Published in final edited form as:

Occup Ther Ment Health. 2015 January 1; 31(1): 19–34. doi:10.1080/0164212X.2014.1002963.

The Home-Based Occupational Therapy Intervention in the Alzheimer's Disease Multiple Intervention Trial (ADMIT)

Arlene A. Schmid, PhD, OTR¹, Carrie Spangler-Morris, MS, OTR^{2,3}, Rachel C. Beauchamp, COTA⁴, Miranda C. Wellington, MOT OTR⁵, Whitney M. Hayden, MOT, OTR⁴, Hannah S. Porterfield, MOT, OTR⁴, Denisha Ferguson, AAS², and Christopher M. Callahan, MD^{2,6,7}

¹Colorado State University, College of Health and Human Sciences, Department of Occupational Therapy, Fort Collins, CO

²Regenstrief Institute, Research Coordinator, Indianapolis, IN

³Home Health Services, Westfield, IN

⁴Eskenazi Health, Department of Occupational Therapy, Indianapolis, IN

⁵Roudebush VAMC, Rehabilitation Services, Occupational Therapy, Indianapolis, IN

⁶Indiana University, Center for Aging Research, Indianapolis, IN

⁷Indiana University, School of Medicine, Indianapolis, IN

Abstract

There is no way to prevent functional declines related to Alzheimer's Disease (AD). The use of occupational therapy (OT) has been shown to be successful in managing some aspects of AD. We added home-based OT to evidence-based best practice for AD with the aim of delaying functional decline in people with AD. OT was delivered in the home to a caregiver dyad including the person with AD and her/his caregiver. This paper describes the OT intervention for the AD Multiple Intervention Trial, a parallel randomized controlled trial. We include baseline data on the 180 caregiver dyads.

Keywords

Alzheimer's Disease; dementia; functional decline; occupational therapy

Background

Alzheimer's Disease (AD) is of important concern to the population and to occupational therapists. AD affects over 5 million Americans and is associated with a high burden of suffering for patients, caregivers, families, and society, with annual estimated costs of \$150 billion (Alzheimer's Association, 2014). AD is a chronic and degenerative disease that

Contact person: Arlene Schmid, PhD, OTR, Colorado State University, Department of Occupational Therapy, OT Building #206, Fort Collins, CO 80523, Office phone 970-491-7562, arlene.schmid@colostate.edu.

Status: Ongoing

ClinicalTrial.gov Identifier: NCT01314950

causes a loss of independence in daily activities and decreased participation in society and inevitable functional decline. AD accounts for up to 80% of all dementia cases (Alzheimer's Association, 2014).

Currently, there are no treatments that can alter or prevent the pathophysiology of AD related dementia, thus it is necessary to explore interventions that may delay the progressive functional decline associated with AD related dementia. Recently, McLaren et al. (McLaren, Lamantia, & Callahan, 2013) completed a systematic review of non-pharmacologic interventions focused on the delay of functional decline in community-dwelling people with dementia. Of the 18 identified published randomized clinical trials included in the review, seven studies focused on occupational therapy (OT) interventions. The OT sessions varied, with a range of duration and frequency but commonly included a focus on daily function, activities of daily living (ADLs), environmental and behavioral modification, cognitive training, and caregiver education. The authors concluded that the OT literature provided a "proof of concept" that dementia related functional decline may be delayed via OT interventions.

