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Analysis of Group Session Processes in a Faith-Based Cognitive-Behavioral Intervention for African-American Caregivers

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ANALYSIS OF GROUP SESSION PROCESSES IN A FAITH-BASED COGNITIVE-
BEHAVIORAL INTERVENTION FOR AFRICAN-AMERICAN DEMENTIA CAREGIVERS

By

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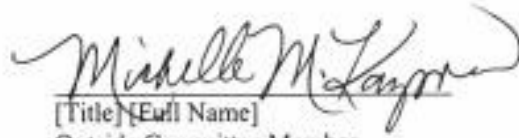
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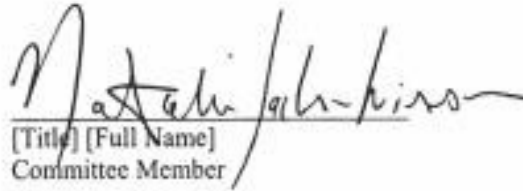
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Abstract

Most adults with dementia (80%) are cared for in the home by family members referred to as caregivers. The proportion of primary family caregivers is highest in minority communities, especially African Americans. The demands of caring for a family member with dementia are typically high and have been found to lead to depression and health-related problems (e.g., new hypertension). Although several studies have shown cognitive-behavioral intervention leads to reduction of emotional distress in dementia caregivers, results are inconsistent in the treatment of depressive symptoms in the African-American dementia caregiver population. Lack of cultural sensitivity and same culture providers potentially may account for diminished efficacy of cognitive-behavioral intervention in this minority group. In the present study, participants were interviewed to provide feedback on their in-session experiences of the ACTS 2 program. A qualitative analysis of caregivers' responses were conducted to assess the group session processes. The responses were used to assess: (a) caregivers' appraisals of the quality of interactions among their peers; (b) caregivers' appraisals of the consequences of group skills training; and (c) caregivers' perceptions of the effectiveness of facilitators during ACTS 2 group based sessions. Caregivers' appraisals of these group process domains suggested the tailoring of group processes led to positive perceptions of sensitivity to cultural and spiritual values, created a sense of unity among participants and provided useful caregiving skills. Negative appraisals were case specific and were not reflective of the findings of the group as a whole. Future direction for research on group process with depressed African-American dementia caregivers are addressed.

Keywords: Alzheimer's, dementia, cognitive behavioral intervention, African-American, caregiving, caregiver, facilitator, depression, stress, burden, faith, goals, self-care, skills

Introduction

Alzheimer's disease and related dementias affect an estimated 5.2 million Americans, 5 million of which are over the age of 65 (Alzheimer's Association, 2017). The prevalence of this disease has been shown to occur twice as often in African Americans than in non-Hispanic Whites (Alzheimer's Association, 2017). Certain health conditions, such as diabetes mellitus and hypertension, have been shown to contribute significantly to the higher rate of dementia in African Americans (Alzheimer's Association, 2017). The disease is progressive and overtime, persons with the condition experience a significant loss in their ability to perform basic activities of daily living, such as eating, dressing and bathing. Eventually, they forget who their loved ones are and ultimately require full-time care (Alzheimer's Association, 2017).

Most adults with dementia (80%) are cared for in the home by family members. Caring for a family member with dementia can be very stressful and may have a significantly negative impact on the emotional and psychosocial functioning of the caregiver (Belle et al., 2006). This is explicated in Pearlin, Mullan, Semple and Skaff (1990) Stress Process model. Pearlin and colleagues theorized caregiving stressors and demands are mediated by caregiver appraisals, which when focused on subjective burden, may lead to compromised emotional and physical health. The time commitment and physical demands put on caregivers may lead to higher levels of stress and perceived burden, and eventually poorer health than age and sex-matched non-caregivers (Chappell, Dujela, & Smith, 2015). Caregiver burden is often associated with health-related problems, including more visits to the doctor, immune dysfunction, burnout, and heightened mortality rate (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995).

