengths-based support to the dyad across the illness continuum and settings through collaborative problem solving and coaching.<sup>25,26</sup> These models have been associated with a range of benefits including improved quality of life for PLWDs, decreased caregiver burden and depression, and lower healthcare costs related to hospitalizations and emergency department visits.<sup>27–37</sup> A recent National Academies of Science, Engineering, and Medicine report on the evidence for dementia care interventions concluded that collaborative care models are ready for broad dissemination and implementation with continued research to support their evidence base.<sup>24</sup>

Prior research on the effectiveness of collaborative care models has typically focused on intervention durations of 6 to 12 months,<sup>27,28,33</sup> with some studies evaluating outcomes up to 18 months or 2 years.<sup>29,30,35</sup> It is unknown whether the effectiveness of these care models is sustained for longer durations. Yet in practice, health systems and community-based organizations often implement care navigation for a longer duration, such as through end-of-life. In the Milken Institute's 2023 report on building the dementia workforce through care navigation, they describe the timeline of care navigation as “all phases of the dementia-care journey, which encompasses early detection and diagnosis, care planning and delivery, end-of-life wishes and care, and all the transition points and moments of crisis in-between.”<sup>38</sup> Similarly, the Centers for Medicare & Medicaid Services (CMS) Innovation's new Guiding an Improved Dementia Experience (GUIDE) dementia care navigation payment model is designed explicitly for patients in all stages and does not mention disenrolling patients or reducing the dosage of care after a certain period.<sup>39</sup> Understanding whether and how long the benefits of collaborative care are sustained is crucial for the effective allocation of limited resources.

For this study, we evaluated the long-term treatment effects of the Care Ecosystem, a telephone-based collaborative care model for dementia with care navigation among PLWDs and their caregivers, who were selected for the study based on high caregiver burden at baseline. We evaluated the overall treatment effect across 5 years and at annual timepoints on PLWD quality of life, caregiver depression, caregiver burden, caregiver self-efficacy, emergency room visits, and hospitalizations.

## 2 | METHODS

### 2.1 | Trial design

This was an extension of the 12-month Care Ecosystem trial, a single-blind, parallel-group pragmatic randomized clinical trial that evaluated the treatment effect of the Care Ecosystem delivered over 12 months on PLWD-caregiver dyads.<sup>27</sup> For this extension trial, all dyads with a caregiver who reported high burden at baseline and were still

active 12 months after randomization were invited to continue study participation for a total of 5 years.

As specified for the 12-month Care Ecosystem trial, participants were randomized in a 2:1 ratio to the Care Ecosystem program and usual care. The trial was administered from two hubs: the University of California, San Francisco (UCSF), for PLWDs living in California; and the University of Nebraska Medical Center (UNMC), Omaha, for PLWDs living in Nebraska or Iowa. All care and research procedures were administered to the PLWD and caregiver in their preferred language (English, Spanish, or Cantonese). The study protocol and consent procedures were approved by the UCSF and UNMC Institutional Review Boards, as described previously.<sup>27</sup> At UNMC, dyads were asked to re-consent to participate in the extension trial and 11 declined.

## 2.2 | Participants and procedures

Participants were enrolled as dyads comprising a PLWD and their caregiver. The PLWD was eligible for inclusion in the 12-month Care Ecosystem trial if they were a person who was diagnosed with dementia, living in the community (not in assisted living or nursing home at enrollment), 45 years of age or older, eligible for or enrolled in Medicare and/or Medicaid, and had a primary caregiver who co-enrolled. There were 780 dyads enrolled in the 12-month Care Ecosystem trial between March 20, 2015, and February 28, 2017, and an additional 24 dyads with a PLWD who identified as Latino were enrolled to the same protocol between June 15, 2018 and May 16, 2019. Of these 804 dyads, 456 included a caregiver with high caregiver burden at baseline (12-item Zarit Burden Index  $\geq 17$ )<sup>40</sup> and were included in this analysis. Recruitment and enrollment methods were described previously.<sup>27</sup> Dyads completed a telephone survey at baseline and every 6 months or until time of death with research coordinators who were blinded to intervention assignment. Due to limited funding in 2017, the 18-month survey timepoint was skipped, but the care delivery for intervention participants was continuous.

