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The Effect of the ‘*Great Village*’ on Psychological Outcomes, Burden, and Mastery on African-American Caregivers of Persons Living with Dementia

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Abstract

The “*Great Village*,” a cultural adaptation of a psychoeducation intervention the “*Savvy Caregiver*” for African American caregivers of persons living with dementia (PLwD), aims to develop caregivers’ skills and improve the quality of the lives of both the PLwD and their caregivers. The goal of this study was to determine the effectiveness of the *Great Village* on depressive symptoms, anxiety, burden, and mastery in African American caregivers ($N = 142$). A three-arm randomized control trial (*Great Village*, *Great Village* + exercise, and attention control) was conducted over a period of 6 months. Caregivers who received either *Great Village* or *Great Village* + exercise reported significant reduction in depressive symptoms and improvement in mastery. Caregivers who received only *Great Village* reported a reduction in anxiety. Receiving no intervention worsened caregiver burden. African American caregivers should receive culturally tailored interventions to support their health and well-being and improve their competence in caregiving.

Keywords

depression; psychoeducational intervention; exercise; Alzheimer’s disease; older adult

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Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Background

Over the next 40 years, the number of persons living with Alzheimer's disease and related dementias (PLwD) is expected to grow from 5.7 million to approximately 14 million (Alzheimer's Association, 2019). Diagnosis of Alzheimer's disease (AD) is projected to increase at a greater rate among African Americans than among White older adults (Matthews et al., 2019; Mayeda, Glymour, Quesenberry, & Whitmer, 2016). African American PLwD are at lower risk for admission to long-term care facilities than White older adults with AD (Thomeer, Mudrazija, & Angel, 2015); however, upon admission, they have greater severity of dementia (Cai & Temkin-Greener, 2015). This finding, coupled with longer survival among African American PLwD (Helzner et al., 2008; Mehta et al., 2008), suggests that the course of caregiving for African American adults is likely lengthier than that for White adults.

Caregiving usually becomes more demanding as the disease progresses, and caregivers are often unprepared for the numerous responsibilities of the role (Zhu et al., 2008). As a result, caregivers have an increased risk for poor physical (Vitaliano, Zhang, & Scanlan, 2003), psychological (D'Aoust, Brewster, & Rowe, 2015; Schulz & Sherwood, 2008), and physiological health outcomes (Gouin, Hantsoo, & Kiecolt-Glaser, 2008). However, recent reviews of the literature have found that caregivers report greater positive affect, better physical health, and reduced mortality compared with non-caregivers (Brown & Brown, 2014; Roth, Fredman, & Haley, 2015). African American caregivers tend to view their experience of caring for their family member more positively than other races (Epps, 2014; Haley et al., 2004). The positive appraisal by African American caregivers can be attributed to their culture of greater participation in a larger extended family context and its influence on family member roles and perceived obligations (Epps, 2014; Haley et al., 2004).

While African American caregivers have similar rates of depression and anxiety as White caregivers (Knight, Longmire, Dave, Kim, & David, 2007; Pinquart & Sorensen, 2005), they report more benefits from caregiving (Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015). They have significant increases in positive aspects of caregiving over time (Haley et al., 2004), better scores on measures of positive coping (Roff et al., 2004), and higher health-related quality of life compared with Whites (Moss et al., 2017). However, African American caregivers do report less use of antidepressant medications (Sleath, Thorpe, Landerman, Doyle, & Clipp, 2005) and lower utilization of formal support services for their family members (Scharlach et al., 2006).

Caregiver Interventions

In general, caregivers of PLwD who have participated in intervention studies have reported beneficial effects (Berwig et al., 2017; Chiu, Wesson, & Sadavoy, 2013; Kishita, Hammond, Dietrich, & Mioshi, 2018; Teri, Logsdon, McCurry, Pike, & McGough, 2018).

Psychoeducation programs have produced some of the best effects (Gallagher-Thompson & Coon, 2007; Pinquart & Sorensen, 2006). Multi-session programs that focus on caregiver concerns and on developing effective coping strategies have also shown good evidence for efficacy at improving caregiver competency, and reducing burden and psychological symptoms (Chiu et al., 2013; Teri et al., 2018). Exercise interventions which have enabled

chronically stressed individuals, like caregivers, to maintain good health, are associated with improved health outcomes including reduced depression (King, Baumann, O'Sullivan, Wilcox, & Castro, 2002) and burden (Lamotte, Shah, Lazarov, & Corcos, 2017).

Racial and ethnic identity often shape cultural beliefs about dementia and the family's responsibility for care (Dilworth-Anderson, Williams, & Gibson, 2002); as a result, they guide how families respond to the challenges of long-term caregiving and should be considered when developing interventions to support caregiving families (Gallagher-Thompson et al., 2000; Hansen, Hodgson, Budhathoki, & Gitlin, 2018; Henderson, Gutierrez-Mayka, Garcia, & Boyd, 1993). The Resources for Enhancing Alzheimer's Caregiver Health intervention considered cultural issues in its development; African American caregivers who received the intervention reported a significant increase in positive aspects of caregiving longitudinally (Burgio, Stevens, Guy, Roth, & Haley, 2003). However, more culturally tailored interventions are still needed for African American caregivers (Matthews et al., 2019; Napoles, Chadiha, Eversley, & Moreno-John, 2010). The aims of this study were to determine the effectiveness of The *Great Village*, a culturally tailored psychoeducation program adapted from a widely disseminated evidence-based program, the *Savvy Caregiver* (Hepburn, Lewis, Tornatore, Sherman, & Lindstrom Bremer, 2007), with or without exercise, compared with attention control on depressive symptoms, anxiety, burden, and mastery in African American caregivers. We hypothesize that caregivers who received The *Great Village* intervention with or without exercise will have reduced symptoms of depression and anxiety, less burden, and greater mastery compared with the attention control group.