Dementia caregivers are also at a greater risk in developing mental health conditions, such as depression (Schulz, O'Brien, Bookwala, & Fleissner, 1995). Depression among

caregivers is a major concern as their physical and psychological stamina is depleted overtime, compromising their psychological and physical health (Richard Schulz & Williamson, 1991). Prevalence rates of clinically diagnosable depression in dementia caregivers were found to range from 27% to 50% (Ory, Yee, Tennstedt, & Schulz, 2000).

Approximately 80% of adults with dementia receive ongoing in-home care and support from family members (Alzheimer's Association & National Alliance for Caregiving, 2004). This may be due to reductions in federal and state health care funding, as well as sociocultural factors related to the care of older family members, especially in the African-American population (Mark, 2016). In addition, some studies have suggested increased length of time persons with dementia remain in the home setting, the greater their life span, whereas institutionalization doubles the risk of mortality in patients with dementia (Aneshensel, Pearlin, Levy-Storms, & Schuler, 2000).

Although caring for a family member with dementia is common across all races and ethnicities, African Americans with dementia rely on family caregiver assistance more than non-Hispanic White individuals with dementia (Napoles, Chadiha, Eversley, & Moreno-John, 2010). The difference in caregiver reliance is attributed to strong adherence to cultural values, particularly care for the elderly in the African-American community (Pinquart & Sorensen, 2005). Research has shown African-American caregivers spend 30 hours per week caregiving compared to non-Hispanic White caregivers who spend 20 hours per week caregiving (Alzheimer's Association, 2017). African-American caregivers also reported higher levels of emotional burden and increased physical symptoms associated with distress than their non-Hispanic White counterparts.

As a result of the negative emotional functioning and health consequences of caregiving, cognitive-behavioral interventions have been used to improve the emotional and psychosocial functioning of dementia caregivers (Mark, 2016). Cognitive-behavioral intervention outcome studies for ethnically diverse caregivers of older adults with dementia have found greater improvements in caregiving burden, self-efficacy, and upset with care recipient difficult behaviors as compared to minimal education control conditions. However, mixed results were obtained on the key outcome of reduction in depressive affect. For example, in a six-month intervention with 12 in-home and telephone sessions targeted to address depression, burden, self-care and social support, Belle et al. (2006) found reduced clinical depression and an improvement in quality of life for African-American caregivers. In contrast, in a 12 month intervention lead by Burgio, Stevens, Guy, Roth, and Haley (2003), designed to aid in behavior management, problem solving, and cognitive restructuring, found no significant changes in depression for African-American caregivers as compared to non-Hispanic White caregivers who showed pre- to post-treatment improvement (Burgio, Stevens, Guy, Roth, & Haley, 2003). One possible explanation for the differences in the results found in Belle's research was their use of a tailored intervention. Positive effects on depression were associated primarily with studies that tailored cognitive-behavioral to the socio-cultural characteristics and preferences of minority caregivers.

Although the federal government has called for interventions to limit adverse health effects in dementia caregivers, a significant disparity exists between caregiver needs and the availability of intervention services (Glueckauf et al., 2012). Lack of cultural sensitivity, transportation difficulties, and financial restrictions have thwarted access to and uptake of

empirically-validated, depression-reduction intervention, especially for African-Americans family caregivers.

African-American caregivers have access to fewer resources, acquire fewer years of formal education, have lower household incomes, and are less likely to receive mental health services (Pinquart & Sorensen, 2005). Furthermore, these programs are predominately located at health care facilities in large metropolitan areas requiring caregivers to travel (Glueckauf et al., 2012). It is shown that because of the high cost of travel and attendant loss of wages caregivers do not access mental health services. Furthermore, mental health services tend to be delivered using providers, service delivery methods, and intervention strategies discordant with the sociocultural characteristics and religious preferences of African-American caregivers.

Glueckauf's (2014) Alzheimer's Caregiving Training and Support 2 (ACTS 2) project was developed to offset the limitations faced by African Americans. ACTS 2 is a faith-based cognitive-behavioral intervention program that includes twelve weekly sessions on various topics designed to provide caregivers with the necessary skills and support to serve as caregivers and mitigate depression. ACTS 2 primary aims are to improve the depression and health status of African-American dementia caregivers and to facilitate the development of skills to cope with the stress and burden of caregiving.

