Supplementary Online Content


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eMethods. Supplemental Methods

Depression protocol

At each survey time point, all caregivers who scored 10-14 points on the PHQ-9 depression screen were informed that their score indicated they might be experiencing depression and they were encouraged to follow-up with their primary care or mental health provider for further evaluation and treatment. All caregivers who scored >14 on the PHQ-9 or endorsed any thoughts that they would be better off dead were also given the national suicide prevention hotline number and were offered a one-time follow-up call with a nurse or social worker who assessed for suicide risk, provided contact information for the Family Caregiver Alliance, the Alzheimer’s Association, and the Friendship Hotline, and encouraged follow-up.

Randomization sequence generation

Subjects were randomized 2:1 Care Ecosystem (CE) : Usual Care (UC). To increase the likelihood of similar types of persons with dementia (PWD)s in the CE and UC groups, we stratified the sample using randomization blocks by dementia severity (mild, moderate, and advanced) and referral site for the California cohort, and dementia severity and geographic locale (urban / suburban and rural / frontier) for the Nebraska and Iowa cohort. California referral sites for the purpose of randomization included self-referral and 6 physician referral sites: UCSF Memory and Aging Center, UCSF General Medicine, UCSF Geriatrics, San Francisco General Hospital, UCSF Palliative Care, San Francisco Chinatown clinics. PWD referrals received from physicians not affiliated with these practices were grouped with self-referrals. Geographic locale determinations were made based on subject’s address and the RUCA classification system developed by the University of Washington. Once RUCA score was determined, it was translated into urban/suburban or rural/frontier designation core using categorization A from the RUCA classification system. Dementia stage was determined by the Quick Dementia Rating Scale (QDRS) using previously published cut-offs for mild (<12.5), moderate (12.5-17.5), and advanced (>17.5) dementia that correspond to Clinical Dementia Rating Scale scores of 1 or less, 2, and 3 respectively. The first 15 participants were randomized prior to the publication of the QDRS. These participants were randomized using the Functional Assessment Staging Tool cutoffs for mild (<5), moderate (5-6), and advanced (6) dementia. The research coordinators entered referral site (UCSF) or geographic locale (UNMC) during the enrollment process into the enrollment module of the Dashboard, which is the Care Ecosystem software platform that is programmed using Salesforce. Dementia stage was calculated automatically during the baseline survey. Once the survey was complete,
the randomization assignment was automatically assigned via sequences, which had been generated by a study statistician (JK), and that were programmed in the Dashboard. The research coordinator supervisor notified dyads if they were randomized to UC, and the care team navigator assigned to each dyad notified the dyad if they were randomized to the CE.

**Outcome measure details**

*Quality of life* of the PWD was measured by the Quality of Life - AD (QoL-AD). This 13-item measure has a 1-4 ordinal scale for each item, which are summed for a total score ranging from 13-52. To measure *health care utilization* of the PWD, caregivers were asked how many times the PWD was hospitalized, used the emergency department (ED), and used an ambulance, using questions adapted from the Health and Retirement Survey.

Although we did not hypothesize any treatment effect on outpatient doctor or nurse appointments, we explored whether the treatment impacted the number of these appointments. Caregivers were asked how many times the patient visited a medical doctor or nurse practitioner in-person about the patient’s health. For this question, the caregiver was prompted to include clinic visits, urgent care visits and house calls, but not visits where a physician or nurse is not seen such as labwork, tests, or physical therapy. For all utilization variables, at baseline, utilization for the past 12 months was queried, and frequencies were divided by two. On the 6- and 12-month surveys, caregivers were asked these same questions about the prior 6 months.

Caregiver outcomes were also evaluated at baseline and at 6- and 12-months post-randomization in both groups, except satisfaction with the CE, which was measured in the treatment group only at 12-months. *Caregiver burden* was measured by the Zarit Burden Interview short version (Zarit-12), which is a 12-item measure with a 0-4 ordinal scale for each item that are summed for a total score ranging from 0-48. Scores of 17 or greater represent a high level of burden. *Caregiver depression* was measured using the PhQ-9. Scores of 10 or greater represent moderate to severe depression. *Caregiver self-efficacy* was measured using a novel measure to assess self-efficacy around knowing where to get needed services and help, and confidence around managing future caregiving challenges and changes in the patient’s behavior. This 4-item measure has a 1-5 ordinal scale for each item, which are summed for a total score ranging from 1-20. Caregiver satisfaction was measured using the following two questions: How satisfied are you with the Care Ecosystem (responses range from very unsatisfied to very satisfied), and would you recommend the Care Ecosystem to another caregiver (responses are yes and no). These satisfaction questions were asked of caregivers in the Care Ecosystem group only, at the conclusion of the 12-month Outcomes
Survey. Of the 369 caregivers enrolled in the Care Ecosystem who completed the 12-month survey, 325 provided ratings for their overall satisfaction with the Care Ecosystem, and 320 answered whether they would recommend the Care Ecosystem to another caregiver. The reasons for missing data on the satisfaction survey were that this survey was introduced on August 1, 2016 (N=24 surveys before this date), due to an administration error the survey was not launched following completion of the Outcomes Survey (N=17), and the caregiver refused to respond because he or she had elected not to receive the treatment (overall satisfaction N=3; recommend question N=8).

PWDs were invited to complete a short survey comprised of a brief cognitive screen (the NINDS-CSN 5-minute protocol\textsuperscript{11}) and the patient report version of the QoL-AD interview at baseline and 12-months. The PWD survey was presented as optional to study participation and no PWD survey measure was a prespecified outcome. Only 270 PWDs at baseline and 140 at 12-months completed the survey, and due to these very low completion rates, the results are not reported.

**Estimation of cost savings and depressions mitigated**

To estimate cost savings attributable to the CE, we added the observed mean change in the three utilization variables (12-month minus baseline) among UC participants with complete utilization data at baseline and 12-months (N=195), added this to the baseline mean utilization for CE participants with complete data (N=358), and compared this to the observed mean change in this CE group. The difference between the mean expected and observed change in utilization was multiplied by the CE sample size to estimate any utilization savings (or increases) that could be attributed to the intervention. Hospital costs and emergency visit costs were estimated based on the unadjusted average per person annual health care expenditures among non-zero expenditures of older adults with Alzheimer’s disease and other dementias, and the unadjusted average per-person annual healthcare utilization.\textsuperscript{12} Based on those data, which were derived from the Medical Expenditure Panel Survey, we estimated the average cost of a hospitalization and emergency visit event. For ambulance use, a median cost value per transport event was used, regardless of diagnosis or age.\textsuperscript{13} Values were adjusted to 2017 US dollars using a 3% interest rate. The adjusted ED, hospitalization and ambulance use average event costs were $1,071, $13,482, and $528, respectively.

To estimate the number of moderate to severe caregiver depressions (PhQ-9 > 9)\textsuperscript{9} mitigated by the CE, we used the same method as above for utilization; that is, we compared the observed change in depression frequency in CE to the expected change estimated based on the observed change rate in UC.
For both ER visits and caregiver depressions, we calculated the number needed to treat (NNT) as $1 / \left( \text{the change in the event frequency for UC} - \text{the change in the event frequency for CE} \right)$. 
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