Theoretical Framework

The theoretical framework for this study merges sociocognitive, and stress and coping theories with a physiologically based understanding of the effect of chronic stress. This framework emphasizes the importance of cognitive and behavioral responses to events that threaten the person's well-being. Two cognitive processes (primary and secondary appraisal) affect the caregiver's selection of emotion-, problem-, and/or meaning-focused coping behavioral responses (Bandura, 1977; Folkman, 1984; Folkman & Lazarus, 1988; Folkman & Moskowitz, 2000). The key mediators of the threat situation, appraisal, reappraisal, and coping responses are viewed as modifiable. The psychoeducation program's Alzheimer's disease content and its emphasis on caregiving skill and strategy development are meant to positively affect primary and secondary appraisal and enhance caregiver mastery. By promoting enhanced physical activity, the exercise intervention is meant to act on the coping responses since exercise is considered a problem-focused coping response to the stress situation.

Method

Design

This study employed a randomized, controlled, repeated measures experimental design, assigning caregivers of PLwD to one of three groups: psychoeducation program (PE) alone, PE plus a home-based exercise program (PE+Ex), or Attention Control (AC). Data

collectors were blinded to group assignment. The study was approved through Emory University's Institutional Review Board (IRB#00026244). All participants provided written informed consent.

Sample and Setting

We used the following inclusion criteria: (a) self-identify as Black/African American; (b) 21 years of age or older and family members of a person who had been told by a physician that the individual has a form of dementia; (c) co-residing or visiting the PLwD at least 4 days per week and providing at least 4 hours of care daily on average; (d) cognitively intact (as determined by a Blessed dementia screening index score ≥ 10 (Katzman et al., 1983); and (e) not engaged in moderate-strenuous exercise 3 days or more each week and with no physician's orders not to engage in exercise. We used the following exclusion criteria: (a) sleep apnea or a medical or physical condition that precludes exercise (e.g., severe arthritis or mobility problems, uncontrolled hypertension or diabetes, or a history of angina with activity); (b) taking steroids on a regular basis and/or having acute inflammation at the time of baseline or follow-up testing; and (c) family member with dementia likely to be placed in a nursing home community within the next 6 months.

The planned recruitment sample size was 198 participants, with 33 cohorts of six participants each, 11 cohorts per group (PE, PE+Ex, AC), 66 participants per group. The random sorting randomization algorithm used with 10% maximum allowable deviation was designated to be balanced (i.e., sample sizes equal in all three groups). The study planned for a final sample size of 51 participants per group (assuming a 29% attrition rate from enrollment) for a total sample size of 153 at 6 months. This estimated final sample size was planned to achieve 80% power for 2 analysis of covariance (ANCOVA) to detect a moderate effect size of $f = 0.25$ ($\eta^2 = 0.06$) to find a difference between the three groups (NCSS 2007/Pass 2005; August 2007, Kaysville, Utah).

Participants were recruited from Atlanta, GA and surrounding areas. Recruitment activities included presentations to community groups and local churches, and posting information in media materials of cooperating entities (e.g., church bulletins), Emory Alzheimer's Disease Research Center, and the Alzheimer's Association.

Intervention

Psychoeducation.—The *Savvy Caregiver* program (Hepburn et al., 2007) was adapted for African American caregivers and called The *Great Village* (Samson, Parker, Dye, & Hepburn, 2016). The *Great Village* expanded and strengthened the "Family as a Resource for Caregiving" section of the *Savvy Caregiver* program. This section discussed how African American caregivers integrate caregiving arrangements and highlighted their diverse patterns of family structure and how that dynamic may differ among families based on the structure in place to provide care. The *Great Village* also included the "Keeping-It-Real" assessment, which allowed for the visualization of the dynamics of the interaction between the caregiver and the anchor institutions that make-up the caregiver's village. There were six 2-hour group sessions over consecutive weeks. A caregiver's manual with appropriate video and visual

aids guided the conduct of each session. Participants received scripted monthly follow-up phone calls and a two-page newsletter summarizing points from the program at month 4.

Psychoeducation with exercise.—This program involved the PE program, described above, and an individualized exercise program. The exercise program consisted of monitored, individually prescribed aerobic and resistance exercise. An exercise specialist made two in-person, home-visits to begin the exercise program. The specialist informed participants about the benefits of exercise, developed the individual exercise schedule, and provided training about the exercises and study procedures. The goal of the program was to have participants walking at moderate intensity for a minimum of 30 minutes, 5 days per week and resistance training sessions for 30 minutes, 2 days per week. Each participant was provided a booklet and a DVD, which guided and illustrated each exercise. Following the home-visits, the exercise specialist maintained phone contact with each participant to reinforce, monitor, and adjust the exercises. Bi-weekly calls were made for one month, weekly calls for one month, and bi-monthly calls for the remainder of the time.

Attention control.—This program included Alzheimer’s disease informational and educational materials drawn from public sources such as Alzheimer’s Disease Education and Referral Center, the Alzheimer’s Association, and the National Institute on Aging. Caregivers attended one group session within the first 2 months to control for the possible benefits from being in a group with other caregivers. This session focused on nutrition education and flexibility and stretching exercises; written handouts with information were provided. A nutrition-exercise specialist led the session. The AC group did not receive structured psychoeducational or aerobic exercise interventions. One attention control follow-up phone call was made at 4–5 months.

Measures

Depressive Symptoms.—The *PROMIS Emotional Distress—Depression* instrument (short form 8a) was used to assess self-reported mood, views of self, and engagement over the previous 7 days (Bevans, Ross, & Cella, 2014; Cella et al., 2010). For this study, the reliability of the PROMIS-Depression was $\alpha = .93$. The PROMIS instruments are “population normed” scored with final scores ranging from 0 to 100; higher scores indicate greater severity of depression.

Anxiety.—The *PROMIS Emotional Distress—Anxiety* (short form 7a) was used to assess symptoms of anxiety over the previous 7 days (Bevans et al., 2014; Cella et al., 2010). For this study, the reliability of the PROMIS-Anxiety was $\alpha = .92$. Scores range from 0 to 100, with higher scores indicating greater severity of anxiety.

Burden.—The *Zarit Burden Interview* (ZBI) is a 22-question, Likert-type instrument, which asks caregivers to evaluate the impact of caregiving on their lives. Scores range from 0 to 88, with higher scores reflecting greater burden (Zarit, Reever, & Bach-Peterson, 1980). The ZBI has good psychometric properties (Reuben et al., 2013). For this study, the reliability of the ZBI was $\alpha = .92$.

