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## African-American Lay Pastoral Care Facilitators' Perspectives on Dementia Caregiver Education and Training

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## African-American Lay Pastoral Care Facilitators' Perspectives on Dementia Caregiver Education and Training

### Abstract

The African-American Alzheimer's Caregiver Training and Support Project 2 (ACTS 2) is a faith-integrated, skills-training and support program for distressed African American family caregivers of persons living with dementia across Florida. Caregivers participate in a 12-week, telephone-based, skills-building and support program led by faith community workers (i.e., lay pastoral care facilitators) who provide volunteer services to their denominations. In this case study, we examined facilitators' perspectives and recommendations for supplementary audiovisual and written training materials to optimize group process and goal-setting skills. Utilizing a qualitative approach, we explored facilitators' needs, experiences in using current training materials, and recommendations for supplementary education. Data were collected through a telephone-based, focus group interview with nine ACTS 2 facilitators deploying grounded theory techniques. We identified six themes: personal reflections on facilitator roles and responsibilities, satisfaction with existing written materials, desire for supplementary audiovisual training materials, desire for additional training on data management and reporting, importance of peer support, and fostering a faith-integrated culture within the program. Our findings underscore the importance of engaging African American faith communities in fostering dementia caregiving skills training and support. We further highlight the implications of providing community-based training for African American facilitators to foster caregiver emotional well-being and physical health.

### Keywords

African American, caregiving, dementia, education, facilitators, faith, faith community workers, focus group, families

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## **African American Lay Pastoral Care Facilitators' Perspectives on Dementia Caregiver Education and Training**

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The African-American Alzheimer's Caregiver Training and Support Project 2 (ACTS 2) is a faith-integrated, skills-training and support program for distressed African American family caregivers of persons living with dementia across Florida. Caregivers participate in a 12-week, telephone-based, skills-building and support program led by faith community workers (i.e., lay pastoral care facilitators) who provide volunteer services to their denominations. In this case study, we examined facilitators' perspectives and recommendations for supplementary audiovisual and written training materials to optimize group process and goal-setting skills. Utilizing a qualitative approach, we explored facilitators' needs, experiences in using current training materials, and recommendations for supplementary education. Data were collected through a telephone-based, focus group interview with nine ACTS 2 facilitators deploying grounded theory techniques. We identified six themes: personal reflections on facilitator roles and responsibilities, satisfaction with existing written materials, desire for supplementary audiovisual training materials, desire for additional training on data management and reporting, importance of peer support, and fostering a faith-integrated culture within the program. Our findings underscore the importance of engaging African American faith communities in fostering dementia caregiving skills training and support. We further highlight the implications of providing community-based training for African American facilitators to foster caregiver emotional well-being and physical health.

*Keywords:* African American, caregiving, dementia, education, facilitators, faith, faith community workers, focus group, families

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### **Introduction**

Recent research has highlighted the need for family caregivers to receive tailored dementia care education, resources, and support services (Byers et al., 2022; Whitlatch & Orsulic-Jeras, 2018). These studies suggest that family caregivers often experience psychosocial stressors when assisting persons with dementia with activities of daily living (Bannon et al., 2020; Whitlatch & Orsulic-Jeras, 2018). Exposure to such stressors has been shown to increase caregiver burden, depression, poor quality of life, and health risks (Alzheimer's Association, 2021; Connors et al., 2020). Coping strategies and social support have been found to moderate and/or mediate caregiver distress and physical health in family caregivers of persons living with dementia (Chen et al., 2015; Pearlin et al., 1990). However,

dementia caregivers' individual experiences and personal needs vary considerably. In fact, experiences of caregiving for family members living with dementia can differ depending on the caregiver's identities (Cohen-Mansfield, Parpura-Gill, & Golander, 2006), resources (Disbrow et al., 2020), their relationships with care partners with dementia (Park et al., 2019) and others within their families and communities (Bjørge, Sæteren, & Ulstein, 2019).

At the same time, family caregivers of persons living with dementia often lack formal dementia caregiver education, training, and resources (Byers et al., 2022). Prior intervention research has demonstrated that dementia family caregivers who participate in formal dementia education and training programs can improve mental health outcomes, reduce caregiver burden, and improve care for their family members living with dementia (Glueckauf et al., 2012). Tailoring formal dementia education and training programs based on shared identities and lived experiences is especially important to safely and effectively assist dementia family caregivers from underserved communities, particularly African American populations (Glueckauf, 2015). However, research on dementia caregiver education and training programs from the perspective of African American program facilitators is limited. There is a critical need to examine facilitators' needs, skills, and recommendations for improving dementia caregiver education and training programs. Therefore, providing individually-tailored dementia caregiver education and training materials to facilitators of family caregiver training programs is essential in meeting the personal needs of dementia caregivers from underserved communities in health care – such as African American caregivers of family members living with dementia.

