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## Effect of Collaborative Dementia Care via Telephone and Internet on Quality of Life, Caregiver Well-being, and Health Care Use

The Care Ecosystem Randomized Clinical Trial

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This randomized clinical trial assesses the effects of dementia care provision via telephone and internet on key outcomes for persons with dementia and their caregivers in rural and urban regions of 3 states compared with usual care.

## Key Points

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### Question

Does the Care Ecosystem, a program for collaborative dementia care delivered over the telephone and internet, improve outcomes important to persons with dementia, their caregivers, and payers?

## Findings

In this randomized clinical trial of 1560 participants in rural and urban regions of 3 states, the Care Ecosystem improved quality of life of persons with dementia, reduced emergency department visits, and decreased caregiver depression and burden.

## Meaning

This study's findings show that dementia care management delivered from centralized hubs over the telephone and internet could mitigate the growing societal and economic burdens of dementia.

## Abstract

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### Importance

Few health systems have adopted effective dementia care management programs. The Care Ecosystem is a model for delivering care from centralized hubs across broad geographic areas to caregivers and persons with dementia (PWDs) independently of their health system affiliations.

### Objective

To determine whether the Care Ecosystem is effective in improving outcomes important to PWDs, their caregivers, and payers beyond those achieved with usual care.

### Design, Setting, and Participants

A single-blind, randomized clinical trial with a pragmatic design was conducted among PWDs and their caregivers. Each PWD-caregiver dyad was enrolled for 12 months between March 20, 2015, and February 28, 2017. Data were collected until March 5, 2018. Study interventions and assessments were administered over the telephone and internet by clinical and research teams in San Francisco, California, and Omaha, Nebraska. Of 2585 referred or volunteer PWD-caregiver dyads in California, Iowa, or Nebraska, 780 met eligibility criteria and were enrolled. A total of 512 PWD-caregiver dyads were randomized to receive care through the Care Ecosystem and 268 dyads to receive usual care. All eligible PWDs had a dementia diagnosis; were enrolled or eligible for enrollment in Medicare or Medicaid; and spoke English, Spanish, or Cantonese. Analyses were intention-to-treat.

### Intervention

Telephone-based collaborative dementia care was delivered by a trained care team navigator, who provided education, support and care coordination with a team of dementia specialists (advanced practice nurse, social worker, and pharmacist).

### Main Outcomes and Measures

Primary outcome measure: Quality of Life in Alzheimer's Disease based on caregiver's rating of 13 aspects of PWD's well-being (including physical health, energy level, mood, living situation, memory, relationships, and finances) on a 4-point scale (poor to excellent). Secondary outcomes: frequencies of PWDs' use of emergency department, hospitalization, and ambulance services; caregiver depression (score on 9-Item Patient Health Questionnaire; higher scores indicate more severe depression); and caregiver burden (score on 12-Item Zarit Burden Interview; higher scores indicate more severe caregiver burden).

### Results

The 780 PWDs (56.3% female; mean [SD] age, 78.1 [9.9] years) and 780 caregivers (70.9% female; mean [SD] age, 64.7 [12.0] years) lived in California ( $n = 452$ ), Nebraska ( $n = 284$ ), or Iowa ( $n = 44$ ). Of 780 dyads, 655 were still active at 12 months, and 571 completed the 12-month survey. Compared with usual care, the Care Ecosystem improved PWD quality of life ( $B, 0.53$ ; 95% CI, 0.25-1.30;  $P = .04$ ), reduced emergency department visits ( $B, -0.14$ ; 95% CI, -0.29 to -0.01;  $P = .04$ ), and decreased caregiver depression ( $B, -1.14$ ; 95% CI, -2.15 to -0.13;  $P = .03$ ) and caregiver burden ( $B, -1.90$ ; 95% CI, -3.89 to -0.08;  $P = .046$ ).

### Conclusions and Relevance

Effective care management for dementia can be delivered from centralized hubs to supplement usual care and mitigate the growing societal and economic burdens of dementia.

