Easing the burden of dementia caregiving: Protocol development for a telephone-delivered mindfulness intervention for rural, African American families

Susan Gaylord a, Keturah R. Faurot a, Jennifer Shafer a,*, Elondra Harr a, Christine Lathren a, Isabel Roth a, Kessonga Giscombe a, Karen Sheffield-Abdullah b, Sharon Williams c

a Program on Integrative Medicine, The University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
b School of Nursing, The University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
c Department of Speech and Hearing Sciences, The University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

ARTICLE INFO

Keywords:
Rural
African American
Caregiver
Care partner
Mindfulness-based stress reduction

ABSTRACT

Background: There have been few interventions targeted for rural African American (AA) caregivers of persons with dementia despite their unique cultural, geographic, health-related and socio-economic needs, including relatively less access to—and willingness to engage with—formal supports and resources. One effective intervention, Mindfulness-based stress reduction (MBSR), has been found to be culturally acceptable in AA populations; however, no studies have assessed feasibility, acceptability and impact of an adapted mindfulness intervention targeting rural AA dementia caregivers.

Aims: The purpose of this study is to 1) determine the feasibility and acceptability of a telephone-delivered mindfulness training intervention in decreasing caregiver burden among rural, AA, informal caregiving teams of people with dementia; 2) to explore the effects of the training on caregiver burden and relevant secondary outcomes for both caregiving team members, including emotional regulation, tolerance of uncertainty, emotional and physical health, family conflict within the informal caregiving team, and self-efficacy; and 3) to explore comfort with and willingness to adopt technologies to access mindfulness practices and existing caregiving educational resources.

Methods: Our study utilizes a single-group, uncontrolled design to assess the feasibility and acceptability of telephone-delivered mindfulness training designed to alleviate burden for rural caregivers of AA individuals with moderate to severe dementia. A care partner—the person who provides additional help—is included in the intervention. The primary outcome is feasibility of the telephone-delivered mindfulness intervention as assessed by an 85% retention rate with completion of at least 6 of the intervention sessions. Pre- and post-participation interviews assess acceptability.

1. Introduction

The number of individuals and families impacted by Alzheimer’s disease and related dementia (ADRD) is projected to triple by 2050 and many of those impacted will be African Americans (AAs) [1]. Further, many older AAs live in rural areas and experience disadvantages by living in areas with fewer resources and poorer infrastructure [2]. Given that AAs 65 and older experience the highest prevalence of ADRD (13.8%) compared to other racial groups (12.2% for Latinx and 10.3% for White populations), and rural older adults—particularly those who lack higher education—are often disproportionately affected by ADRD, this study seeks to meet the need for culturally and geographically tailored research for rural AA caregivers of older adults with ADRD [1, 3–7].

Most families, including AA families, provide dementia care in the home. When compared with other caregivers (CGs), dementia CGs experience higher levels of physical, financial, and emotional burden, including anxiety and stress as well as higher rates of family discord [9, 16–19]. In one study, over 50% of spousal CGs and over 80% of adult children CGs endorsed some level of family conflict [10]. Some

* Corresponding author. Program on Integrative Medicine, Campus Box 7260, University of North Carolina, Chapel Hill, NC, 27599-7200, USA.
E-mail address: jenni_shafer@med.unc.edu (J. Shafer).

https://doi.org/10.1016/j.conctc.2022.101031
Received 21 March 2022; Received in revised form 22 October 2022; Accepted 26 October 2022
Available online 28 October 2022
2451-8654/© 2022 Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).
researchers have called dementia ‘the great divider’, as caregiving stress tends to accentuate long-standing interpersonal issues among family members [11].

Aspects of family functioning most strongly associated with caregiving burden include ineffective communication and difficulties around roles (i.e. distribution of caregiving tasks) [12]. In AA families, there is often a cultural expectation of high family involvement [13], so family conflict around roles and provision of social support may be particularly distressing [14]. Despite these findings, few CG interventions address family relationship difficulties.

