Official Title:	Pair 2 Care: Peer Support for Caregivers of Black Americans Living With Dementia
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Research Protocol

Title: Pair 2 Care: Peer Support for Caregivers of African Americans Living with Dementia

I. Objective

The purpose of this study is to test a peer support intervention for family caregivers who are caring for a loved one living with dementia. Peer Support for Caregivers of African Americans Living with Dementia (Pair 2 Care) is a co-created culturally sensitive family caregiver peer support intervention. We will determine if Pair 2 Care is feasible and acceptable by evaluating eligibility criteria, recruitment and retention data, protocol adherence, satisfaction, and feedback on appropriateness of the intervention for broader dissemination. At 6 months as compared to baseline, current family caregivers will report less anxiety and depression, higher quality of life, perceived social support, and self-efficacy for surrogate decision making as well as intent to use palliative care or hospice services as part of advance care planning and healthcare decision making for their care recipient living with dementia.

Throughout this protocol the terms ‘caregivers’ or ‘family caregivers’ will be used interchangeably to refer to family caregiver participants. Unless otherwise specified, both terms will be used to reference current and former family caregiver participants. Former family caregivers are ‘mentors’ and current family caregivers are ‘mentees' and they referred to as such throughout this proposal. Study participants are current family caregivers (mentees) and former family caregivers (mentors). No professional, hired, formal caregivers such as nurses, physicians, and nursing assistants are included in the study. The terms Black and African American are also used interchangeably to represent Blacks residing in the US who are descendants of Sub-Saharan Africa.

II. Background and Rationale

African Americans are twice as likely to develop Alzheimer’s disease and related dementias (ADRD) than their White counterparts.[1] These individuals are, however, more often diagnosed later, creating additional physical, spiritual, psychosocial challenges for both the person living with ADRD and their family caregivers.[2] African American ADRD family caregivers are therefore at greater risk for adverse physiological and psychological health effects of family caregiving, including significant burden and stress.[3,4] Evidence suggests that peer to peer support using storytelling may be effective in assisting ADRD caregivers with surrogate healthcare decision making,[5] an important aspect of palliative care. Access to and use of palliative care, a recognized approach to serious illness care symptom management, among African Americans are low.[6,7] The impact of this healthcare inequity further reduces the quality of life for African American ADRD family caregivers and subsequently their care recipients.

Prior approaches to serious illness care have failed to address the needs of African Americans living with ADRD from a palliative care perspective. This inability to meet their needs leads to increased unmet caregiver needs. Peer mentorship, a relationship-centered person-to-person approach may reduce healthcare decision making burden within cultural groups such as African Americans through cultural tailoring by promoting oral traditions, personal contact, and storytelling.[8] Our previous study included perspectives of lower socioeconomic status African American ADRD caregivers who have expressed the need for person-centered, non-judgmental, on-demand, culturally congruent caregiving support for advance care planning and healthcare decision making. Simultaneously, our former family caregivers retrospectively described

perceived benefits of peer support while caregiving and their willingness to serve as peer mentors to current family caregivers. Additional data from healthcare provider and community stakeholders support the need and potential benefits of peer support for ADRD caregivers. Based on these preliminary findings, there is an urgent need and exciting opportunity to address the unmet palliative care needs of current caregivers through peer support. For this innovative study, we will use the experiential expertise of former family caregivers as mentors to help current family caregivers as mentees with advance care planning and healthcare decision making. The purpose of this study is to test a peer support intervention for family caregivers who are caring for a loved one living with dementia. Peer Support for Caregivers of African Americans Living with Dementia (Pair 2 Care) is a co-created culturally sensitive caregiver peer support intervention. The following specific aims will be addressed:

Aim 1: Conduct feasibility and acceptability testing of Pair 2 Care in current (*n*=15) and trained former (*n*=15) African American ADRD family caregiver peers paired based on congruent identity traits (e.g., relationship to care recipient, gender identity, etc.). We will determine if Pair 2 Care is feasible and acceptable by evaluating eligibility criteria, recruitment and retention data, protocol adherence, satisfaction, and feedback on appropriateness of the intervention for broader dissemination.

Aim 2: Assess preliminary intervention outcomes of caregiver anxiety, depression, quality of life, social support, self-efficacy for surrogate decision making, and intent to use palliative care or hospice services to determine potential effectiveness of the Pair 2 Care Intervention. At 6 months as compared to baseline, current caregivers (mentees) will report less anxiety and depression, higher quality of life, perceived social support, and self-efficacy for surrogate decision making as well as intent to use palliative care or hospice services as part of advance care planning and healthcare decision making.

African Americans are at high risk for developing ADRD and, thus, to experience the negative impacts of ADRD caregiving. African Americans are twice as likely to develop ADRD as compared to Whites.[1,9] Caregiving for older adults living with ADRD is complex. A lack of personal time, socialization opportunities, and ADRD stigma results in caregiver isolation.[10] Therefore, these African American ADRD caregivers may face significantly more caregiver stress, physical, and psychological effects as compared to other caregivers.[11–13]

Access and use of palliative care is low among African Americans.[14] Much of the focus on palliative care for African Americans is on cancer and other serious illnesses.[15,16] However, there is a lack of data on the use of palliative care in African Americans living with ADRD. Alzheimer's disease and related dementias are a set of serious, life limiting illnesses where both the person living with ADRD, and their family caregiver(s) can greatly benefit from palliative care. Yet, African Americans are less likely to have access to or receive palliative care than other racial/ethnic groups.

Evidence-based caregiver support interventions are lacking[17] and therefore often do not meet the needs of African American ADRD caregivers in a culturally sensitive manner.[11] Interventions that provide support for the persons living with other chronic diseases such as cancer are more widely available than those available for ADRD caregivers. While support groups are shown to be beneficial, they are often ridged with inflexible meeting times, locations, topics covered, etc. Similar to the term 'dementia,' 'support groups' may have negative connotations among African Americans.[18] Although serious illness caregiving can be similar, the nature of ADRD caregiving differs primarily because of the associated cognitive decline and behavioral symptoms.