## Trial Registration

ClinicalTrials.gov identifier: [NCT02213458](#)

## Introduction

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Dementia is a public health challenge with often devastating consequences for persons with dementia (PWDs) and their caregivers.<sup>1</sup> Persons with dementia experience frequent emergency department (ED) visits and hospitalizations,<sup>2,3</sup> multiple care transitions,<sup>4,5</sup> inappropriate and potentially harmful medication use,<sup>6</sup> and aggressive end-of-life care that is often inconsistent with their values.<sup>7</sup> There are substantial geographic disparities in access to dementia specialist care.<sup>8</sup> Furthermore, most health care systems lack sufficient integration and communication across medical teams, social service agencies, and other community resources to meet dementia-related needs.<sup>9</sup> The challenges of navigating a health care system, accessing resources, and providing day-to-day care usually fall on informal caregivers,<sup>10</sup> whose needs are unmet by patient-centric health care models.<sup>11</sup> As dementia progresses, caregiver burden and patient quality of life worsen,<sup>12,13</sup> increasing the risk of unnecessary hospitalizations and premature placement in long-term care.<sup>14,15</sup>

Our objective in this randomized clinical trial was to test the effectiveness of the Care Ecosystem, a telephone- and internet-based dementia care delivery system designed to fulfill the unmet needs of PWDs, caregivers, and payers by extending the reach of the limited dementia specialist workforce to rural areas, accommodating new payment models, and aligning with initiatives by the Centers for Medicare & Medicaid Services for better health, better care, and lower costs.<sup>16</sup>

## Methods

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### Trial Design

This was a single-blind, parallel-group pragmatic randomized clinical trial with imbalanced randomization (2:1 ratio between Care Ecosystem and usual care)<sup>17,18,19</sup> ([Figure 1](#) and [Figure 2](#)). The full trial protocol is available in [Supplement 1](#). No changes were made to the study design or eligibility criteria after trial commencement. The program was administered from 2 hubs: the University of California, San Francisco (UCSF), for all PWDs living in California, and the University of Nebraska Medical Center (UNMC), Omaha, for those in Nebraska or Iowa. All care and research procedures were administered to the PWD and caregiver in their preferred language (English, Spanish, or Cantonese). The study protocol and consent materials were approved by the UCSF and UNMC Institutional Review Boards. The PWDs with capacity to provide informed consent were given the opportunity to consent for themselves; otherwise, consent was obtained from a legally authorized representative. Caregivers also consented to enrollment. Consent was provided with written or electronic (digital) signature. Following consent, caregivers completed a baseline telephone survey and then were randomized to either the Care Ecosystem or usual care group. For randomization sequence generation details, see the eMethods in [Supplement 2](#).

### Participants

Participants were enrolled from March 20, 2015, to February 28, 2017, and data were collected until March 5, 2018. Participants were referred by treating providers or were self-referred after learning about the study at a community outreach event, in the news, or on the internet. Once referred, prospective participants were telephoned by a research coordinator who described the study and screened them for eligibility. Of 2585 referred or volunteer PWD-caregiver dyads in California, Iowa, or Nebraska, 780 met eligibility criteria and were enrolled. A total of 512 PWD-caregiver dyads were randomized to receive care through the Care Ecosystem and 268 dyads to receive usual care. Eligibility criteria for PWDs followed a pragmatic approach to include anyone who would be likely to be a candidate for the intervention if it were provided in usual care.<sup>17</sup> These criteria were a dementia diagnosis made by a treating provider; age older than 45 years; enrollment in, or eligibility for enrollment in, Medicare or Medicaid; California, Nebraska, or Iowa residence; and the presence of an identified caregiver who agreed to co-enroll. Eligibility criteria for both the PWD and caregiver required fluency in English, Spanish, or Cantonese. Persons with dementia living in a nursing home at the time of screening were excluded. As shown in [Figure 3](#), PWDs throughout the states of California, Nebraska, and Iowa—from both urban (primarily the San Francisco Bay and Omaha areas) and rural areas—were enrolled in the study.

