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Racial Differences in Program Evaluation of a Lifestyle Physical Activity Randomized Controlled Trial

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Abstract

The purpose of this study was to compare program-evaluation responses between African American and Caucasian caregivers of persons with Alzheimer's disease and related dementias who completed a lifestyle physical activity randomized controlled trial. The aim was to determine if African Americans evaluated the study differently than Caucasians. Family caregivers (N=211) were randomly assigned to a 12-month physical-activity intervention or a control condition. Upon intervention completion, (n=114) caregivers responded to an 11-item questionnaire using Likert scale responses and three open-ended questions about the overall intervention quality. Findings indicated that African American caregivers evaluated both conditions more favorably than Caucasian caregivers (p=0.02). Content analysis of the narrative responses revealed five major qualitative themes: Support, Resources, Responsibility, Adjusting, and Time. These findings suggest the value of both access to resources, and support for African American caregivers who participate in intervention research.

Keywords

Program Evaluation; African American; Dementia Caregiving

Alzheimer's Disease and Related Dementias (ADRD) are the third most prevalent group of chronic diseases in the United States, affecting over 5 million persons over the age of 65 years (Alzheimer's Association, 2015). The majority of persons with ADRD reside in the community where they primarily receive care from family caregivers, including spouses and adult children (Alzheimer's Association, 2015; National Alliance on Caregiving, 2011). Caring for persons with ADRD has received significant attention particularly because caregiving demands increase over time, family members' care duties extend over many years, and caregiving affects their physical health and mental well-being (Sörensen, Pinquart, & Duberstein, 2002; Sörensen & Conwell, 2011).

However, despite the increased attention to caregiving, considerably less is known about the experiences of African American caregivers. Because of the increased risk of ADRD in this population (Barnes & Bennett, 2014; Clark et al., 2005), African American caregivers are more likely to assume the caregiving role, but less likely to utilize formalized community resources or institutionalize loved ones. Importantly, they are also underrepresented in caregiver studies (Clark et al., 2005; Dilworth-Anderson, Williams, & Gibson, 2002). Given the higher prevalence and incidence of ADRD in African Americans (Barnes & Bennett, 2014; Clark et al., 2005) in combination with cultural obligations related to caregiving, such as familial responsibility in the African American community (Dilworth-Anderson et al., 2002; Dilworth-Anderson, Goodwin, & Williams, 2004; Pinquart & Sörensen, 2005) meeting these caregivers' needs remains a concern in ADRD-intervention research (Napoles, Chadiha, Eversley, & Moreno-John, 2010).

Despite promising outcomes from the limited ADRD caregiving information and support interventions that have included African Americans, results have varied for this group (Belle et al., 2006; Burgio, Stevens, Guy, Roth, & Haley, 2003; Czaja, Loewenstein, Schulz, Nair, & Perdomo, 2013; Elliott, Burgio, & Decoster, 2010; Glueckauf et al., 2012; Haley et al., 2004; Kally et al., 2014). For example, in the Resources to Enhance Alzheimer's Caregiver Health II (REACH II) study, African American caregivers did not experience the same benefit of improved quality of life in comparison to Caucasian and Latino caregivers (Belle et al., 2006). Further, there were differences based on the relationship to the care recipient—spouses of African American care recipients experienced slightly higher benefit of quality of life, whereas African American adult-child caregivers did not report improved quality of life (Belle et al., 2006).

In a translational study of the Savvy Caregiver intervention, African American and Latino caregivers were compared (Kally et al., 2014). In this study, African American caregivers reported improvement in competency and response to care-recipient behaviors, but did not report a benefit of well-being from the intervention (Kally et al., 2014). These findings suggest that the intervention helped improve African Americans' caregiving skillset, but not necessarily their quality of life. Despite inclusion of African American caregivers in these studies, the reason why these differences exist has not been the subject of focused investigation.

Program evaluation of caregiver interventions

Program evaluation, which is completed at the end of an intervention study, notes participants' perception of the overall value of the program, self-reported satisfaction with the program, and any recommendations for future change (Glasgow, Vogt, & Boles, 1999). Such information offers researchers an opportunity to directly learn from participants' perspectives and adjust further research interventions accordingly (Glasgow et al., 1999). Although ADRD caregiver interventions commonly focus on caregiver outcomes, relatively few report program evaluations and fewer include racial differences in program evaluations.