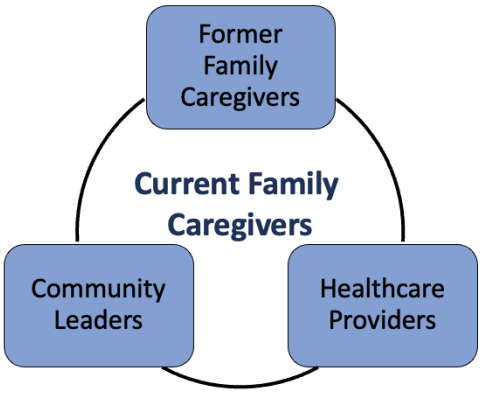


Figure 1: FamCare Study Stakeholder Engagement for Healthcare Decision Making

Family caregiver peer support as a potential adjunct to palliative for African American ADRD caregivers. Peer support interventions can help to support caregivers with care recipient behavioral, psychological, and other symptoms of ADRD and also improve caregiver quality of life.[19] Lay (social) and professional (healthcare provider) support are important and integral to health promotion.[20] Supportive social relationships include both embedded (i.e. family, friends, church members, neighbors) and created social networks.[19,20] These self-help support networks may be in group form or one-to-one involvement as well as paraprofessional (involving extensive training and professional involvement).[20] The former involves peer relationships, a provision of peer support. Peer support is an established concept and social relationships such as for family caregivers providing care for a loved one living with ADRD are important for health and wellbeing promotion.[20] Peer support has also been established as supportive for transitional stressors such as bereavement and for situational stressors as well as health promotion.[20] Peer support has been previously used for individuals who have experienced significant loss.[20] For example, among African Americans receiving long-term dialysis, peer mentoring has resulted in an increase in advance directive discussions and advance directive completion, improving anxiety and overall quality of life.[21]

This study is novel because it combines cultural tailoring with the concept of peer support to meet the unique needs of African American ADRD caregivers. Our Pair 2 Care caregiver support intervention poses a highly innovative strategy that has the potential to address advance care planning and healthcare decision making, a significant health disparity problem and thereby promote health equity. It includes the flexibility needed for African American ADRD caregivers. Our innovative approach will advance the field toward improving ADRD caregiving outcomes. The Pair 2 Care model has potential for adaptation to meet the needs of caregivers of persons living with other diseases and/or racial/ethnic populations in the future. It is responsive to the National Alzheimer's Plan[22] and request for proposals from professional organizations such as the Hospice and Palliative Nurses Association and the American Academy of Hospice and Palliative Medicine. This progress places significant focus on equity in palliative care.

Preliminary Work. Our prior work as well as that of others have shown that perceived understanding of end-of-life terminology in health-related decision-making matters and that cultural tailoring is critical to improving advance care planning approaches.[16,23,24] By using a multistakeholder approach, we have found that access to culturally-specific mechanisms is an unmet need to improve advance care planning and healthcare decision making engagement (see Figure 1). Factors such as shared understanding, identity, and experiences through storytelling are consistent with embracing cultural affinity in the African American community.[8]

Figure 1 depicts our Current Family Caregiver Community Research (FamCare) Study approach which included perspectives from former family caregivers, healthcare providers, and community leaders to identify the healthcare decision making needs of those who are currently caregiving. This foundational work was guided by the Model to Explain Factors Impacting Advance Care Planning Among African Americans developed by Sanders et al (2016),[16] including the

development of interview guides. This model describes personal, intrapersonal, and structural barriers to advance care planning and healthcare decision making and stresses the likelihood of informal discussions instead of documented plans among African Americans.[16] Cultural affinity is similar to social identity, which is defined as one's emotional closeness to and in-group identification to a specific sub-culture.[25,26] The family caregivers in our previous FamCare study expressed a strong desire for advance care planning and healthcare decision making to be more aligned with cultural affinity for easier adoption, to match patients' needs and wishes, and improve completion. In this proposed study, we will also leverage the desire of former family caregivers to 'give back'. We will, therefore, use our existing participant cohort of former family caregivers for this proposed study. This approach promotes trust and continued engagement in research for a group already at high risk for low research participation.

Pair 2 Care is a low-cost intervention that maximizes flexibility for peer connections using technology. Available financial assistance for reduced Wi-Fi cost may be recommended for family caregivers who request Wi-Fi access. In the future, the Pair 2 Care framework can be implemented into existing programs such as African American Alzheimer's and Wellness Association (AAAWA) and the Alzheimer's Association and scaled for adaptation to other caregiver types and racial/ethnic groups ensures sustainability. Future policy development will ensure its inclusion in national caregiver programs.

While there are no direct benefits to the individual study participants, the proposed study will be highly important in filling gaps in essential information that will lead to improved interventions and policy changes. It will provide feasibility and acceptability pilot data with this initial intervention testing to support efficacy testing.

