

African American Alzheimer's Caregiver Training and Support Project 2 (ACTS2) Pilot Study: Outcomes Analysis

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Purpose/Objective: The purpose of this study was to conduct an initial evaluation of the quantitative and qualitative outcomes of the African American Alzheimer's Caregiver Training and Support Project 2 (ACTS2). Quantitative objectives focused on assessing changes in caregiver depression and health status, as well as the severity of caregiving and self-care problems from pre- to postintervention. Secondary quantitative analyses examined posttreatment changes in social support and caregiver burden. Qualitative objectives included examining caregivers' perceptions of the effectiveness of in-session training activities, quality of relationships among group participants and their facilitator, and appraisals of spiritual elements of the program. **Research Method/Design:** Nine African American family caregivers of older adults with dementia completed the ACTS2 lay pastoral care facilitator-led, telephone cognitive-behavioral intervention. The 12-week training program included seven skills-building groups and five individual problem-solving sessions. **Results:** Significant improvements were found on the majority of dependent measures, including caregiver depression, health status, problem severity, and social support. Qualitative analysis highlighted the value caregivers placed on relationships with coparticipants and group facilitators, the role of spirituality in the program, and the importance of goal setting for improving caregiver distress and self-care. **Conclusions/Implications:** Convergence was found between quantitative and qualitative findings, particularly improvements in caregiver distress, health status, and social support. Overall, the findings of the pilot study were promising. Replication using a randomized controlled design with a larger sample size is needed to test the reliability of the findings. The benefits of tailoring intervention to caregivers' sociocultural preferences and spiritual values are also addressed.

Impact and Implications

Although the number of studies on the effects of telehealth-based, cognitive-behavioral intervention for distressed African American caregivers of older adults with dementia has increased over the past few years, most investigations have not tailored treatment to the cultural preferences and faith traditions of this at-risk population. The present study represents the initial stage of

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a grant-funded program addressing these shortcomings in telehealth and dementia caregiving research. Despite the widespread recognition of the impact of sociocultural and religious values in ensuring uptake and effectiveness of telehealth-based cognitive-behavioral intervention for African American dementia caregivers, a significant gap exists between the availability of culturally-responsive interventions and the needs of this population. If the current program of research proves successful, it has the potential of serving as a prototype for dementia care organizations to follow.

Keywords: African American, caregiving, cognitive-behavioral therapy, dementia, telehealth

Introduction

By 2050, the prevalence of older adults with progressive dementia (i.e., Alzheimer's disease and closely related conditions) in the United States is expected to more than double. The number of older adults with dementia is currently 6.2 million, the largest proportion of which (72%) is 75 years of age and older (Alzheimer's Association, 2021). This syndrome of neurological disorders is characterized by substantial deficits in cognitive, psychosocial, and physical functioning. As the condition progresses, persons with dementia typically experience incremental losses in their capacity to engage independently in basic and instrumental activities of daily living, such as bathing, cooking, and driving a car (Alzheimer's Association, 2021).

Although dementia affects older adults across all races and ethnicities, African Americans have a significantly greater risk of developing dementia than their non-Hispanic White counterparts (Alzheimer's Association, 2021). Previous research has found that older African Americans are twice as likely to develop Alzheimer's disease compared with older non-Hispanic Whites (Rajan et al., 2019). Potential risk factors, such as type II diabetes, hypertension, obesity, low socioeconomic status, poor quality of education, and greater exposure to adversity and discrimination may increase African Americans' propensity for developing Alzheimer's disease and other related dementias (Lines et al., 2014).

Most older adults with dementia (83%) receive assistance in performing daily activities from family members and significant others (Friedman et al., 2015). Although caregiving demands are substantial across races and ethnicities, African American caregivers (CGs) spend more time providing direct assistance in strenuous tasks (e.g., bathing and lifting) compared with non-Hispanic White CGs. They also spend a higher proportion of monthly family income on assisting loved ones with dementia than their non-Hispanic White counterparts (National Alliance for Caregiving & American Association of Retired Persons, 2020).

As a result of such stressors, CGs of older adults with dementia experience high levels of emotional distress and decline in physical health. Several studies have reported elevated rates of depression, anxiety, and cardiovascular disorders in this population (e.g., Mausbach et al., 2013; Sallim et al., 2015). However, a substantial gap remains between CGs' mental health problems and needed services. The CG populations most negatively affected by this shortage of services are rural individuals and minorities, especially African Americans (Sheridan et al., 2014). African American CGs have reported significantly poorer levels of emotional and community resources than non-Hispanic White CGs (e.g., Fields et al., 2021).

The effectiveness of mental health services to this minority group has been limited by financial and logistical constraints, as well as lack of cultural concordance (Epps et al., 2019). Dementia CGs typically must travel for consultation and intervention at hospitals or health science centers. However, many African American CGs are unable to take advantage of these services due to financial limitations in obtaining attendant care and the high cost of travel (Glueckauf et al., 2012). Translation of stress reduction programs to African Americans also has been thwarted by sociocultural barriers. Prior research has found African American CGs tend to be somewhat mistrustful of both providers and programs originating outside their community, especially when the provider and/or the treatment approach appear to conflict with their family and religious values (Brewster, Bonds, et al., 2020; Lampe et al., 2022; Napoles et al., 2010).

Although awareness of the barriers in engaging African American dementia CGs has grown considerably, only a small number of stress-reduction programs have addressed these challenges. Using a telephone-based intervention focusing on problem-solving strategies, Burgio et al. (2003) found significantly greater reductions in the number of care recipient problem behaviors and CG bother appraisals (i.e., emotional distress) for cognitive-behavioral intervention (CBI) as compared with routine care control participants. However, no posttreatment differences in depressive affect or anxiety were obtained for distressed African American dementia caregivers between the problem-solving and control conditions.

In a recent three-arm randomized trial assessing the effects of the "Great Village" program, a culturally tailored psychoeducation intervention for African American CGs, Brewster, Epps, et al. (2020) found significant reductions in depressive symptoms among CGs who received either the Great Village intervention or the Great Village intervention with exercise programming as compared with an attention control condition. Note, however, that the majority of the sample fell within the normal range for depressive affect and anxiety at both baseline and posttreatment phases. Thus, participants in the Great Village intervention did not appear to be a distressed sample of African American CGs. Although the Great Village is a culturally responsive program, it is unclear whether changes in depression symptoms in this study reflected clinically meaningful reduction in CG depression.