Recent reviews of the literature indicate that OT is effective in management of behavioral problems associated with AD and dementia (Hall & Skelton, 2012; Kim, Yoo, Jung, Park, & Park, 2012). In a recent meta-analysis, Kim et al., identified the purpose of OT for people with dementia as to both maintaining and enhancing a person's ability to participate in societal activities, complete ADLs, improve quality of life, and reduce caregiver burden (Kim et al., 2012). The meta-analysis included randomized controlled trials focused on behavioral problems and depression concurrent with dementia. Of the nine studies, four were based in sensory stimulation, three focused on functional task activity, and two included environmental modification. The authors concluded that OT interventions focused on sensory stimulation were effective in improving behavioral problems but that other research is necessary. Other researchers have studied the effectiveness of OT interventions that included home and behavior modification, ADL training, or occupation based activities with results indicating that OT may be of great benefit to people with dementia and their caregivers (Gitlin, Kales, & Lyketsos, 2012; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Gitlin et al., 2009). Based on reviews of the literature, conversations with experts, and clinical reasoning, we have developed a home-based OT intervention to be tested as an integrated aspect of best practice primary care for people with AD.

Purpose

This paper describes home-based OT intervention for the Alzheimer's Disease Multiple Intervention Trial (ADMIT), a parallel randomized controlled clinical trial. The primary objective of the ADMIT clinical trial is to determine whether best AD primary care practice plus OT delays functional decline more successfully than AD primary care practice alone. The methods and design of the ADMIT trial can be found in *Trials* (Callahan et al., 2012). In summary, 180 caregivers and their care-recipients were randomized to one of two study arms. Participants were block randomized and randomization was 1:1 to each study arm via a computer developed randomization scheme. The two study arms included: best practices within primary care (n=89) (control arm) or best practices within primary care plus home-

based occupational therapy (n=91) (intervention arm). Any care-recipient enrolled in the study met diagnostic criteria for possible or probable AD, was 45 years and older, was living in the community at time of enrollment, and had a caregiver 18 years old. Both members of the dyad were willing to receive home visits. The primary outcome of the ADMIT trial is the Alzheimer's Disease Cooperative Studies Group Activities of Daily Living Scale (Galasko et al., 1997).

Both the control and intervention arms are briefly described in *Trials* (Callahan et al., 2012). The control arm was considered best practice and included: written materials and face-to-face counseling about the diagnosis; written materials regarding local resources; written consultation to the primary care physician with results of the diagnostic assessment; and collaborative care-management. Collaborative care-management included: collaboration with physicians, geriatricians, nurses, and social workers; appropriate drug treatment; education on communication and coping skills; legal and financial advice; a caregiver guide; enrollment in the local "safe return" program; and education regarding management of behavioral disturbances. This is considered best practice as it has previously been proven effective in a prior trial (Callahan et al., 2006).

The OT arm included everything in the best practice arm plus OT. The purpose of the paper is to fully describe the OT intervention arm of the ADMIT trial. The authors include how the OT intervention was developed, progression of the intervention, and how the OTs and OT assistants (OTAs) were trained to provide a standardized research protocol, but still tailor the intervention to the individual dyad and be occupation-based and client-centered.

Development of the Home Occupational Therapy Intervention

Goal of the intervention—The primary goal of the home-based OT intervention was to delay functional decline among study participants with AD who were randomized to the intervention arm compared to the control arm. We assumed that at least some functional decline is inevitable with AD, but our goal was to work with the caregiver and care recipient dyad to provide OT that included activity, problem solving, and meaningful occupation to strive to delay functional decline. Improving the caregiver's ability to solve problems and safely provide care to the person with AD may also reduce institutionalization. Our primary theoretical model was the Person-Environment-Occupation Model (PEO) (Law et al., 1996). The PEO model views the person as a holistic being who is shaped by her or his roles, personal attributes, and experiences and that the relationships between the person, the environment, and occupations all contribute to occupational performance. The standardized home-based OT intervention was focused on the individual with AD and the caregiver dyad, was delivered in the home environment, and was occupation (activity) based.