Our diverse team of interdisciplinary health care providers and health service researchers, all of whom have lived experience in caring for family members with chronic health conditions, assisted in the design and implementation of the current qualitative case study. The first author lives with multiple chronic health conditions and has direct lived experience with caregiving for a family member experiencing cognitive changes. The second author has participated in the caregiving of multiple family members with chronic illnesses from a young age. The third author lives with multiple chronic health conditions and has direct lived experience with caregiving for multiple relatives experiencing cognitive changes. The fourth author lives with progressive chronic illness and post-traumatic stress themselves, and also has direct lived experience with caregiving for relatives experiencing cognitive changes. The fifth author is a care partner for his spouse with early-stage dementia whose unwavering support has fostered the growth and evolution of the African-American Alzheimer's Caregiver Training and Support Project 2 (ACTS2).

Data were collected through a telephone-based, focus group interview with 9 African-American-Alzheimer's Caregiver Training and Support Project 2 (ACTS 2) African American lay pastoral care facilitators. A semi-structured format was used to inquire about their previous experiences in using existing training materials and their specific needs for supplementary dementia caregiver education and training for themselves as facilitators. Overall, the specific objectives of the study were to (a) determine current strengths of ACTS 2 facilitators' dementia caregiver education and training, (b) identify specific areas for improvement in ACTS 2 facilitators' dementia caregiver education and training, and (c) investigate which types of dementia caregiver training materials and resources would improve the ACTS 2 facilitator trainee program.

## **Background**

### **Dementia Caregiving**

Approximately 6.2 million older adults are living with Alzheimer's disease and related dementias (ADRD) in the United States. This population is expected to more than double to 13.8 million older Americans by 2060 (Alzheimer's Association, 2021). Although dementia

affects people of all racial and ethnic backgrounds, African Americans are at greater risk for developing ADRD (Epps et al., 2018). Specifically, research has shown older African American adults are approximately twice as likely to have ADRD, as compared to their non-Hispanic White counterparts (Alzheimer's Association, 2021). Furthermore, African American caregivers spend more time in daily care activities than their non-Hispanic White counterparts. African American caregivers also are more likely than family caregivers from different racial/ethnic backgrounds to perform the most demanding caregiving tasks, such as bathing and lifting (Fabius, Wolff, & Kasper, 2020; Fredman, Daly, & Lazur, 1995). Furthermore, African American caregivers spend a disproportionately higher percentage of their monthly income on dementia caregivers' needs than their non-Hispanic White counterparts (Rainville, Skufca, & Mehegan, 2016).

Dementia caregiver education and training programs provide dementia care resources skills training, and support for family caregivers of persons living with dementia. Prior research has highlighted the unique benefits and effectiveness of dementia caregiver education and training programs, such as reduced caregiver burden and emotional distress among family caregiver trainees. However, these programs are most effective when they are culturally responsive to the unique needs and experiences of underserved communities in dementia research. Older African American adults living with dementia are underrepresented in clinical intervention research. Underrepresentation in clinical trials stems both from a history of limited engagement of African American participants in clinical trials and an extensive history of medical racism and discrimination against African American communities in the U.S. (Portacolone et al., 2020). Thus, dementia caregiver education and training programs need to be culturally responsive, tailor skills-training, and support interventions to the needs and preferences of African American communities.

Researchers increasingly use narratives of caregiver experience to capture richness and emotion among understudied populations in dementia research (Kazmer et al., 2013; Kazmer et al., 2018). However, there is limited research using narratives of facilitators engaged in dementia caregiver education and training programs for underserved communities (Byers et al., 2022). These narratives about facilitator experiences, personal needs, and recommendations may serve as valuable resources in educating researchers and clinicians (Charmaz, 2000). Following this line of research, the current qualitative study focuses on the evaluation of the training needs of ACTS 2 lay pastoral care facilitators. The results of this qualitative evaluation will be used to enhance the training experiences of future ACTS 2 facilitators as the program expands to the Southeastern region of the United States.

### **Program Mission and Goals**

The primary mission of the ACTS 2 Project is to provide faith-integrated skills-training and support to distressed African American caregivers of family members with dementia across Florida. This caregiver skills-training program has its roots in cognitive-behavioral intervention for depression (see Glueckauf et al., 2009, 2012). ACTS 2 consists of 12 telephone-based, weekly sessions, seven one-hour small groups, and five one-hour, individual caregiver goal setting and implementation sessions. The program includes seven major components: (a) basic characteristics of progressive dementia, (b) relaxation-training integrated with prayer and meditation, (c) effective thinking about the challenges of caregiving coupled with pastoral care messages emphasizing self-care, (d) building in pleasant, daily activities as a guard against emotional distress (e.g., chatting with valued friends, taking brief prayer breaks, and listening to inspirational music), (e) communicating assertively with family members and health professionals, (f) developing effective problem-solving skills through goal setting, goal implementation, and daily monitoring, and (g) building a social support network.