Czaja and associates (2013) compared the effects across videophone-based CBI, attention control telephone support, and information-only on changes in CG burden, social support, caregiving appraisals, and depression. For African American CGs who received videophone, CBI showed significantly greater perceived social support and positive appraisals of caregiving. In contrast, no

significant differences were found for CG depression and burden. Similar to Brewster, Epps, et al. (2020), African American participants did not report clinically significant levels of depression at either baseline or posttreatment.

To both mitigate emotional distress and bolster the magnitude of treatment effects, Glueckauf and associates (2019) developed a faith-integrated, telephone CBI for African American dementia CGs with moderate depression. The unique components of their CBI were the incorporation of trained lay faith community workers (also known as lay pastoral care facilitators) to deliver treatment and the integration of spiritual elements into the framework of CBI (i.e., prayer, inspiration readings and faith sharing).

A major shortcoming of most telecommunicated-based, stress reduction programs for African American dementia CGs lies in their reliance on mental health professionals to deliver the intervention (Lampe et al., 2022). Such providers are likely to be eschewed by African American CGs due to perceptions of lack of concordance with family and religious values and the stigma of seeking assistance for mental health problems from such individuals (Conner et al., 2010). Attesting to the importance of religious values, Dupree et al. (2005) found that African American adults were twice as likely as their non-Hispanic White counterparts to seek assistance from church ministries when they had mental health challenges. This difference was associated with several factors, such as stigma in obtaining mental health services and conceptualizing distress within a spiritual framework. Thus, incorporating spiritual components into the narrative of stress reduction intervention may enhance acceptance and outcomes of CBI for distressed African American dementia caregivers (Wilks et al., 2018).

The primary purpose of the study was to assess the quantitative and qualitative outcomes of the ACTS2 pilot study. The quantitative objectives focused on changes in CG depression, health status, and severity of caregiving and self-care problems from pre- to postintervention. The qualitative objectives were to examine CGs' perceptions of the effectiveness of in-session activities, the quality of their relationships with coparticipants and facilitators, as well as their appraisals of the spiritual elements of the program.

Method

Transparency and Openness

The authors provided information about the following elements of the ACTS2 mixed-methods pilot study: recruitment strategies, inclusion and exclusion criteria, participant attrition, facilitator training procedures, caregiver CBI program, as well as descriptions of quantitative and qualitative data analytic procedures. Deidentified data and analysis codes are not currently available owing to the preliminary nature of the study. We plan to provide such data and codes following the completion of a future randomized clinical trial. Quantitative data were analyzed using SAS Version 9.4 and IBM SPSS Statistics 27. Microsoft Excel was used to support the qualitative data coding and analysis process (see Meyer & Avery, 2009). The authors followed Mixed Methods Article Reporting Standards (MMARS) to fulfill reporting standards. The study was not preregistered.

Research Design and Conceptual Framework

The design of the mixed methods pilot study was an open-ended trial (pre-post evaluation with no control group). The study was initiated December 2017 and completed November 2020, including recruitment, performance of four CG groups, and data collection and analysis.

A modified version of Pearlin et al.'s Stress Process model (Pearlin et al., 1990; Pearlin & Schooler, 1978) was used to guide the development of the conceptual framework of the pilot study. The framework consisted of four primary elements: (a) CG and care partner with dementia's background characteristics (e.g., age, education, and diagnosis), (b) CG stressors (e.g., appraisals of caregiving demands), (c) CG psychosocial resources (e.g., social support), and (d) CG depression and health status (see Glueckauf et al., 2012, for a detailed description of the conceptual model).

Participants

Caregivers

Twelve African American family CGs, six from Jacksonville, Florida, and six from Tallahassee, Florida, were enrolled in the ACTS2 12-session, faith-integrated CBI. The 12 CGs were assigned randomly to one of two groups in their respective areas (i.e., Jacksonville or Tallahassee). Each group initially consisted of four members, three CGs and one lay pastoral care facilitator. Three CGs, two from Tallahassee and one from Jacksonville, dropped out from the study after assignment to treatment. The first Tallahassee CG attrited after the 4th session and the second dropped after the 6th session. Both Tallahassee CGs left the program owing to unanticipated, additional family caregiving obligations. The Jacksonville CG dropped out prior to the first session as a result of the demands of a new job.

Of the remaining nine completers, eight were female and one was male. The mean age of CGs was 56.00 ($SD = 13.49$). Their average years of education was 15.89 ($SD = 2.03$), and the mean months spent in caregiving were 37.67 months ($SD = 41.05$). Six CGs were employed full- or part-time; the remaining six did not have paid positions. The relationships of the CGs with their care partners with dementia were as follows: daughters ($n = 5$), son ($n = 1$), wife ($n = 1$), granddaughter ($n = 1$), and niece ($n = 1$).

Seven care partners with dementia were women and two were men. Their years of age ranged from 70 to 91 ($M = 83.33$, $SD = 6.73$); their average years of education were 13.22 years ($SD = 4.68$). The care partners' average score on basic activities of daily living was 4.00 ($SD = 1.22$) and instrumental activities of daily living were 4.22 ($SD = 2.59$), respectively. Moderate levels of dependence on assistance from primary CGs were found for basic and instrumental activities of daily living.

Facilitators

Four African Americans from Tallahassee ($n = 2$) and Jacksonville, FL ($n = 2$) were randomly selected by region from a larger pool of 12 faith community workers (seven from Jacksonville and five from Tallahassee) to serve as lay pastoral care facilitators for the ACTS2 pilot study. Three of the facilitators were women and one was a man. Facilitators' ages ranged from 48 to 68 years ($M = 59.75$, $SD = 8.88$). Their mean years of education was 16.25 ($SD =$

1.71) and their mean years of lay ministerial service was 16.50 ($SD = 11.70$). Facilitators were paid on an hourly basis for time spent in session preparation, direct service, and documentation. Their duties consisted of leading both group and individual problem-solving sessions and recording progress notes, session attendance, and CGs' ratings of change in problem severity from individual sessions 7 to 11. One of the Tallahassee female facilitators was replaced with another female facilitator owing to unexpected work-related demands.