We know cultural experiences associated with race, including ways of coping, and ways of seeking help often differ for AA CGs compared with CGs of other ethnicities [15–18]. Evidence also suggests that, contrary to previous findings, AA CGs, who are likely to be adult children, also experience high levels of anxiety and distress [19,20,23]. Therefore, within-group studies of AAs, and other racial minorities, are needed to provide characteristics and processes critical for tailored interventions [21]. Hence, innovative theory-based programs, culturally and geographically tailored to rural AA populations, are needed to ease the burden of dementia-related caregiving in rural AA populations.

Two theories form the basis for a Mindfulness-based CG intervention (see Fig. 1): the Stress Process Model and the Uncertainty in Illness Theory. Pearlin et al.’s Stress Process Model posits complex relationships between background characteristics (demographics), primary stressors (care recipient ((CR) neuropsychiatric symptoms and level of functional and cognitive impairment), secondary stressors/outcomes (interpersonal and intrapersonal strain) and CG health outcomes (physical and mental health) all mediated by coping and social support [37]. The theory conceptualizes family conflict as a secondary but potent source of stress outside of the caregiving situation, with both direct and indirect effects on negative CG outcomes [37]. Family conflict is associated with high CG burden and negative CG mental and physical health outcomes [27,38–40], even after controlling for CG and CR characteristics typically associated with stress outcomes. Moreover, there is evidence that the structured, often repetitious ways that family members interact with each other, can either promote positive CG outcomes or contribute to CG distress in families caring for someone with dementia [41]. In addition to these interpersonal strains, intrapersonal stressors such as role captivity and poor self-efficacy both result from and contribute to negative health outcomes [37].

Mishel’s Reconceptualized Uncertainty in Illness Theory (RUIT) [42,43], like her original theory, conceptualizes uncertainty as either a danger or an opportunity. Unlike in her original theory, in her reconceptualized model, she recognizes that, when the outcome is negative, such as decline of a relative, appraisal of uncertainty as negative vs. positive can change over time [42]. In a study applying the RUIT to dementia caregiving, uncertainty was seen to impact the appraisal of primary stressors [44], making it conceptually consistent with other mediators.

Mindfulness is a behavioral technique involving the intentional self-regulation of attention to present-moment experience, using the breath or other object as the focal point [31,32]. In mindfulness practice, when thoughts and emotions lead to distractions away from present-centered awareness, the practitioner can notice them, release them, and return to attending to the breath or other present experience [31–33]. With practice, the mindfulness-awareness experience can expand to become a significant part of daily life. Mindfulness-based stress reduction (MBSR) is a widely used evidence-based mindfulness intervention, and has been shown to decrease stress and anxiety, enhance well-being, and improve self-efficacy, positive reappraisal, and self-regulation in a variety of healthy and clinical populations, including AA and caregivers [34–38,66–68]. Mindfulness has been shown to be associated with cognitive flexibility [36], a construct that is related to uncertainty [45]. Similarly, mindfulness training can shift emotion regulation strategies from negative (e.g., self-blame) to positive (e.g., planning) [69].

Accordingly, for this study, we hypothesized that training in mindfulness could enhance the CG’s shift from a resistance to uncertainty to an acceptance of uncertainty as a natural part of life. Additionally, the proposed focus on improving family conflict should affect perceived social support, another mediator of health outcomes, thereby leading to greater self-efficacy and positive emotions [38]. Moreover, since mindfulness training programs have been successfully adapted to distance-based formats, including use of the internet, smart-phone and telephone-delivered mindfulness training formats, we hypothesized that a distance-based training format would be feasible and acceptable [45–48].

In light of the above findings, we are implementing a telephone-delivered mindfulness training intervention that incorporates the following elements: 1) training for primary caregivers (CGs) and their caregiving partner (CP) in a telephone-based mindfulness training intervention; 2) groups of up to eight participants (four CG-CP pairs) plus an instructor, on a shared telephone line; and 3) training in an 8-week, modified Mindfulness-based Stress Reduction (MBSR) program, which places additional emphasis on training in the following: a) mindful experiencing, including mindfulness of feelings and body sensations; b) identifying personal strengths and being aware of their use in coping; c) mindful communication, including non-verbal mindfulness, mindful listening, and mindful speaking; and d) mindful compassion for self and others. Additionally, homework assignments involve listening to exercises on a dial-in telephone line; and assignments for CG-CP dyads (e.g. mindful listening and communication practices) as well as CG mindfulness practices in the presence of CRs (e.g. mindful eating, and mindful listening)). Based on theory and evidence from previous mindfulness studies, we believe that this intervention holds promise of making a significant impact on reducing burden in AA rural CGs.