Process of developing the standardized home-based OT intervention—Two OTs (AAS and CSM) were involved in the original development of the 16-week intervention standardized manual. The study OTs met with each other throughout the duration of the study as needed and during scheduled meetings. The 16-week home intervention was developed to be patient-centered and occupation based and was developed based on: scientific literature; the *American Occupational Therapy Association Practice*

Guidelines for Adults with Alzheimer's Disease and Related Disorders (Schaber & Lieberman, 2010); conversations with experts in OT and dementia care; and clinical reasoning. Reviews of the literature (Hall & Skelton, 2012; Kim et al., 2012) and the Occupational Therapy Guidelines (Schaber & Lieberman, 2010) indicated that OT for AD and dementia commonly includes: functional tasks and activities; home modification; skill building; problem solving; and tailored activity programming. We chose to include these aspects of OT in the intervention with each week building upon the last session and progressing as appropriate. Importantly, as the original OT began to enter into the homes and deliver the protocol, we realized that it was of utmost importance to maintain flexibility in the protocol. We therefore elected to develop a protocol that was flexible based on the needs of the dyad.

Over the years of the trial, other OTs and Certified OT Assistants (COTA) were introduced into the study. It remained evident that a highly standardized or uniform protocol could not always be followed because of changes in the home or needs of the dyad; therefore, we continued to be flexible with the protocol. We believed that it was important to capture whether each element of the intervention was delivered, regardless of timing during the 16-week cycle (see Table 1 for a list of the elements in the OT intervention). Thus, we collected data on whether the OT addressed each element with the dyad, regardless of the order or timing. The 16-week intervention can be found in Table 2.

Occupational Therapy Assessment and Intervention

Duration and frequency—Study participants received home-based OT for two years, with decreased frequency over the study. This intervention plan was developed with the thought that the dyad would need more help in the beginning of the study to learn to manage the behaviors and functional declines considered to be inevitable with this population. Each participant assigned to receive OT received up to 24 sessions, each session lasting for up to 90 minutes, for a potential total of 36 hours of OT focused on the dyad. Planned phone calls from the OT or COTA were included in the intervention; and the OT or COTA could be contacted to assist as necessary.

We included one 16-week intervention protocol that was replicated three times during three cycles over the two-year period (see Table 2). During the first 16-week cycle, the participant dyad received home OT eight times over the 16 weeks and a planned phone call on the alternating weeks. All study dyads then started the second cycle. The same intervention protocol was then used for the next cycle, which was 36 weeks in length. For example, in the second cycle, the home OT session occurred every four weeks. The third cycle included the same 16 weeks of intervention protocol, but was spread over an entire year. In general, the protocol progressed to fewer home visits and more phone calls over the two years. Phone calls were continued and the OT or COTA could be contacted for assistance with problem solving during all cycles. The decreased frequency of the intervention allowed for continuous re-evaluation and extended therapy, as well as evaluation of intervention dosing.

Occupational therapy assessment and progress—The first session of each cycle began with an in home OT evaluation (or re-evaluation for cycle 2 or 3). The evaluation

included a number of standardized assessments typically completed during home therapy. Basic demographic and AD information is known from the completed study assessments. We used an occupational profile, standardized assessments, and learned about the concerns and worries of the caregiver by asking about behaviors and symptoms, including wandering, pain, sleep, and safety issues (See Table 3). Finally, we also asked both the caregiver and care recipient about meaningful activity, or how the care recipient might choose to occupy her or his time. As it was possible, the chosen activity was integrated throughout the 16 weeks of home OT. Use of a meaningful activity allowed for tailoring of the standardized protocol.

The OT completed standardized assessments to gather data for goal setting and treatment planning. Multiple assessments were included: Caregiver Assessment of Management Problems (CAMP) (Gitlin et al., 2010); dichotomous fear of falling questions (yes or no) (Arfken, Lach, Birge, & Miller, 1994); Berg Balance Scale (Berg, Wood-Dauphinee, Williams, & Maki, 1992); Functional Independence Measure (Granger, Hamilton, Linacre, Heinemann, & Wright, 1993); Mini-Nutritional Assessment (Bauer, Kaiser, Anthony, Guigoz, & Sieber, 2008; Vellas et al., 2006); Allen Cognitive Levels-5 (Allen, 1988; Velligan et al., 1998); and range of motion and manual muscle testing as needed. The OT also completed a home evaluation which included items such as: the number of levels in the home; stairs in and out of the home; bathroom and kitchen set up and needs; and safety issues such as lighting or clutter. After the completion of the assessments and home evaluation, the OT developed an occupational profile. An occupational profile is the summary of information that “describes the client’s occupational history and experiences, patterns of daily living, interests, values, and needs” (AOTA, 2008, page 649) and supports a client-centered approach.

