Development of Dementia-Friendly Guidelines for the Black Faith Community: Caregiver Focus Group Analysis

Recipient of The Nancy Casper Hillis and Mark Hillis Undergraduate Research Award

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Background

- Alzheimer’s disease is currently the sixth-leading cause of death in the US and the fifth leading cause of death among adults 65 years and older. **(Alzheimers Association, 2021)**

- 5.2 million adults in the United States have Alzheimer’s disease and closely related conditions. **(Alzheimers Association, 2021)**

- Progressive dementia has been of special concern for the black community because of the disproportionate rate of Alzheimer’s disease in black people compared to non-Hispanic whites **(Barnes & Bennett, 2014)**

- Black caregivers spend significantly more time in providing direct care than non-Hispanic White caregivers, which, in turn, means that they are more likely to experience a higher level of the burden from caregiving **(Bannon et al., 2020; Whitlatch & Orsulic-Jeras, 2018)**

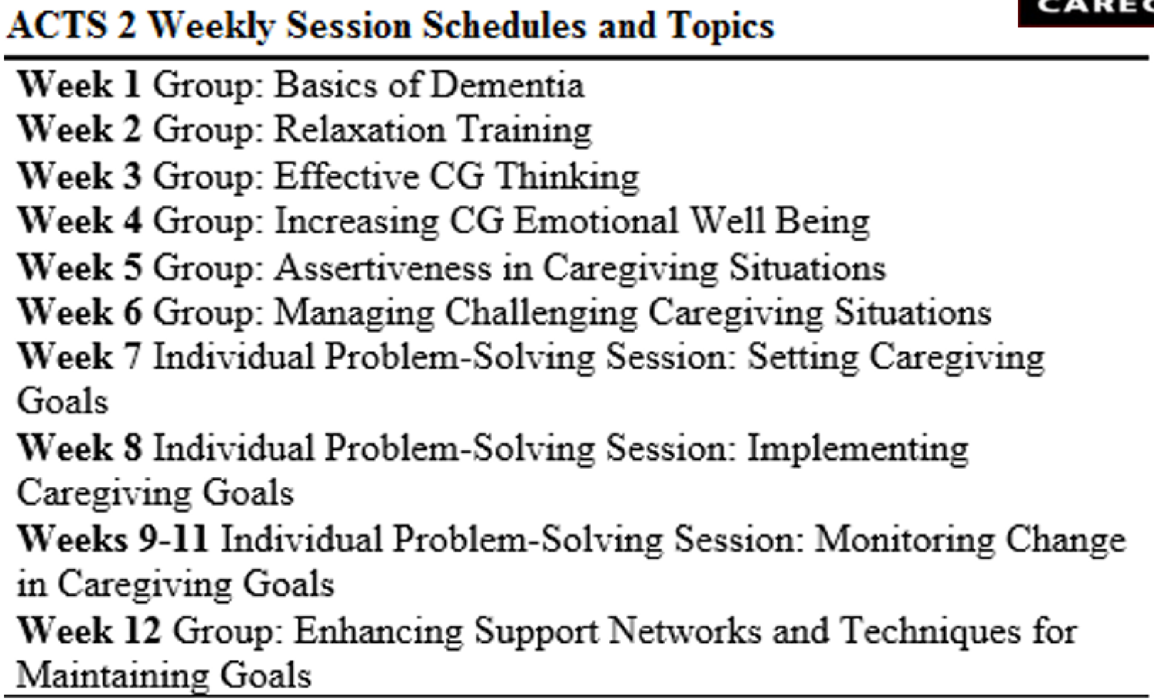
Background CtD.

- Using therapists, treatment protocols, and therapy settings geared to the majority White population may be culturally discordant with the preferences, beliefs, and values of a large proportion of African Americans (**Glueckauf et al., 2007; Glueckauf et al., 2005)**

- Black caregivers have coped and found their solace in their faith community; while that may be beneficial, they still lack formal dementia education and training programs to improve their mental health, reduce caregiver burden, and improve care for their family members living with dementia **(Glueckauf, 2015)**

- the ACTS 2 program at FSU College of Medicine has made it their mission to provide faith-integrated, skills-training and support to distressed black caregivers of family members with dementia across Florida.