Caregiver mastery.—The *Caregiving Competency Scale* is a 4-item subscale of the Pearlin Stress Scale and assesses caregivers' evaluation of how adequately they are doing in the job of caregiver using a Likert-type scale (Pearlin, Mullan, Semple, & Skaff, 1990; Skaff & Pearlin, 1992). The score range from 1 to 4, with higher scores reflecting greater mastery. For this study, the reliability for the *Caregiving Competency Scale* was $\alpha = .79$.

Demographics.—Caregivers provided their age, gender, marital status, education, occupation, length of caregiving, and relationship and residence status with regard to the PLwD.

Data Analysis

Descriptive statistics were run for all measures. Cronbach's alphas were computed for all instruments to assess internal consistency at baseline. Prior to analysis, square-root and natural log transformations were performed as needed for skewed measures. Baseline group differences were tested using analysis of variance (ANOVA) or chi-square tests (for proportions). To obtain effect size estimates for significant changes from baseline to 6 months, unadjusted paired *t*-tests were run and Cohen's *d* computed. To test for the effect of the intervention on depression, anxiety, burden, and mastery, ANCOVA was performed to test for differences between the three groups for the measures at 6 months adjusting for baseline. ANCOVA was chosen instead of repeated measures ANOVA (RM-ANOVA) since any group differences at baseline are assumed to occur at random (Senn, 2006). Post hoc tests for differences between the three groups at 6 months were performed using the Sidak error rate adjustment for multiple pairwise comparisons.

Results

Of the 194 enrolled participants, 11 participants failed at screening and another 41 withdrew prior to baseline, a loss of 26.8%. Thus, the sample size that was enrolled, randomized, and baselined was 142 participants. The mean age of the caregivers was 55.1 ($SD = 9.7$) years and the mean age of the AD care recipients was 79.3 ($SD = 8.7$). The majority were female (85.9%, $n = 122$), children (40.6%, $n = 56$), and had a college or post-graduate degree (70.8%, $n = 97$). Table 1 further displays the demographic characteristics across study groups.

A total of 41 participants were randomized to PE, 48 to PE+Ex, and 53 to AC. Overall, 94 participants (66.2%) completed the study at 6 months. The 48 participants who did not complete the study did so for different reasons: 19 were lost to follow-up, 14 withdrew, and 15 discontinued participation because of the death of the care recipient (See Figure 1). Some missing data did occur intermittently for various measures due to missing or incomplete responses. While the attrition rates from baseline were slightly higher for the two intervention groups (PE = 31.7%, PE+Ex = 43.8%, AC = 26.4%), there were no significant difference in 2 attrition rates among the three groups, $\chi^2(2) = 3.56$, $p = .17$. There were no significant differences between completers and non-completers for any of the demographics. Given the size of the PE+Ex group was the smallest with 27 completers, at 80% power and 5% level of significance, we were only powered to detect a moderate-to-large effect size of $f = 0.35$ ($\eta^2 = 0.11$) for group differences.

Depression

While there were no significant differences between the three groups at baseline for the PROMIS-Depression ($p = .32$), there were significant differences among them at the 6-month follow-up adjusting for baseline, $F(2, 84) = 6.95$, $p = .002$, with a moderate effect size ($\eta^2 = 0.142$). At 6 months adjusted for baseline, the PE+Ex group had significantly lower PROMIS-Depression scores than AC ($p = .001$). For the changes from baseline to 6 months, the PROMIS-Depression scores for the PE group decreased by an average of 2.7 points (standard deviation [SD] = 6.3, Cohen's $d = 0.43$, a small-to-moderate effect size, $p = .04$) and the PE+Ex group by an average of 4.2 points ($SD = 7.6$, Cohen's $d = 0.55$, moderate effect size, $p = .01$), See Table 2.

Anxiety

There were significant differences among the three groups at baseline for PROMIS-Anxiety ($p = .034$) which is assumed to have occurred at random. However, at 6 months adjusting for baseline, there were no significant differences among the three groups, PROMIS-Anxiety, $F(2, 84) = 1.64$, $p = .20$. The PROMIS-Anxiety scores for the PE group decreased by an average of 3.5 points ($SD = 5.3$) between baseline and 6 months (Cohen's $d = 0.66$, moderate-to-large effect, $p = .004$), See Table 2.

Burden

There were no significant differences among the three groups at baseline or at 6 months adjusting for baseline, $F(2, 84) = 0.91$, $p = .41$. The PE and the PE+Ex groups reported small declines, whereas the AC group reported small increase of burden over 6 months, See Table 2.

Caregiver Mastery

There were no significant differences among the three groups at baseline or 6 months adjusted for baseline, $F(2, 83) = 1.59$, $p = .21$. However, there were notable within-group changes: mastery increased for the PE group by an average of 0.17 points ($SD = 0.4$, Cohen's $d = 0.43$, moderate effect, $p = .05$) and the PE+Ex group by an average of 0.31 points ($SD = 0.5$, Cohen's $d = 0.60$, moderate-to-large effect, $p = .006$) from baseline to 6 months, See Table 2.

Discussion

We conducted a randomized controlled trial with African American caregivers of PLwD to determine the effect of a psychoeducation intervention, The *Great Village*, with or without exercise compared with attention control on depression, anxiety, burden, and mastery. We found depressive symptoms and anxiety decreased and mastery improved within-groups for participants who received *Great Village*. Participants who also completed the exercise reported further declines in depressive symptoms and improvement in mastery over time.