Participating in the ACTS 2 Project is free of charge and participants receive up to \$90 for providing feedback on the effectiveness of the program (ACTS 2 Project, 2022; Glueckauf, 2015; Scarlett & Glueckauf, 2017; Walker & Glueckauf, 2016). Further, the skills-training intervention is updated annually using feedback from current research, family caregiver trainee evaluations, attendee evaluations from community outreach events, the coordinating and oversight teams, and lay pastoral care facilitator trainee evaluations. Other key foci of ACTS 2 are a statewide outreach effort to raise awareness about dementia through virtual and community-based presentations (reaching over 8,000 people annually) and to provide telephone consultations and community referrals. Due to the COVID-19 pandemic, the ACTS 2 Project also has delivered monthly Facebook Live workshops for African American caregivers, elder care advocates, and other stakeholders throughout Florida (ACTS 2 Project, 2022).

### **Program Format and Content**

Dementia family caregivers who enroll in the ACTS 2 Project participate in a 12-week, telephone-based, skills-building and peer support program covering various topics of dementia caregiver education, such as relaxation, effective thinking, and problem-solving skills (Kazmer et al., 2018). Utilizing a hybrid model of caregiver training, seven of the 12 telephone-based sessions are conducted in a small group of three family caregivers and a lay pastoral care facilitator, while the other five sessions are one-on-one sessions with each caregiver and their assigned facilitator, focusing on the family caregiver's self-identified goals.

Each caregiver receives an evidence-based, training guidebook that covers important topics on dementia caregiving education and skills, such as information on dementia and dementia care, relaxation, effective thinking, and problem-solving techniques. Additionally, delivery of the contents of the training guidebook is integrated with faith sharing, prayer, and inspirational readings (ACTS 2 Project, 2022). Thus, the ACTS 2 Project is tailored to center, affirm, and amplify the voices of African American family caregivers of persons living with dementia from a faith and cultural perspective. The knowledge and skills that dementia caregivers acquire during the program seek to improve their psychosocial and physical well-being.

### **Trained Facilitators**

ACTS 2 training sessions for dementia family caregivers are led by trained, lay pastoral care facilitators from African American faith communities across Florida. As noted previously, lay pastoral care facilitators are faith community workers who provide direct care and peer-support services to their local congregations and communities. Recruitment of ACTS 2 lay pastoral care facilitators is primarily through referrals from faith community leaders, including clergy and lay leaders, as well as self-nomination. Some facilitators were former participants of the ACTS 2 Project's family caregiver training program. Facilitators receive 30 hours of training, including a two-day (i.e., 16 hours) training workshop, followed by seven two-hour, telephone-based practice sessions. Training topics include general information on memory disorders, relaxation techniques, effective thinking, increasing emotional well-being, assertive responding to care partners with dementia, challenging situations involving care partners with dementia, and problem-solving skills. Furthermore, ACTS 2 facilitators receive weekly consultation from ACTS 2 staff-licensed providers (e.g., licensed clinical psychologists) during their delivery of the program.

Although all lay pastoral care facilitators were provided comprehensive introductory training, they did not receive ancillary education materials to optimize their skills in delivering

the ACTS 2 12-session program, such as videos of relaxation-training methods, taking a caregiver's problem history, and effective group facilitation. Thus, the primary objective of the current study was to obtain ACT 2 facilitators' perspectives on supplementary audiovisual (e.g., DVDs) and written (e.g., facilitator handbook) training materials regarding dementia caregiving and dementia care resources to better assist them in serving family caregiver trainees. This evaluation examining facilitators' needs, recommendations, and experiences in seeking and using supplementary training materials may benefit other dementia caregiver education and training programs serving racial and ethnic minority communities in the U.S. Providing supplementary training materials, resources, and support to facilitators – based on their unique needs and recommendations – may better equip them in helping dementia caregivers to practice self-care, achieve their personal goals, and navigate challenging caregiving situations involving family care partners with dementia.

## **Methods**

### **Study Design**

Drawing on prior research of inductive, qualitative methods (Charmaz, 2006), we used an exploratory, qualitative approach to examine lay pastoral care facilitators' perceptions of the breadth of coverage and usefulness of existing dementia caregiver education and training materials from the ACTS 2 Project. Because we were interested in achieving rich descriptions of facilitators' strengths, weaknesses, and recommendations with dementia caregiver education and training, a qualitative approach was the method of choice for this proposed study (Nowakowski & Sumerau, 2019). Specifically, integrating facilitator narratives into dementia research through qualitative approaches can transform dementia caregiver education and training programs while creating opportunities to fill existing gaps at these intersections of scholarship (Charmaz 2006). In addition, we queried facilitators about supplementary training materials and resources that could benefit them and their family caregiver trainees. Data for this study were drawn from a telephone-based, semi-structured, focus group interview with nine African American lay pastoral care facilitators from the ACTS 2 Project living in North and Central Florida. We chose a focus group approach to interview facilitators because of its efficiency and synergistic opportunities emerging from exposure to different perspectives and lived experiences.

