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Palliative Care Program for Community-Dwelling Individuals With Dementia and Caregivers
The IN-PEACE Randomized Clinical Trial

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IMPORTANCE Care management benefits community-dwelling patients with dementia, but studies include few patients with moderate to severe dementia or from racial and ethnic minority populations, lack palliative care, and seldom reduce health care utilization.

OBJECTIVE To determine whether integrated dementia palliative care reduces dementia symptoms, caregiver depression and distress, and emergency department (ED) visits and hospitalizations compared with usual care in moderate to severe dementia.

DESIGN, SETTING, AND PARTICIPANTS A randomized clinical trial of community-dwelling patients with moderate to severe dementia and their caregivers enrolled from March 2019 to December 2020 from 2 sites in central Indiana (2-year follow-up completed on January 7, 2023). Electronic health record screening identified patients with dementia; caregivers confirmed eligibility, including dementia stage.

INTERVENTION The intervention consisted of monthly calls from a trained nurse or social worker and evidence-based protocols to help caregivers manage patients' neuropsychiatric symptoms, caregiver distress, and palliative care issues (eg, advance care planning, symptoms, and hospice) (n = 99). Usual care caregivers received written dementia resource information and patients received care from usual clinicians (n = 102).

MAIN OUTCOMES AND MEASURES The primary outcome was Neuropsychiatric Inventory Questionnaire (NPI-Q) severity score (scores range from 0-36, with higher scores indicating worse patient symptoms). Secondary outcomes included Symptom Management in End-of-Life Dementia scores, caregiver depression (Patient Health Questionnaire-8) scores, caregiver distress (NPI-Q distress) scores, and combined ED and hospitalization events. Outcomes were assessed quarterly for 24 months or until patient death.

RESULTS A total of 201 dyads were enrolled (patients were 67.7% female; 43.3% African American; mean [SD] age, 83.6 [7.9] years); 3 dyads withdrew and 83 patients died over the course of the study, with at least 90% of eligible dyads in both groups completing each of the quarterly assessments. For the dementia palliative care vs usual care groups, mean NPI-Q severity scores were 9.92 vs 9.41 at baseline and 9.15 vs 9.39 at 24 months, respectively (between-group difference at 24 months, −0.24 [95% CI, −2.33 to 1.84]). There was no significant difference in the rate of change in NPI-Q severity from baseline between groups over time (P = .87 for the group and time interaction). There were no significant differences in the secondary outcomes, except that there were fewer combined ED and hospitalization events in the dementia palliative care group (mean events/patient, 1.06 in dementia palliative care vs 2.37 in usual care; between-group difference, −1.31 [95% CI, −1.93 to −0.69]; relative risk, 0.45 [95% CI, 0.31 to 0.65]).

CONCLUSIONS AND RELEVANCE Among community-dwelling patients with moderate to severe dementia and their caregivers, dementia palliative care, compared with usual care, did not significantly improve patients' neuropsychiatric symptoms through 24 months.

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Dementia is a leading cause of death and associated with significant distress and hardship in people living with dementia and their caregivers.[1] Patients often experience neuropsychiatric and physical symptoms that are difficult to manage, especially in the disease's later stages.[2] Patients may also receive potentially burdensome and nonbeneficial treatments near the end of life, with emergency department (ED) visits or hospitalization being disruptive and associated with accelerated functional decline.[3,4] Dementia also takes a toll on caregivers.[1] Despite newly approved drugs for patients in early-stage Alzheimer disease, a majority of patients will have contraindications or disease too advanced to benefit from these treatments.[5] Thus, palliative care interventions are needed for patients with moderate to severe dementia.[2]

Palliative care for patients with advanced dementia has been tested primarily in the nursing home setting[6] and focused on single interventions targeting advance care planning,[7] goals of care conversations,[8] or utilization of artificial nutrition and hydration.[9] Few palliative care studies have enrolled patients residing in the community, although community-dwelling individuals with advanced dementia more frequently receive life-sustaining treatments than persons without dementia.[10] Studies of dementia care management programs in community settings either excluded patients with advanced disease or enrolled few of them, did not incorporate palliative care, and have failed to reduce health care utilization, such as ED visits or hospitalizations.[11-17] Notably, prior studies of palliative care and dementia care management interventions typically involved few participants from racial and ethnic minority populations.[17-19] This is despite African American individuals having an almost 2-fold higher risk of developing dementia, with diagnosis often delayed or missed.[20] African American individuals are also less likely to receive palliative care interventions, including advance care planning and hospice.[21-23]

This article presents the main outcomes of the Indiana Palliative Excellence in Alzheimer Care Efforts (IN-PEACE) trial, a 24-month randomized clinical trial of dementia care management integrating palliative care for community-dwelling patients with moderate to severe dementia and their caregivers. The primary hypothesis was that dementia palliative care would be superior to usual care in improving neuropsychiatric symptoms in patients. Secondary hypotheses were that the intervention would improve management of other symptoms in patients, reduce caregiver distress and depression, and reduce ED visits and hospitalizations.

Key Points

Question Among community-dwelling individuals with moderate to severe dementia, does a dementia care management program with integrated palliative care reduce patients' neuropsychiatric symptoms?