A major limitation of existing ADRD caregiver interventions is that very few discussed program evaluation that compares African American caregivers' perspectives with those of

other groups (i.e., Caucasian, Latino). Our review of the literature concerning program evaluation of ADRD caregiver interventions tends to fall into three categories: a) quantitative evaluations with no analysis by race, b) qualitative evaluations alone, with no analysis by race, or c) quantitative evaluations with analysis of differences between racial/ethnic groups, but no qualitative components.

In the first category, researchers quantitatively reported how ADRD caregivers evaluated interventions, but did not analyze the evaluations by race. For example, one study examined the use of a videophone psychosocial intervention with minority caregivers (Czaja et al., 2013). Although the sample included African Americans and Latinos, program evaluation data were reported only in aggregate; whether each group evaluated the intervention differently, could not be determined.

The second category of program evaluation data includes qualitative evaluation of interventions, but with limited or no analyses by race. Quayhagan and colleagues (Quayhagen et al., 2000) evaluated four non-pharmacological interventions for caregivers using a 6-item semi-structured questionnaire with open-ended responses, without regard to race. Another study (Samia, Hepburn, & Nichols, 2012) collected program-evaluation data from participants who completed a caregiver intervention; and they examined responses to open-ended questions that asked how caregiving had changed, inquired about interest in a follow-up program, and solicited content/topics the participants suggested that would guide a future qualitative study for determining learning needs and preferences. Themes were analyzed and used to guide focus-group interviews. However, the majority of this sample was Caucasian and only characteristics of that group were reported.

The third category of program-evaluation compared quantitative data in various racial/ethnic groups. For example, Belle and colleagues (Belle et al., 2006) found that African Americans favored a caregiver intervention even though they scored lower than their Caucasian and Latino counterparts on the study outcomes. However, because the study did not report a qualitative component, it was not clear why African American caregivers favored the intervention more highly than Caucasian and Latino counterparts.

This literature suggests that additional research is needed concerning how minority groups evaluate intervention programs. Further, to our knowledge, there are no single studies that combine both quantitative and qualitative findings, and highlight racial differences in evaluations. Such information from African American caregivers, obtained via a combined quantitative and qualitative program-evaluation approach, will contribute knowledge to this science and be helpful in developing future culturally tailored interventions.

Purpose

The purpose of this study was to compare how African American and Caucasian caregivers evaluated the treatment and control interventions in a lifestyle physical-activity randomized controlled trial.

Method

Design

The parent study, Telephone Resources and Assistance for Caregivers (TRAC) was a two-arm randomized controlled trial of a 12-month intervention designed to increase physical activity in community-based ADRD family caregivers. Caregivers were randomly assigned to either the Enhanced Physical Activity Intervention (EPAI) treatment intervention, which combined physical activity and caregiver skill-building content; or to the Caregiver Skill Building Intervention (CSBI), the control, which focused on caregiver skill building content alone (N=211; Farran, Paun, et al., 2016). This was a manualized intervention where the intervention group (EPAI) received individual physical activity coaching and caregiver support, and the control (CSBI) received only individual caregiver support. The Rush University Institutional Review Board approved the study and all caregivers provided written informed consent.

The TRAC study was guided by the stress process model and the physical activity component was guided by social cognitive behavioral approaches (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Bandura, 1997). The stress process model suggests that a variety of factors such as caregiver background characteristics including age, gender, and education, as well as primary and secondary caregiver stressors influence the caregiving process. Primary caregiver stressors include care recipient level of cognitive impairment, dementia-related behaviors, and deficits in activities of daily living. Secondary caregiver stressors include the number of hours per day of care provided, care recipient care needs, and the caregiver's emotional response. Resources, which also affect the caregiving process by way of support, include formal or informal services and perceived social support (Lawton et al., 1989). The current program evaluation study was guided by program evaluation literature (Chen, 2015), as well as literature specific to racial differences (Napoles et al., 2010; Dilworth-Anderson et al. 2002, 2005; Pinquart & Sorenson, 2005).

Participants

Details of the intervention have been previously reported (Farran, Paun, et al., 2016). Briefly, participant recruitment occurred on a rolling basis between January 2008 and December 2013. A total of 211 participants were enrolled, n=138 Caucasian, n=56 African American, and n=17 Other (which included a small sample of Hispanic and Asian caregivers). Participants received health clearance from their primary healthcare provider, and no monetary incentives were provided during this study. Because the focus of the current study was to compare program evaluation responses between African American and Caucasian caregivers, the small groups of 'Other' minorities were excluded.