Our research team had four specific aims for the focus group interview in conducting this qualitative study: (1) to identify existing training materials that have been most helpful to facilitators and aspects of their training that may have been improved through access to additional resources, (2) to identify which formats (e.g., web, CD, DVD, booklet) would be most helpful for resources to supplement facilitator training and what topic areas these resources should cover, (3) to explain which aspects of facilitators' program delivery need refinement using additional training resources, and (4) to discuss which types of materials would improve skills-training of caregivers in the ACTS 2 Project. No specific hypotheses were tested in this study.

Using an interview instrument, we asked facilitators about the strengths and limitations of their existing training materials, training sessions, and assistance with program delivery, as well as other pertinent information about their training program. We also probed for in-depth knowledge regarding which formats, topic areas, and activities would be most helpful for facilitators as resources to supplement their training and further support their family caregiver trainees. Furthermore, the use of multiple item probes afforded facilitators ample opportunities to share their thoughts during the focus group.

The third author led the focus group, using the interview instrument to guide the discussion and asking follow-up questions to engender conversations among facilitators. The

second and fifth authors also attended the focus group interview and listened carefully to facilitators' perspectives and recommendations while also taking notes. We also audio-recorded the focus group interview, which was subsequently transcribed verbatim by the first author and was later fidelity-checked by the second, fourth, and fifth authors for accuracy.

### Recruitment and Participation

We identified 14 lay pastoral care facilitators who met our inclusion criteria (i.e., completion of the ACTS 2 Project's lay pastoral care facilitators program and led at least one 12-session training program with dementia family caregivers). The third author contacted facilitators who met these criteria by email and/or telephone. Of the original pool of 14 facilitators, 12 facilitators agreed to volunteer for the study. Nine of 12 facilitators participated in the focus group; three dropped out due to scheduling conflicts. The two-hour focus group interview was conducted in November 2019. Upon completion, each facilitator received a \$50 honorarium for their participation in the study.

The nine focus group participants varied in years of experience as a facilitator and prior ministry experience. Facilitator demographic characteristics are located in Table 1.

**Table 1: ACTS 2 Facilitator Demographic Characteristics ( $N = 9$ )**

Broad Demographic Category	Specific Demographic Identification	Number of Facilitators	Percentage of Facilitators
Race	African American*	9	100.0%
Sex	Female*	8	88.9%
	Male	1	11.1%
Years of Age	30-39	1	11.1%
	40-49	0	0.0%
	50-59	3	33.3%
	60-69*	4	44.5%
	70-79	1	11.1%
Years of Formal Education	12-13	1	11.1%
	14-15	1	11.1%
	16-17*	5	55.6%
	18-19	2	22.2%
	Years in Faith Ministry	10-14*	3
	15-20	2	22.2%
	Not Reported	4	44.5%

\* Modal category for each demographic measure

Given the small sample size in our study and the unique features of our program, we protected confidentiality by (1) de-identifying all personally identifiable information during interview transcription and fidelity-checking processes, (2) obtaining informed consent verbally during the focus group interview rather than collecting written documentation of informed consent, and (3) storing study files and the interview transcript using password-protected, data storage with no personally identifiable information in the filename. The focus group interview was audio-recorded with facilitators' permission beforehand. This study was approved by the Florida State University Institutional Review Board.



## **Data Collection**

Qualitative data were collected using the focus group interview with nine African American lay pastoral care facilitators from North and Central Florida. The focus group was 110 minutes in duration and was conducted via telephone. Following established best practices for grounded theory data collection approaches (Charmaz, 2006), our interview instrument was developed collectively by our research team to ensure questions were clear, affirming, and insightful. Informed consent was given by facilitators during study enrollment via email and before the focus group interview verbally. The third author facilitated the focus group interview, using the interview script shown above. The recorded focus group interview was transcribed verbatim by the first author and then its fidelity was checked by the fourth and fifth authors to ensure accuracy.

The proceedings of the focus group closely followed the structure of the interview instrument. Note that facilitators and research team members started and ended the focus group discussion in prayer. Since the ACTS 2 Project uses a faith-integrated approach in program delivery, facilitators often start and end each of their caregiver training sessions and meetings in prayer. To meaningfully serve caregivers in African American faith communities across Florida, the ACTS Project maintains a faith-integrated culture within training sessions, community outreach events, and other program activities. Therefore, prayer before and after the focus group interview was very important for our study to further center the program mission and goals of the ACTS 2 Project.