III. Procedures

Overall Procedures

All study procedures will be approved by The Ohio State University (OSU) Institutional Review Board (IRB). Procedures will be conducted remotely allowing flexibility for participation. Intervention development initially began using stakeholder data collected from our FamCare Study as previously described. A total of 15 people who are currently caring for a loved one (current caregivers) and total of 15 people who cared for a loved one who lived with dementia (former caregivers) will be enrolled in the Pair 2 Care research study. Mentors may be assigned an additional mentee. Former caregivers (mentors) will complete up to two 1-hour training sessions to become mentors to current caregivers (mentees). Former caregivers will be called mentors and current caregivers will be called mentees. Each mentor and mentee will be paired for 6 months for peer support. We will attempt to select mentors and mentees for pairing based on something they have in common as identified using the (see Participant Intake Form). During the Pair 2 Care program/intervention, mentors will provide non-judgmental, flexible, culturally sensitive support to their mentees and share their personal caregiving experiences. This may include information such as the following: accessing/selecting healthcare providers, attending doctor visits, attending worship services, coronavirus pandemic/endemic, exercise, faith, family dynamics, finances, healthcare decision making, mental health, nutrition, physical health, sleep, social activities, spirituality. Data collected during the participant screening process such as family caregiver type, etc., may be used from consented individuals. Once each week during the 6 months connection, mentees will be sent a short survey (see Appendix for Weekly Mentee Interaction Assessment Response Form) by text, email, and/or phone call to complete about their interaction with their mentor during the last week. If not completed by the mentee, a text email

and/or phone call reminder will be sent within a couple days after as a reminder to complete it. A weekly text/email/reminder phone call message may be used to: 1) thank participants for being in the study, 2) remind mentees and mentors to connect, and or 3) remind mentees to complete their Weekly Mentee Interaction Assessment Response Form.

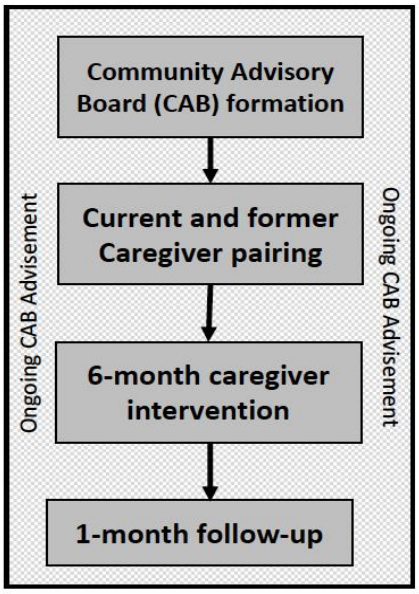
A. Research Design

Design. A community-based participatory approach will be used to further develop and pilot test Pair 2 Care. The proposed intervention was initially developed based on data provided by stakeholder participants from the principal investigator's (PI) completed studies (Decision Making for African American with Dementia Study - DAADS and FamCare Study).

Community Advisory Board - FamCAB. The Family Caregiver Community Research (FamCare) Lab Community Advisory Board Community Advisory Board (FamCAB) has been formed. The FamCAB members and are not part of the research and therefore are not research study participants. However, their engaged work is informing this and other research within the PI's research program. As non-research participants, the overall goal of the FamCAB is to assist in tailoring the Pair 2 Care intervention to meet the needs of the current caregiver mentee participants and provide recommendations for problem-solving and promote equity by meeting the needs of African American ADRD caregivers and for intervention sustainability over time. The purpose of the FamCAB will be to: 1) assist the study team with accessing potential caregiver participants in the local community, 2) introduce study staff to key community leaders and members, 3) identify community assets (e.g., resources, organizations) to support the proposed study, 4) develop the protocol and ensure content validity by reviewing the preliminary Pair 2 Care study protocol (including mentor training and materials) prior to participant enrollment, and 5) provide iterative feedback on intervention development before, during, and after pilot testing the intervention to help ensure acceptability and usability. The FamCAB will advise the research team on study procedures (e.g., discussion topics, frequency of interactions, etc.). As the FamCAB will not access data or participant identifying information.

See Figure 2 for intervention development process. The FamCAB will help to ensure goals for this community-engaged study efforts are met[27] and will be partners in the development and testing of the intervention even beyond the proposed study. For the Pair 2 Care Study, the mentors and mentees will be brought together for peer support. Both qualitative and quantitative data will be collected. Various types of data will be collected from mentors and mentee at baseline, pre-, intra, and post intervention to pilot test Pair 2 Care for this Stage I intervention study.[28]

Figure 2: Program Development Process



B. Sample and Setting

A sample of *n*=15 current family caregivers (mentees) and *n*=15 former family caregivers (mentors) who self-identify as being Black/African American caregiver of an older adult living with or who lived with ADRD will be recruited to pilot test the Pair 2 Care program/intervention. For this short duration study, participants will be recruited from the Central Ohio area – Columbus area and surrounding communities. As requested by our prior study participants for this co-created intervention, this study is being conducted virtually. While recruitment may occur via phone, video call, email, or in-person using the IRB-approved study flier and recruitments scripts, consenting and data collection will be completed remotely. Therefore, participants (mentors and mentees) are not required to meet in-person for this study.

C. Recruitment

Potential participants will be recruited from the Central Ohio area – Columbus area and surrounding communities through research registries, community partnerships and events such as health fairs and at churches, snowball methods, and social media. For this remotely conducted study, all study-related materials will be organized online from the PI's College of Nursing office or the remote work site of the research team members. Research team members may work in-person at The Ohio State University or remotely. If recruiting remotely (as with data collection), research team members will ensure that they are located in a private location and their computer is connected to the CON remote access VPN to ensure security. Headsets will be used as needed to help to ensure privacy of conversations. No participant information will be stored at research team members' remote locations. All electronic study data will be stored on a secure OSU College of Nursing research server or in Research Electronic Data Capture (REDCap)[29]. This includes demographic and other survey data as well as interview audio and transcripts. Each participant will be assigned a unique study identification alpha-numeric code. Only members of the study team will be able to link participants with study identification alpha-numeric code. Names, phone numbers, and mailing addresses will be stored separately from study alpha-numeric code numbers, verbal consents, study data, and interview transcripts. Data collected as part of this study will be stored in an established data repository per The OSU Policy and Procedures. The participants will be able to choose the location they make phone, or video call or email from for interacting with study team members.