Procedures

Caregivers in both arms of the TRAC study received an initial 60–90 minute in-home visit at baseline, weekly 15-minute telephone calls for months 1-2, bi-weekly 15-minute telephone calls (months 3–4) and monthly 15-minute telephone calls through the duration of the study (months 5–12). A total of 20 intervention contacts for up to 6–7 hours total were provided in both conditions by two PhD prepared interventionists, (one for each condition), with

background in geriatrics and family caregiving, health behavior change, and physical activity. Weekly session content for both conditions focused on basic information/support and stress management; the intervention study arm (EPAI) emphasized increasing caregiver physical activity. Each weekly session ended with prompting caregivers to establish personal goals. The EPAI treatment goals focused on physical activity, and the control arm (CSBI) focused on support goals.

Program evaluation assessment

Upon intervention completion, caregivers telephonically responded to the Program Evaluation Questionnaire, which included quantitative and qualitative components. An 11-item quantitative measure assessed intervention content, interventionist approaches, and satisfaction with the intervention. Responses used a Likert response scale (0–3 *not at all* to *very much*). This measure was modeled after the program evaluation/consumer satisfaction survey used in a prior clinical trial with dementia caregivers, and adapted to address common issues across treatment conditions (Table 1; Farran, Loukissa, Lindeman, McCann, & Bienias, 2004). Cronbach's alpha of this 11-item evaluation measure was α 0.90.

Three additional open-ended qualitative questions were included on the program evaluation: 1) what was *most helpful* about this program, 2) what was *least helpful* about this program, and 3) what suggestions do you have for things *to do differently*.

Data Analysis

Chi square and t-tests were used to examine quantitative differences in scores for African Americans and Caucasians by race between intervention groups (EPAI and CSBI). Ad hoc linear regression analyses examined sociodemographic differences (i.e., age, gender, marital status, and relationship) by race on program evaluation and controlled for these differences if they were present.

Caregiver open-ended qualitative comments were directly entered into the BLAISE database. All program evaluation responses were retrieved from the electronic database according to caregiver's research identification number and race. Researchers initially separated responses by question and then organized them into an Excel spreadsheet and printed this output. Using content analysis (Miles & Huberman, 1994), researchers manually reviewed responses line by line and identified key words/phrases to determine major themes. Frequencies of themes were counted and rank ordered to examine racial differences. Interrater reliability of data was determined by two researchers (Cothran and Paun) where each rater individually reviewed printed responses and categorized key words/phrases and themes. These same two individuals compared, discussed and condensed these themes until 100% agreement was attained.

Results

Overall Description of Sample

A total of 114 caregivers responded to the program evaluation questions: African American (n = 34) and Caucasian (n = 80). Response rates by race were comparable with 61% of total

African Americans (n=56) and 58% of total Caucasians (n=138). There were no racial differences in basic demographic factors between caregivers who completed the program evaluation and those who did not (Table 2). Reasons for study attrition included such factors as person-based, programmatic, and environmental factors, and are described in detail elsewhere (Farran, Etkin, et al., unpublished data).

Quantitative

Using chi-square analyses and t-tests, we compared caregiver baseline descriptive variables by race, which indicated significant differences in four out of six sociodemographic variables. African Americans were younger (M=58.16 years, SD=12.38) than Caucasians (M=63.41 years, SD=11.57; p=0.03), and more likely to be female (p=0.06), unmarried (p=<0.001), and an adult child caregiver (p=0.01; Table 3). Overall, African American caregivers rated the 11 program evaluation items higher—somewhat to very much—compared to Caucasian caregivers (Table 4). Across intervention group evaluations, significant racial differences were found in African Americans on total evaluation (p=0.02), as well as individual items learned new information (p=0.02), learned new ways to bathe/toilet (p=0.02), learned new ways to manage behavior (p=0.05), and manual helpful (p=<0.02). No significant differences were found on the remaining seven items.

Ad hoc linear regression models revealed African Americans rated program evaluation higher across interventions. The estimate for African American caregivers was significant and remained so without much change in the magnitude after adjusting for sociodemographic characteristics of the caregiver.

Qualitative

Five major themes were identified across responses to three open-ended questions (i.e. *most* and *least helpful* and *suggestions to do differently)*. Some responses contained information about more than one theme, resulting in a total of 293 occurrences. The themes identified were Support, Resources, Responsibility, Adjusting, and Time. Themes are highlighted in order of overall prevalence and defining characteristics in Table 5.