AFRICAN-AMERICAN ALZHEIMER'S
ACTS
CAREGIVER TRAINING AND SUPPORT



ACTS 2 Weekly Session Schedules and Topics

Week 1 Group: Basics of Dementia
Week 2 Group: Relaxation Training
Week 3 Group: Effective CG Thinking
Week 4 Group: Increasing CG Emotional Well Being
Week 5 Group: Assertiveness in Caregiving Situations
Week 6 Group: Managing Challenging Caregiving Situations
Week 7 Individual Problem-Solving Session: Setting Caregiving Goals
Week 8 Individual Problem-Solving Session: Implementing Caregiving Goals
Weeks 9-11 Individual Problem-Solving Session: Monitoring Change in Caregiving Goals
Week 12 Group: Enhancing Support Networks and Techniques for Maintaining Goals

PURPOSE OF STUDY

- (1) to gather information about the experiences of Black caregivers and their loved ones with dementia interacting with clergy and church lay leaders in the faith community environment

- (2) to obtain recommendations for ensuring active and meaningful involvement in faith community services, social, and community activities.

Methodology: Participants

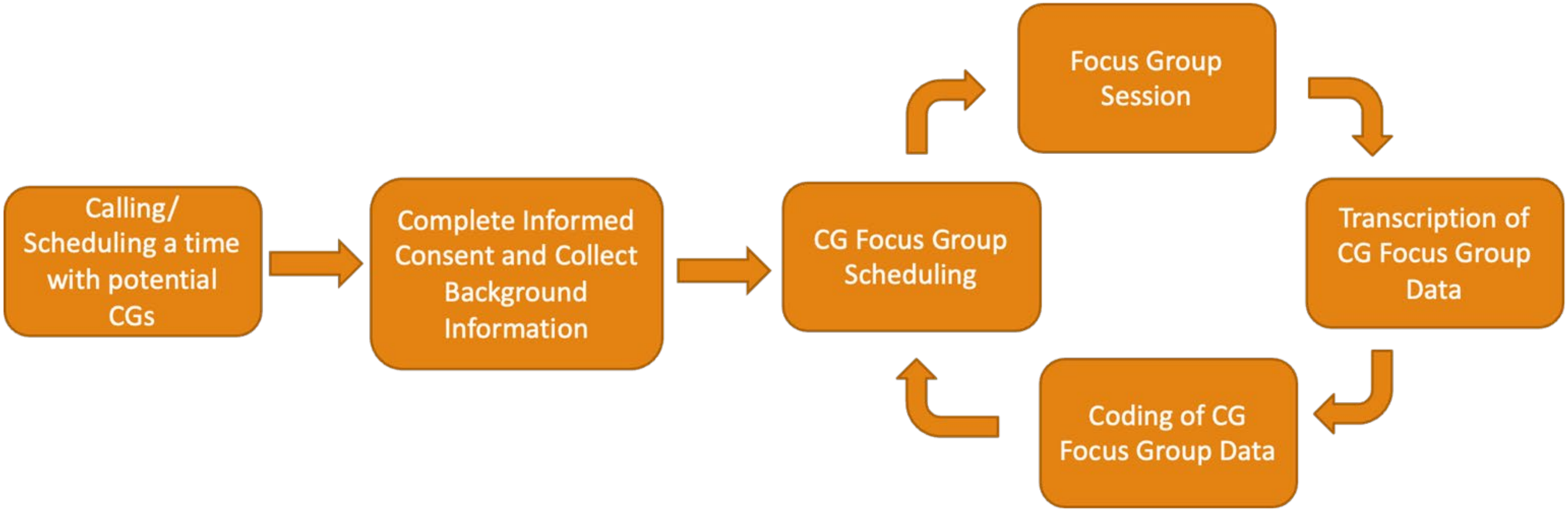
Caregivers were eligible for inclusion into this study if:

- they had an adult family member that was clinically diagnosed with progressive dementia,
- spent at least six hours per week providing direct care
- scored above a 9 on the Patient Health Questionnaire-9 (PHQ-9) assessment
- were at least 18 years of age
- completed the 12 weeks program with ACTS2.