In this study, depressive symptoms using the PROMIS-Depression measure significantly decreased in both intervention groups over 6 months. There were also significant differences among the groups at 6 months. Similarly, participants in the *Great Village* program reported

a reduction in depressive symptoms at 5 and 12 months (Samia, Aboueissa, Halloran, & Hepburn, 2014). Previous research has shown that physical activity interventions have a medium effect size in reducing the depressive symptoms in caregivers of PLwD suggesting that caregivers who participate in regular physical activity experience improvements in their mental health (King, Baumann, O'Sullivan, Wilcox, & Castro, 2002; Loi et al., 2014). However, another meta-analysis showed that physical activity had no effect on depressive symptoms (Orgeta & Miranda-Castillo, 2014). The differences in the measures could possibly account for the difference among the outcomes. The PROMIS-Depression scale asks about affective and cognitive manifestations of depression instead of the somatic symptoms such as appetite, fatigue, and sleep, which are symptoms addressed in the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and the Center for Epidemiologic Studies-Depression Scale (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993), the two scales used in the meta-analysis.

Although there were no group differences post-intervention with anxiety, participants who received the psychoeducation intervention reported improvement in their anxiety symptoms after 6 months. Similarly, Livingston and colleagues (2014) reported improvements in anxiety symptoms after receiving a psychoeducation intervention. The effects of exercise on anxiety is mixed; one meta-analysis reported significant benefits (Rebar et al., 2015), whereas other studies reported no benefits (Castro, Wilcox, O'Sullivan, Baumann, & King, 2002; Orgeta & Miranda-Castillo, 2014).

In addition to the statistical significance, clinical significance is also important when evaluating the impact of intervention on outcomes. The minimally important difference is the smallest change in a treatment outcome that an individual patient would identify as important (Lee et al., 2017). For the PROMIS-Depression, Lee and colleagues (2017) reported that the minimally important difference was 3, and for the PROMIS-Anxiety, the minimally important difference was 2.3. Six months after baseline, the PE+Ex group had a change greater than the minimally important difference for the PROMIS-Depression; while both the psychoeducation and the psychoeducation plus exercise groups had declines greater than the minimally important difference for the PROMIS-Anxiety.

Contrary to our expectations, we found no significant between-or within-group changes in caregiver burden scores over time, although we do note a non-significant increase in the burden score of the control group. Similar to our study, Gitlin et al. (2008) reported that the caregivers who were waitlisted caregiver for an intervention reported worsening burden. Our results are in contrast to results from a pilot study of a psychosocial intervention for working caregivers (Jimenez, Schulz, Perdomo, Lee, & Czaja, 2019) and a review of exercise interventions, both of which reported reduced burden (Castro et al., 2002; Orgeta & Miranda-Castillo, 2014). Any intervention that results in a reduction in burden may be clinically significant for the caregiver since not receiving an intervention can increase burden. The notion of familism may also have contributed to the minimal changes in burden for African American caregivers in this study. Strong familism among African American families may potentially override perceived burden (Epps, 2014; McCallum, Longmire, & Knight, 2007), contributing to the interventions' lack of effectiveness. In addition, Lindauer, Harvath, Berry, and Wros (2016) found African American caregiving experiences and

perceived burden was related to their coping styles with these families often focusing on the older adult's remaining personhood rather than grieving dementia-related losses.

It is imperative for caregivers to gain the knowledge, skills, and attitudes needed to carry out their caregiver role. For this study, there were significant within-group improvements from baseline to 6 months for caregiver mastery for caregivers who participated in the psychoeducation and the psychoeducation plus exercise groups. Kally et al. (2014) reported similar result with their study, which compared competence of African American caregivers who received the *Savvy Caregiver* program over a year. They found that these caregivers had a significant increase in competence from baseline to 6 and 12 months after the intervention. This increase in mastery supports the benefits of a training approach for caregivers of persons living with dementia for improving caregiving skills and confidence.

This study has several limitations. This study was conducted only with African American caregivers. The sample was highly educated; the generalizability to other races/ethnicities and people with different levels of education is limited. This study needs to be repeated in a larger, more representative cohort since a larger sample size might have provided greater power to detect effects on outcomes. The augmented attention that the intervention group received also has the potential to improve the well-being of caregivers also having an effect on the caregiver outcomes. While the majority of the sample was female, similar to the general caregiving population, it would be important to examine whether there are gender differences in the outcomes and whether length of caregiving has any influence on mastery and emotional well-being. This study had a high rate of attrition, particularly attributed to loss to follow-up and withdrawal with no reason provided. Since there were no significant differences in attrition rates across the three study arms, we speculate that a certain proportion of those who left did so because they could not organize their caregiving responsibilities in ways that would enable them to attend the in-person group sessions. We did not provide any respite services for the caregivers to participate in the programs. An additional limitation for this study was the lack of data collected on the care recipients. For example, behavior and psychological symptoms of dementia were not collected so could not be accounted for in the analysis.

Dementia caregiving affects African American family caregivers as much as it affects their White counterparts, but the effects may be different across racial and ethnic groups (Hansen et al., 2018). This study is unique in that it demonstrates the effectiveness of a program developed for the African American community with credible and culturally appropriate AD education and information to effect significant within-group reductions in certain measured aspects of depression, anxiety, and mastery. These programs should be offered to caregivers since they support their health and well-being and have the potential to improve their competence to care for the PLwD, and receiving no intervention can worsen certain caregiver outcomes like burden.