## **Data Analysis**

Data analysis squarely focused on interpreting facilitators' descriptions of their personal needs, perspectives, and recommendations for supplementary audiovisual and written training materials on dementia caregiving and dementia care resources. Specifically, data were coded using NVivo (Release 1.3) software. This qualitative software application helps users organize, analyze, and share research findings from qualitative and mixed-methods data (QSR International, 2020). Data were analyzed inductively by the research team through grounded theory analysis (Charmaz, 2006), whereby a coding scheme consisting of sets of networked codes was developed from the data. Developed categories and themes were reviewed throughout both data collection and analysis to discern emergent patterns and connections.

Our research team first engaged in initial or open coding, wherein we read the interview transcript to develop a general sense of the data and generated an initial list of codes. Subsequently, the first author engaged in focused or thematic coding, which involves the identification of coding overlaps and divergences, followed by combining and collapsing open codes to form broader thematic codes/themes. Lastly, the first author engaged in axial coding, whereby social and demographic attributes in the dataset (such as facilitators' relationships with care partners with dementia, geographic residence, etc.) were linked to specific codes and themes, providing information about patterns among and between sub-groups of facilitators who participated in the focus group interview. Codes and the relationships among them were then analyzed by the rest of the research team for qualitative data analysis accuracy and reliability.

We then shared our findings with facilitators who participated in the focus group interview to give them the opportunity to provide additional feedback or add information that would further inform our research findings. Using detailed notes from our research team's analysis of the focus group interview transcript, the recurring themes, and the existing literature, we reflected analytically on our central research question: "What are ACTS 2

African American lay pastoral care facilitators' strengths, weaknesses, and recommendations for continuing dementia caregiver education and training?"

## Results

In reviewing and analyzing these data, we revisited our central research question, "What are African American lay pastoral care facilitators' strengths, weaknesses, and recommendations for continuing dementia caregiver education and training?" We identified six key themes related to facilitators' perspectives for program activities that spoke to this primary question. First, facilitators emphasized the importance of their roles and responsibilities in seeking and utilizing supplementary dementia caregiver education and training materials. Second, most facilitators expressed considerable satisfaction with existing written training materials received from the ACTS 2 Project during their training program. Third, facilitators noted the importance of including supplementary audiovisual training materials in the project's lay pastoral care facilitators training program. Fourth, several facilitators underscored the need for additional training on data management and reporting. Fifth, nearly all participating facilitators described the importance of creating and maintaining peer support services (i.e., support provided by facilitators to caregivers and facilitators to one another) within the ACTS 2 program. Sixth, facilitators appreciated how ACTS 2 staff trainers nurtured a faith-integrated culture within the facilitator training program, incorporating scriptures, prayers, references, and meditation exercises from existing ACTS 2 training materials.

### Theme 1: Personal Reflections of Facilitators' Roles and Responsibilities

Respondents heavily relied on their personal reflections of facilitators' roles and responsibilities when finding supplemental training materials and resources. When discussing their experiences in seeking and incorporating supplementary training materials on dementia caregiver education and care resources, most respondents reflected on the roles and responsibilities of a lay pastoral care facilitator. Some facilitators noted they obtained additional training materials to enhance their understanding of dementia knowledge and care approaches, and in turn, to boost their confidence in collaborating with family caregivers about difficult caregiving situations. Some examples of training materials that were obtained by facilitators included video documentaries, toll-free phone numbers to local, state, and national organizations dedicated to dementia caregivers, and memoirs written by former dementia caregivers. Others identified dementia care resources for caregivers to use in goal implementation, such as books or cell phone apps that offer daily notifications with spiritual scriptures and poems.

Facilitator experience played a major role in respondents' personal reflections of facilitators' roles and responsibilities. Facilitators' perceptions of their caregiver training roles and responsibilities varied by years of facilitator experience, professional backgrounds, and their caregivers' personal needs. Facilitators with more experience in conducting groups tended to more clearly articulate participants' personal needs and the types of training materials from which the latter would benefit. One respondent with substantial program experience noted that "ACTS 2 helped [her] to be able to help [caregivers] because they were going through some denial periods and not understanding that they really did need to take some action on what was happening with their loved ones [living with dementia], as well as what they need to do for themselves. So, both parts of the training that helped [facilitators] identify [caregiver needs] and then to assist the caregiver were most unique and most helpful." This respondent assessed facilitator roles and responsibilities within the ACTS 2 Project, elaborating on how she

pinpoints family caregivers' unique needs to guide her actions in supporting them during skills-building training activities. Overall, facilitators in this study emphasized how influential the ACTS 2 primary training materials have been in enhancing their skills, expertise, and communication with family caregivers about challenging caregiving situations and dementia care resources.