### Interventions

The Care Ecosystem is a telephone- and internet-based supportive care intervention for dementia delivered by care team navigators (CTNs) and dementia expert providers (advanced-practice nurse, social worker, and pharmacist).<sup>18,19</sup> Participants randomized to the Care Ecosystem were informed by telephone about their randomization result by their CTN. The CTN is an unlicensed, trained

dementia care guide who served as the PWD's and caregiver's primary point of contact to the program under nurse supervision. Care team navigators responded to caregivers' immediate needs first, then screened for common problems and provided personalized support and standardized education using the care plan protocols ([Figure 2](#)).<sup>18,19,20</sup> Care team navigators telephoned dyads approximately monthly for 12 months. This frequency was adjusted according to each dyad's needs and preferences. The mean (SD) number of telephone calls per dyad was 15.3 (11.9) (median, 12; interquartile range, 8-19 calls). Additional contact was provided via email and mail, and dyads were encouraged to contact their CTN with any dementia-related concerns. Participants who declined regular CTN contact were offered a "light" version of the intervention: they were sent personalized educational materials via mail or email and told they could contact the CTN if needed. A bilingual CTN was assigned to dyads in which the PWD or the caregiver preferred to speak Spanish or Cantonese. The CTNs' mean monthly caseloads between September 2016 and May 2017 were 49 (range, 44-79) cases at UNMC and 35 (range, 28-41) cases at UCSF, and the maximum caseload for a CTN was 90 cases. Longer continuity of the CTN-dyad relationships at UNMC allowed for higher efficiency.<sup>21</sup>

At each hub, a full-time advanced-practice nurse and social worker were co-located with the CTNs, and a pharmacist was available part-time.<sup>21</sup> These expert health care professionals were available for situations beyond the CTN's scope, such as medical needs, problematic behavioral symptoms, complex legal or financial circumstances, and safety concerns. The specialists addressed these situations through consultation with the CTN, direct consultation with the dyad, or care coordination with outside health care and service professionals. The level of interaction with outside professionals was determined by caregivers' preference and the responsiveness of the outside professional. Direct calls with outside professionals were usually conducted by the nurse, social worker, or pharmacist with the CTN present. The CTN discussed all new cases and ongoing challenging cases with the nurse and social worker during weekly case reviews and supervision. The pharmacist reviewed all medication lists at enrollment and consulted via telephone and secure messaging when medication changes, questions, or problems arose. Pharmacist recommendations were sent by the CTN to prescribing providers via secure facsimile and were also sent to and discussed with caregivers. The nurse assisted with communicating medication recommendations for most cases.

Care team navigators were hired for their strong communication and listening skills and an interest in helping people. To prepare for their role, they underwent 40 hours of focused training through video-recorded or in-person lectures, assigned reading, and clinical observation. Ongoing training occurred during weekly case reviews and supervision conversations. The expert health care professionals (nurse, social worker, and pharmacist) were selected based on their prior experience, training, and interest in dementia. They reviewed the care model and protocols. The nurse-supervisors at both sites also completed all of the CTN training to prepare them for their supervisory role.

Participants randomized to usual care were informed by telephone about the randomization result and were offered contact information for the Family Caregiver Alliance, Alzheimer's Association, and Area Agencies on Aging. These participants were sent quarterly newsletters with general dementia-related articles, staff biographies, and word games.

All caregivers were invited to complete telephone surveys in their preferred language at baseline and at 6 and 12 months after randomization. Caregivers who reported significant depressive symptoms on the surveys were offered specific resources (eMethods in [Supplement 2](#)). Caregivers received a \$25 gift card for every completed follow-up survey. Birthday cards were mailed to all PWDs and caregivers. All PWDs continued to receive usual health care and services from other professionals.