## 2.3 | Intervention

Telephone-based collaborative dementia care was delivered for the 5 years by trained, unlicensed care team navigators (CTNs) who provided resources via email or mail, as guided by care protocols with as-needed support and weekly supervision from a clinical team, which included a pharmacist, advanced practice nurse, and social worker. Follow-up calls typically occurred monthly, with dosage adjusted to dyad needs and preferences. During calls, CTNs responded to any immediate needs first, and then screened for behavior, function, safety, medication changes, and unmet caregiver needs. Following the calls, CTNs provided personalized information, support, and resources as guided by care protocols via email or mail. CTNs revisited goals of care annually, during care transitions, and when a significant health event occurred (e.g., aspiration pneumonia). CTNs monitored for acute changes in health status and changes in the patient's function and

### RESEARCH IN CONTEXT

1. **Systematic review:** The authors reviewed the literature using traditional (e.g., PubMed) sources and meeting presentations. Although collaborative dementia care models that feature care navigation have been shown to improve patient and caregiver outcomes, prior research has evaluated these models for a short period but not over longer periods of participation. The relevant citations are appropriately cited.
2. **Interpretation:** The benefits of collaborative dementia care with care navigation on quality of life for the persons living with dementia (PLWDs) and well-being for the caregivers are sustained for 5 years, and the PLWD-caregiver dyads may experience the greatest benefit during the first 2 years of participation.
3. **Future directions:** Implementation of effective collaborative care in diverse health care settings with continued evaluation is needed. Future work may examine the effects of reducing the dosage of care after 2 years and the effects of the care on dyads from underrepresented racial and ethnic groups.

symptoms that might impact the caregiver's ability to provide care at home. Caregivers were supported to anticipate and prepare for the next steps in their caregiving journey.

## 2.4 | Outcomes

The pre-specified outcomes were consistent with the outcomes examined in the 12-month Care Ecosystem trial and focused on both the PLWD and the caregiver.<sup>27</sup> The primary outcome was quality of life of the PLWD, as measured by the Quality of Life in Alzheimer's Disease (QoL-AD; score range 13–52). The secondary outcomes were the number emergency department (ED) visits of the PLWD, the number of hospitalizations of the PLWD, caregiver depression (9-Item Patient Health Questionnaire: PHQ9; score range 0--27), caregiver self-efficacy (Care Ecosystem Self-Efficacy Scale; score range 5–15), and caregiver burden (Zarit-12; score range 0–48). This trial also examined time to nursing facility placement and long-term care placement, which were not included in the 12-month Care Ecosystem trial. Nursing facility placement was defined as the date of placement for a PLWD living in a nursing facility at the end of follow-up or at time of death. Long-term care placement was defined as the date of placement for a PLWD living in a nursing facility, memory care unit, or board and care home at the end of the follow-up or at time of death, but did not include independent assisted living facilities, respite stays, or rehab stays. All outcomes were collected via the caregiver surveys.

## 2.5 | Statistical methods

Baseline characteristics of the PLWDs and caregivers included in the extension trial are described. All analyses were conducted with an intention-to-treat approach by including the available data from the 456 dyads who reported high caregiver burden at baseline.

We evaluated treatment effects of the Care Ecosystem in two ways. The first analysis was pre-specified and estimated the cumulative effect of the Care Ecosystem intervention over 5 years. To do this, we fit linear mixed-effects regression models for continuous, noncount outcomes (quality of life, self-efficacy, depression, and burden) and Poisson models for count outcomes (ED visits and hospitalizations). Models included treatment group, timepoint (12 months preceding enrollment and each 6-month interval from 6 to 60 months), concurrent dementia severity, and an interaction term for the treatment group and time point as fixed effects and participant as a random effect to capture participant-specific differences. We did not include a random effect for ED visits and hospitalizations because most time points had zero utilization for most patients. The unstandardized beta ( $B$ ) coefficients and confidence intervals (CIs) of the interaction term represented the estimated treatment effect at each timepoint (every 6 months through 60 months, except month 18). We then calculated a weighted treatment effect at each timepoint to account for duration of time and loss to follow-up (e.g., due to death). The estimated treatment effect ( $B$ ) was multiplied by duration of the corresponding time interval (e.g., multiply by 6 for the 42-month  $B$  corresponding to months 36–42) and the number of participants still active. The 12- and 24-month treatment effects were assigned an interval of 9 months to account for missing data at 18 months. Using the linear combinations postestimation command, we summed these weighted treatment effects to provide a cumulative measure of the overall 5-year treatment effect for the primary and secondary outcomes.