When offering personal reflections about facilitators' roles and responsibilities, facilitators' personal caregiving experiences offered instrumental knowledge and support to dementia family caregivers. Facilitators with personal caregiving experience were also more likely to take active roles in educating caregivers and others outside the program about the characteristics, assessment, and treatment of the dementias and strategies for enhancing the quality of dementia caregiving experience. One respondent explained that they have been a caregiver for over two decades and are still "learning something [about dementia caregiving] each time and all the time," primarily as a result of friends seeking their advice about caring for their family members who live with dementia. Another respondent stated that incorporating supplementary training materials into their facilitator training "helped [them] gain confidence [in] being able to discuss challenging behaviors some dementia caregivers experienced with their loved ones." Overall, respondents reflected on prior caregiving experiences and strategies for optimizing their facilitator roles and responsibilities in conducting skills-building and support groups for dementia family caregivers. Furthermore, they were able to more effectively articulate their perspectives in identifying and using supplementary training materials for their own development or the benefit of groups participants.

## **Theme 2: Satisfaction with Existing Written Materials**

Although respondents differed in their approaches to facilitating and supporting their family caregiver trainees, they showed substantial appreciation and satisfaction with existing written materials provided by the ACTS 2 Project. For example, facilitators described the written training materials they received overall as "adequate," "very detailed," "great," "excellent," "very easy to follow," "well broken down," "interactive," and "helpful" for them and their family caregiver trainees. They also expressed appreciation and satisfaction with the ACTS 2 Project lay pastoral care facilitator manual. The ACTS 2 Project lay pastoral care facilitator manual covers (1) the basics of dementia, (2) relaxation techniques for family caregivers, (3) effective thinking strategies for family caregivers, (4) strategies to increase family caregivers' emotional well-being, (5) assertive responding techniques for family caregivers, and (6) solving challenging situations with family care partners with dementia. Facilitators emphasized elements of the handbook that were particularly informative, including Session 1 on the basics of dementia, Session 6 on enhancing skills in managing difficult caregiving situations, Sessions 7 and 8 on setting personal caregiving and self-care goals, and handbook appendices with available local, state, and national resources for caregivers to use at no cost.

About half of the facilitators emphasized the importance of ACTS 2 program partners (i.e., supervisors) offering detailed feedback, peer support, and answers to facilitator trainee questions. When referring to the written training materials, most facilitators mentioned detailed accounts of "following the script" or "role-playing" parts of preliminary training sessions where facilitators "read the material prior and following the script [problem-solving exercise] and letting the group interact with the training." Some facilitators noted that completing problem-solving exercises using such approaches gave them the confidence to practice problem-solving skills with their caregiver trainees while having their facilitator program trainers "interject if... they need to give [them] some pointers to really bring out the point of view." Facilitators also noted how the manual provided knowledge on dementia and more

specifically the different stages of Alzheimer's disease, which made this information "very easy to understand" and "easier for [facilitators] to deliver the materials to the caregivers." Overall, facilitators described the ACTS 2 Project lay pastoral care facilitator manual as a helpful, user-friendly, and valuable resource when offering feedback on existing training materials from the ACTS 2 Project.

### **Theme 3: Desire for Supplementary Audiovisual Training Materials**

Facilitators conveyed the need to include supplementary, audiovisual training materials during their preliminary training program. As a group, respondents noted the importance of offering supplementary audiovisual training materials on dementia symptoms, different types of dementia, and providing care to older adults living with dementia. Almost all respondents noted how helpful it would be to have accessible videos on platforms (e.g., YouTube) to reference and use when facilitating caregiver training sessions. Specifically, one respondent noted that she has seen multiple Netflix documentaries on dementia, which "assisted [her] in learning, ... gaining confidence, and conducting the group [caregiver training sessions]." Another facilitator referenced how movies on Alzheimer's disease strengthened her caregiving practices by fostering a better understanding of caring for a loved one with dementia. Others focused on their preferred video content or topics. For example, one facilitator desired videos containing "a synopsis or summary of what had happened with that particular individual [caregiver] and then how the facilitator helps the individual [caregiver] come to their goals." This recommendation led to another facilitator requesting a video that helps caregivers use assertive language when interacting with their care partners with dementia.