Caregivers of both races appreciated the *Support* provided by the telephone counselors in the form of listening, being there for them, and guiding them in their caregiving journey. Some examples included "...knowing that somebody was really interested..."; "Looking forward to someone asking 'how are you'..."; "Somebody to discuss my feelings with..." The theme *Resources* covered a broad range, but the oral and written information that the counselors provided appeared to have a real impact on both African American and Caucasian caregivers. Some examples included "In the beginning, the information about the disease..."; "Providing information and strategies I could use..."; "I liked the manual; "laid things out and prepared me for things that might come up."

Caregivers acknowledged the need to change themselves as their major *Responsibility*, and provided examples of *Adjusting* to their caregiving situation such as relearning new ways of approaching their care recipients and accepting the changes brought on by the ADRD process. Some examples of *responsibility* included "You have to make the time and schedule and be flexible to...do the calls and meetings"; "Getting me to recognize different situations

and doing something about them"; "It gave me good understanding of how to go about controlling myself..." Some examples of *adjusting*, "The program helped me learn how to respond to her questions..."; "Zero in on what to expect and how to respond"; "Learning how to control myself and patience" Caregivers' concerns about *Time* were reflected in their desire to find more time for talking with counselors and their efforts to schedule calls and/or caregiving and self-care activities. "The short length of time on the phone with [interventionist]; wanted more time talking to her" "Finding time to do some of the things that were suggested."

The themes emerged according to three open-ended questions: 1) what was *most helpful* about this program, 2) what was *least helpful* about this program, and 3) what suggestions do you have for *things to do differently?* Table 6 highlights themes by their frequency of occurrence and percent by race. The same five themes emerged (i.e. support, resources, responsibility, adjusting, time), although with differing frequency for each question.

Most helpful—For the question of *most helpful, Support* overall was the most frequent theme across both racial groups. For African Americans, *Support* was the most common theme, followed closely by *Responsibility* and *Adjusting*.

Least helpful—For the question of *least helpful*, the most frequent theme for both African Americans and Caucasians was *Resources*. Because the same themes were identified, some examples of *least helpful Resources* included comments such as "the book of references," "the lack of stipend," and "the manual." Some examples of *least helpful Support* included comments such as "I wanted more time talking to the telephone counselor," "I wish I could connect more with other caregivers," and "Having the counselor come out more often..." However, African Americans more frequently responded with a neutral *nothing/don't know* to the *least helpful* question for the remaining themes of *Support*, *Time*, *Responsibility*, and *Adjusting*.

Do differently—For the last question of what to do differently, the most frequent theme across both racial groups was Resources (Table 6). Caregivers voiced a need to have more resources such as written/electronic information about the ADRD process, and community-based resources or programs made available to them. Caucasian caregivers' suggestions overwhelmingly included phrases such as "investigate and spread the word about good places and agencies like ... [and] recommend these places in our manual;" "...books out there that cover material better than manual"; "include resources available at Alzheimers.org..."; "like to see more discussion of support groups and in-home services specific to the area you live in"; or "include an index in manual." Overall, African Americans had fewer recommendations to do differently, and responses that included the remaining themes of Support, Time, Responsibility, and Adjusting had considerably fewer or no comments, more frequently reporting a neutral response of nothing/don't know.

Discussion

The aim of this study was to examine racial differences in program evaluation data from a completed randomized controlled trial. Our findings suggest that African American

caregivers evaluated both arms of the intervention higher than Caucasian caregivers. This result is similar to that of one study that included program evaluation with African Americans (Belle et al., 2006), in that African Americans evaluated the intervention positively. However, our results suggest four considerations. First, there is evidence that African American caregivers had less access to and use of resources than their Caucasian counterparts (Haley et al., 2004; Sorenson & Pinquart, 2005; Toth-Cohen, 2004; Vickrey et al., 2007). To illustrate, African American caregivers reported "learning new information" and "bathing techniques," and that they "found the manual helpful," suggesting that this may have been information that was not otherwise available. Their participation in both the control and the treatment conditions of the TRAC study may have provided resources not otherwise accessible and may have contributed to their positive evaluation. Alternatively, there is literature suggesting that African Americans in general tend to cluster higher on general Likert scale responses, evaluating or rating items more positively (Bachman & O'Malley, 1984; Harzing, 2006; He, Van De Vijver, Espinosa, & Mui, 2014) but the reason for this effect is not well detailed or understood.