Findings In this randomized clinical trial that included 201 patient-caregiver dyads, the mean Neuropsychiatric Inventory Questionnaire (NPI-Q) severity score (range, 0-36) at 24 months was 9.15 in the dementia palliative care group and 9.39 in the usual care group, and there was no significant difference in the rate of change in NPI-Q severity from baseline between groups over time.

Meaning In this randomized clinical trial, a dementia care management program with integrated palliative care did not significantly improve patients' neuropsychiatric symptoms.

Methods

Study Participants

Recruitment took place from March 2019 through December 2020. Participants were recruited as dyads consisting of a patient and their primary caregiver from a safety net health care system and a combined academic and community hospital system. Trial protocol details have previously been described[24] and the study protocol is in Supplement 1. The Indiana University Institutional Review Board approved this study. Patients 65 years and older were eligible if they (1) had a diagnosis of dementia of any etiology in their electronic medical record, (2) had a caregiver willing to participate and provide proxy consent for the patient and informed consent for themselves, (3) dementia severity confirmed as moderate to severe based on caregiver report by phone using the Functional Assessment Staging Tool (FAST; scores range from 1-7, with 1 indicating normal aging and 7, end-stage dementia), and (4) lived in a private home or assisted living facility. Caregivers responded "yes" or "no" to 12 questions regarding the functional ability of the patient. Questions aligned with the stages in the FAST tool, allowing assignment of the patient to stage 5 (moderate) through stages 6 (severe) and 7 (very severe).[25] Individuals were ineligible if they had a serious mental illness diagnosis (eg, schizophrenia or bipolar disorder) or were already enrolled in hospice.

Caregivers 18 years and older were eligible if they (1) identified as the primary caregiver of the patient (ie, the main person helping with the patient's daily tasks) and (2) had at least 1 in-person or 2 phone interactions with the patient per week. Caregivers were ineligible if they did not speak English or had serious mental illness.

Potentially eligible persons with dementia were identified based on *International Classification of Diseases, Ninth* and *Tenth Revisions* (*ICD-9* and *ICD-10*) diagnostic codes in their electronic medical records using a regional health information exchange, the Indiana Network for Patient Care.[26] Research assistants used contact information in the patient's electronic medical record to help identify the primary caregiver. They then scheduled an appointment with eligible dyads to conduct the informed consent and baseline interview and to deliver the basic dementia care educational materials and a $30 grocery store gift card for this and all quarterly assessments.

Reporting race and ethnicity was mandated by the National Institutes of Health. Caregivers reported these for both themselves and the patient in response to the standardized categories offered.

Randomization

Research assistants reported new enrollments to the research manager, who used a computer-generated assignment

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in a block size of 4 developed by the study biostatisticians to randomize each dyad's assignment, stratified by dementia disease severity of moderate (FAST stage = 5) or severe (FAST stage = 6-7) derived from baseline assessment.[25] The research manager then assigned each dyad randomized to the intervention to 1 of the 2 dementia care managers, either a registered nurse or master's prepared social worker.

Intervention

Dyads randomized to the dementia palliative care group were assigned to a care manager with specific training on study protocols. These protocols incorporated existing, proven approaches to dementia management, especially nonpharmacological approaches to patients' symptoms and caregiver well-being[12,13,27,28] (see the Indiana University website[29] for examples), plus new strategies on advance care planning, goals of care, and palliative care and hospice.[30] The care managers made 24 monthly phone calls to the caregivers to proactively ask open-ended questions regarding symptoms experienced by the patient and caregiver distress. Additional calls could be scheduled to follow up on active problems or by the caregiver as needed for new or worsening issues. Caregivers also received the IN-PEACE Caregiver Manual, which contained educational resources for nonpharmacologic management of dementia symptoms and self-care materials. Care managers met weekly with 1 or both team physicians with clinical expertise in dementia care and palliative care (G.A.S., A.M.T.) to review calls with caregivers and modify care plans.

Usual Care

Dyads assigned to the usual care group received basic educational and informational materials from the local chapter of the Alzheimer's Association and other publicly available resources. Caregivers in the usual care group did not have access to the IN-PEACE Caregiver Manual, intervention protocols, or contact with a care manager.

Outcome Measures

Baseline and follow-up assessments were predominantly phone-based and conducted with the caregiver by research assistants blinded to the treatment group. Outcomes were assessed every 3 months for up to 24 months. If a patient died before the next assessment in the series, an end-of-life interview was conducted with the caregiver.

Details of study measures have been reported.[24] The primary outcome was the presence and severity of patients' neuropsychiatric symptoms in 12 domains assessed using the Neuropsychiatric Inventory Questionnaire (NPI-Q) reported by the caregiver (NPI-Q severity; scores range from 0-36, with higher scores indicating more severe symptoms).[31] Prespecified secondary outcomes included patient symptoms assessed by the Symptom Management at the End of Life in Dementia (SM-EOLD) scale (scores range from 0-45, with higher scores indicating better control of 9 symptoms),[32] caregiver distress assessed by the NPI-Q distress scale (scores range from 0-60, with higher scores indicating greater distress),[31] caregiver depression assessed by the Patient Health Questionnaire-8 (PHQ-8) depression scale (scores range from 0-24, with higher scores indicating more depression symptoms),[33] and a combined measure of ED and hospitalization events. ED visits that resulted in hospitalization are not included in ED visit counts from the regional health information exchange, as the hospitalization captures these acute care episodes. Additionally, post hoc sensitivity analyses were conducted excluding any ED visits followed by a hospitalization within 2 days. All acute care utilization data were extracted from the regional health information exchange.