The Recruitment Script (see appendix) will be used for phone, video call, email, or in-person recruitment along with the study flier (see appendix). Community-based organizations such as nursing homes, churches, and dementia-focused organizations may share study fliers with potential participants such as through email via listservs, posting on their organization social media sites, or posting study fliers within their organizations using the Community Partner Recruitment (via email, phone, video call, or in-person) along with the study flier. The FamCare Lab Website will have a page dedicated to the Pair 2 Care Study that will include the study flier, Study Introduction Note, and the Study Welcome Video (see script in appendix). The Study Welcome Video will also be placed on the lab website's home page. Potential participants or community partners may choose to share the study flier with others in their contacts, and they may post the flier on their social media sites e.g., Facebook©, Twitter©, and Instagram©. Additionally, the PI and study team members may give caregiving presentations in the community as requested, attend health fairs, such as at nursing homes or other community-based organizations that may include sharing the study flier and offering continuing education credits as needed. These community presentations are educational presentations that the PI conducts as part of her citizenship in the local community based on her expertise. These presentations are given regularly on topics such as palliative and end-of-life care, family caregiving, and dementia, etc. as requested by community-based organizations. Following such community engagements, the IRB-approved study flier may be made available to attendees as with distribution at local health fairs. There will be no additional study information included in the presentations. Snowball methods will also be used for recruitment of study participants. Potential participants will contact the research team either in-person, via phone call, or email for additional study information, and eligibility screening. This convenience sampling approach will be augmented with snowball recruitment methods to identify additional potentially eligible caregiver study participants. Additionally, enrolled participants will also be asked if they know of anyone else who may qualify to participate in the study. If so, the participant will either pass along the study information and PI contact information and potential participant themselves will contact the PI if interested to facilitate snowball recruitment methods. Otherwise, if the participant agrees to reach out to other potential caregiver(s) to ask if it is okay to share their contact information with the study team, the PI or a member of the research team will contact the potential participant to provide study information and determine eligibility using the Caregiver Recruitment Script followed by the Caregiver Screening Form (see appendix).

Recruitment efforts will ensure that each current family caregiver as mentee will be paired with a former caregiver mentor. Participants will also be recruited from FamCare Lab Participant Registry and Website. We will build on established research partnership with current and former family caregivers who previously participated, provided input and feedback, and indicated willingness to be included in future research studies. From our FamCare Study, current and former caregivers expressed their desire to be recontacted to be in research studies as indicated via the prior consent processes. Therefore, they are willing to be recontacted to be screened (using the Screening Form) and invited to participate in this Pair 2 Care study. The following criteria will be used to determine family caregiver participant eligibility:

Inclusion Criteria: Current and former family caregivers will be included if they are: 1) at least 18 years old, 2) self-identify as being African American/Black, 3) either currently provide or manage care for at least 8 hours per week for an African American/Black older adult (60 years or older) family member or otherwise fictive kin living with ADRD or did so in the past (at last 6 months post care recipient death). Former family caregivers will be assessed for readiness to be a mentor, including comfort discussing grief and loss. They must indicate that they have experience with palliative care and/or hospice services.

Exclusion Criteria: Current and former family caregivers will be excluded if they state that they: 1) do not have this experience, or 2) are uncomfortable discussing healthcare decisions, end-of-life decision making, grief, loss, death, and dying, particularly as it relates to the loss of their loved one who lived with ADRD.

During screening potential participants will be asked if they have access to a Wi-Fi-enabled smart phone or table for use during the study. If they respond 'No', the research team member will provide information for accessing a study-provided Wi-Fi-enabled tablet for study use.

D. Screening

The Caregiver Screening Form will be used to determine if the caregiver meets study inclusion criteria. This form may be completed in-person, or via phone or video call. If study criteria are met and the family caregiver agrees to participate, they will be offered several potential dates and times for scheduling verbal consenting and data collection. In preparation for the appointment, a copy of the Study Consent Information Document will be emailed or mailed to potential participant in advance of consenting for them to read in advance of consenting and to keep a copy for their records. This email will contain the Study Introduction Note and the Study Welcome Video (see scripts in appendix), and the Caregiver Study Information Document, Mental Health Resources Sheet, and Zoom© Instructions will be attached (see appendix). Data collected during the screening process such as family caregiver type may be included as study data from participants once consented.

Participants will verbally agree to participate in the study. Prior to establishing the peers, the Participant Intake Form (see appendix) will be completed to ensure the best matches based on similar qualities. This form will also include their preferences for receipt of email/text/phone call communication.

E. Consenting

All data from study participants will be collected following IRB approval of study procedures. Each study participant will provide a verbal informed consent prior to all data collection. Consent procedures will be conducted remotely allowing flexibility for participation. Potential caregivers will be emailed (using Caregiver Recruitment Script) the Caregiver Consent Information Document, Mental Health Resources Sheet, Zoom© Instructions, along with a copy of the IRB-approved Study Flier ahead of the consenting appointment. A reminder text/phone call/email will be placed/sent at least 1 day prior to the appointment using the Text Message or Email Scripts – see appendix). The research team member will meet with potential participant via phone or video call. The Caregiver Consent Information Document will be read aloud by the research team member, or the participant may choose to read it for themselves before providing verbal consent. Time will be allowed for the participants to ask questions and responses will be provided. Once all information has been clarified, the research team member will ask the following questions and their responses documented in REDCap[29] by the research team member:

In order to provide your verbal consent, can you please answer the following questions:

1. "Do you agree to participate in the Pair 2 Care: Peer Support for Caregivers of African Americans Living with Dementia Study? YES or NO

2. "Is it okay for me to record the audio during the interview?" YES or NO

3. “When the study is completed, would you like to receive a copy of the study results?” YES or NO

4. “Would you like to be contacted about the chance to be in other research studies?” YES or NO

A response of ‘Yes” must be provided for question #1 for the participant to be enrolled.

Once the participant is enrolled in the study, they will be sent a welcome email/text containing the study introduction video developed using the Study Introduction Video Script (see appendix) recorded by the PI. Alternatively, a brief welcome letter will be mailed (see appendix for Study Welcome Video/Note).