The second analysis estimated the average annual effect of the Care Ecosystem intervention over 5 years. To do this, we fit generalized linear mixed-effects regression models with the same specifications as the pre-specified analysis. We then calculated a weighted treatment effect at each timepoint by multiplying the estimated treatment effect ( $B$ ) and the number of active participants (i.e., still alive and participating in the study) at each timepoint. We summed the weighted treatment effects at each year (e.g., weighted 6-month  $B$  + weighted 12-month  $B$ ) and divided by the number of timepoints (e.g., divided by 2 for year 1 average, annual effect). We calculated the average, annual effect for each year of the extension trial.

We estimated the cumulative effect of the Care Ecosystem on the outcomes separately for spouse (including domestic partner;  $N = 263$ ) and child (including child-in-law;  $N = 169$ ) caregivers using the same specifications as the primary analysis. These analyses were conducted separately as we were not adequately powered to test differences in the treatment effect between caregiver roles. To help with the interpretability of significant utilization outcomes, we fit linear regressions with the same specifications to estimate the change in expected visits over the 5 years and calculated the cumulative effect of the Care Ecosystem weighted by the number of active participants.

To examine the effect of the Care Ecosystem on nursing home placement, we fit Cox proportional-hazards models adjusting for baseline dementia severity.

Quantitative analyses were conducted with statistical software (R version 3.5.2 and Stata version 17). Two-sided  $p$ -values of  $< 0.05$  denoted statistical significance. We focused on the effect size and CI of each point estimate and did not formally adjust for multiple comparisons because we were examining multiple related outcomes and expected that statistically significant differences would reinforce rather than threaten our scientific hypothesis.

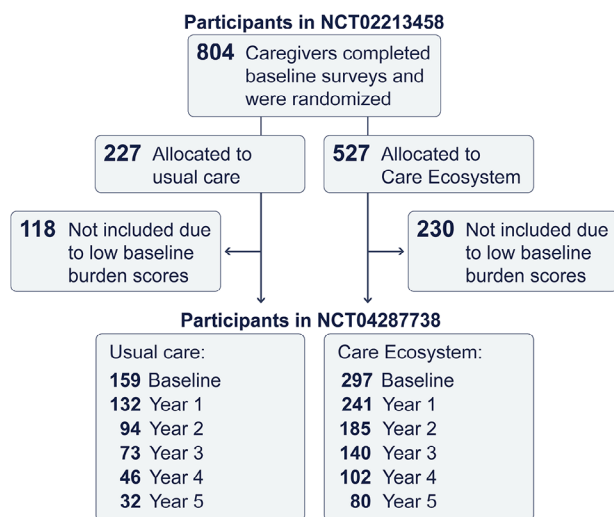
## 2.6 | Qualitative data collection and analyses

To qualitatively understand the benefit of the Care Ecosystem over time, a subset of caregivers who were active in the study after September 2021 were asked two questions about the perceived value of the Care Ecosystem program during their final telephone survey. The first close-ended question asked caregivers to select which statement best described their experience with the program: (1) it was helpful to be in the Care Ecosystem for the full 5 years, (2) the first year of the Care Ecosystem was the most helpful and staying in longer did not add a lot of value, or (3) the Care Ecosystem has not been helpful. The second open-ended question asked caregivers to elaborate, and responses were transcribed verbatim (Supplementary Material). Responses were exported into Excel and M.K. first familiarized herself with the responses and developed a preliminary codebook with code definitions. M.K. and A.B.S. then double coded the entire data set, meeting to revise the codebook, discuss and resolve any discrepancies in coding, and recode responses if needed. Overarching themes were developed based on the codes and were reviewed with K.L.P.