Data on mortality, hospice enrollment, and location of death were not prespecified outcome measures, although these data were collected and descriptively reported.

Sample Size Calculation

The targeted sample size of 200 dyads was estimated using our preliminary data and based on having 80% power to detect a decrease in NPI-Q severity score by 0.45 at 3-month intervals (estimated slope), while the usual care group was expected to show an increase in severity by 0.2 at 3-month intervals with a common SD of 4.[24] The estimation was derived using a mixed effects model at $\alpha = .05$ and assumed at least 170 patients would complete the 3- and 6-month assessments. Details of the sample size calculation are included in the statistical analysis plan (Supplement 1).

Statistical Analysis

Longitudinal measures of patient NPI-Q severity, SM-EOLD, caregiver NPI-Q distress, and PHQ-8 scores were compared between the 2 groups using separate mixed-effects models and analyzing patients according to their randomization groups. Each mixed-effects model included a group indicator variable, time since baseline, and an interaction between the group and time as independent variables. A significant group × time interaction would indicate differences in changes in outcome measures between the 2 groups over time, while a significant main group effect (in the absence of an interaction) would suggest differences between the groups across all time points. Unstructured variance-covariance matrices were used to adjust for within-subject correlations over time. Predicted differences in mean scores between the 2 groups at each time point were estimated using the contrast procedures in the mixed-effects models. Subgroup analyses were conducted based on 5 predefined variables: NPI-Q severity at baseline (low vs high by median split), sex, race (African American patients and others), income (household income <$25 000 vs ≥$25 000), and health care system (academic vs safety net). Three-way interactions among each subgroup variable, group, and time were tested in each mixed-effects model to explore whether any of these subgroups exerted differential intervention effects on the outcome variables. Subgroup analyses were prespecified for the primary outcome, but not for secondary outcomes. Our randomization plan included stratification by dementia severity (moderate or severe). However, only 8 of the 201 enrolled patients were in the moderate dementia stratum (FAST stage = 5). Due to the small size of this group, we did not adjust for dementia severity in any of our models.

To compare the rates of ED and hospitalization events between the 2 groups, we used a Poisson regression model with

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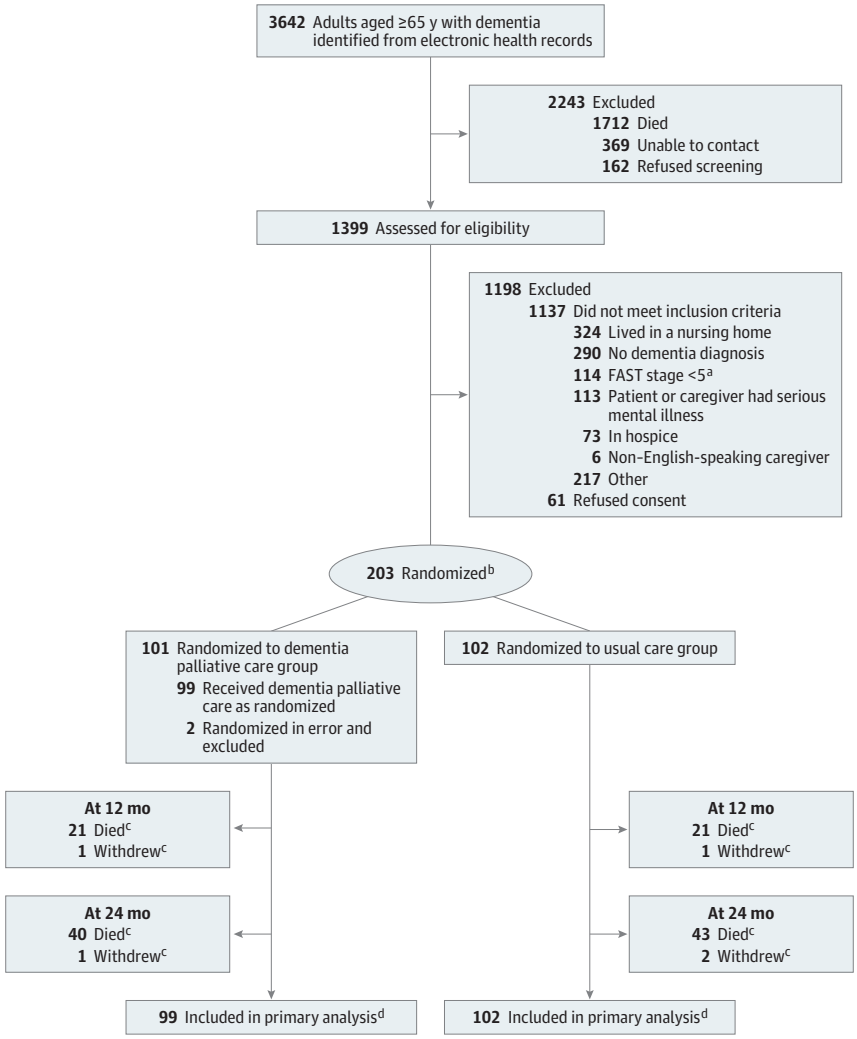
Figure 1. Flow of Participants in the IN-PEACE Trial



See eFigure 1 in Supplement 2 for an extended version of participant flow by quarter. FAST indicates Functional Assessment Staging Tool; and IN-PEACE, Indiana Palliative Excellence in Alzheimer Care Efforts.