Consent Addendum

Mentors will be invited to complete an optional 1-hour audio-recorded individual interview at the end of the study (Month 6 or 7) about their experience as a mentor in the study. This interview will be audio recorded using two voice recorders. During the interview, they will have the option to choose not to answer any question that they do not wish to answer. The interview will be completed over the telephone or video call. Prior to the mentees completing the interview, mentors will be provided a copy of the consent addendum (see appendix) via mail and/or email using the Consent Addendum Email Script (see appendix). The following questions will be asked to obtain verbal consent prior to completing the interview:

1. “Do you agree to complete the optional mentor interview for the Pair 2 Care Study?” YES or NO

2. “Is it okay for me to record the audio during the interview?” YES or NO

A response of Yes” must be provided for question #1 in order for the interview to be completed.

At the beginning of the study, we will ask caregivers to provide us their phone number so we can add it to our participant communication platform. During the study, we will use Twilio integrated into REDCap to communicate with participants via text messaging. Participants will not pay any additional charges for this service over and above what they normally are charged by their mobile network provider for sending and receiving text messages or transmitting/receiving any data. Twilio is completely integrated into the OSU version of REDCap and does not require use of a separate app to communicate with participants. All participant information will be kept within the REDCap platform. Participants are unable to respond to text messages sent via Twilio. Only trained study staff will be able to access the REDCap project.

F. Mentor Training

Prior to engaging with their current caregiver mentee, former caregivers will complete up to two 1-hour virtual training sessions either individually or via group session(s) over Zoom© (see appendix for Mentor Training Slides). This training will include video-recorded communication scenarios using culturally congruent actors for four exemplar scenarios: Training video script #1 - Support for Caregivers, training video script #2 – Near End-of-Life Scenario, training video script #3 - Happy Peer Connection, and training Video Script #4 – Long-term Care Decision Making

(see appendix). A Black-owned media company such as, SpencerHigherforMedia© will be hired to review scripts and for talent acquisition to support cultural congruency. Manipulation checks will be conducted using verbal questions posed by the study team using following training sessions (see Mentor Training Manipulation Checks Survey). This will include "what if" scenarios to ensure understanding of content delivered. If responses reveal that former caregivers are not receiving the intervention as intended, we will immediately reassess, discuss with the FamCAB, and may schedule an additional training session, if needed. The additional one-on-one training sessions may be scheduled to review previously covered information with former family caregivers and answer any questions as needed. A brief 1–2-page Mentor Training Summary Sheet (see appendix) will be provided at the end of the training sessions once the mentor is paired with their mentee. While former caregiver (mentee) training may be completed in group settings or individually, no surveys, questionnaires, or interviews, etc. will be collected on a group setting. Following the training, mentors will complete the Mentor Training Evaluation Form (see appendix) via text or email to provide feedback on the training session(s) Table 1 outlines former caregiver training activities. Emails and or texts will be sent prior to mentor trainings using the Text Message or Email Script. Once the mentor training is completed, a certificate of completion (see appendix) will be sent to each via mail and email using the Mentor Training Certificate Email Script (see appendix). Mentors will be able to meet with a research team member as needed.

Table 1: Mentor Training Activities

Day	Activity
1	• Explain purpose of Pair 2 Care Intervention • Introduce ice breaker conversations - demonstrate and practice • Review meaning of palliative care and end-of-life care-related terminology • Discuss rules for engagement with current caregivers e.g., method, frequency, duration • Review topics to be discussed – provided a 1–2-page summary format • Review and provide and handout of discussion topics with conversation starters and topic schedule • Model practice conversations with tips provided using training videos
2	• Review of Day 1 activities • Practice icebreaker conversations • Practice peer interactions through role play • View and discuss "what if" scenarios including training videos e.g., if current/former caregiver become emotional, reporting to study staff • Summarize training and intervention purpose • Questions and answers

G. Data Collection

All data will be collected remotely by a study team member using REDCap software.[29] Data collection will be scheduled at a time that is convenient for the participants via telephone or video conference call. Options for during the days, evenings, and weekends may be offered to be flexible in meeting the needs of the study participants. A 2-week window will be given around each data collection timepoint for data collection to take place. The appointment reminders will be used to send reminder email, phone call, or text messages for all study appointments and weekly nudges/reminders using the Text Message or Email Scripts. A weekly text/email/reminder phone call message may be used to: 1) thank participants for being in the study, 2) remind mentees and mentors to connect, and/or 3) remind mentees to complete their Weekly Mentee Interaction Assessment Response Form.

Pairing of Mentors and Mentees: Once mentor training session(s) are completed, mentors and mentees will be paired based on similar qualities such as caregiving relationship and gender identity based on information provided on the Caregiver Intake Form. Mentors may be assigned an additional mentee. A virtual introduction of current and former caregiver pairs will be made by a study team member using the Peer Introduction Meeting with Research Team Member Agenda (see appendix).

Each pair will complete at least five virtual face-to-face (video) interactions and at least 10 other interactions either via phone call, email, or text messaging over the 6-month time period based on average timeframe and number of interactions for similar research studies.[19,21,30] A weekly check-in via text, email or phone call from a research team member will be completed to confirm and document mode and frequency of interactions as well as topics discussed (see Table 2) using the Weekly Mentee Interaction Assessment Response Form (see appendix). It includes indication for if the form was completed directly by the mentee via text message or email link or of completed by a research team member with them over the phone. This information will be tracked such as on a peer interaction log. These records will serve as manipulation checks to determine if the suggested topics are being discussed. Caregiver interactions will be flexible i.e., scheduling, duration, content, medium (telephone vs video).