## Outcomes

All outcomes were based on answers to telephone surveys administered to caregivers by research coordinators who were blinded to the study group assignment. The primary outcome measure was the Quality of Life in Alzheimer's Disease (QoL-AD) score based on caregiver interview.<sup>22</sup> Using an ordinal scale of 1 to 4 (poor, fair, good, or excellent), caregivers rated the following 13 aspects of PWD quality of life: physical health, energy level, mood, living situation, memory, family, closest relationship, friends, self, ability to do things for fun, finances, and life as a whole. Quality of life was recently ranked as the most important domain for outcome measurement in palliative care by an international expert consensus workshop,<sup>23</sup> and the QoL-AD measure in particular was recommended by an empirically based consensus study as the measure of choice for evaluating patient quality of life in dementia intervention studies.<sup>24</sup> Scores on the QoL-AD scale can range from 13 to 52, with a higher score representing a better quality of life. Secondary outcomes that also focused on the PWD were frequencies of ED, hospital, and ambulance use by the PWD (eMethods in [Supplement 2](#)). Secondary outcomes that focused on the caregiver were depression score (from the 9-Item Patient Health Questionnaire [PHQ-9]; range, 0-27, with higher scores indicating more severe depression),<sup>25</sup> caregiver burden score (using the 12-Item Zarit Burden Interview; range, 0-48, with higher scores indicating more severe caregiver burden),<sup>26</sup> and caregiver self-efficacy.<sup>27</sup> Moderate to severe depression was defined by a PHQ-9 score of 10 or higher. The outcomes were evaluated at baseline and at 6 and 12 months after randomization. Caregivers enrolled in the Care Ecosystem also were asked to rate their level of satisfaction with the intervention at the end of the 12-month outcome survey. Measures were described in a prior publication<sup>19</sup> and are described in more detail in the eMethods in [Supplement 2](#).

## Blinding

All outcomes were assessed by research coordinators who were blind to treatment group assignment, with the exception that when completing each 12-month survey call, the coordinator was unblinded to the randomization status of that dyad. If the dyad was in the Care Ecosystem group, the questions relating to caregiver satisfaction were asked.

## Statistical Methods

To evaluate treatment effects, we used linear mixed-effects models in the intention-to-treat sample. Covariates were baseline dementia severity,<sup>28</sup> treatment group (usual care, 0; Care Ecosystem, 1), and time (baseline, 6 months, and 12 months). The random effect was included to capture participant-specific effects. To evaluate for treatment effect, an interaction term between treatment group and time was included, and unstandardized beta ( $B$ ) coefficients and confidence intervals for the interaction are reported to represent the magnitude of the treatment effect (treatment group multiplied by time) on each outcome, taking into account the effects of the other variables in the model (baseline dementia severity and the random effect). Treatment effects for PWD outcomes were hypothesized to occur at 12 months after randomization, and treatment effects for caregiver outcomes, at 6 and 12 months, in accordance with the timeline of care, in which caregiver needs were addressed before action was taken to address PWD needs (eMethods in [Supplement 2](#)). A 2-sided  $P$  value of  $\leq .05$  was used as the criterion for statistical significance. Multiple comparison adjustments were not applied because there was a single prespecified primary outcome and the secondary outcome results followed a coherent pattern that was supportive of the primary outcome result.<sup>29</sup> Methods for estimating cost savings attributable to the Care Ecosystem and the number of caregivers whose depression was mitigated by the Care Ecosystem are detailed in the eMethods in [Supplement 2](#). Analyses were conducted with statistical software (SPSS, version 25 [IBM], and Stata, version 15.2 [StataCorp]) by 2 of us (K.L.P. and I.E.A.). Satisfaction results are presented using descriptive statistics.

## Results

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### Participant Flow

Among the 780 PWDs, 439 (56.3%) were female. The PWDs' mean (SD) age was 78.1 (9.9) years. Among the 780 caregivers, 553 (70.9%) were female. The caregivers' mean (SD) age was 64.7 (12.0) years. Of the 780 dyads, 452 resided in California, 284 in Nebraska, and 44 in Iowa. Other baseline demographics and clinical characteristics are presented in [Table 1](#). Following the baseline survey, the 780 dyads were randomly assigned to either the Care Ecosystem ( $n = 512$ ) or usual care ( $n = 268$ ). Of the 512 dyads randomized to the Care Ecosystem, the intervention dosage per dyad preference was as follows: 463 received the full intervention, 27 received the light version, 10 shifted between the full and light versions, and 12 did not receive the intervention. Among active participants, 6-month survey completion rates were 93% for Care Ecosystem and 92% for usual care, and 12-month completion rates were 87% for Care Ecosystem and 88% for usual care ([Figure 1](#)). Participants who no longer met criteria were disenrolled. Specific reasons for disenrollment were that the enrolled caregiver was either too ill to participate or had died (Care Ecosystem, 3; usual care, 1), the caregiver was no longer caregiving (Care Ecosystem, 1; usual care, 0), or the PWD relocated outside of California, Nebraska, or Iowa (Care Ecosystem, 4; usual care, 0).

