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Abstract

Objective: To examine factors associated with adherence to a walking program in community-dwelling individuals with Alzheimer's disease (AD). **Methods:** Data were analyzed for 66 participants with AD asked to walk 30 continuous minutes per day. Adherence data (number of days walked, minutes walked, days walked 30+ minutes) were obtained from daily logs. Predictor variables included age, spousal relationship, health limitations, depression, participant dementia severity and behavioral disturbance, and caregiver stress and dementia management style. **Results:** During week 1, participants significantly ($P < .0001$) increased number of days walked/week compared to baseline. However, walking frequency and duration declined over 6 months. Nonwalkers had higher behavioral disruption scores. Regression analyses indicated that participants who walked more were less depressed. Caregivers of walking participants tended to be spouses, and reported less stress. **Conclusions:** Both participant and caregiver factors (participant behavioral disruption and depression; caregiver stress and spousal relationship) impacted whether community-dwelling individuals with AD adhered to a walking program.

Keywords

walking, exercise, adherence, dementia, caregivers

Introduction

There is growing interest in the role of exercise for improving quality of life in persons with Alzheimer's disease (AD). Epidemiological studies suggest that even low levels of regular physical activity may reduce risk for development of incident dementia and slow cognitive decline.¹⁻⁴ Exercise can reduce falls, improve fitness and functional status, reduce risk for depression onset, and alleviate symptoms of comorbid medical conditions that impact caregiver burden and patients' ability to remain at home.⁵⁻¹⁰ Exercise interventions, with and without additional treatment components (eg, socialization or increased pleasant events), have been shown to improve mood, sleep, behavior, cognitive function, and social outcomes in persons with AD.¹¹⁻¹⁴ Caregivers can be trained as exercise "coaches" for community-dwelling individuals with dementia,^{15,16} and many older adults with cognitive impairment enjoy participating in structured exercise programs.¹⁷

Despite growing evidence that increased exercise can be beneficial for persons with dementia, there is still much to be learned. There is no consensus as to what frequency, intensity, duration, and type of exercise program is optimal. In a meta-analysis of exercise training programs for persons with cognitive impairment and dementia, Heyn et al⁶ found that studies with a large-effect size required participants to exercise more

times per week but for shorter durations than those in the medium or small-effect size groups, suggesting that exercise may have to be at a certain "dose" to produce maximal benefits. However, participation in more frequent exercise may be challenging for persons with dementia. Rolland et al⁹ reported that only 19% of 67 nursing home AD residents had high adherence to a year-long exercise program (completed > two thirds of possible exercise sessions) and 52% had low adherence (completed < one third of possible sessions) or were nonadherent (completed no exercise sessions during the year). Reasons for nonadherence were predominantly due to patient unwillingness to participate (35%) and other dementia-related behavioral disturbances (40%).

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The evidence for a positive relationship between mood, physical function, and exercise adherence in persons with dementia is also mixed and needs further investigation. Teri et al.¹³ reported that an exercise plus behavior management program (RDAD) improved physical function and lowered depression in community-dwelling patients with AD at 3- and 24-month follow-ups, but these results were not analyzed with respect to exercise adherence. Rolland et al.⁹ reported that increased exercise adherence in nursing home residents was significantly associated with less ADL decline, but not with any improvements in depression or overall level of behavioral disturbance. A few smaller randomized and case control studies^{18,19} have found that depression and behavioral agitation actually worsened following implementation of an exercise program, suggesting that there may be cognitively impaired individuals for whom certain kinds of activity programs are contraindicated. Physical activity programs for persons with dementia are more likely to be successful if they are individualized, enjoyable, and caregivers are provided with the tools to understand and deal with patient physical, environmental, or cognitive limitations that impact their cooperation or ability to participate.¹⁶ We need more information about the physical, cognitive, psychological, and environmental factors that influence whether patients are willing and able to participate in exercise activities, to maximize their benefits.

The majority of studies to date involving exercise training with persons with dementia have been conducted in nursing homes and adult day programs. The environmental and social factors affecting participation in exercise groups within institutions are very different from those in community-based home settings, where family caregivers provide reminders, guidance, and encouragement to persons with dementia who are generally more independent and self-directed in their daily activities. This study provides new information about: (1) to what extent community-dwelling persons with AD (participants) and their family caregivers implemented recommendations to walk every day; (2) how adherence changed over a 6-month follow-up; and (3) what participant and caregiver characteristics were associated with adherence to the walking program.