Inclusion and Exclusion Criteria

Caregivers

African American CGs were included if they: (a) were the primary CG for a family member or significant other at least 60 years of age meeting Neurological and Communicative Disorders and Stroke-Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) criteria for dementia (McKhann et al., 1984), (b) provided assistance to a care partner with dementia in at least two instrumental activities of daily living, (c) spent at least 6 hr per week in direct care provision to the care partner, (d) scored 10 or above on the Patient Health Questionnaire-9 (PHQ-9; Kroenke & Spitzer, 2002), and (e) were 18 years of age or older. The PHQ-9 was used to screen for clinically significant levels of CG depression (i.e., moderate depression).

CGs were excluded if they: (a) met criteria for moderate or high suicide risk on the Mini-International Neuropsychiatric Interview (M.I.N.I.) 5.0 (Sheehan et al., 1998) or (b) provided assistance to a care partner with a terminal diagnosis (i.e., death anticipated in six or fewer months). The reason for excluding CGs of care partners with terminal diagnoses was their concerns are likely to differ from CGs with care partners in the early and middle stages of dementia; the former may not benefit from CBI focused heavily on managing difficult care partners' behaviors and instrumental activities of daily living.

Lay Pastoral Care Facilitators

Facilitator inclusion criteria were: (a) minimum of two years of college, (b) at least two years of experience in a lay ministry focusing on the needs of older congregants, (c) received a positive recommendation from their pastor or ministry supervisor, (d) 21 years of age or older, and (e) experience using web-based technology and access to a personal computer with web connectivity. Facilitators were excluded if they: (a) were unable to make a commitment to undergo a 30-hr training program, and (b) were unable to dedicate an average of five hours per week to the 12-session program during the intervention.

Procedure

Caregiver and Facilitator Recruitment

Multiple methods were used to recruit family CGs of persons with dementia: (a) church and senior center presentations, (b) African American radio and TV public service announcements and ACTS 2 staff media interviews, and (c) local newspapers. African American lay pastoral care facilitators were recruited

through referrals from pastors and ministerial supervisors in their communities.

Facilitator Training

Approximately two months following an initial screening interview, facilitators underwent a two-day intensive training workshop. The contents of the workshop focused on (a) the basics of dementia, (b) instruction and practice in observation and listening, (c) noting and reflecting feelings, and (d) discussion about different faith traditions, sensitivity to CG preferences, and ethical issues. Subsequently, facilitators received six, biweekly two-hour telephone sessions during which they delivered mock ACTS2 group and individual sessions (e.g., assertiveness training and goal setting) using a round-robin format. Note, also, that facilitators obtained weekly supervision from a doctoral-level licensed mental health provider during the actual CG intervention.

Caregiver Screening and Assessment Procedures

Using a Florida State University (FSU) IRB-approved protocol, informed consent was obtained from CGs, followed by a screening interview to assess their caregiving responsibilities, level of caregiving distress, and presence of any hearing and reading difficulties, as well as their care partner with dementia's level of dependence in basic and instrumental activities of daily living. The tenth author screened prospective participants and entered their data into the ACTS2 database. Approximately 1 week before intervention, CGs who qualified for the ACTS2 pilot study underwent a 60-minute baseline assessment consisting of a battery of standardized questionnaires. CGs completed a second administration of the same set of dependent measures 1 week after the completion of the CBI program. The ninth author who worked independently at the FSU Survey Lab administered the standardized questionnaires. Both the ninth and tenth authors used telephone to collect these data.

Intervention Protocol

ACTS2 faith-integrated CBI consisted of 12 telephone-based weekly sessions, seven 1-hour small groups and five 1-hour, individual goal-setting and implementation sessions. The intervention included seven major components: (a) basic characteristics of dementia (e.g., types of dementias, common symptoms, stages of the condition and risk factors), (b) relaxation training integrated with prayer and meditation, (c) effective thinking about caregiving challenges coupled with pastoral messages emphasizing self-care, (d) building in pleasant daily activities (e.g., taking a walk or listening to gospel music) as a guard against emotional distress, (e) communicating assertively with family members and health professionals, (f) developing effective problem-solving skills through goal setting, goal implementation and monitoring change over time, and (g) promoting strategies for maintenance of treatment gains.

During weeks 1–6, CGs met with their facilitator over toll-free telephone in groups of three for one-hour weekly sessions. At the outset of each group session, facilitators offered a brief explanation of (a) how the specific skill set covered in the session linked to CGs overall self-care and caregiving goals and (b) how systematic practice of core skills led to improved emotional and physical well-being. Facilitators used open-ended questions to encourage

participants to share their caregiving experiences with each other and to reflect on how the target skill of each group session (e.g., effective thinking or autogenic relaxation) might enhance their caregiving and self-care activities. Facilitators also made a concerted effort to ensure all caregivers had opportunities to participate. Group discussion among participants was encouraged rather than dyadic interactions between facilitator and individual group members. In so doing, facilitators provided conditions for caregiver engagement and empowerment, as well as the formation of strong bonds among group members.

Across weeks 7–11, each CG received five 1-hour, weekly individual telephone sessions focusing on self-identified, caregiving goals. All participants were encouraged to select and implement at least two caregiving and/or self-care goals. They initially were instructed how to conduct a basic behavior analysis of identified problems, followed by practice of cognitive-behavioral strategies shown in previous research to lead to problem improvement (Burgio et al., 2003; Glueckauf et al., 2007). Participants were asked to monitor and report changes in the severity of identified problems from week 7 to 1-week posttreatment. In the last group session (i.e., week 12), CGs shared their successes and challenges during the goal attainment process and identified strategies for promoting effective problem-solving when faced with future caregiving and self-care challenges. Note that the inclusion of specific pastoral care elements, such as prayer, faith sharing, and scripture readings, across sessions was based on the judgment of ACTS2 facilitators in consultation with group members.

Screening and Dependent Measures

Screening Measures

The PHQ-9 contains nine items assessing Diagnostic and Statistical Manual of Mental Disorders, 4th edition (*DSM-IV*) criteria for depression. Respondents were asked to rate depressive symptoms on a scale from 0 (*not at all*) to 3 (*nearly every day*) over the past two weeks. A composite PHQ-9 score of 5–9, 10–14, 15–19, and 20–27 indicated mild, moderate, moderately severe, and severe depression, respectively. Previous research has shown the PHQ-9 has acceptable psychometric properties, including 88% sensitivity and 88% specificity and criterion-oriented validity (Kroenke & Spitzer, 2002).