[a]FAST measures dementia severity through stages ranging from 1 to 7, with 1 indicating normal aging and 7, end-stage dementia. Caregivers responded "yes" or "no" to 12 questions regarding the functional ability of the patient. Questions aligned with the stages in the FAST tool allowed assignment of the patient to stage 5 (moderate) through stages 6 (severe) and 7 (very severe). Those who screened with a FAST stage less than 5 (moderate) were ineligible.

[b]Randomization was stratified based on dementia disease severity (moderate [FAST = 5] vs severe [FAST = 6-7]). The total of 203 participants randomized includes 2 randomized in error.

[c]Values are cumulative.

[d]All randomized patients were analyzed according to treatment group, with separate mixed-effects models for all longitudinal outcome measures.

a robust standard error estimate and an offset for the length of time in the study. Since the number of patients with 0 ED or hospitalization events exceeded what would be expected from an underlying Poisson distribution, we also conducted a post hoc sensitivity analysis using a zero-inflated Poisson (ZIP) model.[34] The ZIP model consisted of a combination of a standard Poisson distribution for count data and a binary logistic regression model to account for additional 0 events. Additionally, subgroup analyses using the Poisson and ZIP models were conducted using the 5 prespecified variables. Post hoc analyses were also reported for the individual components that made up this outcome.

We compared patient and caregiver characteristics and baseline outcome measures between those who completed the 24-month follow-up and those who did not. Under the missing at random assumption, results from mixed-effects models for the longitudinal outcomes are unbiased, with a moderate number of dropouts.[35] All hypothesis tests were 2-sided, with a significance level set at .05. We did not adjust for multiple comparisons for the secondary outcomes, so these results should be interpreted with caution and confirmed in future studies. Analyses were conducted using SAS software version 9.4 (SAS Institute). This report follows the Consolidated Standards of Reporting Trials (CONSORT) reporting guideline for randomized clinical trials.

Results

Study Participants

Among the 201 dyads enrolled in the study, the mean age of the patients was 83.6 years and 67.7% of patients were female; the mean age of caregivers was 60.5 years and 81.1% were female. Nearly all patients (96%) were FAST stage 6 or 7 (moderately severe to severe dementia) and more than 40% of both patients and caregivers were African American. The mean baseline NPI-Q severity score was less than 10, indicating a low burden of neuropsychiatric symptoms. **Figure 1** summarizes study participant flow (see eFigure 1 in Supplement 2 for an extended version). Quarterly assessments were completed for at

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Table 1. Baseline Patient and Caregiver Characteristics

Characteristic	Patients, No. (%)		Caregivers, No. (%)	
	Dementia palliative care group (n = 99)	Usual care group (n = 102)	Dementia palliative care group (n = 99)	Usual care group (n = 102)
Age, mean (SD), y	83.7 (7.7)	83.4 (8.1)	60.8 (12.3)	60.2 (10.1)
Female	67 (67.7)	69 (67.7)	82 (82.8)	81 (79.4)
Male	32 (32.3)	33 (32.4)	17 (17.2)	21 (20.6)
Race[a]				
African American	44 (44.4)	43 (42.2)	43 (43.4)	46 (45.1)
White	48 (48.5)	53 (52)	49 (49.5)	52 (51)
Other[b]	7 (7.1)	6 (5.9)	7 (7.1)	4 (3.9)
Ethnicity, Hispanic or Latino[a]	2 (2.02)	3 (2.94)	2 (2.02)	3 (2.94)
Education				
High school or less	53 (53.5)	53 (52.5)	13 (13.1)	18 (17.8)
Some college or college degree	30 (30.3)	29 (28.7)	60 (60.6)	54 (53.5)
Postgraduate	16 (16.2)	19 (18.8)	26 (26.3)	29 (28.7)
Marital status				
Widowed	36 (36.4)	52 (51)	1 (1)	3 (2.9)
Married or living together	32 (32.3)	30 (29.4)	66 (66.7)	71 (69.6)
Divorced or separated	25 (25.3)	12 (11.8)	13 (13.1)	15 (14.7)
Never married	6 (6.1)	8 (7.8)	19 (19.2)	13 (12.7)
Living arrangement of patient[c]				
House, condo, apartment, or mobile home	83 (83.8)	81 (79.4)	NA	NA
Assisted living	15 (15.2)	18 (17.7)	NA	NA
Independent senior housing	1 (1)	3 (2.9)	NA	NA
Income, $[d]				
<24 999	48 (49.5)	40 (39.2)	13 (13.1)	13 (12.7)
25 000-49 999	19 (19.6)	27 (26.5)	26 (26.3)	29 (28.4)
≥50 000	16 (16.5)	21 (20.6)	47 (47.5)	50 (49)
Do not wish to answer	14 (14.4)	14 (13.7)	13 (13.1)	10 (9.8)
Relationship to patient				
Daughter, son, daughter-in-law, or son-in-law	NA	NA	68 (68.7)	67 (65.7)
Spouse or partner	NA	NA	22 (22.2)	22 (21.6)
Other relationship	NA	NA	9 (9.1)	13 (12.7)
Study site				
Public or safety net	56 (56.6)	65 (63.7)	NA	NA
Academic or community	43 (43.4)	37 (36.3)	NA	NA
Dementia severity[e]				
Severe (FAST = 6-7)	95 (96)	98 (96.1)	NA	NA
Moderate (FAST = 5)	4 (4)	4 (3.9)	NA	NA
Medical conditions, mean (SD)[f]	2.6 (1.4)	2.7 (1.5)	NA	NA
Scale scores, mean (SD)				
NPI-Q severity score[g]	9.9 (6.7)	9.4 (6.4)	NA	NA
SM-EOLD symptom management[h]	29.8 (9)	28.8 (8.8)	NA	NA
Caregiver distress NPI-Q[i]	NA	NA	10.8 (9.2)	10.4 (8.4)
Caregiver depressive symptoms PHQ-8[j]	NA	NA	3.7 (4.2)	4.1 (4)