The purpose of this study is to explore the following three specific aims: 1) To determine the feasibility and acceptability of a telephone-delivered mindfulness training intervention (TMT) in decreasing CG

![fig_1](https://example.com/fig_1.png)

**Fig. 1.** Stress process and uncertainty theories informing caregiver mindfulness training.
burden among rural, AA, informal caregiving teams of people with dementia; 2) to explore, on a preliminary basis, the effects of the training on CG burden and relevant secondary outcomes for both caregiving team members, including emotional regulation, tolerance of uncertainty, emotional and physical health, family conflict within the informal caregiving network, and self-efficacy; and 3) to explore comfort with and willingness to adopt technologies (e.g. telephone-based, web-based) to access mindfulness practices and existing caregiving educational resources. As part of intervention planning, using interviews, we are investigating comfort with a smartphone/tablet. For half of the groups of participants, we are providing a tablet loaded with the handbook and all of the intervention materials. In this way we can compare engagement and program acceptability rates between groups who received the tablets and those who did not.

2. Materials and methods

2.1. Study design

Our study utilizes a single-group, uncontrolled design to assess the feasibility and acceptability of telephone-delivered mindfulness training designed to alleviate CG burden for rural CGs of AA individuals with moderate to severe dementia. A CP—the person who provides additional help—is included in the intervention. The primary outcome is feasibility of the telephone-delivered mindfulness intervention as assessed by an 85% retention rate with completion of at least 6 of the intervention sessions. Pre- and post-participation interviews assess acceptability. A diagram of the intervention and assessment plan is provided in Fig. 2.

2.2. Eligibility

Informal caregiving teams are composed of a primary and secondary informal CG, as defined as any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for an older person or an adult with a chronic or disabling condition (in this case ADRD). These individuals may be primary or secondary CGs and live with, or separately from, the person receiving care.

To meet inclusion criteria, the primary CG must:

- Care for a family member with dementia who identifies as Black or AA
- Care recipient must have a diagnosis of dementia or have a score of at 2 or higher on the AD8 Dementia Screening Interview [70] or a score of 8 or higher on the Functional Activities Questionnaire (FAQ) [71].
- Be living in rural areas in Eastern North Carolina. (Eastern is defined as east of Wake County, North Carolina. Rural is defined as listed as rural within the website https://www.ruralhealthinfo.org/am-i-rural)
- Be at least 18 years old
- Live with or very near a family member who has dementia (CR)
- Provide regular, daily care (at least 4 h per day) for a family member who has dementia
- Have another adult CP who is willing to participate; someone who shares caregiving or helps make decisions regarding the person with ADRD (may be remote and family member or friend)
- Have a telephone and be willing to participate in weekly calls

The CP is eligible if they are 18 or older, have a telephone and are willing to attend weekly sessions. CPs do not need to be living in the same geographic region as the primary CG.

A candidate primary CG or CP is excluded from participation under the following conditions:

- Too unwell to participate; e.g., cognitive impairment that would make participation difficult, with an active diagnosis of cancer or more than 3 hospitalizations in the past year;
- Unable to identify and recruit a CP willing to commit to the study requirements;
- The CR does not meet criteria for moderate-severe dementia;
- Either the primary CG or CP is unable to understand study procedures or unwilling to comply with them for the entire length of the study.

We aim to recruit approximately 32 CG/CP dyads.

2.3. Recruitment

Participants are recruited in rural Eastern North Carolina in conjunction with local service providers and community organizations.
Recruitment partners (Area Agencies on Aging, local hospitals and neurology practices, ADRD support groups Alzheimer’s Association of Eastern North Carolina, affiliated sororities, pastors, and other community organizations who provide outreach to elders) are advertising the study to their memberships. Our original plan included participation in local fairs and church-sponsored events in specific counties in Eastern North Carolina. After engaging local organizations, including support groups, as well as a community advisory board, the coronavirus pandemic necessitated a change in plans. The planned in-person community engagement activities were switched to online and additional recruitment efforts now include television interviews, radio advertising, and social media advertising. With the assistance of the community advisory board, we also conducted an online summit to share information about mindfulness and the study with community partners and answer their questions. Community partners received a small incentive for participating (a phone stand with the study logo on it and entry into a raffle for a gift card), and were mailed study flyers to disseminate to their constituents. Interested individuals are encouraged to interact with study staff through the study website. A study cell phone is listed as the primary study number so that individuals who indicate interest on the website might recognize the phone number.