The Suicidality module of the M.I.N.I. 5.0 (Sheehan et al., 1998) is a screener that assesses suicide risk. The instrument contains six yes/no items that assess core elements of suicide risk, including suicidal ideation, plan to inflict self-harm, and previous attempts of suicide. The suicidality module has shown acceptable internal reliability and validity properties.

Lawton and Brody (1969) nine-item instrumental activities of daily living (IADL) scale was used to assess independence in performing household and related activities. CGs rated their care partner with dementia's functioning on tasks, such as cleaning the house, preparing meals, and grocery shopping, on a scale ranging from 0 = *unable to complete the task*, 1 = *able to complete the task with some help* to 2 = *able to complete the task without any help*. The IADL scale has shown acceptable validity and reliability properties (Graf, 2008).

Dependent Measures

Primary quantitative outcome measures included CGs' level of depression, health status, and severity of self-identified caregiving and self-care problems. Secondary quantitative measures consisted of perceived social support and CG burden.

CG depression was assessed using the Center Epidemiological Studies-Depression (CES-D; Radloff, 1977) and the depression subscale of the Depression-Anxiety-Stress Scale (DASS; Lovibond & Lovibond, 1995). The 20-item CES-D measures the frequency of depressive symptoms the respondent has experienced over the past week on a scale ranging from 0 (*rarely or not at all*) to 3 (*most of the time*). The 14-item depression subscale of the DASS assesses the extent of depressive affect noted over the past week on a scale of 0 (*did not apply to me at all*) to 3 (*very much or most of the time*). Both the CES-D and DASS have shown good validity and reliability properties (Knight et al., 1997; Page et al., 2007).

Health status was assessed using the Caregiver Health and Health Behavior Inventory composite (CHHB; Elliott et al., 2010) and the PHQ-15 (Kroenke et al., 2002). The CHHB is a three-item composite scale that assesses CGs' perception of their overall physical health. CGs were asked to rate the following statements: (a) "In general, would you say your health is?" on a scale of 0 (*poor*) to 4 (*excellent*), (b) "Compared with 3 months ago, how would you rate your health in general?" on a scale of 0 (*much worse now*) to 4 (*much better now*), and (c) "In the past 3 months, do you feel your physical health has improved?" with 0 (*no*) and 1 (*yes*). The 48-item CHHB, the source of the three-item composite, was developed by REACH II investigators to assess CG perceived health, sleep quality, unhealthy behaviors, and health problems.

The PHQ-15 assessed physical symptoms commonly associated with distress. CGs were asked to report whether they experienced any bother with physical symptoms (e.g., headaches and stomach pain) over the last four weeks on a scale of 2 (*bothered a lot*) to 0 (*not bothered at all*). PHQ-15 has low correlations with mental health measures and significant associations with functional disability questionnaires (Kroenke et al., 2010).

The Problem Severity Scale (Glueckauf, 2000) measured changes in the severity of CG-identified problems. CGs rated problem severity on a scale from 1 (*no problem*) to 6 (*severe problem*). Problem severity was calculated by subtracting the baseline score at the outset of goal setting from the score that best represented final change. The latter was obtained by examining problem severity scores from the initial goal setting session to the end of intervention (i.e., session 12) and selecting the modal score across these sessions. The Problem Severity Scale has shown good inter-rater reliability and criterion-oriented validity.

The 30-item Interpersonal Support Evaluation List (ISEL; Cohen et al., 1985) evaluated social support across a variety of domains, including perceptions of belonging, emotional support, tangible support and self-esteem. Each item was rated on a scale from 0 (*definitely false*) to 3 (*definitely true*). The ISEL has shown good internal consistency and acceptable predictive validity (e.g., Rogers et al., 2004).

The 19-item Caregiver Appraisal Inventory (CAI) measured participants' perceptions of the emotional, psychosocial, and physical consequences of caregiving activities. CAI items were rated on a scale from 0 (*never true*) to 4 (*nearly always true*). The CAI

has shown good internal consistency and validity properties (Lawton et al., 1991).

Qualitative, Semistructured Interviews

Semistructured interviews were performed with each CG over telephone within 48 hr after group sessions 2 and 5 and individual sessions 9 and 11. Two trained M.S. students independently conducted these interviews balanced across session type and number. The primary domains of inquiry included: (a) appraisals of the desirability and impact of spiritual elements in each session, (b) CGs' in-session experiences, particularly interpersonal relationships, and (c) effects of ACTS2 training on daily caregiving and self-care activities. Probes about spirituality focused on CGs' feelings about in-session spiritual activities (e.g., prayer and faith sharing) and how these activities influenced their caregiving activities. Interview probes of in-session experiences examined the quality of relationships among participants and their group facilitator, as well as topics covered in the session and session duration. Questions related to the impact of the ACTS2 CBI program solicited examples of in-session skill training activities and their impact on caregiving challenges and self-care strategies.

The average duration of the semistructured interviews was 30 minutes. The sessions were digitally recorded and converted to compressed WAV audio files. A group of three trained undergraduates subsequently transcribed verbatim the audio files using a web-based application, oTranscribe (oTranscribe, 2022). A separate group of 3 trained undergraduate students performed "quality checks" to confirm accuracy and completeness of each transcript.

Fidelity of Treatment Implementation

Treatment fidelity checklists (Glueckauf & Lustria, 2009) were developed to assess the extent to which facilitators performed key components of both group and individual sessions. The primary components selected for fidelity assessment were either organizational elements (e.g., facilitator stated goals of the session) or fundamental skills (e.g., facilitator described key elements of targeted caregiving strategies) delineated in the CBI manual. Although deployment of spiritual activities was left at the discretion of facilitators, level of engagement in such practices during group and individual sessions was also explored. Two group sessions (sessions 3 and 6) and two individual sessions (sessions 7 and 10) were audio recorded by each facilitator and subsequently reviewed by two independent, trained coders. The number of items in each of the four session checklists ranged from 5 to 21; all items were coded either 0 or 1, with 0 = *task not performed* or 1 = *task completed or partially performed*.