## 3 | RESULTS

Of 456 dyads with high caregiver burden at baseline that were included in the analytic cohort, 297 were randomized to the Care Ecosystem and 159 to usual care (Figure 1). At the end of the 5 years, there were 80 dyads that were active in the Care Ecosystem arm (27% of original cohort) and 32 dyads active in the usual care arm (28% of original cohort). The most common reason for study discontinuation was death of the PLWD (155 Care Ecosystem, 92 usual care) (Table S1). The mean time of active participation was  $37 \pm 19$  months. The survey completion rate was 85%.

Baseline characteristics were similar between the intervention and usual care arms (Table 1). The mean (SD) age was 77.7 (8.8) years for PLWDs and 63.9 (11.8) years for caregivers enrolled in the Care Ecosystem compared to 77.4 (13.9) and 63.3 (10.1) years, respectively, in usual care. At enrollment, most PLWDs had mild dementia (46.1% Care Ecosystem, 42.8% usual care), with the remaining having either moderate (28.3% Care Ecosystem, 28.3% usual care) or advanced (25.6% Care Ecosystem, 28.9% usual care) dementia. Most caregivers were female (75.1% Care Ecosystem, 79.2% usual care).



**FIGURE 1** Participant flow.

The 5-year cumulative effect of being randomized to the Care Ecosystem was associated with higher quality of life for the PLWDs (cumulative weighted *B*: 26.1 points, 95% CI: 0.08–52.2,  $p = 0.049$ ), higher caregiver self-efficacy (cumulative weighted *B*: 27.5 points, 95% CI: 13.4–41.7,  $p < 0.001$ ), and lower caregiver depression (cumulative weighted *B*: –24.0 points, 95% CI: –45.6 to –2.4,  $p = 0.03$ ). Caregiver burden was 37.5 points lower among dyads randomized to the Care Ecosystem, but this difference did not meet statistical significance (95% CI: –78.7 to 3.7,  $p = 0.07$ ). There was no difference in the number of ED visits and hospitalizations in the two arms (Table S2). The mean number of ED visits and hospitalization visits was less than 1 and usually less than 0.5 for each measured interval of the study period (Table S3).

The average, annual treatment effect of the Care Ecosystem on quality of life of the PLWD, caregiver depression, caregiver self-efficacy, and caregiver burden was significant through nearly every time point (Figure 2). Upon visual inspection, the average, annual effect of the Care Ecosystem on PLWD quality of life and caregiver burden was the highest at year 2, when randomization to Care Ecosystem was associated with a 0.62 point higher quality of life per year (95% CI: 0.02 to 1.21,  $p = 0.04$ ) and a 1.17 point lower caregiver burden per year (95% CI: –2.05 to –0.29,  $p = 0.01$ ), whereas the average, annual effect of the Care Ecosystem on caregiver self-efficacy and caregiver depression was the highest at year 1 when randomization to Care Ecosystem was associated with a 0.77 point lower caregiver depression per year (95% CI: –1.34 to –0.21,  $p = 0.01$ ) and a 0.75 point higher caregiver self-efficacy per year (95% CI: 0.37–1.14,  $p < 0.001$ ).

Upon visual inspection, the non-weighted treatment effects of the Care Ecosystem on quality of life of the PLWD, caregiver depression, caregiver self-efficacy, and caregiver burden (but not ED visits or hospitalizations) varied over time in a pattern similar to that of the average, annual treatment effects (Tables S4 and S5). The maximal non-weighted treatment effects for each outcome occurred within the first 2 years of the trial, and the effects plateaued or attenuated subsequently. Statistical testing of the trend over time was not per-

formed given the small sample size at later time points and inadequate statistical power.

We explored the cumulative effect of the Care Ecosystem separately for child and spouse caregivers on the study outcomes. For child caregivers, the cumulative effect on caregiver outcomes (depression, burden, and self-efficacy) were significant, but the PLWD outcomes (quality of life, hospitalizations, and ED visits) were not. A different pattern of treatment effects was found for the spouse caregivers: the cumulative effect on the PLWD's quality of life and hospitalization rate were significant, as well as caregiver self-efficacy, whereas the effect on caregiver depression, burden, and ED visits were not. The reduction in hospitalizations for PLWDs with spouse caregivers was equivalent to 1.3 avoided hospitalizations over the 5 years (95% CI: –2.0 to –0.5,  $p = 0.001$ ). (Please see Table S6.)