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References

- Alzheimer's Association. (2019). 2019 Alzheimer's disease facts and figures. Retrieved from <https://www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf>
- Bandura A (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84, 191–215. doi:10.1016/0146-6402(78)90002-4 [PubMed: 847061]
- Beck AT, Ward CH, Mendelson M, Mock J, & Erbaugh J (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 561–571. [PubMed: 13688369]
- Berwig M, Heinrich S, Spahlholz J, Hallensleben N, Brähler E, & Gertz HJ (2017). Individualized support for informal caregivers of people with dementia—Effectiveness of the German adaptation of REACH II. *BMC Geriatrics*, 17(1), Article 286. doi:10.1186/s12877-017-0678-y
- Bevans M, Ross A, & Cella D (2014). Patient-Reported Outcomes Measurement Information System (PROMIS®): Efficient, standardized tools to measure self-reported health and quality of life. *Nursing Outlook*, 62, 339–345. doi:10.1016/j.outlook.2014.05.009 [PubMed: 25015409]
- Brown RM, & Brown SL (2014). Informal caregiving: A reappraisal of effects on caregivers. *Social Issues and Policy Review*, 8, 74–102. doi:10.1111/sipr.12002
- Burgio L, Stevens A, Guy D, Roth DL, & Haley WE (2003). Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia. *The Gerontologist*, 43, 568–579. doi:10.1093/geront/43.4.568 [PubMed: 12937335]
- Cai X, & Temkin-Greener H (2015). Nursing home admissions among Medicaid HCBS enrollees: Evidence of racial/ethnic disparities or differences? *Medical Care*, 53, 566–573. doi:10.1097/mlr.0000000000000379 [PubMed: 26067880]
- Castro CM, Wilcox S, O'Sullivan P, Baumann K, & King AC (2002). An exercise program for women who are caring for relatives with dementia. *Psychosomatic Medicine*, 64, 458–468. doi:10.1097/00006842-200205000-00010 [PubMed: 12021419]
- Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, ... Hays R (2010). Initial adult health item banks and first wave testing of the Patient-Reported Outcomes Measurement Information System (PROMIS™) network: 2005–2008. *Journal of Clinical Epidemiology*, 63, 1179–1194. doi:10.1016/j.jclinepi.2010.04.011 [PubMed: 20685078]
- Chiu M, Wesson V, & Sadavoy J (2013). Improving caregiving competence, stress coping, and mental well-being in informal dementia carers. *World Journal of Psychiatry*, 3, 65–73. doi:10.5498/wjp.v3.i3.65 [PubMed: 24255878]
- D'Aoust RF, Brewster G, & Rowe MA (2015). Depression in informal caregivers of persons with dementia. *International Journal of Older People Nursing*, 10, 14–26. doi:10.1111/opn.12043 [PubMed: 24433320]
- Dilworth-Anderson P, Williams IC, & Gibson BE (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000). *The Gerontologist*, 42, 237–272. doi:10.1093/geront/42.2.237 [PubMed: 11914467]
- Epps F (2014). The relationship between family obligation and religiosity on caregiving. *Geriatric Nursing*, 35, 126–131. doi:doi.org/10.1016/j.gerinurse.2013.11.003 [PubMed: 24314743]
- Folkman S (1984). Personal control and stress and coping processes: A theoretical analysis. *Journal of Personality and Social Psychology*, 46, 839–852. doi:10.1037/0022-3514.46.4.839 [PubMed: 6737195]
- Folkman S, & Lazarus RS (1988). Coping as a mediator of emotion. *Journal of Personality and Social Psychology*, 54, 466–475. doi:10.1037/0022-3514.54.3.466 [PubMed: 3361419]
- Folkman S, & Moskowitz JT (2000). Positive affect and the other side of coping. *American Psychologist*, 55, 647–654. doi:10.1037/0003-066X.55.6.647 [PubMed: 10892207]
- Gallagher-Thompson D, Areán P, Menendez A, Takagi K, Haley WE, Arguelles T, ... Szapocznik J (2000). Development and implementation of intervention strategies for culturally diverse caregiving populations In Schulz R (Ed.), *Handbook on dementia caregiving: Evidence-based interventions for family caregivers*(pp. 151–186). New York, NY: Springer.
- Gallagher-Thompson D, & Coon DW (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging*, 22, 37–51. doi:10.1037/0882-7974.22.1.37 [PubMed: 17385981]

- Gitlin LN, Winter L, Burke J, Chernett N, Dennis MP, & Hauck WW (2008). Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: A randomized pilot study. *The American Journal of Geriatric Psychiatry*, 16, 229–239. doi:10.1097/JGP.0b013e318160da72 [PubMed: 18310553]
- Gouin JP, Hantsoo L, & Kiecolt-Glaser JK (2008). Immune dysregulation and chronic stress among older adults: A review. *Neuroimmunomodulation*, 15, 251–259. doi:10.1159/000156468 [PubMed: 19047802]
- Haley WE, Gitlin LN, Wisniewski SR, Mahoney DF, Coon DW, Winter L, ... Ory M (2004). Well-being, appraisal, and coping in African-American and Caucasian dementia caregivers: Findings from the REACH study. *Aging & Mental Health*, 8, 316–329. doi:10.1080/13607860410001728998 [PubMed: 15370048]
- Hansen BR, Hodgson NA, Budhathoki C, & Gitlin LN (2018). Caregiver reactions to aggressive behaviors in persons with dementia in a diverse, community-dwelling sample. *Journal of Applied Gerontology*. Advance online publication. doi:10.1177/0733464818756999
- Helzner EP, Scarmeas N, Cosentino S, Tang MX, Schupf N, & Stern Y (2008). Survival in Alzheimer disease: A multiethnic, population-based study of incident cases. *Neurology*, 71, 1489–1495. doi:10.1212/01.wnl.0000334278.11022.42 [PubMed: 18981370]
- Henderson JN, Gutierrez-Mayka M, Garcia J, & Boyd S (1993). A model for Alzheimer's disease support group development in African-American and Hispanic populations. *The Gerontologist*, 33, 409–414. doi:10.1093/geront/33.3.409 [PubMed: 8325530]
- Hepburn K, Lewis M, Tornatore J, Sherman CW, & Bremer KL (2007). The Savvy Caregiver program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. *Journal of Gerontological Nursing*, 33, 30–36. doi:doi.org/10.1093/geront/43.6.908
- Jimenez DE, Schulz R, Perdomo D, Lee CC, & Czaja SJ (2019). Implementation of a psychosocial intervention program for working caregivers. *Journal of Applied Gerontology*. 38(9), 1206–1227. doi:10.1177/0733464817748777 [PubMed: 29271282]
- Kally Z, Cote SD, Gonzalez J, Villarruel M, Cherry DL, Howland S, ... Hepburn K (2014). The Savvy Caregiver Program: Impact of an Evidence-Based Intervention on the Well-Being of Ethnically Diverse Caregivers. *Journal of Gerontological Social Work*, 57(6–7), 681–693. doi:10.1080/01634372.2013.850584 [PubMed: 24820315]
- Katzman R, Brown T, Fuld P, Peck A, Schechter R, & Schimmel H (1983). Validation of a short orientation-memory-concentration test of cognitive impairment. *The American Journal of Psychiatry*, 140, 734–739. [PubMed: 6846631]
- King AC, Baumann K, O'Sullivan P, Wilcox S, & Castro C (2002). Effects of moderate-intensity exercise on physiological, behavioral, and emotional responses to family caregiving: A randomized controlled trial. *The Journals of Gerontology: Series A*, 57, M26–M36. doi:10.1093/gerona/57.1.M26
- King AC, & Brassington G (1997). Enhancing physical and psychological functioning in older family caregivers: The role of regular physical activity. *Annals of Behavioral Medicine*, 19, 91–100. doi:10.1007/BF02883325 [PubMed: 9603683]
- Kishita N, Hammond L, Dietrich C, & Mioshi E (2018). Which interventions work for dementia family carers?: An updated systematic review of randomized controlled trials of carer interventions. *International Psychogeriatrics*, 30, 1679–1696. doi:10.1017/S1041610218000947 [PubMed: 30017008]
- Knight BG, Longmire CV, Dave J, Kim JH, & David S (2007). Mental health and physical health of family caregivers for persons with dementia: A comparison of African American and White caregivers. *Aging & Mental Health*, 11, 538–546. doi:10.1080/13607860601086561 [PubMed: 17882592]
- Kohout FJ, Berkman LF, Evans DA, & Cornoni-Huntley J (1993). Two shorter forms of the CES-D (Center for Epidemiological Studies Depression) depression symptoms index. *Journal of Aging Health*, 5, 179–193. doi:10.1177/089826439300500202 [PubMed: 10125443]
- Lamotte G, Shah RC, Lazarov O, & Corcos DM (2017). Exercise training for persons with Alzheimer's disease and caregivers: A review of dyadic exercise interventions. *Journal of Motor Behavior*, 49, 365–377. doi:10.1080/00222895.2016.1241739 [PubMed: 27870597]