### Numbers Analyzed

The dementia severity measure<sup>28</sup> was not published until shortly after we initiated our study, so dementia severity data from baseline are missing for 15 of the 780 dyads. Three participating dyads were each missing data on a single baseline variable (number of ED visits, ambulance use, and quality of life). For these reasons, the sample size analyzed for these measures varies from 764 to 765. Sensitivity analyses were performed with mean imputation for missing baseline data from all 780 dyads, and the results were nearly identical.

The numbers analyzed for the caregiver satisfaction questions are provided in the eMethods ([Supplement 2](#)).

### Primary Outcome

The primary outcome, PWD quality of life, declined more in the usual care group than in the Care Ecosystem group from the baseline survey to the 12-month survey ( $B, 0.53$ ; 95% CI, 1.30-0.25;  $P = .04$ ) ([Table 2](#)).

### Secondary Outcomes

**PWD Hospitalization and Use of Emergency Services** The rate of ED visits over a 12-month period increased less in the Care Ecosystem group than in the usual care group ( $B, -0.14$ ; 95% CI, -0.29 to -0.01;  $P = .04$ ). The number needed to treat to prevent a single ED visit was 5. Treatment effects on rates of ambulance use ( $B, -0.10$ ; 95% CI, -0.23 to 0.03;  $P = .12$ ) and hospital use ( $B, -0.03$ ; 95% CI, -0.18 to 0.12;  $P = .71$ ) were not statistically significant. Although we had not planned to include treatment effect on physician or nurse practitioner outpatient visit rates as a study outcome, we explored whether such an effect was present (eMethods in [Supplement 2](#)); it was not ( $B, -0.09$ ; 95% CI, -0.33 to 0.15;  $P = .46$ ). When we compared hospital and emergency services use by

PWDs in the Care Ecosystem with expected use based on usual care data, we found that the Care Ecosystem intervention prevented 120 ED visits, 16 ambulance use events, and 13 hospitalizations over a 12-month period. Based on national average costs for provision of these services to PWDs, we estimated a mean cost savings of \$600 per PWD across these 3 service types. Cost savings accrued during the latter 6 months of enrollment.

**Caregiver Outcomes** Caregiver depression scores declined more in the Care Ecosystem than in usual care between baseline and 12 months ( $B, -1.14$ ; 95% CI,  $-2.15$  to  $-0.13$ ;  $P = .03$ ) points. The 6-month treatment effect on depression was also statistically significant ( $B, -0.87$ ; 95% CI,  $-1.44$  to  $-0.30$ ;  $P < .001$ ). The frequency of moderate to severe depression increased slightly in the usual care group, from 16 caregivers (8.0%) at 6 months to 22 (11.1%) at 12 months after baseline ( $P = .22$ ), but decreased in the Care Ecosystem group, from 49 caregivers (13.4%) at baseline to 29 caregivers (7.9%) at 12 months ( $P = .004$ ). Given the expected change in depression frequency as defined by the usual care data, the Care Ecosystem appeared to mitigate depression in the moderate to severe range for 43 caregivers; the number needed to treat in order to mitigate depression for 1 caregiver was 12. The self-efficacy scores increased more in the Care Ecosystem group than in the usual care group at 6 months from baseline ( $B, 0.86$ ; 95% CI, 0.42-1.29 points;  $P < .001$ ). Most of this increase was maintained at 12 months, but the 12-month treatment effect was not statistically significant ( $B, 0.64$ ; 95% CI, 0.14-1.41;  $P = .11$ ). Caregiver burden declined more in the Care Ecosystem group than in the usual care group at 12 months ( $B, -1.90$ ; 95% CI,  $-3.89$  to  $-0.08$ ;  $P = .046$ ); the 6-month treatment effect was also statistically significant ( $B, -1.51$ ; 95% CI  $-2.63$  to  $-0.39$ ;  $P = .008$ ). Results for treatment effects on all primary and secondary outcomes are reported in [Table 2](#).

