

Official Title:	Pair 2 Care: Peer Support for Caregivers of Black Americans Living With Dementia
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The Ohio State University Consent to Participate in Research

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

Protocol Number: 2023B0071

Researcher: Karen O. Moss, PhD, RN, CNL

Sponsor: Cambia Health Foundation Sojourns Scholars Leadership Award

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate.

Purpose: The purpose of this study is to test a peer support program/intervention for caregivers who are caring for a loved one living with dementia. The program/intervention is called Pair 2 Care: Peer Support for Caregivers of African Americans Living with Dementia.

Procedures/Tasks:

A total of 15 people who are currently caring (current caregivers) for a loved one living with dementia and a total of 15 people who cared for (former caregivers) a loved one who lived with dementia will be included in this study. Former caregivers will complete up to two 1-hour training sessions over Zoom® 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 pair mentors and mentees based on something they have in common. 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. Information collected during the screening process such as the type of family caregiver you are may be included as study information from participants once they are consented.

At the beginning of the study, we will ask you to provide us with your phone number so we can add it to our participant communication system, called Twilio. While you are in the study, we will communicate with you via text messaging. Please note that you will not pay any additional charges for this service over and above what you normally are charged by your mobile network provider for sending and receiving any text messages or transmitting/receiving any data. When you are no longer in the study, we will stop sending you text messages. At any point, if you reply to a message with STOP or QUIT, you will no longer receive messages from the system. Our research team is also able to help you "opt out" of the messaging service through the system.

Duration:

During this research study we will contact you to ask you to provide answers to short surveys about yourself and your loved one living with/or who lived with dementia. As mentees, you will complete surveys at the beginning, at 3 months, 6 months, and at 1-month follow-up. Completion of these surveys should take about 1 hour each time. A member of the research team will connect with mentees regularly for feedback on how the mentoring process is going. During the research study mentees will receive text, email, and or phone call reminders to ensure you are connecting with your mentor and to schedule and remind you of when we have appointments to complete the trainings (mentors only) surveys and the interview (mentees only). One month after the study is completed, mentees will also complete an audio-recorded 1-hr interview about the experience of being in Pair 2 Care. This interview will be audio recorded using two voice recorders. You can choose not to answer any question that you do not wish to answer. We will do these surveys and the interviews either over the telephone or video call.

During the Pair 2 Care research study, we will ask you to connect with your mentor/mentee for at least five virtual face-to-face (video) calls (using e.g., Zoom[®] or FaceTime[®]) and at least 10 other interactions either via phone call, email, or text messaging. You will use your regular mobile phone service to text your mentor/mentee. When you connect with your mentor/mentee, feel free to discuss caregiving-related topics such as any of 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, managing multiple responsibilities, respite care, self-care, social support, work (inside and outside*

75 *of the home), activities of daily living, attending public events, adult daycare,*
76 *advance care planning, assistive devices, coping with dementia-related*
77 *behavioral symptoms, end-of-life planning, financing care, hospitalizations,*
78 *mobility, nursing homes, nutrition, palliative care, hospice, support*
79 *services/resources, skin care, urinary incontinence.* Once each week during
80 the 6 months connection, mentees will be sent a short survey by text or email
81 to complete about their connection with their mentor during the last week. This
82 information may also be received over the phone by a researcher. If not done
83 by the mentee, a text, email and/or phone call will be sent/made a couple days
84 after as a reminder to do it.

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86 Mentors in this study are not health or healthcare experts, therefore, mentees
87 will be reminded to get call or visit a healthcare provider for all health and
88 safety issues. This includes calling 911 for all emergencies.

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90 If you are unable to contact your peer mentor or mentee after four (4) tries, we
91 ask that you do not make any more attempts to reach them and let a study
92 team member know. The team member will try to reconnect you with your peer
93 mentor or mentee and then let you know what will happen next.

94
95 You may leave the study at any time. If you decide to stop participating in the
96 study, there will be no penalty to you, and you will not lose any benefits to
97 which you are otherwise entitled. Your decision will not affect your future
98 relationship with The Ohio State University. If your mentor or mentee is unable
99 to stay in the study for any reason you may be allowed to continue being in the
100 study.

101 **Risks and Benefits:**

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103
104 The risks for harm to you for participating in this study are minimal.

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106 Discussion about your loved one may make you feel sad. It may include
107 discussions about healthcare decisions, end-of-life decision making, grief,
108 loss, death, and dying. We might suggest that you see your primary healthcare
109 provider and have included a list of Mental Health Resources to contact for
110 additional follow-up if needed. Cost for these additional services will not be
111 covered by the research study.

112
113 If you learn about or have any health or safety concerns about your mentor/
114 mentee or their loved one, please contact a study team member as soon as
115 possible who will report it to the study leader. The study leader is a mandated

reporter and is therefore required by the state of Ohio to report abuse. The study must notify the relevant authority for safety concerns and the research ethics board.

If you choose to leave the study or are asked to leave the study at any time for any reason, you will be asked not to be in contact with your mentor or mentee for any further study-related activities.

There are no specific benefits to you from being in the study. The knowledge gained in the study will help us to make the Pair 2 Care program/intervention better. There are no costs to you for participating in this study.

Confidentiality:

We will work to make sure that no one sees your online responses without approval. But, because we are using the Internet, there is a chance that someone could access your online responses without permission. In some cases, this information could be used to identify you.

Also, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- Authorized Ohio State University staff not involved in the study may be aware that you are participating in a research study and have access to your information; and
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Audio recordings will be stored on an encrypted (secured), password protected computer. Once checked for accuracy and examined, the audio will be destroyed by erasing the electronic recording.

Future Research:

Your de-identified information may be used or shared with other researchers without your additional informed consent.

Incentives:

By law, payments to participants are considered taxable income. You will receive a \$25 gift card and thank you note (electronically or by mail) each time a set of surveys, mentee interview, or 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 check in. You will receive a total of \$100 over the time of the study. Once the study results are completed, and you chose to, you will receive a letter with the results of the study. Gift cards will be sent either electronically (text message or email) or by mail via a secure service called Virtual Incentives[®] depending on which one you prefer. We will provide Virtual Incentives[®] your name, mailing address, phone and/or email address. Virtual Incentives[®] will not share your information with others. There is no cost to you for using this service.

Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By agreeing to participate, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study, or you feel you have been harmed as a result of study participation, you may contact **Dr. Karen Moss at 614-688-3100 or moss.391@osu.edu**.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Office of Responsible Research Practices at 1-800-678-6251 or hsconcerns@osu.edu.

Providing consent

I have read (or someone has read to me) this page and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study. I am not giving up any legal rights by agreeing to participate.

To print or save a copy of this page, select the print button on your web browser.

In order to provide your verbal consent, you will tell the research team member your responses to the following questions. In order to be in this study, you must respond 'Yes' to question #1:

1. "Do you agree to participate in the Pair 2 Care: Peer Support for Caregivers of African Americans Living with Dementia Research 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