Note that programs with caregiving interventions similar to that of ACTS 2 telephone-based intervention (Glueckauf, 2014) have reported that emotional support, education, problem solving, and skills training delivered through a collaborative care model have favorable outcomes for caregivers in terms of responding to the stresses of caregiving, emotion management, and effective responding to the care recipient's symptoms of dementia (Mavandadi, Wright, Graydon, Oslin, Wray, 2017). However, no published data were provided

on the group processes. However, a recent study (Brune et al., 2016) indicated that connection, sharing, learning from other's experience and advice, and support, may have led to positive appraisal of the group processes. These findings were largely global in nature and did not focus on specific group processes that led to positive perceptions of the quality of group interactions. Noting this significant shortcoming, Mavandadi et al. (2017) suggested future studies incorporate qualitative analytic procedures to determine which components of the group processes may serve as important predictors of positive intervention outcomes.

Thus, the three primary aims of the study were to assess: (a) caregivers' appraisals of the overall quality of peer interactions during ACTS 2 groups and the specific factors influencing their perceptions of the quality of interactions; (b) caregivers' appraisals of the consequences of group skills training on their daily caregiving and self-care activities; and (c) caregivers' appraisals of the factors contributing to facilitator effectiveness.

Method

Participants

Caregivers. Twelve African-American caregivers participated in the pilot study of ACTS2. The ACTS 2 randomized clinical trial (RCT) is currently in process. For the purposes of this study, the semi-structured interview responses of twelve African-American participants from the RCT were analyzed in addition to those of ACTS 2 pilot study. 19 CGs were women and 5 were men. The relationships of the CGs with their dementia care recipient were as follows: (a) daughter (n = 9), son (n = 4), spouse (n = 8), granddaughter (n = 1), and niece (n = 2). Participants in both Tallahassee and Jacksonville were randomly assigned by region to one of 7 lay pastoral care facilitators. Each group consisted originally of four members, three CGs and one facilitator. However, 2 caregivers dropped from the study after assignment to treatment. The first

Tallahassee CG dropped after the 4th session and a second dropped after the 6th session, both as a result of unanticipated additional family caregiving obligations. The Jacksonville CG dropped prior to the first session as a result of acquiring a new job.

Care recipients. All 24 care recipients with dementia were African Americans, 12 from the ACTS 2 pilot study and 12 from the ACTS 2 Randomized Clinical Trial. All care recipients were a minimum of 60 years of age. Data were not specifically collected from the care recipients via semi-structured interviews. However, care recipients were mentioned in the interviews.

Facilitators. Seven facilitators were African Americans. In the ACTS 2 pilot study, three were female and one was male. Four facilitators initially agreed to participate in the ACTS 2 pilot study. One Tallahassee female facilitator withdrew from the program prior to the first group sessions as a result of increased job demands. This facilitator was replaced by another trained female facilitator who met inclusion criteria for the program. In the ACTS2 RCT, all four facilitators will be female, with one returning from the ACTS 2 pilot study. For the purposes of this study, data collected from the facilitators via semi-structured interviews were not reported on.

Inclusion criteria. The specific inclusion criteria were required for both caregivers, care recipients and facilitators to be eligible for participation in the ACTS 2 program. Caregivers were included in this study if they: (a) were the primary caregiver to an adult family member (>59 years) who was clinically diagnosed with progressive dementia, (b) spent at least 6 hours per week providing care to their care recipient, (c) scored greater than 9 on the Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001), and (d) were at least 18 years of age. The PHQ-9 is a depression screener used by clinicians to identify depression and monitor the effectiveness of treatment. Dementia care recipient were included in the study based upon

dementia diagnoses made by physicians at the Jacksonville and Tallahassee MDCs using established NINCDS-ADRDA criteria. Facilitators were eligible for inclusion if they: (a) had a minimum of a high school degree, (b) had at least two years of experience as a lay pastoral worker, and (c) received a positive referral from a faith organization's ministry supervisor or pastor.