The *Caregiver Assessment of Management Problems (CAMP)* was used with the caregiver to assess family/caregiver perceptions about managing ADLs/IADLs, and behaviors (Gitlin et al., 2010).

A dichotomous variable was used to measure *fear of falling (FoF)*, a modified version of a previously developed yes/no question, “are you worried or concerned about falling?” (Arfken et al., 1994).

The *Berg Balance Scale (BBS)* is a physical performance measure which includes 14 items assessing static and dynamic balance (Berg et al., 1992). The BBS is reliable and valid and higher scores indicate less balance impairment and lower risk for falls with a scoring range of 0–56.

Frequently used in rehabilitation settings, the *Functional Independence Measure (FIM)* was included. The reliability and validity of the FIM are well established and the FIM is widely used as a method of assessing functional ability in persons with disability (Granger et al., 1993).

The *Mini-Nutritional Assessment* was included because of the negative effect of malnutrition on rehabilitation efforts. The Mini-Nutritional Assessment is considered valid and reliable and is the nutrition-screening tool most often used with older adults (Bauer et al., 2008;

Vellas et al., 2006). The OT did not make decisions regarding nutrition or supplements, but instead shared information regarding malnutrition with the study team as appropriate. The OT may have integrated feeding/eating into goal planning or intervention as appropriate and provided agreed upon nutritional supplements during the home visits.

The *Allen Cognitive Levels-5 (ACL)* leather lacing and placemat test was included in the OT assessments. ACL scoring is well established in measuring cognitive abilities (Allen, 1988; Velligan et al., 1998). Clients started with the placemat test and those who scored at least a 4.8 proceeded to the lacing task associated with the ACL. These data were taken into consideration as the tailored program and goals were developed.

An occupational profile was included and addressed: the living situation; predominant concerns; functional and community mobility and functional concerns; leisure and routine activities; family impression of the cognitive involvement; and safety concerns and precautions.

Progress during the 2-year study period was documented after each session. All phone calls, including attempts for phone calls, were also documented on a standardized form. There was reassessment at the beginning of each cycle to further document progression and change during the study.

Goal setting—It has been said that “goal setting is the essence of rehabilitation” (Doig, Fleming, Cornwell, & Kuipers, 2009). Therefore, to gather data to support appropriate goal setting, standardized assessments were completed during the first home OT visit (assessments listed above). As in any clinical setting, data derived from these assessments and the occupational profile were used to develop short and long term goals. After the completion of all of the assessments and development of short and long-term goals, the OT developed a tailored plan of care for the individual dyad based on the standardized 16-week protocol. Short and long-term goals and the care plan were discussed with the dyad during the first and second visit of each cycle. As appropriate, each dyad was to have at least one ADL goal and a plan for a progressive home exercise program. Other goals were set during the 16-week interventions through the use of a SOAP note (Subjective, Objective, Assessment, Plan) and assessments after the 16-week cycle (SOAP notes are common notes used by health care professionals, including OTs (Sames, 2010). The second and third cycles included the same goal setting. As typical in home care, the OT did all initial goal setting; goal setting during the 16-week intervention could be enhanced and modified by the treating COTA after collaboration with the OT.

Intervention: standardized 16 week protocol—As stated, the goal of the home OT was to delay functional decline for people with AD. In general and as appropriate, the OT or COTA addressed the following in each session: a review of goals; home modification; safety; ADL and/or IADL; physical exercise or balance training; meaningful activity; social role functioning; and identification of any new issues to be addressed (See Table 1).