2.4. Screening/consent/enrollment

Participants are recruited in cohorts with a goal to include 4 caregiving pairs per cohort. Potential participants are screened over the telephone and provide verbal consent. Originally, the research assistant visited CGs who met the eligibility criteria in their homes to obtain a formal written consent for participation and to administer the baseline measures. However, after the onset of the pandemic, all enrollment activities occur by telephone. After enrollment, participants are provided with a handbook with local CG resources, general educational material on dementia, and mindfulness activity instructions for each weekly session. Participants may also access audio files with recorded mindfulness activities. In cohorts 5–8, primary CGs receive a tablet loaded with the contents of the binder as well as bookmarked links to ADRD information sites and the recorded audio files. The tablet includes a voice-activated assistant, but, since privacy concerns have emerged, set-up of the assistant is left to the discretion of the CG.

Primary CGs are asked to invite a CP to participate in the study and obtain that person’s permission for study personnel to contact them. Once permission is confirmed with the CG, the potential CP is contacted and enrolled.

2.5. Intervention design

The study intervention is the mindfulness training for CGs and CPs. The intervention is offered in 8 weekly 1-h telephone sessions plus one 2.5-h retreat (see Fig. 3). Respite care for the CR is offered for the retreat. To access the sessions, participants are asked to use their telephone to dial into a scheduled Zoom meeting; they do not need access to a smart phone or computer since the meeting is audio-only. However, during the retreat, we do ask CGs and CPs to use the video feature if possible so that participants can interact with the instructor and other group members “face to face.”

In follow-up interviews after the weekly sessions have concluded, CGs are asked how they used the handbook, tablet (if relevant), and call-in lines. Given it is unclear if and how technologies would be used, this aspect of the study will provide insight on which components of the intervention will be most useful to include in future iterations. CGs and their partners are also asked qualitative questions to gather their feedback on the training and program itself.

For the intervention, the experienced mindfulness instructor works from an instructor’s manual prepared by the investigators. The instructor’s manual details the intervention components, providing tips on teaching the material and responding to participant questions. CGs and CPs are not restricted from participating in any care recommended by their physicians but are asked to delay additional Mindfulness-based therapies until after the end of the intervention.

2.6. Retention plan

In order to encourage participant engagement and adherence, staff provide thorough descriptions of study requirements during enrollment and throughout the study. Staff provide weekly telephone reminders to participants to encourage attendance at the training sessions and to track their home practice efforts. Participants receive renumeration for completing assessment sessions ($25 per assessment/interview). Each primary caregiver in cohorts 5–8 also receives a data-enabled tablet.

2.7. Outcome measures

The primary outcome is feasibility. We define feasibility as 85% of participants who start the intervention and complete at least 6 of the intervention sessions. Feasibility is measured by class session attendance records; these are collected at the time of the calls by the research assistant who facilitates the technical aspects of the calls (e.g., making sure everyone can get on the call using Zoom).

A second primary outcome is acceptability. We define acceptability

![Fig. 3. Curriculum for telephone-delivered mindfulness training.](image-url)
as 85% of participants expressing comfort with the majority of the intervention components and homework. Other exploratory outcomes assessed before and after the intervention are delineated as follows:

1) Change in caregiver burden as measured with the Zarit Burden Interview [49];
2) Change in emotion regulation/coping styles as measured with the Cognitive Emotion Regulation Questionnaire (CERQ) [50];
3) Change in uncertainty tolerance as measured with the Intolerance of Uncertainty Scale (IUS) [51];
4) Change in perceived social support among caregivers as measured with the PROMIS social support short forms for emotional, informational, and instrumental support [53];
5) Change in family conflict around caregiving as measured by the 4-item Family Conflict Scale [22];
6) Change in emotional distress as measured by the anger and anxiety PROMIS short forms [55];
7) Change in perceived health as measured by the PROMIS global health short form [56];
8) Change in hopefulness and optimism as measured by the PROMIS [72] meaning and purpose short form;
9) Change in caregiver self-efficacy as measured by the PROMIS self-efficacy short forms [53].
10) Evaluation of the comfort with and willingness to adopt technologies to access mindfulness practices and existing caregiving educational resources.