During the study period, 37 PLWDs in the Care Ecosystem arm and 17 in usual care were placed in a nursing facility, and 89 PLWDs in the Care Ecosystem arm and 44 in usual care were placed in long-term care. Due to the small number of placements, this analysis is underpowered. The Care Ecosystem was not associated with a significant delay in nursing facility placement (hazards ratio [HR]: 1.16, 95% CI: 0.65–2.06,  $p = 0.62$ ) or long-term care (HR: 1.12, 95% CI: 0.78–1.60,  $p = 0.56$ ) relative to usual care.

In the final telephone survey, 46 caregivers were asked one closed- and one open-ended question about the value of participating in the Care Ecosystem for a longer duration. Among the 33 (61.7%) who responded that all 5 years were helpful, themes derived from the free text responses focused on the value of the ongoing emotional and practical support provided. Among the eight (17.4%) who responded that the first year was the most helpful, themes derived from the open-ended responses indicated that the emotional and practical support provided by the program was not as helpful over time or as they became more settled in the caregiver role. One caregiver (2.2%) responded that the Care Ecosystem had not been helpful (Table S7).

## 4 | DISCUSSION

We present results from the first randomized clinical trial to evaluate the long-term effects of collaborative dementia care. In this 5-year extension of the Care Ecosystem trial<sup>27,41</sup> enrollment in the Care Ecosystem was associated with a sustained effect on quality of life of the PLWD, caregiver depression, and caregiver self-efficacy. The benefits of the collaborative dementia care were greatest during the first 2 years. When caregivers are new to the role, they experience emotional challenges related to their new responsibilities and planning for what to expect in the future. They must make decisions about how to provide medical care and make plans to oversee future medical, financial, and legal decisions. Collaborative care models with care navigation, such as the Care Ecosystem, provide support and education for caregivers to support them through these challenges. As the caregiver becomes more experienced with the role and knowledgeable about what to expect, the benefits of this support may decrease, although not diminish completely over 5 years.

**TABLE 1** Baseline demographic and clinical characteristics of persons living with dementia (PLWDs) and caregivers enrolled in the study.

A. PLWD		
	Care Ecosystem	Usual care
<b>N</b>	297	159
<b>Age, mean (SD)</b>	77.7 (8.8)	77.4 (13.9)
<b>Female, N (%)</b>	161 (54.2)	77 (48.4)
<b>Ethnicity, N (%)</b>		
Not Hispanic or Latino	256 (86.2)	138 (86.8)
Hispanic or Latino	41 (13.8)	21 (13.2)
<b>Race, N (%)</b>		
American Indian or Alaska Native	0 (0)	1 (0.6)
Asian	19 (6.4)	12 (7.5)
Black	12 (4.0)	3 (1.9)
Native Hawaiian or other Pacific Islander	2 (0.7)	0 (0)
White	235 (79.1)	131 (82.4)
Another race, unknown, or declined	28 (9.4)	12 (7.5)
<b>More than one race</b>		
White, American Indian or Alaska Native	1 (0.3)	0 (0)
<b>Preferred language, N (%)</b>		
Cantonese	4 (1.3)	3 (1.9)
English	271 (91.2)	150 (94.3)
Spanish	22 (7.4)	6 (3.8)
<b>Education N (%)</b>		
< 12 years	36 (12.1)	14 (8.8)
12 years	61 (20.5)	31 (19.5)
13–15 years	57 (19.2)	30 (18.9)
≥ 16 years	143 (48.1)	84 (52.8)
<b>State of residence, N (%)</b>		
California	189 (63.6)	93 (58.5)
Nebraska	97 (32.7)	54 (33.9)
Iowa	11 (3.7)	12 (7.5)
<b>Annual household income, N (%)</b>		
< \$15,000	3 (1.0)	5 (3.1)
\$15,000–\$49,999	76 (25.6)	27 (17.0)
\$50,000–\$99,999	72 (24.2)	46 (28.9)
\$100,000–\$149,999	38 (12.8)	22 (13.8)
≥ \$150,000	29 (9.8)	18 (11.3)
Don't know or refused	14 (4.7)	14 (8.8)
<b>QDRS dementia stage, N (%)<sup>a</sup></b>		
Mild ( $1.5 \leq x < 12.5$ )	137 (46.1)	68 (42.8)
Moderate ( $12.5 \leq x < 17.5$ )	84 (28.3)	45 (28.3)
Advanced ( $x \leq 17.5$ )	76 (25.6)	46 (28.9)