The intervention was completed in the home and had a specified plan for both the caregiver and care recipient for each visit (See Table 2 for a synopsis of the week to week protocol

that was a synthesis of the developed protocol manual). Almost every session included a new task or activity, as well as home-based activities (homework) to be addressed during the weeks without the OT in the home, to allow for progression over the 16-week protocol. During the second and third cycle, the same protocol was used but spread out over increasing periods of time. While the 16 weeks employed the same standardized protocol for each cycle, the protocol was flexible, allowing individual dyads to address current issues and goals, thereby allowing each cycle to be different and to develop as necessary. For example, Week 4 included medication management and a focus on toileting as needed; however, if the individual had fallen since the last visit, fall prevention, transfer training, home modification, and strength training exercises could become the focus of Week 4 as needed. Changing the order of the elements of the intervention may have some impact on overall outcomes, however, we believed that it was of utmost importance to maintain the tailoring and flexibility of the intervention. It was hoped that increased frequency during the first cycle, compared to the second and third cycles, allowed for better problem solving and uptake of skills that could then be used and adjusted as both the study and the dementia progressed. Conversations about individual dyads occurred as needed and the intervention was varied to accommodate changes in health status, short-term hospitalizations, travel, etc.

The integration of the OT home intervention into “best practice”—ADMIT is a multifaceted intervention study that integrated home based OT into what is considered best practice in dementia care within primary care. An important benefit of integrating OT into current best practice was that best practices were developed and delivered and included ongoing physician, nursing, and social work care. Additional nursing care and social work were delivered in the home. The integration of OT into best practice was facilitated through scheduled team meetings and conversations that happened as needed. The team, including the treating OTs, met and discussed individual cases as needed. If the dyad expressed a concern about ADLs or safety, the nurse or social worker gave a handout about dressing or safety and then connected with the OT. With the addition of OT, the dyad could express a concern, receive the handout, but also remain engaged in home OT that emphasized dressing or safety, delaying functional decline. The OT was to work on dressing with the dyad and educate the caregiver to maintain function and independence for a longer period of time.

Training protocols—As this was a large trial lasting for five years (a two year intervention period for each dyad) and because we sought to improve the generalizability of the OT intervention, we employed multiple OTs as well as a COTA over the study period. In addition, we recruited the OTs for the study from Eskenazi Health, which is the same health system from which the patients were recruited. Our partnership with the Eskenazi Occupational Therapy Department greatly increased the efficiency of the OT intervention. A training module was created so that all therapists learned about the study trial and intervention. For example, our standardized training protocol included: basics of dementia; review of the ADMIT trial; explanation of evidence-based practice; and a review of the 16-week intervention protocol. Each new therapist then completed three to five home visits with one of the experienced OTs. Training included completion of assessments and intervention. As common in rehabilitation trials and clinical settings, the new therapists

moved from observation of the intervention, to becoming independent in delivering the intervention while being observed by the experienced therapist.

Occupational Therapy in ADMIT

At the end of year four, all participants have been enrolled in the study and are currently still receiving care from the ADMIT team. We include basic demographics for the care recipient and caregiver dyad randomized to the OT intervention in Table 4. In total, 89 caregivers provided care for 91 care recipients (2 caregivers each provided for 2 care recipients). The average age of the caregiver and recipient was 56 and 79.6 years, respectively. Caregivers included adult children, grandchildren, other adult relatives, and spouses. The age of the caregiver was normally distributed and was not bimodal.

Conclusion

The OT intervention described here was embedded into what is considered best practice, including care management. Additionally, the OT joined a group of clinicians to provide best practice for people with dementia, other clinicians in the trial included medical physicians, nurses, and social workers. We hypothesize that the combination of OT and best practice, delivered in the home to the caregiver-care recipient dyad, will delay functional decline.