- Lee AC, Driban JB, Price LL, Harvey WF, Rodday AM, & Wang C (2017). Responsiveness and minimally important differences for 4 patient-reported outcomes measurement information system short forms: Physical function, pain interference, depression, and anxiety in knee osteoarthritis. *The Journal of Pain*, 18, 1096–1110. doi:10.1016/j.jpain.2017.05.001 [PubMed: 28501708]
- Lindauer A, Harvath TA, Berry PH, & Wros P (2016). The meanings African American caregivers ascribe to dementia-related changes: The paradox of hanging on to loss. *The Gerontologist*, 56, 733–742. doi:10.1093/geront/gnv023 [PubMed: 26035890]
- Livingston G, Barber J, Rapaport P, Knapp M, Griffin M, King D, ... Cooper C (2014). Long-term clinical and cost-effectiveness of psychological intervention for family carers of people with dementia: A single-blind, randomised, controlled trial. *The Lancet Psychiatry*, 1, 539–548. doi:10.1016/S2215-0366(14)00073-X [PubMed: 26361313]
- Loi SM, Dow B, Ames D, Moore K, Hill K, Russell M, & Lautenschlager N (2014). Physical activity in caregivers: What are the psychological benefits? *Archives of Gerontology and Geriatrics*, 59, 204–210. doi:10.1016/j.archger.2014.04.001 [PubMed: 24798641]
- Matthews KA, Xu W, Gaglioti AH, Holt JB, Croft JB, Mack D, & McGuire LC (2019). Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015–2060) in adults aged 65 years. *Alzheimer's & Dementia*, 15, 17–24. doi:10.1016/j.jalz.2018.06.3063
- Mayeda ER, Glymour MM, Quesenberry CP, & Whitmer RA (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & Dementia*, 12, 216–224. doi:10.1016/j.jalz.2015.12.007
- McCallum TJ, Longmire CF, & Knight BG (2007). African American and White female caregivers and the sociocultural stress and coping model. *Clinical Gerontologist*, 30, 25–37. doi:10.1300/J018v30n04_02
- Mehta KM, Yaffe K, Perez-Stable EJ, Stewart A, Barnes D, Kurland BF, & Miller BL (2008). Race/ethnic differences in AD survival in US Alzheimer's disease centers. *Neurology*, 70, 1163–1170. doi:10.1212/01.wnl.0000285287.99923.3c [PubMed: 18003939]
- Moss KO, Deutsch N, Hollen P, Rovnyak V, Williams IC, & Rose K (2017). Understanding end-of-life decision-making terminology among African American older adults. *Journal of Gerontological Nursing*, 44, 33–40. doi:10.3928/00989134-20171002-02 [PubMed: 28990634]
- Napoles AM, Chadiha L, Eversley R, & Moreno-John G (2010). Reviews: Developing culturally sensitive dementia caregiver interventions: Are we there yet? *American Journal of Alzheimer's Disease & Other Dementias*, 25, 389–406. doi:10.1177/1533317510370957
- Orgeta V, & Miranda-Castillo C (2014). Does physical activity reduce burden in carers of people with dementia? A literature review. *International Journal of Geriatric Psychiatry*, 29, 771–783. doi:10.1002/gps.4060 [PubMed: 25191688]
- Pearlin LI, Mullan JT, Semple SJ, & Skaff MM (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583–594. doi:10.1093/geront/30.5.583 [PubMed: 2276631]
- Pinquart M, & Sorensen S (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, 45, 90–106. doi:10.1093/geront/45.1.90 [PubMed: 15695420]
- Pinquart M, & Sorensen S (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics*, 18, 577–595. doi:10.1017/S1041610206003462 [PubMed: 16686964]
- Rebar AL, Stanton R, Geard D, Short C, Duncan MJ, & Vandelanotte C (2015). A meta-meta-analysis of the effect of physical activity on depression and anxiety in non-clinical adult populations. *Health Psychology Review*, 9, 366–378. doi:10.1080/17437199.2015.1022901
- Reuben DB, Evertson LC, Wenger NS, Serrano K, Chodosh J, Ercoli L, & Tan ZS (2013). The University of California at Los Angeles Alzheimer's and dementia care program for comprehensive, coordinated, patient-centered care: Preliminary data. *Journal of the American Geriatrics Society*, 61, 2214–2218. doi:10.1111/jgs.12562 [PubMed: 24329821]
- Roff LL, Burgio LD, Gitlin L, Nichols L, Chaplin W, & Hardin JM (2004). Positive aspects of Alzheimer's caregiving: The role of race. *The Journals of Gerontology: Series B*, 59, P185–P190. doi:10.1093/geronb/59.4.P185