(Continues)

**TABLE 1** (Continued)

A. PLWD		
	Care Ecosystem	Usual care
<b>Charlson comorbidity score, mean (SD)<sup>b</sup></b>	2.56 (2.64)	2.22 (2.48)
<b>Comorbidities, N (%)</b>		
Cardiovascular	85 (28.6)	35 (22.0)
Arthritis/rheumatism	133 (44.8)	63 (39.6)
Depression	131 (44.1)	63 (39.6)
Stroke	55 (18.5)	22 (13.8)
Diabetes	44 (14.8)	22 (13.8)
<b>B. Caregivers</b>		
	Care Ecosystem	Usual care
<b>N</b>	297	159
<b>Age, mean (SD)</b>	63.9 (11.8)	63.3 (10.1)
<b>Female, N (%)</b>	223 (75.1)	126 (79.2)
<b>Ethnicity, N (%)</b>		
Not Hispanic or Latino	257 (86.5)	142 (89.3)
Hispanic or Latino	40 (13.5)	17 (10.7)
<b>Race, N (%)</b>		
American Indian or Alaska Native	0 (0)	0 (0)
Asian	22 (7.4)	11 (6.9)
Black	9 (3.0)	3 (1.9)
Native Hawaiian or other Pacific Islander	2 (0.7)	1 (0.6)
White	235 (79.1)	132 (83.9)
Another race, unknown, or declined	27 (9.1)	11 (6.9)
<b>More than one race</b>		
White, Asian	1 (0.3)	1 (0.6)
White, Native Hawaiian, or other Pacific Islander	1 (0.3)	0 (0)
<b>Preferred language, N (%)</b>		
English	280 (94.2)	151 (95.0)
Spanish	12 (4.0)	5 (3.1)
Cantonese	5 (1.7)	3 (1.9)
<b>Education N (%)</b>		
< 12 years	10 (3.4)	6 (3.8)
12 years	20 (6.8)	17 (10.7)
13–15 years	70 (23.6)	31 (19.5)
≥ 16 years	197 (66.3)	105 (66.0)
<b>Caregiver relationship, N (%)</b>		
Wife	112 (37.7)	71 (44.7)
Husband	48 (16.2)	21 (13.2)
Non-binary spouse	1 (0.3)	0 (0)
Unknown gender spouse	1 (0.3)	0 (0)

(Continues)

**TABLE 1** (Continued)

B. Caregivers		
	Care Ecosystem	Usual care
Domestic partner	2 (0.7)	4 (2.5)
Daughter	91 (30.6)	45 (28.3)
Son	20 (6.7)	10 (6.3)
Sibling	9 (3.0)	0 (0)
Other family	2 (0.7)	2 (1.3)
Hired caregiver	1 (0.3)	0 (0)
Friend	2 (0.7)	3 (1.9)
Neighbor	0 (0)	0 (0)
Other	8 (2.7)	3 (1.9)
Depressive symptoms, N (%) <sup>c</sup>		
None (PHQ-9 < 5)	126 (42.4)	70 (44.0)
Mild (5 ≤ PHQ-9 < 10)	101 (34.0)	59 (37.1)
Moderate to severe (PHQ-9 ≥ 10)	70 (23.6)	30 (18.9)

<sup>a</sup>Calculated using the caregiver-reported Quick Dementia Rating Scale.<sup>47</sup>

<sup>b</sup>Calculated using the self-reported Charlson comorbidity index using the highest possible Charlson weight<sup>48</sup>.

<sup>c</sup>Defined by the 9-item Patient Health Questionnaire (PHQ-9).