Abbreviations: FAST, Functional Assessment Staging Tool; NA, not applicable; NPI-Q, Neuropsychiatric Inventory Questionnaire; PHQ-8, Patient Health Questionnaire-8; SM-EOLD, Symptom Management at the End of Life in Dementia.

[a] Based on caregiver self-report for race (African American, American Indian or Alaska Native, Asian, Filipino, Pacific Islander, and White) and ethnicity (Hispanic or Latino and not Hispanic or Latino).

[b] Participants who identified as American Indian or Alaska Native, Asian, Filipino, or Pacific Islander.

[c] No caregivers responded with residential facility, nursing facility, or other.

[d] If the relationship was spouse, the patient's household income was the same as the caregiver.

[e] Range, 1-7; 1 indicates normal aging and 7, end-stage dementia. Caregivers responded "yes" or "no" to 12 questions regarding functional ability of the patient aligned with the stages in the FAST tool, allowing assignment to stage 5 (moderate), 6 (severe), or 7 (very severe).

[f] Caregivers responded "yes" or "no" to whether a clinician diagnosed or treated the patient with the following in the past 3 years: asthma, emphysema, or chronic bronchitis; hypertension; diabetes; arthritis; angina, heart failure, or other heart disease; neurological condition (not including dementia); liver disease; kidney disease; or cancer.

[g] Range, 0-36; higher scores indicate more severe symptoms and were based on caregivers' responses to the presence and severity of 12 neuropsychiatric symptoms in the patient, with each item being not present or present and rated as mild (1), moderate (2), or severe (3).

[h] Scores range from 0 to 45, with higher scores representing better control of 9 symptoms experienced by patients in the previous 90 days per caregiver report.

[i] Caregiver distress NPI-Q range, 0-60; higher scores indicate greater caregiver distress.

[j] Caregivers' self-report of depressive symptoms; range, 0-24; higher scores indicate more symptoms of depression.

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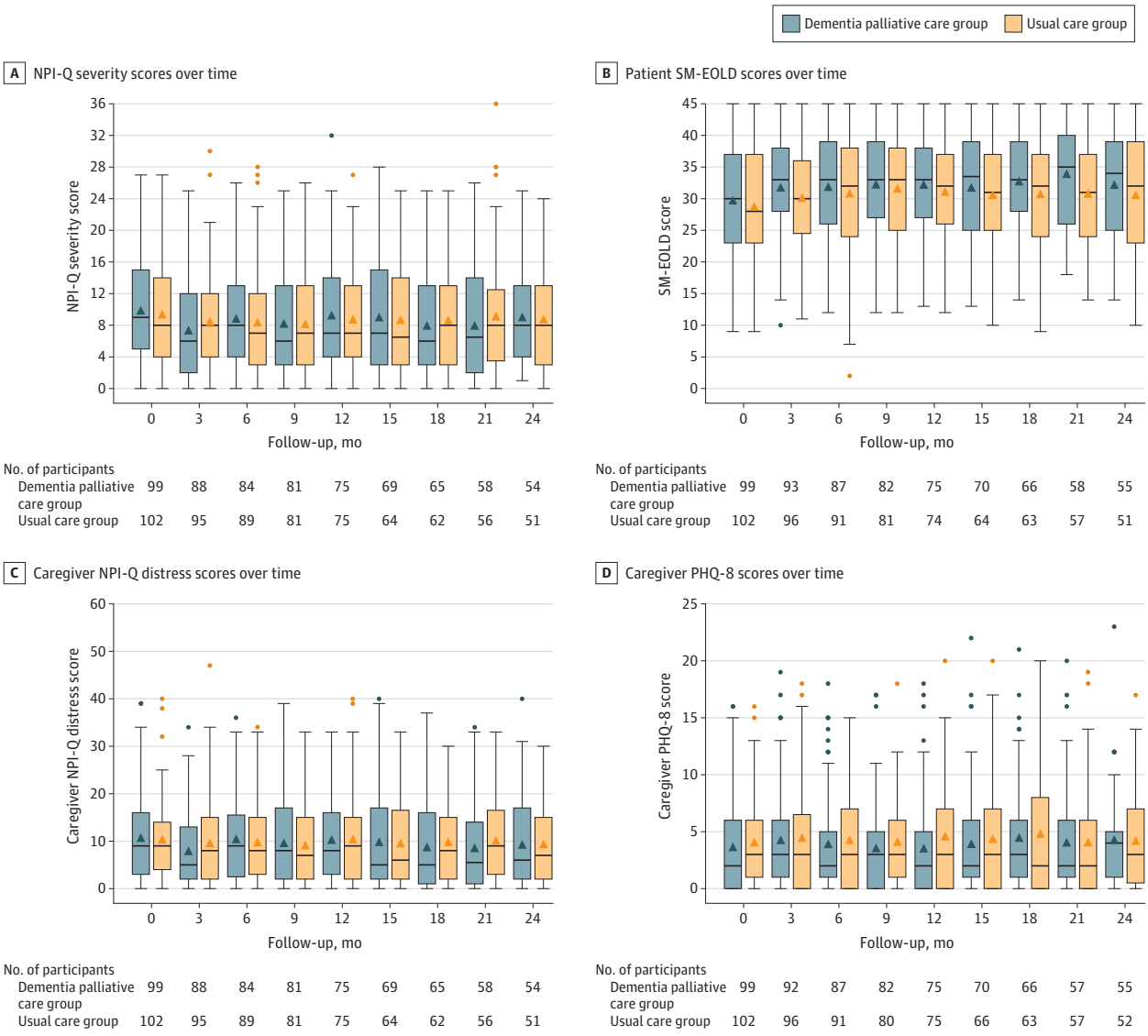
Figure 2. Primary and Secondary Outcomes Related to Participant Symptoms