Ninety-seven percent of the Care Ecosystem caregivers surveyed (309 of 320 respondents) reported that they would recommend the Care Ecosystem to another caregiver. When asked to rate their satisfaction with Care Ecosystem services, 45.4% (148 of the 325 who responded) indicated that they were very satisfied, and 32.9% (107 of 325), that they were satisfied. A total of 57 (17.5%) were neutral, while 9 (2.8%) were unsatisfied and 4 (1.2%) were very unsatisfied.

## Discussion

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In this single-blind, randomized, pragmatic trial of the Care Ecosystem that included community-dwelling PWDs and their caregivers throughout California, Nebraska, and Iowa, we found that the Care Ecosystem significantly improved PWD quality of life. The treatment reduced the frequency of ED visits and did not significantly affect hospitalization or ambulance use frequencies. For caregivers, the Care Ecosystem was associated with improvements in caregiving burden, depression, and self-efficacy at 6 months, and the treatment effects were maintained for burden and depression at 12 months. To prevent 1 visit by a PWD to the ED and 1 moderate to severe caregiver depression, the numbers needed to treat were 5 and 12, respectively. Most caregivers were satisfied with the intervention, and 97% reported that they would recommend the program to another caregiver.

The development of the Care Ecosystem<sup>19</sup> was deeply informed by innovative dementia care programs with proven efficacy that directly address unmet needs of both the PWD and the caregiver. In the UCLA (University of California, Los Angeles) Alzheimer's and Dementia Care Program, nurse practitioners and physicians create and implement individualized dementia care plans that address PWD and caregiver needs via office, telephone, and home visits. The UCLA program demonstrated improved care quality in a fee-for-service academic health system with reduced admissions to long-term care facilities and was estimated to be cost neutral.<sup>32,33</sup> The Partners in Dementia Care program, a collaboration between several Veterans Affairs medical centers and the Alzheimer's Association to address needs reported by PWDs and their caregivers, found reductions in ED visits and hospitalizations among intervention participants with higher cognitive function and fewer behavioral symptoms.<sup>34</sup> Indiana University's Aging Brain Care Program<sup>35</sup> provided support and care coordination in the home for persons with mild cognitive impairment, dementia, and/or depression, with a resultant decrease in overall costs within an integrated safety-net health care system. A program launched by Johns Hopkins University, Maximizing Independence at Home, used unlicensed community workers as frontline staff to deliver multicomponent home-based care coordination. Although rates of use of emergency and inpatient care services were not affected by this program, use of dementia-related outpatient medical care and nonmedical supportive community services that may delay long-term care placement was increased.<sup>36</sup> A home-based, nurse-led dementia care management program in Germany reduced caregiver burden and decreased behavioral and psychiatric symptoms in PWDs.<sup>37</sup> Several interventions that focused on addressing caregiver needs have shown improved caregiver and PWD outcomes, including reduced PWD use of health care services and delayed long-term care placement.<sup>15,38,39,40</sup> Though innovative and effective programs exist that could improve outcomes for PWDs, caregivers, and payers, they have not yet been widely adopted.<sup>41</sup>

There are unique features of the Care Ecosystem that offer unprecedented scalability. First, the Care Ecosystem addresses both PWD and caregiver needs without face-to-face visits. Persons with dementia and caregivers who are homebound or who live long distances from specialist centers can easily access dementia specialist services. Second, CTNs are the first point of contact, with an expanded role that includes monitoring health status, reviewing medications, providing caregiver support and education, and guiding families through advance care planning.<sup>20</sup> Licensed dementia specialists only performed work that required their specific expertise, which is cost-efficient and expands the impact of the limited dementia specialist workforce.<sup>8</sup> Third, the Care Ecosystem model may be uniquely well aligned with new, complex chronic care management codes that govern reimbursement for unlicensed clinical staff time, including non-face-to-face visits, under physician or nurse practitioner supervision.<sup>42</sup> The CTNs would need to maintain caseloads greater than 50 for adequate reimbursement.<sup>21</sup> Additional reimbursement opportunities include value-based and alternative