Most facilitators sought ongoing training opportunities that help them to apply the knowledge and skills they learned from primary and supplementary training materials, such as participating in session activities that include role-playing situations between facilitators who act out caregivers' interactions with their care partners with dementia. One respondent mentioned that incorporating existing videos or creating specialized training videos in future facilitator training opportunities would "give [them] more information and build confidence prior to having a group." This respondent further described the benefits of reviewing these audiovisual materials in the process of helping their caregiver trainees during training sessions. The majority of facilitators also preferred reviewing audiovisual training materials compared to materials in a written format when describing their approaches to learning program content. However, almost all facilitators found the ACTS 2 training manual to be very informative and useful when challenges arise within training sessions. Overall, facilitators emphasized the usefulness of referring to the training handbook during caregiver sessions, while suggesting the incorporation of supplementary audiovisual training materials to further enhance their knowledge and skills on program content.

### **Theme 4: Desire for Additional Training on Data Management and Reporting**

Several facilitators mentioned the desire for additional training on data management and reporting. They emphasized the importance of skill in negotiating the program database, documenting participant data, and reporting results to program leaders and funders. Some facilitators gave detailed accounts of the significance of identifying and documenting measurable goals for each family caregiver trainee. By contrast, others noted receiving limited opportunities in understanding the importance of program evaluation data and providing guidance for high-quality strategies with managing and reporting program data. One respondent who recalled prior facilitator training sessions emphasized how they "needed a more thorough methodology to show [facilitators] what [is] actually needed and how [program

leadership] needed it.” This facilitator described their own challenges with managing and reporting program data while emphasizing the need for additional training on data management and reporting. Other facilitators mentioned technological challenges in initiating and terminating audio recordings of their telephone-based, caregiver training sessions but noted that they would typically solve these issues with the assistance of the program director (the fifth author), program coordinator (the third author), or among themselves. Finally, some facilitators said they needed training materials describing how they can help caregivers develop and assess goals that are both person-centered and achievable within the time frame of the training program.

### **Theme 5: Importance of Peer Support**

Although respondents’ specific perspectives in facilitating caregiver training sessions varied by group experience, professional backgrounds, and caregivers’ personal needs, nearly all facilitators described the importance of creating and maintaining support from other facilitators in the program. Some facilitators contacted co-facilitator trainees from their specific training groups for assistance when faced with challenging situations, in addition to identifying supplementary training materials. Other facilitators explicitly mentioned the importance of calling and getting information from project supervisors (i.e., partners) to guide them during the actual intervention program. Additionally, one facilitator noted that they “still keep in contact with some members of some of the [family caregiver] groups,” especially during the holiday season, to “check on them to find out how they’re doing and what’s happening in their lives.” They specifically emphasized the importance of support among caregiver trainees and how building and maintaining relationships with each other provided an affirming space for caregivers to benefit maximally from participating in the program.

When asked about how the program could provide support for facilitators, some respondents suggested creating a telephone-based, peer support program among facilitators who volunteer to assist other facilitators when faced with challenging situations or when they would like additional support. One respondent noted that such peer support services could be moderated through an open session via telephone for whoever would like to talk to other facilitators “about challenges and things [facilitators] want to get out or issues or anything.” Another facilitator suggested “involving facilitators in the training of new facilitators,” which could be particularly beneficial as another source of peer support for less experienced facilitators or facilitator trainees. Likewise, nearly all respondents expressed the value of having opportunities to build peer support and meaningful relationships with other facilitators, caregiver trainees, and project supervisors within the ACTS 2 Project.

### **Theme 6: Fostering a Faith-Integrated Culture**

Facilitators noted an abiding presence and importance of a faith-integrated culture within the ACTS 2 Project. Respondents frequently incorporated pastoral care practices, such as prayer, spiritual scripture, faith-sharing, and meditation, in facilitating the 12-session skills-building and support program. Some facilitators shared inspirational Bible verses or poetry with caregivers who were dealing with challenging caregiving situations. One respondent viewed her facilitator role and responsibilities as a conduit for serving her community and being a blessing to others. She specifically mentioned “pray[ing] to God [to] be of convenience [to help others] and [she] just want[s] to continue [to] be able to be a blessing.”

Some participating facilitators described challenges related to providing a non-judgmental environment for caregivers from different faith traditions or those without a faith orientation and how supplementary training materials on this topic would be beneficial. One

respondent openly acknowledged their discomfort when communicating with caregivers about faith-integrated program content: “There are different types of religions, so talking about their faith to take the faith walk... I got to get comfortable with that, ‘cause different [family caregivers] have different beliefs, [so] be careful what you say, so you won’t offend no one.” This respondent was concerned about offending caregivers with faith beliefs and practices different from their own, while delivering a faith-integrated dementia caregiver education and training program. Thus, facilitators suggested supplementary training materials to enhance their knowledge in working with dementia family caregivers from different faith traditions and practices, further supporting their therapeutic role.