Exclusion Criteria. CGs will be excluded if they: (1) meet criteria for psychotic disorder and/or moderate or high suicide risk on the Mini-International Neuropsychiatric Interview (M.I.N.I) 5.0.0, [36,37] (2) provide care for a care recipient with a terminal diagnosis, or (3) have a terminal diagnosis themselves. The reason for excluding CGs of care recipients with terminal diagnoses is their concerns differ from CGs with care recipients in the early and middle stages of dementia; the former may not benefit from CBI focused heavily on managing difficult care recipient behaviors and instrumental activities of daily living.

Caregiver recruitment. Recruitment of African-American caregivers included church and senior center presentations, African-American radio station ads and interviews, and local newspaper articles.

Measures

Semi-structured interview schedule. In the ACTS 2 pilot study, semi-structured telephone interviews were scheduled after group sessions 2 and 5. In the ACTS 2 RCT, semi-structured telephone interviews were scheduled after group session 4. Each session participant was contacted by the interviewer to set up an interview time. Interviews were scheduled within 24 to 48 hours after session completion to enhance recall. The duration of each interview sessions was 30 minutes to one hour. The sessions were recorded and converted to WAV files,

an uncompressed audio file format, for transcription. (See Appendix A on page 36-40 for samples of interview instruments).

Interview training. Research assistants conducting the interviews participated in interview training sessions totaling 10 hours. The ACTS 2 project director and ACTS 2 project coordinator role played caregivers and facilitators, using different hypothetical scenarios and caregiver interpersonal characteristics and attitudes to train the research assistants. Training was focused on enhancing interviewers' comfort and skill. Systematic feedback was provided to interviewers by training staff. Training sessions also included practicing the procedures used to record the conference call interviews.

Interview transcription. Undergraduate research assistants used a software application, oTranscribe (2017), to transcribe verbatim interview transcriptions. Completed transcripts were placed into a web-based file folder that will be accessible to all transcribers. Quality checks of each transcribed interview were also performed.

ACTS 2 Intervention Program

Caregivers participated in a faith-based, 12-week telephone-based cognitive-behavioral intervention, consisting of both group and individual sessions facilitated by a lay pastoral care volunteer (see Table 1). The ACTS 2 group sessions were peer-focused and encouraged caregivers to share their observations with one another while developing caregiver skills and techniques. Individual sessions focused on problem-solving and fostered collaboration between the caregiver and facilitator to further implement caregiving and self-care goals.

ACTS 2 Weekly Session Topics
Session 1: Group- Basics of Memory Disorders
Session 2: Group- Relaxation Techniques
Session 3: Group- Effective Thinking
Session 4: Group- Increasing Emotional Well Being
Session 5: Group- Assertive Responding
Session 6: Group- Challenging Situations
Session 7- 11: Individual- Problem Solving
Session 12: Individual- Wrap-Up and Techniques for Maintaining Gains

(Table 1. ACTS 2 Weekly session topics and schedule for telephone-based intervention.)

Data analytic strategy

The caregivers' perceptions of in-session activities were executed in the group sessions using qualitative data analysis. For the purpose of this study, data was extracted from caregiver interviews on the group sessions 2 and 5 of the ACTS Pilot Study, and will be extracted from group session 4 of the ACTS 2 RCT.

Caregiver interview responses gathered from group sessions of the ACTS 2 pilot study and the first two sets of group interviews from the ACTS 2 RCTS served as the primary data source. Entire interview transcripts were included in the qualitative analysis to prevent exclusion of relevant data.

Caregivers' responses to semi-structured interview questions were content analyzed using a data analytic approach focused on creating qualitative description with the goal of generating "straight and largely unadorned answers" to meet the aims of the study (Sandelowski, 2000, p. 337). Coding began after all interviews were completed.

The techniques employed were open coding, axial coding, and categorization via concept mapping. During open coding, the research team focused on in vivo coding to keep the representation of the categories as close as possible to the data. The axial coding, in which codes were further defined and began to be related to one another adhered to Kazmer's (2010) practices that "include thinking about how codes relate to each other in a three-dimensional concept space, accounting for relationships such as orthogonality and inverseness and for features such as directionality and magnitude" (p. 763).