PLWDs with a spouse caregiver experienced significant improvements in quality of life and fewer hospitalizations over the 5-year period, whereas adult child caregivers experienced improvements in caregiver burden and depression. Both spouse and child caregivers experienced improvements in self-efficacy. The emotional impact of dementia caregiving may be different for spouses and children. Spouses often face profound emotional strain due to the loss of their partner's previous identity and the shift in relationship dynamics, whereas child caregivers may be more likely to struggle with juggling caregiving with other responsibilities, such as work and raising their own families, while also experiencing the toll of witnessing a parent's decline. It may be that the Care Ecosystem model, which includes care coordination and connecting caregivers with resources including respite services, was more effective at reducing the types of burden and depression experienced by child caregivers. On the other hand, the effect on outcomes for the PLWD (quality of life, hospitalizations) were significant only in the spouse subgroup. A possible explanation is that spouse caregivers may be more directly involved in the day-to-day care and thus more affected by changes in caregiver strategies that benefit the PLWD.

Apart from reduced hospitalization rates for PLWD with spouse caregivers, we did not find that the Care Ecosystem impacted 5-year health care utilization. Direct health care costs attributable to dementia are highest early in the disease, with nearly 50% of costs to Medicare incurred in the year after diagnosis and decreasing with disease duration.<sup>42,43</sup> Hospitalizations in dementia are more common when the caregiver is new to the caregiver role (< 1 year) versus more experienced (4 years or longer in the role).<sup>22</sup> The opportunity to impact health care utilization and costs in dementia with caregiver education

and support may be highest, therefore, when the caregiver is new to the role and relatively inexperienced. The null effect could also be explained by low utilization during the year before enrollment (Table S3), the nature of comorbidities in our sample, and system-level factors including the availability of other ongoing care received by PLWDs in both groups.

Participation in the Care Ecosystem was not associated with nursing facility or long-term care placement. Two factors may have impacted our study results on this outcome. First, the extension of the Care Ecosystem trial overlapped with the coronavirus disease 2019 (COVID-19) pandemic. Participants reached their 5 years of participation between 2020 and 2022, when caregivers were avoiding nursing facility placement due to concerns about exposing the PLWDs to COVID-19 and the inability to visit and take part in care.<sup>44</sup> Only 12% of PLWDs were placed in a nursing facility and 29% in long-term care during this study, and so we were underpowered to evaluate this prespecified outcome. Second, it was not an explicit goal of the Care Ecosystem to delay placement. When placement was aligned with the family's goals or was considered the safest option for the PLWD or their caregiver, the clinical teams supported families in their decisions around when and where to place and assist with the care transition including providing support with difficult emotions like guilt. In this way, the Care Ecosystem helped facilitate placement for some families when the time was right for them, which may have been particularly important during the pandemic.<sup>29</sup>

There are limitations. Our power to detect treatment effects on health care utilization was limited by our relatively small sample size for this type of analysis: our sample started at 456 but decreased to 112 by the end of the study period, primarily due to death. Prior studies that have reported a beneficial effect of collaborative dementia care on health care utilization or costs, including with the Care Ecosystem, have had a larger sample size.<sup>29,33,41</sup> Another limitation was that end-of-life health care utilization was not available for inclusion in this analysis. Finally, although we did enrich our sample for Latino participants following the 12-month trial and provided care in Spanish and Cantonese, most participants were non-Hispanic White ( $N = 339$ ; 74%). More research is needed to evaluate the effects of collaborative care on dyads from underrepresented racial and ethnic groups.

In summary, we found that the benefits of collaborative dementia care with care navigation are sustained over 5 years, and that the most robust benefits occur in the first 2 years after care is initiated. The long-term benefits observed by this study on person-centered outcomes for PLWDs and caregivers strongly support the review of these interventions by the National Academies of Sciences, Engineering, and Medicine review and conclusion that collaborative dementia care is ready for broad implementation.<sup>24</sup> Furthermore, these results have implications for how this dementia care is implemented. Health systems and community-based organizations are increasingly implementing collaborative dementia care with care navigation funded by CMS's GUIDE alternative payment model, Medicare Advantage plans, grant funding, and philanthropy.<sup>45-47</sup> When evaluating the costs and benefits of approaches to implement collaborative dementia care, these results will be important for guiding decisions about how to allocate limited



**Patient Quality of Life**

year 1	0.33 (-0.35, 1.01)
years 1-2	0.62 (0.02, 1.21)
years 1-3	0.55 (0.03, 1.07)
years 1-4	0.47 (-0.002, 0.94)
years 1-5	0.44 (0.001, 0.87)