Data Analytic Approach

Quantitative Analytic Strategies

CGs' and care partners' with dementia demographic and background characteristics were analyzed using descriptive statistics. Paired-samples *t* tests were performed to assess changes in the dependent measures from pre- to posttreatment. Next, Cohen *d* coefficients were calculated to assess the postintervention effect size of each dependent measure. Cohen's *d* = .20 is considered a small

effect size, *d* = .50 represents a medium effect size, and *d* = .80 is a large effect size (Grande, 2022; van den Berg, 2022).

Change scores for the Problem Severity Scale were calculated by subtracting the rating that best represented the final level of severity from the baseline severity rating. The final severity rating was selected by examining the overall pattern of scores from baseline to the final week of treatment and subsequently identifying the modal severity value across weekly severity ratings. The rationale for using the most representative rating was the possibility that the final weekly severity rating may be disproportionately affected by situational factors, such as hospitalization of a care partner with dementia or an unanticipated return of a close family member to provide a vacation break.

Prior to conducting paired-samples *t* tests, a three-step procedure was used to assess the effects of potential covariates on change scores of the dependent measures. First, a list of 14 potential covariates was identified based on a review of the literature (see Table 2). Second, Pearson product-moment or point-biserial correlations were performed on each prospective covariate and the change score for each of the seven dependent measures. A total of three prospective covariates (i.e., average time CG spent with their care partner with dementia per week, location [i.e., Jacksonville or Tallahassee], and CG lives in the same household with the care partner with dementia) showed moderate correlations (.49 or above) with 50% of their corresponding dependent measures. The remainder exhibited small correlations with the seven dependent measures. Third, a within-subjects measures ANCOVA was performed to assess the impact of the three prospective covariates on the dependent measures. Only two of 27 ANCOVAs showed a significant interaction effect between the covariate and pre-post change on the dependent measures. As a result, paired-samples *t* tests were performed on each of the seven dependent measures.

Last, CGs' adherence to treatment was assessed using three key indicators: (a) mean proportion of sessions attended, (b) mean number of session cancellations, and (c) completion level of session outside assignments.

Qualitative Analytic Strategies

Qualitative data from the four session interviews were analyzed using an inductive approach (Charmaz, 2006). Open coding was used initially to process the raw data. Three trained undergraduate coders carefully read individual transcripts and generated general themes and ideas. Separate codes for each transcript were created from this preliminary analysis. Open coding was used initially to process the raw data. Entire transcripts were read closely and evaluated for general themes and ideas. Reoccurring ideas across transcripts were identified and grouped into themes and subthemes. The second author subsequently inspected each theme and subtheme and as needed, modified them to ensure clarity and coherence through concept mapping.

Results

The quantitative results of the ACTS2 pilot study are presented first, including paired-samples *t* tests and effect size calculations, followed by analyses of treatment adherence and implementation fidelity. Qualitative findings are delineated subsequently, focusing on content analyses of primary themes and subthemes from telephone-based semistructured interviews.

ACTS2 Pilot Study Quantitative Findings

Primary Outcome Measures

Paired-samples *t* tests were performed to test the statistical significance of changes on the five primary CG outcome measures, including depression (CES-D and DASS), health status (PHQ-15 and CHHB), and Problem Severity (see Table 1 below). The significance of *p* values was set at $\alpha \leq .05$. Effect sizes (i.e., Cohen's *d*) also were calculated to assess the magnitude of change from pre- to postintervention across all measures.

Pre- to postintervention changes in CG depression were mixed. Significant improvement in depression was found on CES-D, $t(8) = 4.19, p = .003$, Cohen's $d = 1.40$. In contrast, no statistically significant difference was shown on the DASS depression subscale, $t(8) = 2.03, p = .077$, Cohen's $d = .677$. Although the pre-post comparison was statistically nonsignificant, a trend of improvement was noted for this measure coupled with a medium effect size.

Next, pre- to postintervention changes in CG health status were mixed. Significant postintervention change on physical symptoms associated with distress was found on the PHQ-15, $t(8) = 2.26, p = .054$, Cohen's $d = .752$. In contrast, no significant difference from pre- and postintervention change was obtained on the CHHB global health appraisal index with an accompanying low effect size, $t(8) = .81, p = .444$, Cohen's $d = .270$.

Turning to problem severity, 25 CG self-identified problems were reported across the nine CGs. Problem Severity Scale baseline and final representative ratings were calculated for each CG problem. Significant pre- to posttreatment reductions in CG problem severity were obtained for CG problem severity, $t(24) = 12.30, p < .0001$; Cohen's $d = 2.46$.

Secondary Outcome Measures

Paired-samples *t* tests were performed on two secondary measures of CG social support (ISEL) and appraisal of caregiver demands (CAI). A statistically significant postintervention increase in perceived social support was evidenced on the ISEL, $t(8) = 2.60, p = .031$, Cohen's $d = .867$. However, the CAI

Table 2

List of Potential Covariates

Potential covariates
1. CG age
2. CG sex
3. Disruptive Behavior Factor of the pre-RMBPC
4. Depression Factor of the pre-RMBPC
5. CG relationship to care partner with dementia
6. Number of hours CG works outside home
7. Number of hours per week CG spends in personal time
8. CG location (Tallahassee vs. Jacksonville areas)
9. CG lives with care partner with dementia
10. CG receives help with caregiving responsibilities
11. Number of hours per week CG spends with care partner with dementia
12. Number of hours per week CG receives emotional support from others excluding family members
13. Number of months spent as a CG
14. CG years of formal education

Note. CG = caregiver; RMBPC = Revised Memory and Behavior Problem Checklist (Roth et al., 2003; Teri et al., 1992).

showed no significant changes in participants' appraisal of caregiving demand from pre- to postintervention, $t(6) = 1.12, p = .305$, Cohen's $d = .423$.

Adherence to Treatment

The proportion of session cancelations was calculated by counting the number of canceled sessions (for all causes) divided by the total number of sessions. The mean number of session cancelations across pilot study participants was low ($M = 2.54, SD = 1.81$), particularly in light of CGs' multiple caregiving, family, and/or work-related demands. Participants' completion of outside assignments (e.g., performed goal implementation activities) was assessed by their facilitators using a 0 to 3 rating scale, ranging from 0 = *did not do the assignment* to 3 = *completed all phases of the assignment*. The mean rating of homework completion was 2.29 ($SD = .96$), indicating a moderately high level of adherence in completing outside assignments on intervention-related tasks.