Table 2: Peer Discussion Topics

Category	Topics
Caregiver and care recipient needs	*accessing/selecting healthcare providers, attending doctor visits, attending worship services, coronavirus pandemic/endemic, exercise, faith, family dynamics, finances, healthcare decision making, mental health, nutrition, physical health, sleep, social activities, spirituality*
Caregiver needs	*managing multiple responsibilities, respite care, self-care, social support, work (inside and outside of the home)*
Care recipient needs	*activities of daily living, attending public events, adult daycare, advance care planning, assistive devices, coping with dementia-related behavioral symptoms, end-of-life planning, financing care, hospitalizations, mobility, nursing homes, nutrition, palliative care, hospice, support services/resources, skin care, urinary incontinence*

Measurement / Instrumentation: Demographic data (e.g., age, gender, caregiving relationship) will be collected from all caregivers using the respective mentor and mentee demographic form (see appendix). State anxiety (Spielberger State Anxiety Inventory - STAI-S),[31,32] depression (Center for Epidemiological Studies – Depression - CES-D),[32] quality-of-life (Caregiver-Targeted Quality of Life – CGQOL[34]), self-efficacy for surrogate decision making (Surrogate Decision Making Self-Efficacy Scale - SDM-SES),[35] social support (Medical Outcomes Study Social Support Survey – MOS SSS),[36] and intent to use palliative care/hospice (Mentee Palliative and Hospice Care Intent Form) data will be collected from mentees. Care recipient dementia stage (Quick Dementia Rating System - QDRS)[37] and behavioral and psychological ADRD symptoms (Neuropsychiatric Inventory Questionnaire - NPI-Q) data will also be collected[38] (see Table 3) (see appendix). Audio-recorded interviews (using the Mentee or Mentor Interview Guide – see appendices) conducted at one-month follow up via Zoom©, phone, or other virtual format with participants will characterize their experiences. Mentors will have the option to complete the interview at Month 6 or 7. Mentees will complete the interview at Month 7 (1 Month follow-up). Interviews will be conducted with participants to gather in-depth data on their Pair 2 Care Intervention experiences, including feedback on the likelihood of the intervention meeting the needs of African American ADRD caregivers. A member of the research team with connect with

former caregivers at the 3- and 6-month timeframe for feedback on how the mentoring process is going.

Table 3: Data Collection by Timepoints

Participant	Timepoint		
	Baseline 0-Month	**Intervention 3 & 6 Months**	**Follow-up 1-Month Post**
Mentee	1. Demographics 2. Participant Intake Form 3. Anxiety (STAI-S) 4. Depression (CES-D) 5. Dementia stage* (QDRS) 6. Behavioral and psychological ADRD symptoms**(NPI-Q) 7. Quality of life (CGQOL) 8. Self-efficacy (SDM-SES) 9. Medical Outcomes Study Social Support Survey (MOS SSS) 10. Mentee Palliative and Hospice Care Intent Form	1. Anxiety 2. Depression 3. Behavioral and psychological ADRD symptoms* 4. Quality of life 5. Self-efficacy 6. Social support	1. Anxiety 2. Depression 3. Behavioral and psychological ADRD symptoms* 4. Quality of life 5. Self-efficacy 6. Social support 8. Satisfaction and Appropriateness Survey 9. Acceptability Survey 10. Mentee Palliative and Hospice Care Intent Form 11. Mentee Interview Guide
Mentor	1. Demographics 2. Participant Intake Form	1. Mentor Interview Guide (month 6 or 7 only)	

*Instrument completed by current caregiver about care recipient

Feasibility and acceptability will be determined by evaluating eligibility criteria, recruitment, and retention data (e.g., consent, drop out, refusal rates), protocol adherence, satisfaction, and appropriateness of the intervention for broader dissemination. The Satisfaction and Appropriateness Survey (see appendix) will be used to rate current caregiver intervention satisfaction and appropriateness. The Acceptability Survey (see appendix) will be used to assess acceptability of Pair 2 Care. This information will be collected on the Study Feasibility Log (see appendix). Benchmarks will be assessed per Table 4.

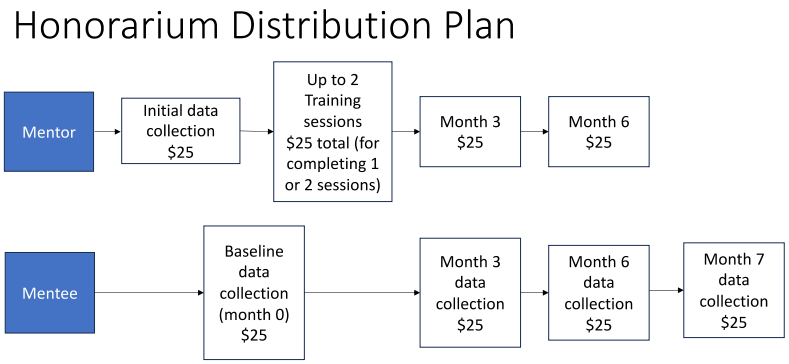
Table 4: Feasibility and Acceptability Benchmarks

Feasibility Benchmarks	
Eligibility Criteria	Criteria allows for enrollment goal to be met
Enrollment	Enrollment of 100% of participants in Year 1
Retention	Retain at least 70% of current and former caregivers
Intervention Training	At least 90% former caregivers complete training
Protocol Adherence	At least 80% adherence and keep record of suggested changes per FamCAB
Acceptability Benchmarks	
Satisfaction Survey	At least 70% completion rate; 80% satisfaction rate; 80% appropriateness rate
Interviews	80% interview completion

H. Participant Incentives/Compensation for Time

Participants will receive a $25 VISA© gift card and thank-you note (see Appendix - Text Message or Email Scripts) each time a set of surveys, mentee interview, mentor training is completed. Current caregivers (mentees) will complete surveys in the beginning, 3 months, 6 months, and 1-month follow-up. The 1-month follow-up will include an audio-recorded interview. Former caregivers (mentors) will complete surveys in the beginning, training, and 3-months and 6-months. You will receive a total of $100 over the time of the study. See Figure 3 for Honorarium Distribution Plan. Data collection points will be tracked by the research team such as by using a data collection log. Gift cards will be delivered electronically via email or via mail (depending on their preference) using Virtual Incentives,© an OSU-reviewed portal. Participants will receive an email from Virtual Incentives© to select their preferred delivery method (electronic or mail). See appendix for sample view of Virtual Incentives© Reward Center Landing Page (see appendix) that includes a thank-you note (see appendix). Virtual Incentives© will be provided with participants name, mailing address, phone and/or email address. Virtual Incentives© will not share participants' information with others. This service is at no cost to the study participants. A security and privacy review was conducted by the OSU IT team to ensure compliance with all OSU guidelines and regulations. There will be no communications with study participants that are not study related and all participant identifiers will be destroyed after study completion. At the end of the study completion, each participant will be mailed a hand-written thank-you note in gratitude for their study participation.