2.8. Study instruments

At baseline, participants complete a pre-participation interview, lasting 10–15 min. The purpose of the interview is to assess, qualitatively, participants’ knowledge about mindfulness or centering prayer, perceived value of telephone-based group classes, and comfort with technology. They also complete a pre-intervention and post-intervention questionnaire (see Table 1) in person (pre-pandemic) or over the telephone with the study staff. If requested, the questionnaires can be completed electronically by sending a secure link via e-mail or text. Finally, post-intervention, participants are invited to share their experiences with the study in a phone or Zoom interview with a study staff member. The semi-structured interview includes open-ended questions regarding their most memorable aspects of program, perceived value and cultural congruence of the mindfulness training, the usefulness, challenges, and recommended changes to the program, the perceived value of the program for management of stress related to caregiving or family conflict, tools that might help maintain practices, unfulfilled expectations of the program, and usefulness of the handbook and technology components (e.g., call-in lines, tablets), if relevant.

If participants withdraw before the end of the intervention, study staff conduct any assessments the participant is willing and able to complete and inquire about reasons for discontinuation. The project manager or study staff report all adverse events (AEs) to the principal investigator (PIs) monthly using the Adverse Event Reporting Form, after having gathered all necessary details. Study staff will immediately report to the PI any AEs that are more than mild and possibly related to study participation to the PIs immediately. Together the PIs determine the severity and the relatedness of the AE, and confer with the Safety Monitoring Committee (SMC) and the Study Physician as needed. If the AE is serious and/or unexpected, possibly related to study participation, and suggests increased risk for participants, the procedures outlined below will also be followed.

All AEs that are deemed 1) unexpected; 2) possibly or probably related to study participation; and 3) suggest increased risk for study participants are reported to the University of North Carolina Institutional Board, the National Institute on Aging project officer, and the SMC. Chair within 48 h of study team awareness of the event, using each organizations’ respective reporting formats. In these reports, the PI