Acknowledgments

We acknowledge Katie Lane who reviewed the text and provided all supportive data for the paper.

Supported by NIA grant R01 AG034946

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Table I

1: List of the Elements Included in the OT Protocol

General element of OT protocol	Examples of what may be addressed	Number of minutes *
Goals	Goal development Review of goals	5
Home assessment, modification, and safety	Fall prevention strategies Grab bars Rugs Phones & rearrangement of furniture Rearrangement of ADL/IADL equipment Use of labels Placement of medications	N/A – integrated where and when appropriate
ADL training	Work on the development of a routine Focus on compensatory not restorative Remembering/cueing for/following all steps of ADLS (choosing clothes for dressing, identifying need to eat, completing toilet hygiene, etc.) Include balance training as appropriate Include energy conservation as appropriate Transfer training	15
IADL training	Decided by checklist	25 minutes combined – tailored to meet needs of the dyad
Meaningful activity	Meaningful activity Social role functioning	
Home exercise program focused on exercise and balance	Progressive Exercise/activity log	15
Caregiver education and training	Education about dementia, Alzheimer's, changes, etc. Teach how to give instructions Behavior modification Discuss communication with family, friends, health care providers Development of lists Development of routine	N/A – integrated where and when appropriate
Cognitive training	Cognitive training tasks are completed throughout the intervention and used for the improvement in meaningful occupations. Attention strategies Memory strategies Time management Stress management Mental flexibility Problem solving Safety awareness Task sequencing Orientation (as appropriate)	N/A – integrated where and when appropriate
Phone calls	Identify new problems Assist with problem solving	

* General layout of each 60 minute home session, however minutes and activities were flexible based on the needs of the dyads.

Table II

Sixteen week OT Intervention Protocol (weeks with home visits only, i.e., no phone calls)

Time	OT Intervention with Person with Alzheimer's Disease (care recipient)	OT Intervention with Caregiver
Week One In the home	INITIAL EVALUATION <ul style="list-style-type: none"> 60–90 minutes including FIM motor, Berg balance, Canadian Occupational Performance Measures, Mini Nutritional Assessment Basic home evaluation Discussion to come to consensus on long term goals 	Occupational Profile Checklist to determine concerns and worries about (see below) <ul style="list-style-type: none"> ☐ Behaviors ☐ Wandering ☐ Aches/pains ☐ Concerns ☐ Decreased sleep/rest ☐ Safety Identify goals with patient, caregiver, and occupational therapist Identify patient and caregiver abilities
Week One After the home visit	Therapist develops a tailored plan of care based on evaluation, long term goals, discussion Develop short term goals Identify home modification needs Develop progressive home exercise program (HEP) Discuss and coordinate dyad-specific, tailored, care plan with dementia care manager and primary care physician	
Week Two	<ul style="list-style-type: none"> Discuss care plan with patient and caregiver Review goals, activities of daily living training, exercise/physical activity/balance training, meaningful activity/instrumental activities of daily living /social role functioning as chosen by dyad Home modification as needed 	<ul style="list-style-type: none"> Discuss care plan with patient and caregiver Caregiving education and training Decrease risk of caregiver injury, transfer training
Week Four	<ul style="list-style-type: none"> Review goals, activities of daily living training, exercise/physical activity/balance training, meaningful activity/instrumental activities of daily living /social role functioning as chosen by dyad; home modification as needed Focus on toileting or activities of daily living of choice Medication management Add meaningful activity of choice 	<ul style="list-style-type: none"> Caregiving education and training Train caregiver to safely assist in activities of daily living and transfer training Medication management Work with CG to decide on appropriate goals and steps for meaningful activity
Week Six	<ul style="list-style-type: none"> Reassess and progress all activities of daily living training, exercise/physical activity/balance training, meaningful activity/instrumental activities of daily living /social role functioning as chosen by dyad; home modification as needed Add social role functioning/community integration 	<ul style="list-style-type: none"> Caregiving education and training Reassess all Work with CG to decide on appropriate goals and steps for social role functioning
Week Eight	<ul style="list-style-type: none"> Reassess and progress all activities of daily living training, exercise/physical activity/balance training, meaningful activity/instrumental activities of daily living /social role functioning as chosen by dyad; home modification as needed Add instrumental activities of daily living of choice 	<ul style="list-style-type: none"> Caregiving education and training Reassess all Work with CG to decide on appropriate goals and steps for instrumental activities of daily living
Week Ten	<ul style="list-style-type: none"> Reassess and progress all activities of daily living training, exercise/physical activity/balance training, meaningful activity/instrumental activities of daily living /social role functioning as chosen by dyad; home modification as needed 	<ul style="list-style-type: none"> Caregiving education and training Reassess and progress, nothing new added