## Discussion

Interviewing nine African American lay pastoral care facilitators with a broad range of group leadership and caregiver experience, professional backgrounds, and learning styles provided a rich medium for examining facilitators’ perspectives on supplementary dementia caregiver training materials and program delivery. Specifically, we were able to capture useful feedback on existing training materials and suggestions to improve ACTS 2 facilitator training programs such as adding (a) supplementary audiovisual training materials, (b) training on data management and reporting, (c) formal peer support services, and (d) program content on providing a non-judgmental approach with caregivers from different faith traditions or those without a faith orientation in the facilitator training program.

Many facilitators specifically mentioned that their pre-caregiver group intervention skills in completing program evaluation duties and data entry tasks were somewhat limited. However, they recognized that “it comes down to the actual evaluation of the program” to ascertain such skills, as well as reporting to partners and funders. Recommendations about how the program data should be utilized among facilitators and the project consultants varied across respondents; these responses often centered on documenting caregivers’ improvement on specific goals throughout the family caregiver program.

Overall, the ACTS 2 Project’s faith-integrated culture has exerted a positive impact on recruiting and maintaining a cadre of African American facilitators. Focus group participants, for example, have been ACTS 2 facilitators for an average of four to five years. We are continuing to foster a faith-integrated culture within the program, while centering the voices of African American family caregivers of persons living with dementia from a faith perspective. We also have identified ways to address how these research findings may impact future iterations of the ACTS 2 Program. We are in the process of creating supplementary audiovisual training materials on dementia caregiver education and training topics that will center the experiences of African American caregivers. Some examples include (1) creating audiovisual recordings of role plays on conducting brief histories and behavioral analyses of specific caregiving problems and (2) providing access to video-recorded presentations on managing stressful caregiving problems, such as refusing to bathe or to take medications, and accessing day care services for loved ones with dementia.

The current investigation has several notable strengths. The third and fifth authors’ strong ties with lay pastoral care facilitators from the ACTS 2 Project helped to encourage participation and rich dialogue during the focus group interview. We engaged facilitators with differing perceptions of their roles and responsibilities as lay pastoral care facilitators. These perceptions may have influenced facilitators’ reported needs in seeking and utilizing supplementary training materials on dementia caregiver education and care resources, such as pinpointing supplementary training materials that would be most beneficial for facilitators in the early stages of their training program. Additionally, the effectiveness of the interview schedule in soliciting future directions in developing supplementary materials was an important

strength in our study. By using a comprehensive interview schedule tailored to the ACTS 2 facilitators training program, we were able to clearly identify facilitators' existing strengths and needs, as well as opportunities to enhance their knowledge and skills within the program.

Our study also had several limitations. Although we engaged African American lay pastoral care facilitators with a broad range of group experience, professional backgrounds, and knowledge about their caregivers' personal needs, it is unclear whether the results of this study can be generalized to other underrepresented communities in dementia caregiver research. The primary emphasis of the study was to garner information about the continuing education needs of African American lay pastoral care facilitators participating in the ACTS 2 Project. However, the findings may help guide the dementia care training efforts of African American faith communities in the Southeastern U.S. region with program missions and goals similar to those of the ACTS 2 Project.

Our results highlight the incremental benefits of implementing faith-integrated elements in dementia caregiver education and training for African American communities. This study highlights the importance of examining African American lay pastoral care facilitators' strengths, challenges, and recommendations in improving dementia caregiver education and training programs for African American caregivers of family members living with dementia. Such assessment helps researchers further understand how African American family caregivers manage psychosocial stressors through the use of dementia caregiver intervention research.

Despite the similarities in facilitators' needs, recommendations, and experiences in seeking and using supplementary training materials, we have cautioned against generalizing our research findings across other underserved minority communities. Rather, we encourage researchers and clinicians to think about how these findings might be similar or different when tailoring dementia caregiver education and care resources for dementia caregivers in the communities they serve. Additionally, we ask researchers and clinicians to consider the implications of such differences and similarities in improving community-based intervention research on dementia family caregivers, and more specifically, delivery of outreach services to African American family care partners with dementia, care partners, and faith-based communities.

We recommend researchers and clinicians actively engage the expertise and support of African American faith community workers, judicatory leaders, and faith-based organizations in performing caregiver intervention research in the Black community. Maintaining transparency, accountability, and rich conversations within intervention research among both trainees in and facilitators of dementia family caregiver training programs offers rich opportunities to help reduce caregiver burden and cumulative health risks among African American communities. Additionally, researchers and clinicians can use our research findings to help tailor their own training materials on dementia caregiver education and care resources for African American caregivers of family members living with dementia. We plan to incorporate the findings of the current investigation in training new facilitators in the Orlando and Tampa-Bay areas of Florida. The development of supplementary training tools will aid in future iterations of ACTS 2. They will enhance the effectiveness of implementation and dissemination of ACTS 2 programs in subsequent expansion efforts to South Florida and the Southeastern region of the U.S.

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