| Measure (construct) | Reliability, validity |
|---------------------|-----------------------|
| Outcome: Zarit Burden Interview (ZBI) (distress associated with caregiving) [49] | This 12-item (SF) version of the popular original 29-item questionnaire measures role strain (α = 0.88) and personal strain (r = 0.77) The short form was highly correlated with the original (0.96) both at baseline and follow-up. |
| Outcome and secondary stressor: Family Conflict Scale (Negative family interactions around caregiving) [22] | The 4-item Family Conflict scale measures the degree of conflict the family experiences about the seriousness of the CR’s condition, concerns about the CR’s safety, what the CR can do for him/herself, and whether a nursing home is indicated. The 18-item short form of the CERQ measures 5 positive coping strategies (acceptance, positive refocusing, planning, positive reappraisal, putting into perspective) and 4 negative strategies (ruminating, catastrophizing, self-blame, other-blame). Subscale reliability (α = 0.68–0.81) and convergent validity was good. The 12-item IUS correlates highly (0.96) with the original 27-item scale and results in a 2-factor (prospective, inhibitory) scale. Item responses range from 1 (not at all characteristic of me) to 5 (entirely characteristic of me). Its reliability was high for both the overall score (α = 0.92) and subscales and it demonstrated convergent validity [52]. We will contact the scale developers to obtain permission to adjust to language of the responses to accommodate individuals without a high school education. |
| Mediating outcome: Cognitive emotion regulation questionnaire (coping styles) [50] | PROMIS investigators created population-standardized scales with improved reliability, validity, and precision [54]. In 1087 patients, self-efficacy measures were correlated with other self-report measures as expected [53]. We will be using the 4-item general self-efficacy short form as well as the 4-item short form for self-efficacy of emotion management. The 4-item anxiety short form and 5-item anger short form are measured across the past 7 days with responses ranging from 1 (Never) to 5 (Always). Scoring is implemented in REDCap to preserve response pattern metrics. |
| Mediating outcome: PROMIS social support measures (emotional, informational, instrumental support) | All three 4-item social support scales assess the frequency of perceived support with responses ranging from 1 (Never) to 5 (Always). Scoring is implemented in REDCap to preserve response pattern metrics. |
| Outcome: PROMIS self-efficacy: general [4], and emotion management self-efficacy [53] | PROMIS investigators created population-standardized scales with improved reliability, validity, and precision [54]. In 1087 patients, self-efficacy measures were correlated with other self-report measures as expected [53]. We will be using the 4-item general self-efficacy short form as well as the 4-item short form for self-efficacy of emotion management. The 4-item anxiety short form and 5-item anger short form are measured across the past 7 days with responses ranging from 1 (Never) to 5 (Always). In MDD, CHF, and back pain patients, the measures were responsive to change with treatment. |
| Outcome: PROMIS Emotional Distress (anxiety and anger) [55] | The global health measure is based on the well-validated RAND measure, assessing general self-rated physical health, physical function, pain, and fatigue. The 4-item scale has a marginal reliability of 0.81. The 12-item SCS-SF measures overall self-compassion along with 6 subscales, including mindfulness, common humanity, self-kindness, self-judgment, isolation, and over-identification. Response range from 1 (almost never) to 5 (almost always). Overall, the SF performed well with α = 0.88 and r = coordination next page)
identifies any corrective action planned or already undertaken. The SMC meets in person (or virtually as needed) at least 4 times throughout the study to review the Data and Safety Monitoring Report: 1) prior to first enrollment; 2) after the first 2 cohorts (2 8-week sessions); 3) after 6 cohorts have completed (6 8-week sessions); 4) at study completion (9 8-week sessions). Additional meetings (ad-hoc) occur as requested by the PI for review of unexpected adverse events or any SAEs that occur. Any recommended changes by the SMC will be submitted to the University of North Carolina Institutional Board for approval.

2.9. Analysis

This is a single-arm pilot feasibility study with one baseline and one post-intervention measure. For all quantitative questionnaire measures, the change in the measure from baseline to post-participation is the post-intervention measure. For all quantitative questionnaire measures, we will conduct exploratory, descriptive analyses to assess the change in the measure from baseline to post-participation is the post-intervention measure. For all quantitative questionnaire measures, we will treat analysis in dealing with missing data using multiple imputation or full information maximum likelihood methods.

We are collecting two types of formal qualitative data: 1) interviews with CG and CP prior to and following each 8-week class; and 2) transcriptions of audio-recorded classes. We will use the insights from CGs and CPs to adjust the intervention including the content and the logistics as needed.

Using transcripts of post-participation interviews, two or more research team members will apply a thematic analysis strategy, coding each transcript and identifying themes within and across interviews, with subsequent discussion of themes among members of the qualitative analysis team and resolution of discrepancies. Results will inform improvements in subsequent iterations of the intervention as well as the development of larger-scale interventions.

3. Discussion

Incidence of ADRD continues to climb and unduly affect AAs. Especially at risk are those older AAs who live in rural areas, where limited resources and lack of infrastructure such as reliable Internet access may serve as a barrier to timely and appropriate healthcare [1,3,6]. Many AAs care for their loved one with AARD at home, and the stress of home caregiving can disrupt familial relationships above and beyond the impact experienced by non-AA caregivers [9,16–19]. This study addresses the need for theory-based [37,42], within-group study of AA caregivers of people with dementia living in rural areas. Our telephone delivered, Mindfulness-based intervention specifically targets the need for culturally and geographically tailored study of this population.

3.1. The Covid-19 pandemic

The first case of Covid-19 was reported in the United States in January 2020, less than a year after our study protocol was approved. Because of the Covid-19 pandemic, we had to pivot from in-person recruitment to virtual, placed advertisements on social media platforms and began recruiting caregivers via telephone. Enrollment procedures also moved to a virtual platform, and verbal consent was obtained for study participation. It is possible that virtual recruitment may impact some caregivers’ decision to participate. However, as our intervention was already telephone-based, we did not have to change any part of the actual intervention other than shifting the retreat from in-person to online—a unique advantage in an ever-evolving pandemic.