- Roth DL, Dilworth-Anderson P, Huang J, Gross AL, & Gitlin LN (2015). Positive aspects of family caregiving for dementia: Differential item functioning by race. *The Journals of Gerontology: Series B*, 70, 813–819. doi:10.1093/geronb/gbv034
- Roth DL, Fredman L, & Haley WE (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55, 309–319. doi:10.1093/geront/gnu177 [PubMed: 26035608]
- Samson ZB, Parker M, Dye C, & Hepburn K (2016). Experiences and learning needs of African American Family dementia caregivers. *American Journal of Alzheimer's Disease & Other Dementias*, 31, 492–501. doi:10.1177/1533317516628518
- Samia LW, Aboueissa A-M, Halloran J, & Hepburn K (2014). The Maine Savvy Caregiver Project: Translating an Evidence-Based Dementia Family Caregiver Program Within the RE-AIM Framework. *Journal of Gerontological Social Work*, 57(6–7), 640–661. doi:10.1080/01634372.2013.859201 [PubMed: 24830961]
- Scharlach AE, Kellam R, Ong N, Baskin A, Goldstein C, & Fox PJ (2006). Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work*, 47, 133–156. doi:10.1300/J083v47n01_09 [PubMed: 16901881]
- Schulz R, & Sherwood PR (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, 108, 23–27. doi:10.1097/01.NAJ.0000336406.45248.4c
- Senn S (2006). Change from baseline and analysis of covariance revisited. *Statistics in Medicine*, 25, 4334–4344. doi:10.1002/sim.2682 [PubMed: 16921578]
- Skaff M, & Pearlin L (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist*, 32, 656–664. doi:10.1093/geront/32.5.656 [PubMed: 1427278]
- Sleath B, Thorpe J, Landerman LR, Doyle M, & Clipp E (2005). African-American and White caregivers of older adults with dementia: Differences in depressive symptomatology and psychotropic drug use. *Journal of the American Geriatrics Society*, 53, 397–404. doi:10.1111/j.1532-5415.2005.53155.x [PubMed: 15743280]
- Teri L, Logsdon RG, McCurry SM, Pike KC, & McGough EL (2018). Translating an evidence-based multicomponent intervention for older adults with dementia and caregivers. Advance online publication. *The Gerontologist*, gny122, 10.1093/geront/gny122
- Thomeer MB, Mudrazija S, & Angel J (2015). How and why does nursing home use differ by race and ethnicity? *The Journals of Gerontology: Series B*, 73(4), e11–e12. doi:10.1093/geronb/gbv056
- Vitaliano PP, Zhang J, & Scanlan JM (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129, 946–972. doi:10.1037/0033-2909.129.6.946 [PubMed: 14599289]
- Zarit SH, Reever KE, & Bach-Peterson J (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20, 649–655. doi:10.1093/geront/20.6.649 [PubMed: 7203086]
- Zhu CW, Torgan R, Scarmeas N, Albert M, Brandt J, Blacker D, ... Stern Y (2008). Home health and informal care utilization and costs over time in Alzheimer's disease. *Home Health Care Services Quarterly*, 27, 1–20. doi:10.1300/J027v27n01_01 [PubMed: 18510196]