Second, during thematic analysis for African Americans the theme of *Support* emerged as *most helpful*, was not mentioned as *least helpful*, and yet was offered as a suggestion to *do differently*. Literature has shown that African Americans rely more on informal supports such as family members (Dilworth-Anderson et al., 2005) as opposed to formal supports. African American participants may have experienced a proxy of such informal support from telephone counselors. Further, literature has demonstrated that caregiving strains relationship quality (Quinn, Clare, & Woods, 2009). In the absence of typical informal supports for African Americans (i.e., family members), the telephone counselors may have been perceived as a proxy for informal support by frequently calling and actively listening.

Third, although not a major theme, it is worth noting that African American caregivers frequently indicated a neutral response to *least helpful* ("I don't know/nothing"). This response may suggest that African Americans value the access and resources when received, but may be hesitant to offer criticism (Dilworth-Anderson et al., 2002; Haley et al., 2004; Sorenson & Pinquart, 2005; Toth-Cohen, 2004; Vickrey et al., 2007). In comparison, and of equal note, Caucasian caregivers also predominantly responded to *least helpful* with "nothing/don't know," but the themes of *Resources* and *Support* were also frequently mentioned as *least helpful*. It is possible that for Caucasian caregivers who possess greater social capital and better access to support and/or resources, they may be seeking more than basic information, as opposed to African American caregivers who differ in access to basic information or resources (Schultz, O'Brien, & Tadesse, 2008).

Fourth, compared to their Caucasian counterparts for suggestions of things to do differently, African Americans more frequently suggested no changes in the intervention—implying that the intervention met their current level of need. It is also possible, however, that because of less familiarity with interventions in general, and resources in particular, African Americans may not be aware of what can or should be done differently (Dilworth-Anderson et al., 2002; Sorenson & Pinquart, 2005). Although caregiving needs change over time, particularly with disease progression, the overall design of the intervention met African American caregiver needs. It is interesting to note that Caucasian caregivers overwhelmingly had more

suggestions of things *to do differently*, particularly in response to the theme of *Resources*. Higher educational attainment and associated employment options, which lead to greater networks/social capital/access (Schultz et al., 2008), suggest the possibility that Caucasian caregivers have help to meet their needs, and/or expect more resources and support. Despite similar educational attainment between African American and Caucasian caregivers, we found significant racial differences in regression models that adjusted for education, which suggests that disparities in access to resources and support exist.

These emerging themes highlight that African American ADRD caregivers still need support and resources, although the need may not be overtly voiced. Our program evaluation results suggest, specifically, providing additional resources and support may be helpful in informing interventions in future research, particularly interventions with African Americans.

This study has several strengths to add to the current body of ADRD caregiving literature. First, data were evaluated at the conclusion of a 12-month randomized controlled trial that represented a high caliber of rigor. Second, this study used a combination of quantitative methods with standardized questions for both the treatment and control arms, and qualitative methods for open-ended questions to explore findings in more depth. Third, racial differences were the focus where few studies have examined racial differences in how interventions are evaluated.

However, despite the strengths, this study had some limitations. In particular, program evaluation was completed by 54% of the total TRAC participants. Potential reasons for attrition have been previously addressed, but aspects such as person-based factors, programmatic factors, and environmental factors may have contributed (Farran, Etkin, et al., 2016). Second, caregivers provided one or two sentence responses and did not elaborate, limiting the ability to analyze data in greater depth. Third, there was a relatively small sample of African Americans (n=56), and few African Americans (n=34) completed program evaluations. Finally, generalizability may be limited as the TRAC study was conducted in one region of the United States, although caregivers from different cities/communities participated in the study.

Although African Americans did not offer suggestions for improving the intervention, participants' evaluations and feedback about their experience provide valuable insights into better intervention design and training. Further, such information may aide study replication with various minority populations across settings and help explain intervention/program evaluation outcomes. By evaluating interventions from an individual, race-specific perspective using both quantitative and qualitative approaches, researchers can use program-evaluation data to incorporate cultural preferences and develop tailored interventions while maintaining fidelity.

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References

Alzheimer's Association. Alzheimer's disease facts and figures. 2015. Retrieved from https://www.alz.org/facts/downloads/facts_figures_2015.pdf