Table 1

Changes in Pre- and Posttreatment Means of Pilot Study Primary and Secondary Outcome Measures and Effect Sizes (N = 9)

Measures ^a	Pretreatment	Posttreatment	<i>p</i> value	Effect size
Primary measures				
CES-D	8.00 (4.30)	2.89 (3.26)	0.003 ^b	1.40 ^c
DASS Depression Subscale	2.89 (3.41)	1.33 (1.58)	0.077	0.677
CHHB Inventory Index	4.67 (1.80)	5.22 (1.64)	0.444	0.270
PHQ-15	6.22 (4.44)	4.67 (3.46)	0.054	0.752
Problem severity	5.03 (0.94)	2.14 (0.97)	0.0001	2.46
Secondary measures				
ISEL	67.89 (13.60)	80.56 (7.23)	0.031	0.867
Caregiver Appraisal Inventory	21.43 (11.30)	17.86 (12.19)	0.305	0.423

Note. Standard deviations are located within the parentheses. CES-D = Center for Epidemiological Studies-Depression; DASS = Depression-Anxiety Stress Scale; CHHB = Caregiver Health and Health Behavior Inventory; PHQ-15 = Patient Health Questionnaire-15; ISEL = Interpersonal Support Evaluation List.

^a The number of participants for each pre-post comparison was $N = 9$, except the Caregiver Appraisal Inventory $N = 7$. ^b Type 1 error rate per comparison was set at $p \leq .05$. Paired-samples *t* tests were conducted to assess changes on dependent measures from pre- to posttreatment. ^c An effect size coefficient (i.e., Cohen's *d*) was calculated for each paired-samples *t* test.

Implementation Fidelity Analysis

Four separate checklists were used to assess the extent to which facilitators performed key components of the group (sessions 3 and 6) and individual sessions (sessions 7 and 10). First, the percent of agreement across three independent coders was calculated across three time intervals for a total of seven months (i.e., two months, two months, and three months, respectively). The proportion of agreement across all sessions collapsed over time and coder pairs (coder 1/coder 2, coder 1/coder 3, and coder 2/coder 3) was 83.70, 84.79, and 90.33, respectively. Only limited coder drift was found across the three time intervals. Second, the percentage of key session components completed was calculated averaging each coder pair for both group and individual sessions across three time intervals. The proportion of key session components completed across all sessions and coders over time was 88.75, 89.9, and 91.2, respectively. The overall pattern of findings suggested facilitators performed successfully over 80% of anticipated core elements of the group and individual sessions. As mentioned previously, engagement in spiritual activities was explored across group and individual sessions. This analysis revealed 86% of probe sessions contained a spiritual practice, typically a beginning and closing prayer.

ACTS2 Pilot Study Qualitative Findings

The findings of telephone interviews with pilot study CGs and facilitators were organized using key themes and attendant sub-themes emerging from the qualitative analysis. Overarching themes were spirituality, interpersonal relationships, caregiving strategies, and self-care.

Appraisals of Spiritual Elements

Qualitative analysis of the spiritual components of the training program focused on (a) spirituality displayed in group sessions, (b) spirituality among CGs and facilitators, and (c) CG perceptions of in-session spiritual activities.

Spiritual practices and statements were noted across most sessions through a combination of relaxation, prayer, and faith-sharing. In group session 2, CGs practiced relaxation techniques and were encouraged by facilitators to integrate their own spiritual practices into these exercises. CG16 stated, "We talked about scriptures that we like to read in the relaxation session and he [facilitator] will tell us that sometimes we just need to sit down, use our relax skills, and meditate on scriptures and stuff."

CGs also incorporated prayer when engaging in conversation with CG peers in group sessions. CG38 noted,

And then like, even in our discussions, we would pray and talk about how, you know, just dealing with tough caregiving situations that come up on a daily basis, we know we probably would respond a different way had it not been for God, you know.

CGs reported the spiritual component of ACTS 2 aligned their faith with the CG role, strengthened group relationships, and enhanced the in-session experience. CG47 stated,

Sharing the Lord with others in the group makes me stronger . . . It makes me able to go through what I'm going through with my mom . . . I think it

helps to make us closer, knowing that we are basically all on the same level as far as God is concerned.

The spiritual component helped to strengthen group relationships and create a strong bond among group participants.

In-Session Experiences

Interactions among CG participants and between CGs and their facilitator were perceived as consistently supportive and nurturing. CGs described their relationships with one another as: team-oriented, insightful, empathetic, and nurturing. Participants concluded that coping with their caregiving issues did not have to be an individual effort, emphasizing instead their many common needs and goals. CG9 reflected that "We get along well . . . no one is trying to outshine another one, you know. Everyone is there because we all have a need and it's almost as pure as you can get." CGs indicated they benefited greatly from their peers' insights. CG3 stated their fellow CGs "can shed some light on something that I may not know at this point, and may be able to look out for."

Having peers available to listen also helped CGs express personal feelings and concerns. For CG4, "Dementia is a whole different animal, and for me to connect with other people who are CGs of people with the same illness, helped me to open up." Sharing similar cultural backgrounds helped to establish trust and comfort with showing vulnerability. Facilitators themselves noted how CGs seemed "relaxed and comfortable and talkative and sharing and opening up during the session," as FA2 reflected.

CGs' perceptions of the CG-facilitator relationship were very similar to those of the CG-CG relationship. The key distinguishing factor between the two types of relationships was the focus on facilitator communication style during group sessions. CGs identified specific facilitator process and communication skills that led to increased cohesion among group members. CG6 noted how instead of "pushing, pushing, pushing our facilitator takes her time with us."

CGs also noted that facilitators made themselves available after scheduled sessions, and openly shared personal experiences that helped CGs relate. CG9 described how her facilitator "actually shared some of the things he was dealing with in his personal life and I think that made it easier." CGs reported feeling free to discuss any topic. They attributed this group dynamic to facilitators' skills in creating a comfortable and open session environment. Facilitators often shared these perceptions about relationships with CGs. FA1 described how "I felt comfortable and I felt that she [CG] was comfortable with me."