Methods

Study Design

This article includes data from a subset of community-dwelling persons with AD and their caregivers who participated in an 8-week clinical trial treating sleep disturbances in dementia. Participants were randomized into 1 of 4 treatment conditions: education contact control, walking only, light exposure only, or a combination of walking, light exposure, and sleep-education (NITE-AD). The University of Washington institutional review board approved the study. Because the focus of the current study was examining factors associated with walking adherence, only participants with walking as part of the intervention (walking, NITE-AD) are included.

Participants

Participants were 66 dyads comprising those diagnosed with probable or possible AD confirmed by their family physician and their family caregivers. Dyads were recruited from Group Health Cooperative (GHC), a large health maintenance organization in Washington State, from newspaper and television ads or announcements, and from community referrals. Participants ranged in age from 59 to 94 years (mean = 81.2 years), were predominantly female (56%), white (86%), and had dementia for an average of 4.9 years. Caregivers' ages ranged from 43 to 93 years (mean = 72.1 years); 67% were female, 88% were white, and 71% were spouses.

Walking Interventions

All participants were instructed to walk for exercise daily under caregiver supervision, with a walking duration goal of 30 continuous minutes per day. Participants who were frail or sedentary at baseline started with less than 30 minutes per day and gradually increased walking duration to minimize risk of exercise-induced injury. All participants and caregivers in the walking groups received information about walking safety, and assistance in dealing with or overcoming obstacles to implementing the 8-week walking program. This assistance included identifying potential walking locations; strategies for dealing with inclement weather; finding walking "buddies" if caregivers were too frail to walk daily with the participant; and developing solutions to dementia-related behavioral problems associated with following the walking plan.

Participants randomized to the walking condition (N = 33) received three 1-hour in-home training visits (weeks 1, 2, and 8), and two 15-minute phone calls (weeks 4 and 6) over the 2-month study period. Participants randomized to the combination NITE-AD condition (N = 33) participated in six 1-hour in-home visits (4 weekly, 2 biweekly) over the 2-month period. In addition to walking, participants with NITE-AD were placed on an individualized behavioral sleep program and instructed to use a light box daily.²⁰

Study Trainers

Trainers were masters-level health care professionals with extensive experience working with cognitively impaired older adults and their caregivers.

Measures

Dependent outcome variables: walking adherence. At the baseline assessment, caregivers were asked how many days and minutes the participant had engaged in exercise during the past week.

Throughout the treatment period, caregivers kept a daily walking log. Logs were used to calculate the (1) number of days participants walked per week, (2) average minutes walked per day, and (3) number of days walked 30 minutes or more per

week. Walking logs were also kept for 1 week at the 8-week posttest and 6-month follow-up.

Between the 8-week posttest and 6-month outcome assessments, caregivers kept a calendar of participant days walked, and reported these data biweekly to a study research coordinator. Following the 6-month assessment, caregivers were asked if the intervention had been “too much work or effort” to implement.

Independent predictor variables. Independent variables were those hypothesized a priori to be associated with walking adherence, including participant and caregiver age, level of depression, and medical morbidity; participant dementia severity and behavioral disturbance; and caregiver relationship, stress, and dementia management style.

Participant and caregiver depression were measured using the Cornell Scale for Depression in Dementia (CSDD)²¹ and the Center for Epidemiological Studies Depression scale (CES-D),²² respectively. In all, 37% of participants and 28% of caregivers scored in the depressed range at baseline.

Medical morbidity was assessed using the Self-Administered Comorbidity Questionnaire (SCQ).²³ In this study, we counted the number of conditions that, according to caregivers, limited either participant or caregiver activities, with total possible scores ranging from 0 to 15.

Participant dementia severity was measured using the Mini-Mental State Examination (MMSE).²⁴ Level of participant behavioral disturbance was rated using the disruptive behavior subscale of the Revised Memory and Behavior Problem Checklist (RMBPC).²⁵

The Perceived Stress scale (PSS)²⁶ was used to measure the frequency of nonspecific stressful caregiver thoughts and reactions during the past month.

The Dementia Management Strategies scale (DMSS)²⁷ rated the frequency with which caregivers used different management strategies (encouragement, active management, criticism) to deal with dementia-related behavior problems in their participants. In the current study, the “encouragement” subscale was selected for use because we hypothesized that high levels of caregiver encouragement might be associated with greater walking compliance.