- Bachman JG, O'Malley PM. Yea-saying, nay-saying, and going to extremes: Black-white differences in response styles. Public Opinion Quarterly. 1984; 48(2):491–509.
- Bandura, A. Self-efficacy: The exercise of control. W.H. Freeman; New York, NY: 1997.
- Barnes LL, Bennett DA. Alzheimer's disease in African Americans: Risk factors and challenges for the future. Health Affairs. 2014; 33(4):580–586. [PubMed: 24711318]
- Belle SH, Burgio L, Burns R, Coon D, Czaja SJ, Gallagher-Thompson D, Zhang S. Enhancing the quality of life of AD caregivers from different ethnic or racial groups: A randomized, controlled trial. Annals of Internal Medicine. 2006; 145(10):727–738. [PubMed: 17116917]
- Burgio L, Stevens A, Guy D, Roth DL, Haley WE. Impact of two psychosocial interventions on White and African American family caregivers of individuals with dementia. Gerontologist. 2003; 43(4): 568–579. [PubMed: 12937335]
- Chen, HT. Practical program evaluation: Theory-driven evaluation and the integrated evaluation perspective (2nd ed.). Sage Publications, Inc; Thousand Oaks, CA: 2015.
- Clark PC, Kutner NG, Goldstein FC, Peterson-Hazen S, Garner V, Zhang R, Bowles T. Impediments to timely diagnosis of Alzheimer's disease in African Americans. Journal of the American Geriatrics Society. 2005; 53(11):2012–2017. doi:10.1111/j.1532-5415.2005.53569.x. [PubMed: 16274388]
- Czaja SJ, Loewenstein D, Schulz R, Nair SN, Perdomo D. A videophone psychosocial intervention for dementia caregivers. American Journal of Geriatric Psychiatry. 2013; 21(11):1071–1081. [PubMed: 23831174]
- Dilworth-Anderson P, Brummett BH, Goodwin P, Williams SW, Williams RB, Siegler IC. Effect of race on cultural justifications for caregiving. Journals of Gerontology, Series B: Psychological Sciences and Social Sciences. 2005; 60(5):S257–S262.
- Dilworth-Anderson P, Goodwin PY, Williams SW. Can culture help explain the physical health effects of caregiving over time among African American caregivers?. Journals of Gerontology, Series B: Psychological Sciences and Social Sciences. 2004; 59(3):S138–45.
- Dilworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). Gerontologist. 2002; 42(2):237–272. [PubMed: 11914467]
- Elliott AF, Burgio LD, Decoster J. Enhancing caregiver health: Findings from the Resources for Enhancing Alzheimer's Caregiver Health II intervention. Journal of the American Geriatrics Society. 2010; 58(1):30–37. [PubMed: 20122038]
- Farran CJ, Etkin CD, Eisenstein A, McCann JJ, Paun OP, Rajan KB, Evans DA. Randomized controlled trial of an individualized physical activity intervention with dementia family caregivers. Unpublished data.
- Farran CJ, Loukissa DA, Lindeman DA, McCann JJ, Bienias JL. Caring for self while caring for others: The two track life of coping with Alzheimer's disease. Journal of Gerontological Nursing. 2004; 30(5):38–45. [PubMed: 15152743]
- Farran CJ, Paun O, Cothran F, Etkin CD, Rajan KB, Eisenstein A, Navaie M. Impact of an individualized physical activity intervention on improving mental health outcomes in family caregivers of persons with dementia: A randomized controlled trial. AIMS Medical Science. 2016; 3(1):15–31. doi:10.3934/medsci.2016.1.15.
- Glasgow RE, Vogt TM, Boles SM. Evaluating the Public Health Impact of Health Promotion Interventions: The RE-AIM Framework. American Journal of Public Health. 1999; 89(9):1322–1327. [PubMed: 10474547]
- Glueckauf RL, Davis WS, Willis F, Sharma D, Gustafson DJ, Hayes J, Springer J. Telephone-based, cognitive-behavioral therapy for African American dementia caregivers with depression: Initial findings. Rehabilitation Psychology. 2012; 57(2):124–139. [PubMed: 22686551]
- Haley WE, Gitlin LN, Wisniewski SR, Mahoney DF, Coon DW, Winter L, Ory M. Well-being, appraisal, and coping in African-American and Caucasian dementia caregivers: Findings from the REACH study. Aging and Mental Health. 2004; 8(4):316–329. [PubMed: 15370048]

Harzing A-W. Response styles in cross-national survey research: A 26-country study. International Journal of Cross Cultural Management. 2006; 6(2):243–266.