Impact of Caregiving Strategies

CGs received instruction and practice in using cognitive-behavioral techniques (e.g., assertiveness training) during group and individual sessions. These skills helped participants manage daily caregiving activities, difficult care partner behaviors, and obtaining assistance from family members.

CGs reported improvements in their communication with loved ones with dementia from skills acquired during group and individual sessions. CG8 described how with "some of the relaxation techniques, and in my tone of voice when I'm speaking to my loved one, I'll stop and think, you know, before I speak and I try not to react in anger." CGs likewise adapted in-session techniques

to gain cooperation in performing activities of daily living. For example, CG9 was able “to be more assertive in getting the job done” when helping her loved one with toileting. Overall, the deployment of skills rehearsed in the training program led to reductions in frustration and disagreements between CGs and their care partners.

In managing difficult behaviors, CGs used self-observation of mood changes, relaxation techniques, effective thinking, and patient responding. CG5 explained that “we discuss our goals and I said that I reach my goals because [of] my patience, I have to have patience and learn and I have patience now, and as I said with the breathing and all that I learn so much of how to deal with the way that my mother act [sic] and not get upset with her because she cannot help it you know.” Practicing these skills helped CGs to focus on that which they could influence and simultaneously, to let go of what they could not control.

Asking for help from family members and/or outside resources during the goal-setting portion of the ACTS 2 program helped CGs increase their sense of mastery. CG8 noted the importance of making time for bonding with loved ones: “For the last 2 sessions . . . I went ahead and made some phone calls to my relatives . . . this helped to put some things in place for spring break so I could have a little family time.” Enacting assertive communication strategies helped CGs obtain needed assistance and support from other family members.

Self-Care

The ACTS2 program encouraged participants to engage in self-care activities. Examples of such activities included taking brief breaks for prayer and relaxation, listening to gospel music, reinitiating socialization with friends, and promoting physical health.

The majority of CGs reported chronic strain and fatigue associated with caregiving responsibilities and periodic neglect of their emotional or physical well-being. Several participants indicated that when they opted not to take breaks from caregiving duties and/or did not use their newly acquired relaxation techniques, they were more likely to feel “stressed” and in turn, provide less than optimal care to their loved ones with dementia. CG7 affirmed that “learning about the different signs of stress and how stress can show up in your body, meaning you know the pains or aches or you know stiffness in the joints . . . that you need to take the time out for yourself and to use relaxation to help you because otherwise it will affect your health and make things worse for your loved one.” By making time for themselves and incorporating relaxation techniques, participants felt better able to care effectively for their loved ones with dementia.

Several CGs struggled with creating sufficient time to participate in community activities, such as church-related activities and socialization with friends. They also periodically felt isolated from family members. Goal setting helped CGs interact more often with family members and friends. CG4 described how focusing on social engagement goals “just made me feel better overall as a CG.” In the process, CGs also found themselves better equipped to provide support for peers in similar roles. For CG1, ACTS2 “helped me help those in need” by listening thoughtfully and providing resources for others in church.

Through this process of mutual support, CGs developed an increased awareness of the importance of their own health. Several

reflected on the importance of relaxation coupled with prayer time. For example, CG6 realized that “I can do some 5- or 10-minute relax exercises and meditating if I want to you know, I could have that time for me.” Many also placed greater emphasis on physical exercise. CG9 began to “get back into my exercises and do something to help myself.” Likewise, CGs began attending more to their own medical needs. For example, CG4 shared about a recent trip to the emergency room, saying “it was a wake-up call for me because I would have just continued on that same, same road and I feel I kind of like needed that to kind of shake me up.” Reflecting on this experience with her facilitator helped CG4 to understand the importance of maintaining good health in her caregiving journey.

Discussion

The findings from the quantitative and qualitative analyses are discussed first, followed by an examination of the pattern of convergence across quantitative and qualitative results. Last, the strengths and limitations of the current study and future directions for research are described.

Quantitative Analysis

The overall findings from the quantitative component of the pilot study provided preliminary support for the effectiveness of faith-integrated CBI on CG depression, health status, problem severity, and social support. The majority of the primary outcome measures (i.e., CES-D, PHQ-15, and Problem Severity) showed statistically significant improvement from pre- to postintervention. Their effect sizes also fell within the high medium to large range. The problem severity measure showed the largest effect size across the five ACTS2 outcomes (see Table 1). CGs reported a significant decrease in problem severity from a mean rating of 5.03 (i.e., moderately severe problem) to 2.14 (i.e., a slight problem). This finding is particularly important since these problems were directly related to CGs’ intervention priorities.

Note that the effect sizes of the CES-D, PHQ-15, and Problem Severity measures were comparable to those found in Glueckauf and Colleagues’ (2012) ACTS1 pilot study deploying mental health professionals to deliver CBI for moderately depressed African American dementia CGs. The major differences between the two interventions were the use of faith community workers and the inclusion of pastoral care elements in ACTS2.

In examining the remaining primary outcome measures, two explanations are proposed for the null findings. Although the DASS Depression subscale did not meet the criteria for statistical significance, a strong positive trend was obtained for the DASS Depression ($p = .077$) with an accompanying Cohen’s d of .677. Thus, the small sample size appears to have contributed to the lack of statistical significance for this measure. Turning to the CHHB Index, only small improvement in CG appraisals of health status was found. A possible explanation for this null result may have been the global nature of this three-item composite. Asking CGs to appraise their general health over a 3-month interval may not have been sensitive to changes in key symptoms associated with health. Corroborating this conclusion, the PHQ-15, a symptom-specific measure (e.g., bother from headaches and stomach pains) showed significant changes from pre- to postintervention.

Analysis of secondary outcome measures showed mixed results. On the positive side, the ISEL showed significant increases from pre- to postintervention. Substantial improvement in CG social support was anticipated because the skills training exercises and discussion in session 4 of the program focused on the buffering effects of social activities. These results were similar to previous studies (Burgio et al., 2003; Gitlin et al., 2003; Glueckauf et al., 2019), all of which showed significant gains in CG social support from pre- to posttreatment.

In contrast, no statistically significant change was found on the CAI. This finding is difficult to interpret since previous cognitive-behavioral outcome studies with African American CGs have found significant effects on similar measures of caregiver burden (e.g., Burgio et al., 2003). Nonetheless, the change in CAI scores was in the expected direction and the effect size was $d = .423$.