**Caregiver Self-Efficacy**

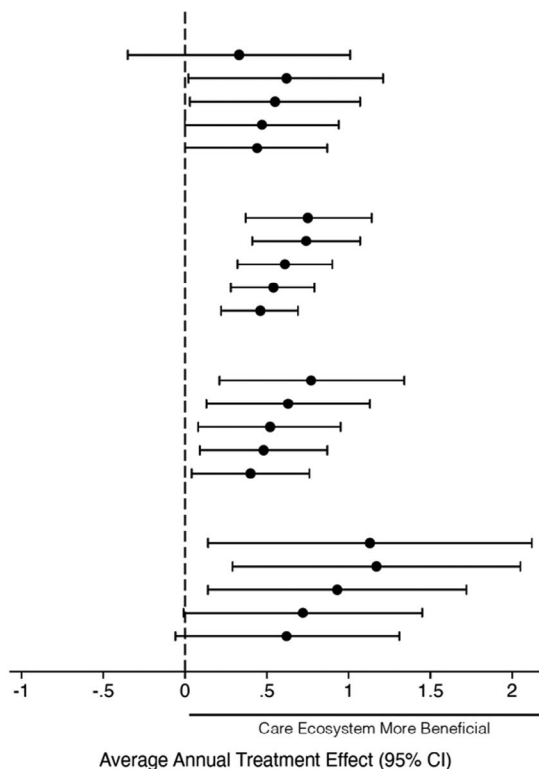
year 1	0.75 (0.37, 1.14)
years 1-2	0.74 (0.41, 1.07)
years 1-3	0.61 (0.32, 0.90)
years 1-4	0.54 (0.28, 0.79)
years 1-5	0.46 (0.22, 0.69)

**Caregiver Depression**

year 1	0.77 (0.21, 1.34)
years 1-2	0.63 (0.13, 1.13)
years 1-3	0.52 (0.08, 0.95)
years 1-4	0.48 (0.09, 0.87)
years 1-5	0.40 (0.04, 0.76)

**Caregiver Burden**

year 1	1.13 (0.14, 2.12)
years 1-2	1.17 (0.29, 2.05)
years 1-3	0.93 (0.14, 1.72)
years 1-4	0.72 (-0.01, 1.45)
years 1-5	0.62 (-0.06, 1.31)



**FIGURE 2** Annualized weighted treatment effect of the care ecosystem over time. Caregiver depression and caregiver burden outcomes have been inverted so that for all outcomes, an increase above 0 denotes that the Care Ecosystem is more beneficial than usual care. The average treatment effect weighted for the proportion of active participants and adjusted for dementia severity are plotted with 95% confidence intervals.

resources, including how long to provide care, and how long to evaluate new programs. We recommend that clinical team members encourage dyads to participate in care for at least 2 years to get a maximum benefit. Afterward, there may be a role for care navigators to connect with caregivers less frequently, being available to help on an as-needed basis, although this approach will require refinement with future research and experience with longer-term collaborative dementia care.

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**CONFLICT OF INTEREST STATEMENT**

Bruce Miller reported serving on the Scientific Advisory Boards of The Bluefield Project to Cure FTD, the John Douglas French Alzheimer's

Foundation, Genworth Inc., the Larry L. Hillblom Foundation, the Kissick Family Foundation, and the Tau Consortium of the Rainwater Charitable Foundation; serving on the External Scientific Advisory Committees of the Arizona Alzheimer's Consortium, Massachusetts General Brigham Alzheimer's Disease Research Center (ADRC), and the Stanford ADRC; receiving royalties from Guilford Press, Cambridge University Press, Johns Hopkins Press, and Oxford University Press; serving as editor for *Neurocase*; serving as section editor for *Frontiers in Neurology*; and receiving grants P01 AG019724 and R01 AG057234 from the National Institutes of Health (NIH) and P0544014 from the Bluefield Project to Cure FTD. No other conflicts were reported. Author disclosures are available in the [Supporting Information](#).

**CONSENT STATEMENT**

All participants provided informed consent before participation.

**TRIAL REGISTRATION**

ClinicalTrials.gov NCT04287738

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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