Figure 3: Honorarium Distribution Plan



I. Study Risks

Though this study poses minimal risks to participants, steps will be taken to ensure that participant risk remains minimal. As peer mentors are not health or healthcare experts, therefore, mentees will be reminded to seek advice from health experts for all health and safety issues (see Health Safety Protocol in appendix). This includes accessing 911 for all emergencies. If the mentor or mentee is unable to contact their mentor or mentee after four (4) attempts, they will be encouraged to cease and notify a study team member who will attempt to connect with the mentor or mentee. Participants with knowledge or concerns about health or safety issues will immediately report them to a study team member, who will report it to the study leader. The study leader is a

registered nurse and thus a mandated reporter and is therefore required by the State of Ohio to report abuse. The PI will notify the relevant authority for safety concerns and the research ethics board per protocol. Relevant health referrals and contact information will be provided directly to participants for health concerns. If found to be an unsafe environment, at the PI discretion, an event report will be made to make the decision to exit the study. The PI may be required to ask a participant to exit the study.

Discussions about death and dying may evoke feelings of related sadness related. Participants will be reminded that they can choose to end the interview at any time by telling the research team member and will be allowed to take breaks as needed. They will also be reminded that they can refuse to respond to a survey or interview question at any time if they are not comfortable or simply do not wish to respond simply by telling the interviewer that they do not wish to respond. Participants can also decide to drop out of the study at any time without penalization by telling the study team member. If a participant exits the study for any reason, their mentor/mentee may be allowed to continue participating if they choose to do so. The research team will thoroughly document the discontinuation of peer relationship, the remaining peer may be given the option to remain in the study, and their data analyzed to reflect this change in their engagement in the study. Their data may be analyzed separately from peers that complete the full study. Also, if the mentor-mentee relationship is not deemed a good match, attempts will be made by the research team, in collaboration with the PI, to address any concerns. It will be at the PI and research team discretion if it is unsafe for relationship and study participation to continue. If so, the peer participation in the study will end. The Study Exit Script will be used to convey, and study exit information. The PI in collaboration with the study team will determine if it is advisable to allow the participant(s) to remain in the study or not. Drs. Moss (PI) as a trained as registered nurse will be able to identify acute physical and/or psychological needs of the participants observed or reported and be able to make appropriate and timely referrals. If caregivers are thought to be experiencing any acute psychological or physical distress, they will be asked to visit their respective primary healthcare provider as well as offered access to community-based mental health resources or 911 services as outlined in the Health Safety Protocol. Participants will be instructed to contact the research team if any issues arise regarding the interaction/relationship with their peer. Any such challenge will be address with participants by the PI, if a solution is not possible or if the participant(s) choose, they will be allowed to exit the study (see appendix for Study Exit Script and Early Exit Form). If a caregiver chooses to leave the study or are asked to leave the study at any time for any reason, they will be asked not to be in contact with their mentor or mentee for any further study-related activities.

All electronic study data will be stored on a secure OSU College of Nursing research server. This includes recordings of demographic data, questionnaires, and interview transcripts. Each participant will be assigned a unique study identification alpha-numeric code. Only members of the study team will be able to link participants with study identification alpha-numeric code. Names, phone numbers, and mailing addresses will be stored separately from study alpha-numeric code numbers, recordings of verbal consents, study data, and interview transcripts. Data collected as part of this study will be stored in an established data repository per The OSU Policy and Procedures.

Contracted platforms such as Virtual Incentives© (secure gift card distribution service) maybe provided participants' names, mailing address, phone and/or email address. Study participants will be made aware of this during the consenting process. As part of their OSU security user agreements all external services used (Virtual Incentives, Rev, and Dedoose) will not share any participant information and they will delete this information at the end of the study. Interview

transcripts will be de-identified and no individual participant identifiers will be used in presentations of study results and publications.

The OSU Information Technology (IT) Department will provide web-based resources such as instructions for connecting to Zoom©, and support to address other technological challenges such as Wi-Fi connectivity. For participants who do not have a Wi-Fi-enabled device or Wi-Fi access, a Wi-Fi enabled device such as a tablet and or Wi-Fi connectivity will be provided to them for the time required for their study participation. If needed, participants will be put in touch with a College of Nursing IT specialist (Mr. John Pryba or another representative) for any technical assistance that is needed. The OSU Center for Clinical and Translational Research Community Connectors Program will assist with social media recruitment and REDCap[29] setup for data collection. Partnership will continue with the local AAAWA and Alzheimer's Association for recruitment and future intervention implementation. Available community-based financial assistance for reduced Wi-Fi cost will be recommended for caregivers who request Wi-Fi access. Pair 2 Care framework implemented into existing programs such as AAAWA and scaled for adaptation to other caregiver types and racial/ethnic groups ensures sustainability. Policy development ensures inclusion in local, state, and national caregiver programs. Additional potential barriers and solutions are proposed in Table 5.