Statistical Methods

Stata statistical software²⁸ was used to perform all analyses. The unit of analysis was the participant–caregiver dyad. Participant walking logs were collected for 7 weeks of treatment following Session 1, and at posttest and 6-month follow-up assessment. We calculated the number of days walked/week, the minutes walked/day, and the number of days walked 30 minutes or more/week for each dyad. At each assessment point, we excluded dyads that lost or failed to complete their logs. Of a total of 66 possible dyads, the final sample included treatment week 1 (N = 62), posttest (N = 63), and 6-month follow-up (N = 60).

Descriptive statistics were computed for walking adherence, demographics, independent predictor variables, and caregiver ratings of how much work or effort the intervention had required. Baseline characteristics and walking adherence for participants in the 2 treatment conditions (walking versus NITE-AD) were compared using nonparametric Wilcoxon rank-sum tests. Wilcoxon tests were also used to examine patterns of differences between walkers and nonwalkers at week 1 on the independent predictor variables.

Multivariate regression analyses were used to examine predictors of walking adherence at week 1. Adherence measures were nonnormally distributed and highly positively skewed, so we used Poisson regression (days walked/week) and negative binomial regression (minutes walked, number of days walked 30+ minutes) to analyze adherence data.²⁹ Because the Poisson and negative binomial regression models were nested, a likelihood ratio test of overdispersion was conducted to compare the fit of these models for each outcome. Given the small sample size and exploratory nature of our study, we developed separate models for relevant participant predictors (age, depression, morbidity, level of cognitive severity, behavioral disturbance) and relevant caregiver predictors (spousal relationship, depression, morbidity, perceived stress, and use of encouragement as a dementia management strategy). Significant participant and caregiver predictors were then examined in a combined model. A *P* value of <.10 was used to identify potential predictors that may be of value to explore in future research.

Longitudinal analyses were performed to examine adherence across the 7 weeks of treatment plus posttest and 6-month follow-up. Analyses were fit using time-varying predictors and random-effects overdispersion models, which allowed the dispersion to vary over participant–caregiver dyads.

Results

Baseline Characteristics

Table 1 shows the baseline characteristics of participants with AD and caregivers in the combined sample.

Comparisons Between Walking and NITE-AD Participants

There were no significant baseline differences between the walking and NITE-AD participants on any demographic or outcome variable or on participant walking adherence variables (number of walking days, average number of minutes walked per day, or number of days walked 30 minutes or more) at week 1, at posttest (week 8), and 6-month follow-up assessments. Thus, for all subsequent analyses, the 2 groups were combined.

Implementation of the Walking Program

The primary questions underlying this study were to what extent community-dwelling persons with AD followed recommendations to walk every day and how walking adherence

Table 1. Baseline Characteristics of Study Participants and Caregivers (N = 66 dyads)^a

	Participant		Caregiver	
	Mean (SD)	Range	Mean (SD)	Range
Age	81.2 (8.3)	59-94	72.1 (13.4)	43-93
Self-Administered Comorbidity Questionnaire—activity limitations	1.3 (1.5)	0-6	1.1 (1.4)	0-6
Mini-Mental State Examination	19.2 (6.7)	0-30		
Revised Memory and Behavior Problem Checklist—Disruption	0.8 (0.7)	0-3		
Cornell Depression scale	7.7 (5.8)	0-25		
Days exercise/week	2.9 (2.4)	0-7		
Minutes exercise/week	95.8 (142.2)	0-840		
CES-Depression scale			11.6 (8.5)	0-41
Perceived Stress scale			19.5 (8.9)	0-42
Dementia Management Strategies—Encouragement			24.3 (6.9)	8-40

^a Participants are older than caregivers $P < .0001$.

changed over the 6-month follow-up. In the first week after the walking program was introduced, 85% of participants walked 1 or more days (average 4.6 days/week, 15.1 min/day). This was a significant ($P < .0001$) increase in number of days walked per week, compared to caregiver reports at baseline (average 2.9 days/week).

A majority of participants continued walking throughout the study; at posttest, 76% of participants walked 1 or more days per week, and at follow-up, 63% were still walking at least once per week. However, the total number of days walked per week declined over time (to 3.8 and 3.3 days at the 8-week posttest and 6-month follow-up, respectively), as did the average minutes walked per day (to 15.8 and 13.6 minutes per day, respectively). In week 1, 60% of participants walked 5 or more days per week; 51% and 47% walked 5 or more days per week at posttest and 6 months, respectively.