Due to the study’s small sample size, it is possible that there may not be any statistically significant changes pre- and post-survey measurement administration. However, we anticipate our intervention will be both feasible and acceptable to participating AA caregivers. Participating CGs are able to enroll in the study and participate in the study intervention on the phone, which should be feasible to most caregivers even if infrastructure for reliable internet is lacking in their area. We will also conduct follow-up study procedures via phone due to the ongoing pandemic. We expect the study intervention will also help to improve caregiver outcomes and increase willingness to explore Mindfulness-based treatment for stress reduction.

Funding

This work was supported by the National Institute on Aging [5R21AG061728-02, 2020].

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.
Appendix A. Study Flyer

![Study Flyer Image]

**Benefits of Participating in the Study:**
- Home Resource Guide
- Earn $100 for participating in study surveys

**Interested? Contact:**
- (219) 966-8586
- mc3med@med.uno.edu

**Program on Integrative Medicine**
UNCG School of Medicine
Chapel Hill, NC 27514

**Instructor:** Kessonga Giscombe

---

**Research Study: Telephone Stress-Support for Caregivers providing at-home care for a person with dementia**

Caring for a person with memory problems can be stressful. This research study uses a technique called mindfulness to help families manage stress, communicate better, and take care of themselves... so they can provide the best care!

**Who’s Eligible?**
- Primary Caregiver must be at least 18 years old
- Primary Caregiver must self-identify as Black or African-American
- Primary Caregiver must provide at least 4 hours of care per day and live with or near the care recipient
- Have a care partner who also provides care to join you in the study

**What’s Involved?**
- Two, in-home sessions with study staff
- 8 weekly, 1-hour group telephone sessions
- One-half day retreat

---

**References**

[1] Alzheimer’s Association, 2017 Alzheimer’s disease facts and figures, Alzheimer’s Dementia 13 (2017) 325–373. [https://www.alz.org/](https://www.alz.org/)

[2] M.M. Weden, R.A. Shih, M.U. Kabeto, K.M. Langa, Secular trends in dementia and cognitive impairment of U.S. Rural and Urban older adults, Am. J. Prev. Med. 54 (2) (2017) 164–172, [https://doi.org/10.1016/j.amepre.2017.10.021](https://doi.org/10.1016/j.amepre.2017.10.021)

[3] T.C. Russ, G.D. Batty, G.F. Hearnshaw, C. Fenton, J.M. Starr, Geographical variation in dementia: systematic review with meta-analysis, Int. J. Epidemiol. (2012), [https://doi.org/10.1093/ije/dys103](https://doi.org/10.1093/ije/dys103)

[4] K. Steenland, F.C. Goldstein, A. Levey, W. Wharton, A meta-analysis of Alzheimer’s disease incidence and prevalence comparing African-Americans and Caucasians, J. Alzheim. Dis. 50 (1) (2015) 71–76, [https://doi.org/10.3233/JAD-150778](https://doi.org/10.3233/JAD-150778)

[5] North Carolina Institute of Medicine, Dementia - Capable North Carolina: A Strategic Plan for Addressing Alzheimer’s Disease and Related Dementias, Morrisville, NC, 2016. [http://nciom.org/dementia-capable-north-carolina-a-strategic-plan-for-addressing-alzheimers-disease-and-related-dementias/](http://nciom.org/dementia-capable-north-carolina-a-strategic-plan-for-addressing-alzheimers-disease-and-related-dementias/)

[6] M.M. Weden, R.A. Shih, M.U. Kabeto, K.M. Langa, Secular trends in dementia and cognitive impairment of U.S. Rural and Urban older adults, Am. J. Prev. Med. 54 (2) (2017) 164–172, [https://doi.org/10.1016/j.amepre.2017.10.021](https://doi.org/10.1016/j.amepre.2017.10.021)

[7] B.S. Black, D. Johnston, P.V. Rabins, A. Morrison, C. Lyketsos, Q.M. Samus, Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study, J. Am. Geriatr. Soc. 61 (12) (2013) 2087–2095, [https://doi.org/10.1111/j.1532-5417.2013.03949.x](https://doi.org/10.1111/j.1532-5417.2013.03949.x)

[8] Ory MG, Hoffman Iii RR, Yee JL, Tennstedt S, Schulz R. Prevalence and Impact of Caregiving: A Detailed Comparison between Dementia and Nondementia Caregivers. 39(2):177-185.