- He J, Van De Vijver F Jr. Espinosa AD, Mui PH. Toward a unification of acquiescent, extreme, and midpoint response styles: A multilevel study. International Journal of Cross Cultural Management. 2014; 14(3):306–322.
- Kally Z, Cote SD, Gonzalez J, Villarruel M, Cherry DL, Howland S, Hepburn K. The savvy caregiver program: Impact of an evidence-based intervention on the well-being of ethnically diverse caregivers. Journal of Gerontological Social Work. 2014; 57(6-7):681–693. [PubMed: 24820315]
- Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A. Measuring caregiving appraisal. Journal of Gerontology: Psychological Sciences. 1989; 44(3):P61–P71.
- Miles, M.; Huberman, A. Qualitative data analysis. 2nd ed.. Sage Publications; Thousand Oaks, CA: 1994.
- Napoles AM, Chadiha L, Eversley R, Moreno-John G. Reviews: Developing culturally sensitive dementia caregiver interventions: Are we there yet? American Journal of Alzheimer's Disease and Other Dementias. 2010; 25(5):389–406.
- National Alliance on Caregiving. What made you think mom had Alzheimer's?. 2011. Retrieved from http://www.caregiving.org/data/NAC%20Alzheimers0411.pdf
- Pinquart M, Sörensen S. Ethnic differences in the caregiving experience: Implications for interventions. Geriatrics and Aging. 2005; 8(10):64–66.
- Quayhagen MP, Quayhagen M, Corbeil RR, Hendrix RC, Jackson JE, Snyder L, Bower D. Coping with dementia: Evaluation of four nonpharmacologic interventions. International Psychogeriatrics. 2000; 12(2):249–265. [PubMed: 10937544]
- Quinn C, Clare L, Woods B. The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. Aging and Mental Health. 2009; 13(2):143–154. [PubMed: 19347681]
- Samia LW, Hepburn K, Nichols L. "Flying by the seat of our pants": What dementia family caregivers want in an advanced caregiver training program. Research in Nursing and Health. 2012; 35(6): 598–609. [PubMed: 22911130]
- Schultz J, O'Brien AM, Tadesse B. Social capital and self-rated health: Results from the US 2006 social capital survey of one community. Social Science and Medicine. 2008; 67(4):606–617. [PubMed: 18555571]
- Sörensen S, Conwell Y. Issues in dementia caregiving: Effects on mental and physical health, intervention strategies, and research needs. American Journal of Geriatric Psychiatry. 2011; 19(6): 491–496. [PubMed: 21502853]
- Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. Gerontologist. 2002; 42(3):356–372. [PubMed: 12040138]
- Sorenson S, Pinquart M. Racial and ethnic differences in the relationship of caregiving stressors, resources, and sociodemographic variables to caregiver depression and perceived physical health. Aging & Mental Health. 2005; 9(5):482–495. [PubMed: 16024408]
- Toth-Cohen S. Factors influencing appraisal of upset in Black caregivers of persons with Alzheimer disease and related dementias. Alzheimer Disease and Associated Disorders. 2004; 18(4):247–255. [PubMed: 15592139]
- Vickrey BG, Strickland TL, Fitten LJ, Adams GR, Ortiz F, Hays RD. Ethnic variations in dementia caregiving experiences: Insights from focus groups. Journal of Human Behavior in the Social Environment. 2007; 15(2-3):233–249. doi:10.1300/J137v15n02_14.

Table 1

Program Evaluation

- 1. Did you learn new information about Alzheimer's disease throughout this program?
- 2. Did you learn new ways to bathe and toilet your relative through this program
- 3. Did you learn new ways to deal with your relative's difficult behaviors through this program?
- 4. Did you learn new ways to manage your stress through this program?
- 5. Did you learn new ways to get more physical activity through this program
- 6. How much have you changed how you care for your relative as a result of this program?
- 7. How much have you changed in caring for yourself as a result of this program
- 8. Did these telephone calls help you learn the things you most needed to know?
- 9. Was the telephone counselor sensitive to your needs?
- 10. Are you currently using the information that you discussed during the individual telephone calls?
- 11. Regarding the manuals and other materials that were used, were these materials helpful? Open Ended Questions:
- 12. What was most helpful about this program?
- 13. What was least helpful about this program?
- 14. What suggestions do you have for things to include or things to do differently?

Cothran et al.

Table 2

Differences in Sociodemographic Variables for African American and Caucasian Caregivers (Non-completers)

Page 13

	African American (n, %) n=22	Caucasian (n, %) n=58	p
Women	21 (91)	48 (82)	0.33
Married	10 (43)	43 (74)	< 0.01
Relationship to care recipient			0.001
Spouse	4 (17)	33 (57)	
Adult child	17 (74)	24 (41)	
Lives with care recipient	20 (87)	52 (91)	0.56
Education			0.59
High school or less	3 (3)	13 (16)	
Vocational training/Associate degree	8 (9)	14 (17)	
College Graduate	4 (5)	14 (17)	
Master's/Doctorate	8 (10)	17 (21)	
Age (M, SD)	(57.00, 9.96)	63.72 (12.03)	< 0.05

Cothran et al.