Values for primary and secondary outcomes, measured every 3 months from baseline to 24 months, are displayed using box and whisker plots. The boxes represent the IQR, with the bars inside indicating the median and the triangles indicating the mean values. The whiskers extend to the highest and lowest values within 1.5 times the IQR, while points outside the whiskers represent more extreme values. See Table 1 footnotes for range, directionality, determination, and meaning for each outcome measure. The NPI-Q severity scores over time were the primary outcomes for this study. All other outcomes presented are secondary outcomes. There were no significant differences between the dementia palliative care group and the usual care group in these outcomes. See eTable 2 in Supplement 2 for differences in means. NPI-Q indicates Neuropsychiatric Inventory Questionnaire; PHQ-8, Patient Health Questionnaire-8; and SM-EOLD, Symptom Management at the End of Life in Dementia.

least 90% of dyads in both trial groups, typically 94% to 100%. Only 3 dyads withdrew from participation. A total of 83 patients died and 80 caregivers completed final assessments within 6 to 8 weeks of the patient's death. The dementia palliative care and usual care groups were balanced with respect to baseline characteristics, including symptom measures (**Table 1**). eTable 1 in Supplement 2 shows there were no significant baseline differences between participants able to complete all 24 months of follow-up vs those unable to complete 24 months of follow-up (most commonly due to death).

Primary Outcome

Figure 2 illustrates the primary and secondary symptom outcomes over time (eFigure 2 in Supplement 2 illustrates another visualization of these outcomes). For the dementia palliative care vs usual care groups, mean NPI-Q severity scores were 9.92 vs 9.41 at baseline and 9.15 vs 9.39 at 24 months (between-group difference at 24 months, −0.24 [95% CI, −2.33 to 1.84]) (**Table 2**). The rate of change in NPI-Q severity scores from baseline did not differ between the groups over time (P = .87 for the group × time interaction).

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Table 2. Comparisons of Primary Outcome and Emergency Department (ED) Visits and Hospitalizations Among Trial Participants

Outcome	Dementia palliative care group (n = 99)	Usual care group (n = 102)	Difference (95% CI)[a]		*P* value for interaction[b]
Primary outcome: NPI-Q severity, mean (SD)[c]					
Baseline	9.92 (0.66)	9.41 (0.65)	0.51 (−1.31 to 2.32)		.87
3 mo	7.75 (0.64)	8.51 (0.62)	−0.76 (−2.51 to 0.91)		
6 mo	8.72 (0.66)	8.68 (0.64)	0.04 (−1.76 to 1.85)		
9 mo	8.35 (0.67)	8.39 (0.67)	−0.04 (−1.90 to 1.81)		
12 mo	9.26 (0.74)	9.52 (0.73)	−0.26 (−2.29 to 1.78)		
15 mo	9.35 (0.80)	10.04 (0.80)	−0.69 (−2.91 to 1.53)		
18 mo	8.49 (0.73)	9.21 (0.73)	−0.72 (−2.75 to 1.31)		
21 mo	8.24 (0.80)	9.22 (0.80)	−0.99 (−3.20 to 1.23)		
24 mo	9.15 (0.75)	9.39 (0.76)	−0.24 (−2.33 to 1.84)		
Acute care utilization[d]			**Absolute difference (95% CI)**	**Relative risk (95% CI)**	***P* value**
Combined events (prespecified outcome)					
No. of ED visits and hospitalizations					
Mean (SD)	1.06 (1.57)	2.37 (2.76)	−1.31 (−1.93 to −0.69)	0.45 (0.31 to 0.64)	<.001
Median (IQR)	1 (0-2)	1 (1-3)			
Component events					
No. of ED visits					
Mean (SD)	0.51 (1.03)	1.23 (1.77)	−0.72 (−1.12 to −0.32)	0.41 (0.25 to 0.67)	<.001
Median (IQR)	0 (0-1)	1 (0-2)			
No. of hospitalizations					
Mean (SD)	0.56 (0.89)	1.15 (1.62)	−0.59 (−0.85 to −0.23)	0.48 (0.32 to 0.74)	<.001
Median (IQR)	0 (0-1)	1 (0-2)			