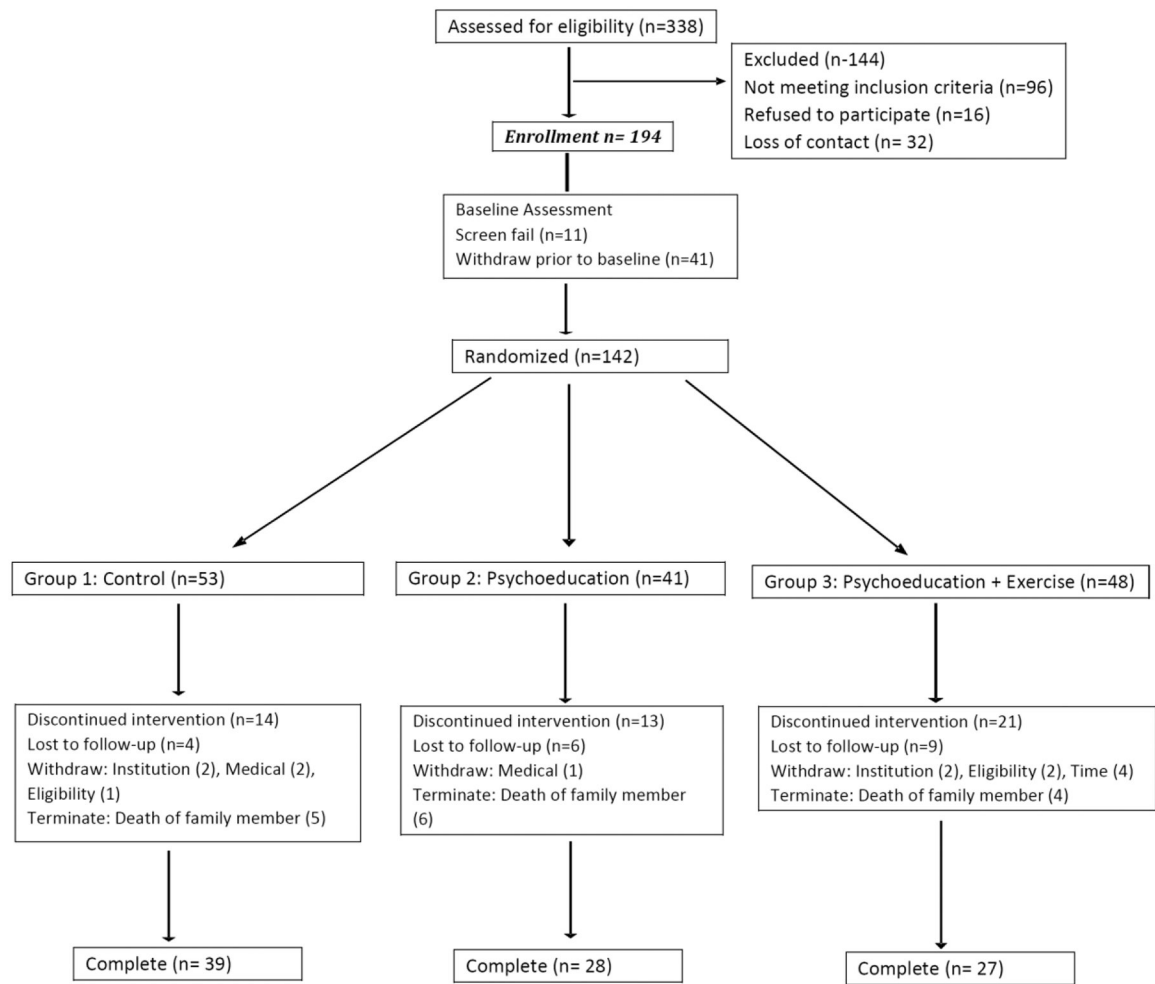


Figure 1:
Study CONSORT diagram

Table 1.

Demographic characteristics.

	All	AC	PE	PE+Ex	Group difference <i>p</i> -value
	142	53	41	48	
Measure	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	ANOVA
Age—caregiver	55.1 (9.7)	56.3 (10.0)	55.4 (9.3)	53.5 (9.7)	.34
Age—care recipient	79.3 (8.7)	78.7 (9.6)	81.6 (7.5)	78.0 (7.9)	.13
	<i>N</i> (%)	<i>N</i> (%)	<i>N</i> (%)	<i>N</i> (%)	Chi-square test
Gender					
Male	20 (14.1)	8 (15.1)	2 (4.9)	10 (20.8)	.09
Female	122 (85.9)	45 (84.9)	39 (95.1)	38 (79.2)	
Ethnicity	100%				
African American					
Marital status					
Married/domestic partner	52 (38.0)	18 (34.6)	17 (43.6)	17 (37.0)	.67
Single/divorced/separated/widow	85 (62.0)	34 (65.4)	22 (56.4)	29 (63.0)	
Relationship to patient ^a					
Spouse	23 (16.7)	9 (17.3)	8 (20.0)	6 (13.0)	.68
Child	56 (40.6)	15 (28.8)	16 (40.0)	25 (54.3)	
Sibling	13 (9.4)	4 (7.7)	6 (15.0)	3 (6.5)	
Other	46 (33.3)	24 (46.2)	10 (25.0)	12 (26.1)	
Live with patient (yes) ^b	95 (70.9)	35 (68.6)	32 (84.2)	28 (62.2)	.08
Education					
High school/tech-vocational	40 (29.2)	17 (32.1)	9 (23.7)	14 (30.4)	.67
College/post graduate	97 (70.8)	36 (67.9)	29 (76.3)	32 (69.6)	
Charlson Comorbidity Index > 0	61 (43.0)	22 (41.5)	20 (48.8)	19 (39.6)	.66

Note. AC = attention control; PE = psychoeducation; PE+Ex = psychoeducation plus exercise; ANOVA = analysis of variance.

^aGroup comparisons of the relationship to patient were performed comparing spouse to the non-spouse categories (child, sibling, and other merged).

^bEight participants were missing for whether they lived with the patient.

Table 2. Baseline and 6-Month Outcomes by Group for Participants Who Completed the Study.

Measure	Group	<i>n</i> ^a	Baseline	6m	Change BL = 6m	<i>p</i> -value, Paired <i>t</i> -test	ANCOVA ^b	Post hoc tests ^c
PROMIS Depression	AC	39	50.8 (9.8)	52.2 (8.8)	-1.4 (7.6)	.26	<i>F</i> (2, 84) = 6.95	PE+EX vs. AC, <i>p</i> = .001
	PE	25	52.7 (7.6)	50.0 (8.1)	2.7 (6.3)	.04	<i>p</i> = .002	
	PE+Ex	24	49.2 (9.2)	45.0 (8.9)	4.2 (7.6)	.01	$\eta^2 = 0.14$	
PROMIS Anxiety ^d	AC	39	54.8 (7.6)	54.0 (8.2)	0.9 (7.5)	.48	<i>F</i> (2, 84) = 1.64	
	PE	24	57.9 (7.6)	54.4 (9.4)	3.5 (5.3)	.004	<i>p</i> = .20	
Zarit Burden	PE+Ex	25	50.9 (9.9)	48.3 (8.7)	2.7 (7.8)	.10		
	AC	39	36.6 (16.0)	38.0 (15.8)	-1.4 (10.8)	.43	<i>F</i> (2, 84) = 0.91	
Inventory	PE	24	41.5 (14.8)	39.7 (13.0)	1.8 (10.2)	.41	<i>p</i> = .41	
	PE+Ex	25	33.6 (15.8)	31.6 (21.2)	2.1 (16.6)	.53		
Competence Mastery	AC	39	3.6 (0.4)	3.6 (90.4)	-0.04 (0.3)	.45	<i>F</i> (2, 83) = 1.60	
	PE	23	3.4 (0.6)	3.6 (0.5)	-0.17 (0.4)	.05	<i>p</i> = .21	
	PE+Ex	25	3.3 (0.6)	3.6 (0.5)	-0.31 (0.5)	.006		

Note. ANCOVA = analysis of covariance; PROMIS = patient-reported outcomes measurement information system; AC = attention control; PE+Ex = psychoeducation plus exercise; PE = psychoeducation. Italics: Significant *p* values for *t*-test.

^aSample sizes vary by measure due to intermittent missing data.

^bANCOVA for 6m outcomes adjusted for baseline.

^cPost hoc tests—*p*-values reported using the Sidak pairwise comparison error rate adjustment.

^dThere were significant differences between the three groups at baseline for PROMIS Anxiety (*p* = .035).