Longitudinal declines in average walking adherence primarily reflect the increasing numbers of participants at each sampling point who stopped walking altogether. Among the subset of participants who continued to walk, there was a non-significant trend for maintained or improved adherence with the program over time. Participants who walked 1 or more days in each of the 3 sampling weeks slightly increased their walking duration from a week 1 average of 17.7 minutes to 20.8 and 21.5 minutes at 8 weeks and 6 months (Figure 1). Among these same walkers, the number of days per week that they walked 30 minutes or more also increased over the same time period from 1.5 to 2.5 and 2.7 days/week, respectively. However, fewer than 1 in 5 participants ever achieved the average walking duration target of 30 minutes per day. Thus, we subsequently conducted exploratory analyses to identify what participant and caregiver characteristics might have impacted treatment adherence in this study population.

Factors Associated With Initial Walking Adherence

Table 2 shows baseline values for the independent variables that we hypothesized might be associated with walking adherence. Nonwalkers (participants who walked zero days in week

1, following introduction to the walking program) had significantly ($P < .05$) higher scores on RMBPC-disruption. Participants with lower depression scores were more likely to walk more days and for longer periods of time (Table 3). Greater walking frequency and duration was associated with the caregiver being the care recipient's spouse and lower perceived stress. Participants with spousal caregivers were more likely to average 30 minutes walk time per day.

Factors Associated With Sustained Walking Adherence

We compared “quitters” (persons who walked in week 1 but did not walk any days at posttest and/or 6 month followup; $N = 13$) with persons who walked all 3 sampling points ($N = 40$). The quitters had lower MMSE scores compared to people who continued walking at posttest (15.5 vs 19.9, respectively; $P = .06$) and 6-month follow-up (15.1 vs 19.7, respectively; $P = .04$). The 2 groups did not differ on any other predictors.

Between 8-week posttest and 6-month follow-up, participants walked an average of 4.1 days/week (range 0-7). Similar to predictions of initial adherence, during the follow-up period, lower participant depression ($\beta = -.030$, $P = .06$) and having a caregiver spouse ($\beta = .403$, $P = .02$) were associated with greater number of days walked per week. Having a caregiver spouse ($\beta = .892$, $P = .10$) and less cognitive impairment ($\beta = -.046$, $P = .10$) were also associated with more minutes walked per day. Finally, lower participant depression ($\beta = -.165$, $P = .02$) and a caregiver spouse were related to achieving the target walking goal of 30 minutes or more per day.

Caregiver Ratings of the Interventions

At the 6-month evaluation, 14% ($n = 9$) of caregivers stated that the intervention had been “too much work or effort.” Three caregivers were in the walking condition, and 6 were in the combination NITE-AD treatment. Caregiver ratings that the intervention was too much work was not significantly associated with walking adherence at any sampling point.