Table 3

Differences in Sociodemographic Variables for African American and Caucasian Caregivers (n=114)

Page 14

	African American (n, %) n=34	Caucasian (n, %) n=80	p
Women	30 (91)	60 (75)	0.06
Married	12 (36)	59 (74)	< 0.001
Relationship to care recipient			0.01
Spouse	8 (24)	40 (50)	
Adult child	24 (73)	36 (45)	
Lives with care recipient	29 (88)	69 (87)	0.94
Education			0.57
High school or less	5 (4)	18 (16)	
Vocational training/Associate degree	11 (10)	18 (16)	
College Graduate	8 (7)	24 (21)	
Master's/Doctorate	9 (8)	20 (18)	

Cothran et al.

Page 15

 Table 4

 Quantitative Program Evaluation Items: Racial Differences between African Americans and Caucasians

Program Evaluation Items	African American	Caucasian	
	(M,SD) (n=34)	(M, SD) (n=80)	p
Learned new Information	2.33 (0.89)	1.85 (1.03)	0.02
Learned new bathing techniques	1.58 (1.28)	1.00 (1.11)	0.02
Learned new ways to manage behavior	2.15 (1.03)	1.68 (0.98)	0.05
Learned new ways to manage stress	2.00 (1.03)	1.85 (0.92)	0.66
Learned new physical activity	1.88 (1.08)	1.71 (0.92)	0.62
Change in care recipient care	2.12 (0.89)	1.83 (0.95)	0.11
Change in self care	1.97 (1.05)	1.70 (0.92)	0.39
Telephone counselor helpful	2.21 (0.78)	2.13 (0.96)	0.66
Telephone counselor sensitive	2.88 (0.42)	2.81 (0.48)	0.65
Using information currently	2.45 (0.79)	2.20 (0.90)	0.20
Manual helpful	2.55 (0.71)	2.03 (0.88)	0.02
Total Evaluation	2.19 (0.60)	1.88 (0.64)	0.02

Note: 0 = Not at all: 1 = A little; 2 = Moderately; 3 = Very much

 Table 5

 Caregiver Qualitative Themes and Exemplars for African Americans and Caucasians

Caregiver Themes by Frequency, Number and Percent	African American and Caucasian Exemplars
Support (119; 41%)	Support received from the telephone counselor:
	"Knowing I had somebody" (Caucasian)
	"The emotional support" (African American)
	"The phone calls made me accountable" (Caucasian)
	"Telephone counselor actually listened"(African American)
Resources (103; 35%)	Resources to aid with caregiving or included in intervention such as activity log, pedometer, information, knowledge, advice, suggestions, questions, services, or manual:
	"The information about diversion"(Caucasian)
	"The book was interesting." (Caucasian)
Responsibility (32; 11%)	Caregiver assuming responsibility for making changes:
	"conscious of the things I should be doing" (African American)
	"Have to change yourself" (Caucasian)
	"I can only control myself" (African American)
Adjusting (27; 9%)	Caregiver adjusting to new ways:
	"Learning how to take care of myself" (African American)
	"Accepting the reality of my husband's illness" (African American)
	"Understanding that they can't help it" (Caucasian)
Time (12; 4%)	Caregiver references to time:
	"Trying to schedule" (Caucasian)
	"wanted more time talking" (Caucasian)
	"Short length of time on the phone" (Caucasian)
	"You have to make the time and schedule" (Caucasian)

Note: Total number of theme occurrences = 293

Note: Some themes emerged more than once per caregiver response

 Table 6

 Open-Ended Comments about Most/Least Helpful and Suggestions To Do Differently by African American and Caucasian Caregivers

Most Helpful	African American n=34 (100%)	Caucasian n=80 (100%)
Support	15 (44%)	55 (69%)
Resources	5 (15%)	22 (28%)
Responsibility	13 (38%)	11 (14%)
Adjusting	13 (38%)	10 (13%)
Least Helpful		
Resources	7 (21%)	21 (26%)
Support	0	11 (14%)
Time	0	7 (9%)
Responsibility	0	6 (8%)
Adjusting	0	3 (4%)
To Do Differently		
Resources	11 (32%)	37 (46%)
Support	7 (21%)	31 (39%)
Time	2 (6%)	3 (4%)
Responsibility	0	2 (3%)
Adjusting	0	1 (1%)