Table 5: Challenges and Solutions

	Potential Challenge	Solution
1	Participant recruitment	Research registries, community partnerships, snowball, and social media
2	Participant retention/dropout	Data collection timepoints, incentives, at least bi-weekly phone calls/text messages/emails
3	Non-adherence	Manipulation checks
4	Access to Wi-Fi enabled device	Wi-Fi enabled device provided, if needed
5	Access to Wi-Fi	Access to Wi-Fi provided, if needed, then resources for free/reduced Wi-Fi
6	Scheduling difficulty	Flexibility, multiple offerings, use of Doodle polling
7	Health or safety concerns	Health resources, notification of IRB and relevant authority as needed
8	Death of a care recipient	Pair transition plan (bereavement support and other resources offered)

J. Internal Validity

Threats to internal and external validity exist. For example, the study team will not be able to control additional external support that the current caregiver is receiving simultaneously that may impact study findings. The team will also not be able to control if the relationship between the peers is not conducive to peer support. However, participants will be instructed to contact the research team should any issues arise. In the conduct of pre- and post- tests are strategically timed based on prior studies with a goal to help avoid any desire of the participants to remain consistent in their responses. Data collection forms will be completed via telephone or video call (via Zoom©) with a research team member for consistency and to avoid missing data. Study participants may have participated in the prior FamCare Study. This relationship over the time with the PI and the study my impact their perception of the study. However, the benefits of their continued participation in this co-created community-based study outweighs this threat and will be acknowledged in the study results. Over the course of the study, participants my drop out. To mitigate this, the research team will maintain constant connection with them through frequent check-ins via phone call, text messages, and email for check-ins and data collection as outlined.

To ensure threats to internal and external validity in the qualitative portion of the study, several measures will be taken to help to ensure trustworthiness of findings. At least three independent coders to help to ensure validation of conclusions. Member checking with up to two participants in each category (current and former caregivers) will be conducted to verify if understanding of data rang true to them. Study team interview training will help to ensure regularity in the delivery process. All interviewers will also be trained in interview data collection procedures for consistency in this process to reduce variability of findings as a result. Data will be reported with sufficient descriptive data with the intent to ensure that data transferability is possible to applicable settings or groups.

For this pilot study, that is thus not fully powered, data obtained regarding feasibility and acceptability of the intervention will not be generalizable to the larger population. Therefore, data obtained will be used to inform the next step study to test effectiveness of the intervention.

K. Data Analysis

Descriptive statistics will be conducted on all participant demographic data using SPSS® or similar software.
Aim 1: Feasibility and acceptability of the Pair 2 Care Intervention in current (*n*=15) and trained former (*n*=15) African American ADRD family caregivers will be determined by our eligibility criteria, recruitment, and retention data (e.g., consent, drop out, refusal rates), protocol adherence, satisfaction, and appropriateness of the intervention for broader dissemination. We will conduct descriptive statistics for this Aim using proportion for categorical measures (recruitment, retention, and protocol adherence) and mean±standard deviation for continuous measures (80% satisfaction and 80% appropriateness). Interviews will be conducted with current caregivers to gather in-depth data on their Pair 2 Care Intervention experiences, including feedback on the likelihood of the intervention meeting the needs of African American ADRD caregivers. Interviews will be analyzed as described below. Aim 2: Descriptive statistics will be used to summarize sample characteristics and outcome measures (anxiety, depression, quality of life, social support, self-efficacy for surrogate decision making, and intent to use palliative care/hospice services) at each time point. For each outcome, we will use mixed-effects linear modeling for repeated measures to model the outcome as a linear function of fixed-effect of time. The model will also include subject-specific random intercepts to adjust for within-subject clustering from repeated measures. We hypothesize that at 6 months as compared to baseline, current caregivers will report less anxiety and depression, higher quality of life, higher social support, higher self-efficacy for surrogate decision making, and higher intent to use palliative care/hospice services. From the mixed-effects modeling, we will test this hypothesize by deriving contrast estimate of change of outcome between baseline and 6 months.
Power analysis suggested that our sample size (*n*=15) will have only 38% power to detect a medium effect size of Cohen's d = 0.5 for outcome change from baseline at 6 months. This effect size is equivalent to a clinical meaningful difference. Therefore, we will not rely on statistical significance. Instead, results interpretation will be guide by point estimates, precision of the estimates (e.g., 95% confidence interval), effect sizes, and their clinical significance.

Qualitative Data Analysis: Caregiver interview recordings will be transcribed, verified for accuracy, and combined with field notes for analysis. Data analyses will be ongoing and iterative to inform additional probes and analyses. Content analysis will be completed via Dedoose software©,[39] using qualitative descriptive methods to describe themes that emerge. Independent coding will be done by three team members for triangulation.[40,41] Coders will discuss and reconcile coding

for consensus. Member checking with up to two participants will be conducted to verify understanding of data.[42]

Transcribed interviews, field notes, and graphic recording will all be considered as part of study data analysis. Data analyses will be conducted as data are collected to determine when data saturation is achieved. Therefore, data analyses will be iterative. All strategies mentioned in the Internal Validity Section of this protocol will continue as described to ensure trustworthiness of data in the analyses process. Content analysis will be conducted using qualitative descriptive methods to describe themes that emerge from these data.[43] Qualitative data analysis by members of the research team as well as using traditional word processing and paper and pencil methods. Dedoose®[39] software supports analysis of implicit "deeper" themes that are not necessarily explicitly identified by the coders based on their thematic coding. Independent coding will be conducted by three members of the research team for triangulation of data. The coders will meet to discuss and reconcile coding to 100% agreement. Member checking with up to two participants in each category (family caregivers, healthcare providers, and community stakeholders) will be conducted to verify if understanding of data rang true to them.[11] Qualitative and quantitative data will be initially analyzed separately then brought together brought together for side-by-side comparisons. Both types of data will be compared and related to provide further explanation of study findings. A plain language summary of the results of the research (prepared at a 4th grade reading level). Study findings will be disseminated via scholarly conference paper and poster presentations as well as local community-based newsletters to ensure a vast and varied readership.

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