payment models that incentivize quality and lower costs<sup>43,44,45</sup> as well as a dementia risk adjustment planned by the Centers for Medicare & Medicaid Services that will provide higher payments for Medicare Advantage beneficiaries with a dementia diagnosis starting in 2020.<sup>46</sup> These payment models offer opportunities for health systems to invest in effective programs, such as the Care Ecosystem, to attend to PWD and caregiver needs before they escalate to emergency levels.<sup>47</sup> Fourth, the Care Ecosystem can be delivered either from a centralized hub to PWDs affiliated with multiple health systems, as was done in this trial and the Maximizing Independence at Home trial,<sup>36</sup> or integrated within a single health system, as has been done with most similar models for collaborative dementia care<sup>32,34,35,37</sup> and by Care Ecosystem implementation projects.<sup>18</sup> Contracting for these services from a hub could be an option when practice redesign is a barrier or when a smaller practice does not have the dementia expertise needed to provide the Care Ecosystem. An implementation toolkit, CTN training materials, and descriptions of current clinical implementation projects are available.<sup>18</sup>

## Limitations

There are several limitations to this study. The economic outcomes are not reported beyond 12-month follow-up and were based only on survey data. (Intervention effects on Medicare data, time to institutional placement, and end-of-life care will be reported as the data become available.) Another limitation is that our sample likely differs in important ways from samples from similar programs that do not have a randomized control condition. During our recruitment and consent process, the only potential benefit communicated to prospective enrollees was that participation might inform and advance the quality of care provided to PWDs and their caregivers in the future. No direct personal benefit from Care Ecosystem services was promised to prospective enrollees. This method was used to minimize differential attrition among persons randomized to usual care. While having a comparable control group is an important advantage of our study design, participants in our study likely had fewer unmet needs on average than would a clinical cohort selected for high needs and enticed to participate by the possibility of personal benefit. This limitation highlights the importance of seeking convergent evidence for effective interventions using both randomized and clinical implementation designs.

## Conclusion

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Dementia places substantial burdens on patients, families, and health care systems. Care models are needed that support caregivers and mitigate these burdens. This study demonstrated that collaborative dementia care provided from a centralized hub via telephone and internet can improve caregiver well-being within 6 months and PWDs' quality of life within 12 months while reducing their need for emergency services. Future research is needed to evaluate the long-term effects of the collaborative care model and investigate potential barriers to its widespread adoption.

## Notes

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### Supplement 1.

Care Ecosystem Trial Protocol and Statistical Analysis Plan

### Supplement 2.

eMethods: Supplemental Methods

eReferences

### Supplement 3.

Data Sharing Statement

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## Figures and Tables

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Figure 1.

### Participant Flow Through the Study

Figure 2.

### The Care Ecosystem Trial Design

Adapted with permission from Possin et al.<sup>19</sup> CTN indicates care team navigator.

<sup>a</sup>The default order is shown. Order and dosage were customized as needed.

Figure 3.

### Zip Codes of Persons With Dementia Enrolled in the Care Ecosystem Trial

Table 1.

#### Baseline Demographic and Clinical Characteristics of Persons With Dementia and Caregivers Enrolled in the Study

Abbreviation: NA, not applicable.

<sup>a</sup>Unless otherwise indicated, data are the number (percentage) of study participants in the specified category.

<sup>b</sup>Dementia stage was based on the Quick Dementia Rating Scale using cutpoints that have been validated to correspond to Clinical Dementia Rating Scale scores of 1 or less for mild, 2 for moderate, and 3 for advanced or severe.<sup>28,30</sup>

<sup>c</sup>The self-report-generated Charlson Comorbidity Index with the highest possible Charlson weights is reported,<sup>31</sup> followed by the most common comorbidities in our sample.

<sup>d</sup>Defined by a 12-Item Zarit Burden Interview score of 17 or higher.<sup>26</sup>

<sup>e</sup>Defined by a 9-Item Patient Health Questionnaire score of 10 or higher.

Table 2.

#### Linear Mixed-Effects Model Results

<sup>a</sup>B indicates unstandardized beta coefficient.