Abbreviation: NPI-Q, Neuropsychiatric Inventory Questionnaire.

[a] Group differences and 95% CIs were estimated using a mixed-effects model that included group, time, and the interaction between group and time.

[b] The *P* value for NPI-Q severity scores tested the interaction effect between group and time.

[c] NPI-Q severity scores range from 0 to 36, with higher scores indicating more severe symptoms. Scores were based on caregivers' responses to the presence and severity of 12 neuropsychiatric symptoms in the patient, with each item ranging from 0 (not present) to present and of mild (1), moderate (2), or severe (3) severity.

[d] For the acute care utilization outcomes, the mean number of events over 24 months, SDs, median, and first and third quartiles were reported for both the dementia palliative care group and the usual care group. Absolute differences, relative risks, and 95% CIs were estimated using Poisson regression models with robust standard errors. ED visits that resulted in hospitalization were not included in ED visit counts from the regional health information exchange, as the hospitalization captures these acute care episodes. Additionally, sensitivity analyses were conducted excluding any ED visits followed by a hospitalization within 2 days (eTable 4 in Supplement 2).

Secondary Outcomes

There were no significant differences between the groups at 24 months for SM-EOLD (mean difference, 1.74 [95% CI, −1.03 to 4.50]), caregiver NPI-Q distress (mean difference, −0.87 [95% CI, −3.83 to 2.10]), and caregiver PHQ-8 (mean difference, −0.05 [95% CI, −1.46 to 1.36]). eTable 2 in Supplement 2 summarizes between-group comparisons of each variable at all time points.

The outcome of combined ED visits and hospitalizations showed significantly fewer events in the dementia palliative care group compared with the usual care group (Table 2). Patients receiving dementia palliative care had mean ED and hospitalization events of 1.06 compared with 2.37 events in the usual care group (between-group difference, −1.31 [95% CI, −1.93 to −0.69]; relative risk, 0.45 [95% CI, 0.31 to 0.65]). In a post hoc sensitivity analysis using a ZIP model, dementia palliative care was associated with a reduction in the proportion of patients who had at least 1 ED visit or hospitalization during the study's 24 months of follow-up (eTable 3 in Supplement 2). One or more events occurred in 50.5% of patients in the intervention group vs 78.4% of patients in the control group. Absolute rates of component events can also be found in eTable 3 in Supplement 2. An additional post hoc sensitivity analysis excluding 8 ED visits occurring 1 to 2 days before hospitalization did not significantly affect the utilization finding (eTable 4 in Supplement 2).

Subgroup Analyses

Subgroup analyses for the primary outcome are not reported, as none were significant. Post hoc subgroup analyses demonstrated 3 statistically significant differential effects on the secondary outcome of combined ED and hospitalization events (eFigure 3 in Supplement 2). Patients with worse baseline neuropsychiatric symptoms (ie, higher NPI-Q severity [*P* = .05 for interaction]), lower income (<$25 000 [*P* = .04 for interaction]), and those who were African American (compared with non-African American patients; *P* = .009 for interaction), experienced greater reductions in ED and hospitalization events. Detailed data on the 5 prespecified subgroup comparisons from the ZIP model are provided in eTable 5 in Supplement 2.

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Additional Data

Intervention Adherence

Care managers completed more than 93% of expected monthly calls. Of the 99 caregivers in the dementia palliative care group, 48 had no unscheduled calls. In the 51 dyads with unscheduled calls, a total of 142 were completed (range, 0-15; median [IQR] 2 [1-3]) and only 7 caregivers required 5 or more calls. eTable 6 in Supplement 2 illustrates the number of calls in which the various protocols were triggered and the frequency of each topic covered. The most common protocols triggered were "Taking Care of Yourself" and "Guidelines for Coping," occurring in more than 20% and 10% of all encounters, respectively. Suggestions for coping included setting realistic expectations, taking breaks from care each week, talking about experiences with friends and family, and asking for help. eTable 7 in Supplement 2 describes the care managers' qualifications and dyad assignments.

Additional Descriptive Data

While mortality, hospice enrollment, and location of death were not prespecified outcomes, these data were collected. Eighty-three patients died during the study, 40 in the dementia palliative care group (40%) and 43 in the usual care group (42%). For the 80 patients with caregivers who completed interviews after death, similar numbers in each group were enrolled in hospice (dementia palliative care, 27/38 [71%]; usual care, 33/42 [79%]) and died outside of a hospital (dementia palliative care, 31/38 [82%]; usual care, 34/42 [81%]). The number of patients who died at home was similar in the 2 groups (dementia palliative care, 24/38 [63%]; usual care, 25/42 [60%]) (eTable 8 in Supplement 2).