[9] S.J. Semple, Conflict in Alzheimer’s caregiving families: its dimensions and consequences, Gerontologist (1992), [https://doi.org/10.1093/geront/32.5.648](https://doi.org/10.1093/geront/32.5.648)

[10] C. Peisah, H. Brodaty, C. Quadrio, Family conflict in dementia: Prodigal sons and black sheep, Int. J. Geriatr. Psychiatr. (2006), [https://doi.org/10.1002/gps.1501](https://doi.org/10.1002/gps.1501)

[11] G. Tremont, J.D. Davis, D.S. Bishop, Unique contribution of family functioning in caregivers of patients with mild to moderate dementia, Dement. Geriatr. Cognit. Disord. (2006), [https://doi.org/10.1159/000090699](https://doi.org/10.1159/000090699)

[12] M. Pinquart, S. Sörensen, Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis, Gerontologist 45 (1) (2005) 90–106, [https://doi.org/10.1093/geront/45.1.90](https://doi.org/10.1093/geront/45.1.90)

[13] D. Pj, A.M.C. Holt, Factors associated with unmet needs among African-American dementia care providers, J. Gerontol. Geriatr. Res. 5 (1) (2016) 1–4, [https://doi.org/10.4172/2167-7162.1000267](https://doi.org/10.4172/2167-7162.1000267)

[14] P. Dilworth-Anderson, L.C. Williams, B.E. Gibson, Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980-2000), Gerontologist 42 (2) (2002) 237–272, [https://doi.org/10.1093/geront/42.2.237](https://doi.org/10.1093/geront/42.2.237)

[15] P. Dilworth-Anderson, G. Pierre, T. Hilliard, Social justice, health disparities, and culture in the care of the elderly, J. Law Med. Ethics 40 (1) (2012) 26–32, [https://doi.org/10.1111/j.1748-720X.2012.00642.x](https://doi.org/10.1111/j.1748-720X.2012.00642.x)

[16] P. Dilworth-Anderson, G. Pierre, T. Hilliard, Social justice, health disparities, and culture in the care of the elderly, J. Law Med. Ethics 40 (1) (2012) 26–32, [https://doi.org/10.1111/j.1748-720X.2012.00642.x](https://doi.org/10.1111/j.1748-720X.2012.00642.x)

[17] M.M. Merritt, T.J. McCallum, T. Fritsch, How much striving is too much? John Henryism active coping predicts worse daily cortisol responses for African-American but not White female dementia family caregivers, Am. J. Geriatr. Psychiatr. 19 (5) (2011) 451–460, [https://doi.org/10.1097/JGP.0b013e3182eaf3ak](https://doi.org/10.1097/JGP.0b013e3182eaf3ak)

[18] A. Graham-Phillips, D.I. Roth, J. Huang, P. Dilworth-Anderson, L.N. Gitlin, Racial and ethnic differences in the delivery of the resources for enhancing Alzheimer’s care caregiver health II intervention, J. Am. Geriatr. Soc. 64 (8) (2016) 1662–1667, [https://doi.org/10.1111/jgs.14206](https://doi.org/10.1111/jgs.14206)

[19] A.N.S. Badana, V. Marino, W.E. Haley, Racial differences in caregiving: variation by relationship type and dementia care status, J. Aging Health (2017), 0898264317743461, [https://doi.org/10.1177/0898264317743461](https://doi.org/10.1177/0898264317743461)

[20] T.J. McCallum, K.H. Sorocco, T. Fritsch, Mental health and Diurnal Salivary cortisol patterns among African American and European American female dementia family caregivers, Am. J. Geriatr. Psychiatr. 14 (8) (2006) 684–693, [https://doi.org/10.1097/01.JGP.0000225109.85406.89](https://doi.org/10.1097/01.JGP.0000225109.85406.89)

[21] K.E. Whitfield, J.C. Allaire, R. Belue, C.L. Edwards, Are comparisons the answer to understanding behavioral aspects of aging in racial and ethnic groups? J. Gerontol.