Caregivers **(n=10)**

- 9 Female, 1 Male
- Ages ranged from 50 to 90 (M=54.5)
- College Educated (90%)
- Caregiver Experience (M=13.4 years)

Methodology: Procedure



Calling/ Scheduling a time with potential CGs

Complete Informed Consent and Collect Background Information

CG Focus Group Scheduling

Focus Group Session

Transcription of CG Focus Group Data

Coding of CG Focus Group Data

OUR FINDINGS

Questions asked……	Caregivers' Responses
1. In what ways do you participate and connect with your faith community?	"Umm… *[Long pause, background noise of dropping/handling pots and pans]* Prior to… Umm… Last year, we were doing uhh services via Zoom, started out with telephone. And I introduce uhh… my husband to Zoom uhh for the services as well as our Sunday school service. And he always got a… a joy."
2. What specific activities do you engage in to participate in your faith community?	"I participate in Leadership Ministry, prayer meeting, our teacher of the Sunday School, the Golden Age Ministry, and uhh I was able to function. Uhh, I guess 100 percent during that time, and it was… uhh due to many factors, but one thing that had a very positive impact on me being able to do that was see… the program Covenant Care that was helping me to take care of my husband. They would provide volunteers…. Uhh… When I needed them to attend church on Sunday mornings or anytime during the week, uh, that I needed them, they would provide a volunteer to come and sit for the time that I needed."

Questions asked……	Caregivers' Responses
3. Provide examples of interactions you have had with church leaders and members related to your role as a caregiver for your loved ones with dementia	"My interactions have been that if I was visiting another church, uh, some time my husband would get fixated on his bladder. So, he's kinda up and down, going to the restroom. And she would tap me on the shoulder on his, when he's getting up the third time… the usher would tap me on my shoulder and say, "You know Mrs. BK. I got this, you know, I have it, you know." And sure enough, she [usher] had, had someone with dementia in her family going through the same thing at some point. So, I could sit there and enjoy the service confidently knowing that she's [usher is] watching him as he goes in and out of the bathroom because he's always, he's also passing near the exit door at the same time."
4. What challenges have you faced during worship services with care partner with dementia?	"Umm, my mother actually was *[VL chuckles]* kind of humorous in her outburst at church. *[VL chuckles]* Umm, I think she actually said things that, umm, a lot of the older members wanted to say, but they, uhh, didn't want to be out of out of place or inappropriate……she would often say, "The music is too loud!" And she would say it very loud, so everyone in the church would hear… And sometimes she would say after the pastors preach too long, "He's preaching too long! He's taking too long!"

Questions asked……	Caregivers’ Responses
5. How did faith community members find out about your care partners’ dementia diagnosis?	“Um, people who have known, uhh, or had known my husband for so long, they noticed, uhh, the change in behavior. The change in dress and those kinds of things. And of course, you know, when he was diagnosed, you know, I did, it wasn't a secret to me, you… You know, people would mention some things and, I would, you know, just tell them, you know, “He's been diagnosed as havin’ Alzheimer's.” So umm to me [*BAR raised her hands in the air]*, you know, it wasn't a secret *[BAR chuckles]*. I just let everybody who, umm, had interest or wanted to know what was going on, what was going on. And, you know, they were very receptive of it and supportive…of it.”
6. What is your faith community doing to help caregivers and their care partners with dementia participate or get involved?	“Currently, we don't have a formal program. And as far as I know, umm, my husband was probably the only person that I know. And we've been in that church - in our church - for a long, long time. Many, many years ,uhh, that umm… Had Alzheimer's had.. was diagnosed as having Alzheimer. But what we are currently doing and, and this is based on experience, experience that I had with my church, I would say that they would support all umm, umm[brief pause] anyone with Alzheimer’s, uh, in whatever way that they need support.”

Questions asked……	Caregivers’ Responses
7. What are some opportunities for your faith community to establish additional support for people living with dementia and their care partners?	“I, um if, if CmC I starts the program, I'm going to go ahead and join in with her on the program there. I know that Brother [ACTS2 recruitment cooridator] works hard with the Council on Aging as well. So, um but if she starts it, I'm going to go ahead and join and see if we can…. COVID has been one of the drawbacks here because a lot of people just… Well, I had COVID and it’s nothing to play with, so, uh, I think that's the drawback now. And we lost a lot of older members because of…. I… OK.”
8. What could your church do to improve the participation of caregivers and their care partners with dementia?	“have like maybe, you know, seminars or, you know, just comin’ together and have lunch and have speakers come in, you know, about umm even just and talk about the ACTS program or talk about, you know, a doctor coming in and talk about, you know, dementia and Alzheimer's… Just educating the people…”

Conclusion

- Analysis of the data we collected is not completed; however, our findings have been insightful in detecting common themes that arised during the discussion

Limitations

- Small sample size
- Population demographics (i.e. gender, religion, location) might indicate that results are not generalizable

Future Studies

- Two other focus groups to complete before proceeding to the analysis: Lay Leaders and Clergy

Acknowledgments

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THANKS!

Any questions?