Time	OT Intervention with Person with Alzheimer's Disease (care recipient)	OT Intervention with Caregiver
	<ul style="list-style-type: none"> Nothing new added 	
Week Twelve	<ul style="list-style-type: none"> Reassess and progress all activities of daily living training, exercise/physical activity/balance training, meaningful activity/instrumental activities of daily living /social role functioning as chosen by dyad; home modification as needed Nothing new added Prepare for completion of cycle or OT discharge 	<ul style="list-style-type: none"> Caregiving education and training Reassess and progress, nothing new added Prepare for completion of cycle or OT discharge
Week Sixteen	<ul style="list-style-type: none"> Reassess and progress all Reevaluate home program Prepare for completion of cycle or OT discharge 	<ul style="list-style-type: none"> Caregiving education and training Reassess and progress all Reevaluate home program Prepare for completion of cycle or OT discharge

Table III

Identification of Concerns and Worries of the Caregiver

Safety procedures/precautions that the caregiver is asked about regarding the care recipient	
	<ul style="list-style-type: none"> • Carries personal identification • Has Life alert system/alarm system – or other system • Wears Life alert system and uses appropriately • Has gotten lost in familiar locations • Has gotten lost in unfamiliar locations • Registered with safe return program • Uses phone for emergencies • Uses appliances • Uses machinery (lawn mowers, etc) • Hunts or handles firearms • Provides child care • At high risk for falls (prior fall)

Table IV

Basic Demographics at Study Enrollment for Participants Enrolled and Randomized to Receive Occupational Therapy (n=91)

Variable of interest	Person with Alzheimer's Disease (n=91)	Caregiver (n=89)*
Age, mean $\pm$ sd	79.6 $\pm$ 8.3	56.0 $\pm$ 12.3 (n=88)
Relationship between care recipient and caregiver with age of the caregiver included (mean $\pm$ sd)		
Adult child/step child		60 (67%) 52.9 $\pm$ 9.2
Grand child/great grand child		6 (7%)
Spouse		20 (22%) 69.4 $\pm$ 11.6
Other adult relative		3 (3%)
Female gender, n (%)	66 (72.5%)	61 (68.5%)
Race, n (%)		
African American	53 (58.2%)	52 (58.4%)
White	36 (39.6%)	35 (39.3%)
Other	2 (2.2%)	2 (2.2%)
Highest Grade Completed, n (%)		
Grades 1–8	14 (15.9%)	N/A
Grades 9–11	21 (23.9%)	
Grade 12 or GED	32 (36.4%)	
College 1–3 years	8 (9.1%)	
College 4 years or more	13 (14.8%) (n=88)	
Mini-Mental State Examination (MMSE), mean $\pm$ sd (Lin, O'Connor, Rossom, Perdue, & Eckstrom, 2013)	19.4 $\pm$ 6.9 (n=90)	N/A
Dyad is Spouse/Spouse-equivalent, n (%)	N/A	20 (22.5%)

* N=89 as 2 caregivers cared for 2 people with AD each