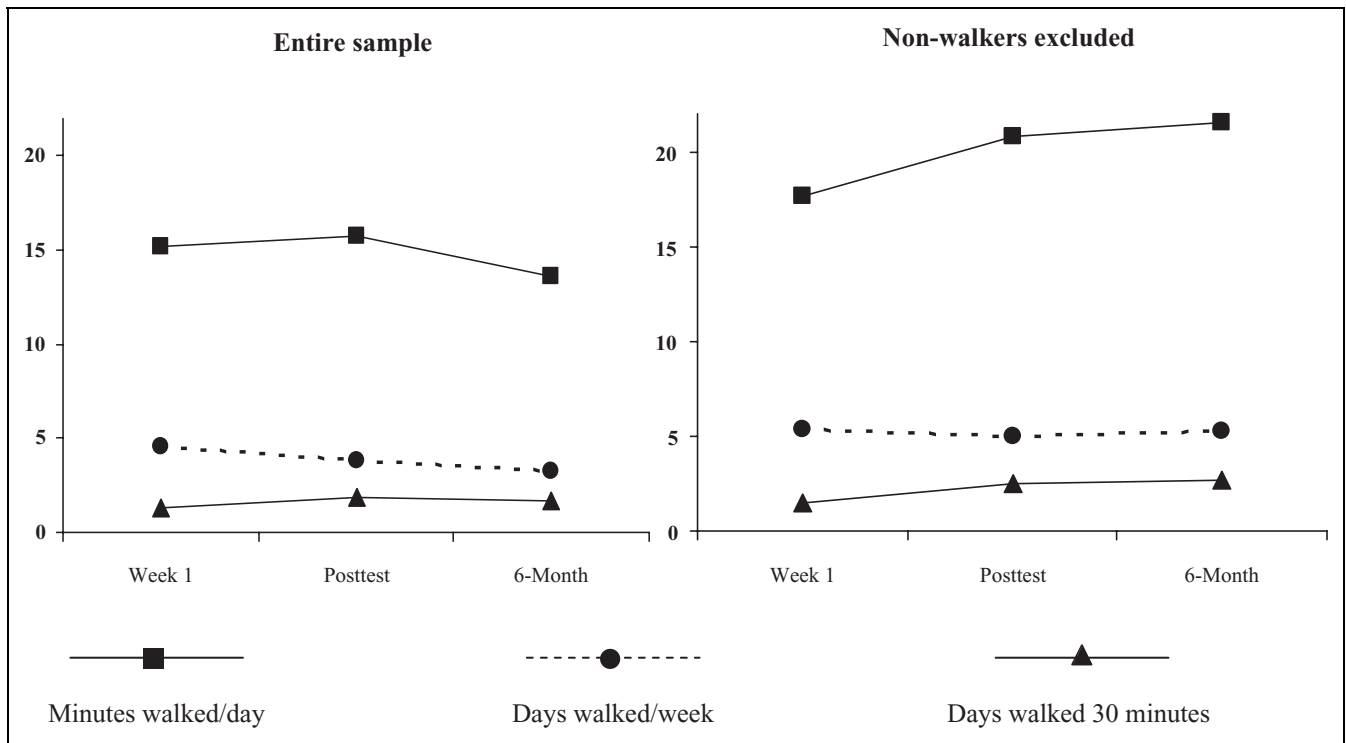


Figure 1. Longitudinal comparison of days walked, minutes walked, and days walked 30+ minutes for entire sample and with nonwalkers excluded.

Table 2. Walking Adherence at Baseline

	Walkers (n = 53) ^a Mean (SD)	Nonwalkers (n = 9) Mean (SD)
Participant age	82.2 (7.3)	75.8 (11.8)
Cornell Depression scale	7.2 (5.6)	9.6 (7.8)
Comorbidity Questionnaire—Activity Limitations	1.3 (1.5)	1.8 (1.8)
Mini-Mental State Examination	19.4 (6.1)	18.6 (9.4)
Revised Memory and Behavior Problem Checklist—Disruption ^b	0.7 (0.6)	1.2 (0.7)*
Caregiver age	73.3 (13.6)	69.1 (12.7)
Spouse, % (n)	75% (39)	56% (5)
Comorbidity Questionnaire—Activity Limitations	1.1 (1.4)	1.1 (1.1)
CES-Depression scale	11.1 (8.1)	13.1 (9.8)
Perceived Stress scale	18.7 (8.7)	23.1 (10.0)
Dementia Management Strategies—Encouragement	25.0 (6.7)	22.6 (6.7)

^a “Walkers” were participants who walked one or more days in the first week after the walking program was introduced.

^b RMBPC disruption $P < .02$, all other group comparisons NS at $P > .05$.

Discussion

This study examined adherence to a daily walking program in community-dwelling persons with AD and their caregivers. Results indicate that a majority of individuals with dementia

can implement and sustain a daily walking program with caregiver support. However, establishing a regular walking program is difficult for some individuals. Although most caregivers stated that the intervention had not required too much effort, and 47% of participants were still walking 5 or more days per week at 6-month follow-up, a substantial percentage of participants did not walk at all, and that percentage increased over time. Exploratory analyses of participant and caregiver factors associated with walking adherence indicated that participants who walked more had lower levels of behavioral disturbance and were less depressed. The caregivers of walking participants tended to be spouses and reported less perceived stress.

It is worthwhile noting that several of these factors associated with participant nonadherence to walking recommendations are potentially modifiable. For example, our data suggest that persons who are less depressed may be more likely to walk. There is considerable evidence that psychosocial treatments can directly reduce depression in persons with dementia.³⁰⁻³² Such treatments can also help caregivers identify ways to make exercise more enjoyable and less likely to trigger resistance or agitation. Partnering the person with dementia with an “exercise buddy” other than the caregiver could further minimize the stress that caregivers might experience from trying to implement a regular walking program with their family member. In some cases, noncaregiver helpers may even be more motivated or better able to encourage the individual with dementia to exercise than an immediate family member, as was

Table 3. Regression Coefficients for Models Predicting Walking Compliance at Week 1^a