Qualitative Analysis

In discussing their ACTS2 experiences, CG participants highlighted the importance of spirituality, relationships among CGs and facilitators, as well as caregiving and self-care strategies. First, CGs emphasized the key role of spirituality in the skills-building and support program across the four semistructured interviews (i.e., sessions 2, 5, 9, and 11). They strongly endorsed the benefits of prayer and faith sharing during the sessions. This aspect of the program facilitated discussion about the positive effects of prayer in CGs' caregiving activities and the importance of "keeping the faith." These interactions provided spiritual strength and increased confidence for CGs in overcoming the challenges and demands of caring for a loved one with dementia. Spirituality was embedded within the framework of ACTS2 to enhance concordance with the sociocultural characteristics and religious beliefs of African American CGs, especially midlife and older adult CGs.

Second, CGs emphasized the pivotal role of peer interaction and the importance of relationships in the group sessions, particularly opportunities for obtaining emotional support and exchange of caregiving tips. CGs received reassurance and positive feedback about their caregiving efforts from other group members. Participants especially appreciated encouragement about their caregiving role from peers who assisted loved ones in the severe stage of dementia. This observation was consistent with Glueckauf and colleagues' (2012) ACTS1 pilot study, buttressing the value of group discussion about the progression of dementia and effective coping strategies for managing decline in care partner functioning over time. CGs also focused on their strong ties with group facilitators and the benefits accrued from this relationship. They reported facilitators were insightful, inviting, and open. Having a knowledgeable and empathic facilitator appeared to enhance CGs' perceptions of social support and provided the foundation for goal-setting activities related to caregiving challenges and self-care.

Turning to caregiving and self-care strategies, CGs emphasized the benefits of goal setting and assertiveness training. Participants perceived goal-setting as a conduit for achieving a balance between meeting their personal needs and those of their family members with dementia. CGs reported substantial increases in both perceived effectiveness in addressing their personal needs (e.g., prayer time) and skills in providing quality care and support to their loved ones with dementia. This shift in CG perspective—recognizing the importance of balancing care partner assistance with personal self-care needs—was a key element of the CBI and appeared to serve as an active therapeutic agent in reducing depressive affect.

Integration of Quantitative and Qualitative Findings

An overall pattern of convergence was shown across key outcomes between the quantitative and qualitative findings. First, significant reductions in the frequency of physical symptoms associated with distress were corroborated by CGs' reports of goal-related successes in improving their personal health status and personal enhancement time (i.e., "me time"). Furthermore, several participants noted in their semistructured interviews the physical strain associated with the demands of caregiving and as a result, incorporated structured relaxation techniques and prayer to mitigate these difficulties.

Second, significant reductions in depression were found on both the CES-D and qualitative reports of the outcomes of caregiving strategies related to care partners' difficult behaviors and self-care. First, CG stressors, such as managing care partners' difficult behaviors and assisting in demanding activities of living (e.g., bathing) were linked to depressive affect. CGs stated how overwhelmed they felt in responding to these challenges during the initial phase of the intervention. During individual problem-solving sessions 7 to 11, CGs implemented caregiving strategies and subsequently reported significant improvements on the Problem Severity scale and concomitant gains related to these strategies in their qualitative semistructured interviews administered following sessions 9 and 11.

It was also common for CGs to report early in the program neglecting their own emotional and physical well-being in the service of supporting their loved ones with dementia. Similar to their management of challenging care partner behaviors, they used goal setting as a vehicle for enhancing self-care (e.g., increasing "me time," social activities, and physical exercise). Implementation of these strategies was associated with a reduction in depressive symptoms on the CES-D and qualitative reports of distress.

Third, significant increases in the social support measure were mirrored in CGs' qualitative findings about the importance and benefits of group interaction with peers from similar cultures and faith traditions, as well as increased socialization with friends and church members. Participating in small groups with similar others offered a comfortable and safe medium for CGs to express themselves, form strong ties and share helpful caregiving tips. In addition, individual problem-solving sessions 7–11 provided a vehicle for increasing socialization in the community through goal setting and implementation.

Strengths, Limitations, and Future Research Directions

The overall findings of the pilot study provided strong preliminary support for the effectiveness of the ACTS2 skills training and support program. African American CGs reported high levels of engagement in intervention, particularly strong alliances among CGs and their facilitators, considerable benefits from the caregiving tips of coparticipants and from the skills-building instruction of their facilitators, as well as high acceptance of and openness in disclosing personal caregiving issues to both CGs and facilitators. Furthermore, CGs reported significant improvements in depression, physical symptoms associated with distress, social support, and self-identified caregiving problems from pre- to posttreatment.

The primary limitations of the current study are the lack of a control group and small sample size. These shortcomings will be addressed in a follow-up efficacy study. We plan to conduct a randomized clinical trial ($N = 114$) comparing the effects of faith-integrated CBI versus a waiting list control group on changes in

depression, health status, and severity of identified caregiving and self-care problems.

Another potential shortcoming of this investigation can be found in the generalizability of the research findings. It is possible that the pilot study sample represented a highly motivated subgroup seeking assistance previously unavailable to African American CGs. These individuals were members of the first cohort of participants to respond to recruitment campaigns mounted in both Tallahassee and Jacksonville. Of course, this is an empirical question amenable to analysis in the proposed randomized clinical trial.

Last, only a limited number of studies have evaluated the impact of CBI on changes in depression and health status in African American CGs of older adults with dementia. Tailoring of intervention to the faith traditions of this population, particularly the role of faith sharing, scripture and prayer, has been largely ignored (Epps et al., 2019). Note that integration of such spiritual elements into the fabric of CBI may not only augment the desirability and impact of treatment for distressed African Americans CGs, it has the potential of yielding similar results for CGs with strong faith traditions from other races and ethnicities, such as Hispanic-Latinos, Arab Americans, and Asian Americans (Balbim et al., 2019; Meyer et al., 2020; Sayegh et al., 2013). Finally, if the ACTS2 faith-integrated intervention proves successful, it may serve as a paradigm for organizations providing behavioral services to distressed African American CGs of persons with dementia to follow. The incorporation of trained lay pastoral care facilitators may provide a viable option for elder care agencies that do not have sufficient resources to pay professional staff to perform such caregiver interventions.

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