Discussion

Among community-dwelling persons with moderate to severe dementia and their caregivers, a dementia care management program with integrated palliative care, compared with usual care, did not significantly improve patients' neuropsychiatric symptoms or secondary outcomes of patient or caregiver symptoms through 24 months. However, it reduced the prespecified secondary outcome of combined ED and hospitalization events.

Regarding the findings for the combined ED and hospitalization outcome, the intervention resulted in both a reduction in the mean number of events per person as well as more patients being event-free over 24 months. Few dementia care management or palliative care studies have had an impact on these utilization outcomes in a rigorous randomized clinical trial.[14-19] From the dementia palliative care perspective, reducing or completely avoiding the ED and hospital also reduces the exposure of patients to the disruptive transitions, adverse events, and functional decline associated with hospitalization, and treatments that could be burdensome and not consistent with goals of care. Although not a specific aim of the IN-PEACE trial, the reduction in utilization could translate into significant cost savings, but this would require further evaluation.

Post hoc subgroup analyses demonstrated that the impact on ED visits and hospitalizations was greatest in 3 subgroups: those with worse baseline neuropsychiatric symptoms, lower income, and African American patients. Although these findings are hypothesis-generating, this suggests that targeting patients with higher NPI-Q scores could maximize intervention benefits since behavioral and psychiatric symptoms and mental status changes frequently trigger ED visits and hospitalizations. The greater impact on ED and hospitalization events in African American patients is especially salient given prior research documenting higher rates of ED use, hospitalization, and hospital readmission in this group.[10,21-23,36,37] Dementia palliative care may have the potential to reduce this disparity.

The absence of a reduction in any of the outcomes relating to symptoms or distress in either the patients with dementia or their caregivers was an unexpected finding because this study incorporated care management strategies from prior studies that did improve some of these measures.[12,13] First, one possible explanation is that the relatively low symptom and distress burdens at baseline may have limited the extent to which these outcomes could be improved. Second, patients with greater symptom burdens or more stressed caregivers may have been less likely to enroll in a study involving quarterly assessments over 2 years. Third, conducting the study at sites with relatively mature dementia care management systems that may have adopted many of the prior trials' interventions into practice might have reduced the possibility of detecting between-group treatment effects. It is possible that the intervention decreased ED and hospitalization events without improving symptom or distress measures because the care managers were available to promptly address patients' changes in condition and care crises and suggest options other than the ED or hospital. These acute events might not be captured by a quarterly assessment asking caregivers about symptoms during the last month.

There were several notable strengths of this study. Among those screened and eligible for inclusion, 77% gave consent and enrolled in the trial. The patients enrolled were older, frailer, and had more advanced dementia than participants in most previous dementia care management trials.[11-17] More than 40% of both patients and caregivers were African American, a proportion greater than in most previous dementia treatment studies.[17-19] Study retention, data collection, and delivery of the care management calls all exceeded 90% throughout the 2-year study despite considerable overlap with the COVID-19 pandemic. Additionally, the telehealth mode of delivery of IN-PEACE further enhances the feasibility of future implementation.

This trial is the first, to our knowledge, to explicitly combine palliative care with a state-of-the-art dementia care management program in the community setting. Improving care for patients and their caregivers is a priority for clinicians, investigators, health policy experts, and advocacy organizations.[11] Interest in dementia care management programs has been sparked further by the new alternative payment model for dementia care management from the Center for Medicare and Medicaid Innovation's Guiding an Improved Dementia Experience (GUIDE) Model.[11,38] GUIDE is intended to provide health systems and

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practices with the financial resources to provide the kind of comprehensive management of patients and support of caregivers that have previously lacked clear financial support in fee-for-service arrangements. Integrated dementia palliative care provides this model of care and addresses the concern that heretofore "care coordination for dementia has not consistently produced a meaningful reduction in emergency department use or inpatient admissions."[39] GUIDE also incorporates attention to health equity issues, so this study's greater impact on the subgroups analyzed with respect to the utilization outcome is another potentially promising finding.

Limitations

This study has limitations. First, patients and caregivers were enrolled from a single metropolitan area and utilized 2 care managers, so the generalizability to other settings needs to be demonstrated. Second, the relatively low level of symptoms in both patients and caregivers at baseline and throughout the trial for both groups may have limited the ability to demonstrate an impact on these outcomes. Third, only patients in the moderate to severe stages of dementia were enrolled, so impact on outcomes for less severely affected patients is unknown.

Conclusions

Among community-dwelling persons with moderate to severe dementia and their caregivers, a dementia care management program with integrated palliative care, compared with usual care, did not significantly improve patients' neuropsychiatric symptoms through 24 months.

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Concept and design: Sachs, Gao, Kroenke.
Acquisition, analysis, or interpretation of data: All authors.
Drafting of the manuscript: Sachs, Johnson, Kroenke.
Critical review of the manuscript for important intellectual content: All authors.
Statistical analysis: Sachs, Gao, Pan.
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