	Days Walked/Week ^b			Minutes Walked/Day ^c			Days Walked 30 Minutes/Week ^c		
	Participant	Caregiver	Overall	Participant	Caregiver	Overall	Participant	Caregiver	Overall
Participant									
Age	.013			-.007			-.041		
Cornell Depression scale	-.035 ^d		-.032 ^d	-.059 ^e		-.050 ^e	-.164 ^d		-.071
Activity limitations	-.017			.078			.316		
Mini-Mental State Examination	.002			-.018			.023		
RMBPC Disruptive Behaviors	-.037			-.232			.304		
Caregiver									
Spouse		.389 ^f	.334 ^d		.714 ^d	.486		3.528 ^g	3.238 ^f
CES-Depression scale		-.006			-.017			-.051	
Activity Limitations		.022			.027			.093	
Perceived Stress scale		-.020 ^d	-.017 ^d		-.023			-.007	
DMS Encouragement scale		.005			-.004			.038	
Intercept	.708	1.528 ^f	1.820 ^f	4.068 ^d	2.818 ^f	2.638 ^f	3.463	-3.329 ^d	-2.202 ^d

Abbreviations: CES, Center for Epidemiologic Studies; DMS, Dementia Management Strategies; RMBPC, Revised Memory and Behavior Problems Checklist.

^a All models N = 54 based on listwise deletion of missing data.

^b Poisson regression.

^c Negative binominal regression.

^d $P < .05$.

^e $P < .10$.

^f $P < .01$.

^g $P < .001$.

found by Arkin,⁵ who reported 100% compliance to an exercise program that paired community-dwelling AD participants with college students who received college credit for coordinating and supervising exercise activities.

This study did not collect systematic data regarding individual dyads' life circumstances or physical environment that could influence walking adherence, such as competing caregiver family or work time demands, neighborhood walkability (sidewalks, hills, etc), or local weather conditions. In follow-up evaluations, caregivers identified several obstacles to walking, including dealing with inclement weather, finding suitable walking routes, caregiver or participant physical limitations, and participant resistance. Some participants and caregivers enthusiastically embraced the walking program, but others did not. Future studies should examine the individualized factors that influence exercise adherence in persons with dementia and caregivers and strategies that may be effective in overcoming adherence difficulties. Future studies are also needed to determine whether addressing factors associated with walking non-adherence might improve not only exercise participation but ultimately have a positive impact on other important patient and caregiver outcomes as well.

Results of this investigation should be considered exploratory. The sample size was relatively small and did not provide sufficient power to observe small or moderate effects. Sample size also limited the number of predictor variables that could be examined, and including different variables might have produced different outcomes. For example, we were unable to include all 3 caregiver management subscales of the DMSS in our analyses and selected the one that we hypothesized would be most associated with walking adherence. We subsequently tested our choice by rerunning

regressions substituting the criticism and active management subscales in place of encouragement. Similar to encouragement, criticism was not associated with any adherence outcome, but active management showed a positive trend for days walked ($p = .06$) and was significantly associated with number of days walked 30 minutes or more ($P = .04$). Lastly, participants enrolled in this study all had physician-confirmed diagnoses of AD or related dementia but varied widely in level of cognitive impairment, from being newly diagnosed to in very advanced stages of disease. The sample size limited our ability to analyze data separately for persons at different dementia stages, although in the longitudinal analyses there was a trend for persons with less cognitive impairment to walk more minutes per day.

Participating dyads were recruited as part of a study examining the treatment of sleep and nocturnal disturbances in persons with dementia. It could be that participants without the burden of comorbid cognitive impairment and sleep problems would have a different walking response than participants in the current study. However, our participants represented a range of ages and premorbid level of physical activity typical of community-dwelling persons with dementia. Study trainers were not exercise professionals or physical therapists, but they were experienced in working with older adults with dementia, and their ability to help caregivers and participants problem-solve obstacles that arose with walking programs were comparable or superior to what would be generally available in the community. Caregiver reports and daily logs may also be subject to reporting bias or error, but their use is standard in sleep intervention studies.

In summary, there is a growing literature investigating whether exercise benefits older adults with dementia by slowing cognitive decline, reducing risk for falls and other age-related

morbidities, and improving mood and behavior. However, not all persons with dementia are necessarily good candidates for exercise participation. The current study provides preliminary evidence that both participant and caregiver factors may contribute to the ability of community-dwelling individuals with dementia to adhere to a regular exercise routine. Programs or health care providers who wish to encourage their clients to be more physically active should consider these dyadic contributions rather than focusing on participant characteristics alone.

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Declaration of Conflicting Interests

The author(s) declared no conflicts of interest with respect to the authorship and/or publication of this article.

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