The data were analyzed three major ways: (a) through codes in the Coding manual for interview data created by Dr. Michelle Kazmer (Appendix B, p. 41-43), (b) through interview questions that correspond to the correct session, and (c) concepts identified through the thematic analysis of both codes and questions.

Themes were represented by relevant codes: (a) effects on caregivers, (b) effects on lay pastoral care facilitators, (c) relationship among caregivers, (d) care recipient issues, (e) in-session experience, (f) problems with training and (g) benefits of training (Appendix B, p. 41-43). These codes will be used to identify and link together related concepts in the data that may emerge in response to different, or seemingly-unrelated, questions asked during the interview.

The following caregiver interview questions from both the ACTS 2 pilot study and ACTS 2 RCT were also incorporated in the qualitative analysis:

- “Please describe your experience in the last session and types of interactions you had with the facilitator and other caregivers.”
- “How connected did you feel with your facilitator during the last group session? How effective was your facilitator at organizing the activities of the group session? Were there any topics you felt uncomfortable discussing with your facilitator?”
- “How connected did you feel with the other caregivers during the session? What was helpful about being in a session with other caregivers? What was not helpful about being in a session with other caregivers?”
- “Please describe how important this session was to you and your caregiving and personal goals.”
- “How did you feel about engaging in those spiritual activities with your group?”
(Appendix A, p.36-40).

Results

Three primary themes emerged from these analyses: (a) caregivers’ appraisals of the quality of interactions among their peers; (b) caregivers’ appraisals of the consequences of group skills training; and (c) caregivers’ perceptions of the effectiveness of facilitators during ACTS 2 group based sessions. Themes were supported by statements made during caregivers’ semi-structured interviews. Reported beneath each theme are the discussed strengths and benefits as perceived by the caregivers. The limitations of the ACTS 2 group sessions emerged in the following domains: Sharing With Others and Developing Caregiver Relationships through Spirituality

Appraisals of the Quality of Interactions among their Peers

Data in assessing the quality of peer interactions among caregivers were gathered from semi-structured interviews following ACTS 2 group sessions 2 and 5 of the Pilot Study and group session 4 of RCT. Two major sub-themes emerged from the qualitative analysis: Sharing with Others and Developing Caregiver Relationships through Spirituality.

Sharing With Others. Multiple caregivers stated sharing with peers provided a sense of social support and knowledge most caregivers had not experienced prior to participating in the ACTS 2 group sessions. One caregiver explained how being fully understood when discussing daily caregiving duties had not occurred before the ACTS 2 group sessions.

... at this point I do see the benefit in participating. I do not believe it's a waste of time. I do see the benefit in participating, like I said, again, because there is no one in my personal life that has shared in this experience that I can go to and can understand 100% what I'm going through day in and day out. SO being able to connect with other PEOPLE who share in this, situation to me has just been helpful, all by itself... (CG12).

CG56 emphasized the commonality that emerged from sharing their day-to-day activities, stating it was “a way of helping people to cope with being a caregiver. It's because you're not alone. We don't know everything. Your situation is different than mine and us sharing together in those kind of setting, help other people cope with their problem, I think is a wonderful thing” (CG56).

In addition to feeling a sense of commonality in knowing that they were not alone in their caregiving experience, group participants reported suggestions and tips they received from one another were very beneficial. CG58 reported the importance of learning from the experiences of each caregiver: “I learn something from all of them, each session is a learning experience for me

and it helps me because there's things I didn't realize as caregiver so I'm learning as I go through you know in this study" (CG58). When asked what was helpful about being in a session with another caregiver, CG61 explained learning occurred not only from sharing common caregiving experiences, but also from the shared aspiration of being a better partner for the care recipient.

...I think we're going after the same goal, so you know I think we can talk freely about what's going on because we're trying to get to the same goal. You know. She's trying to help her caregiver and I'm trying to help mine, so maybe she can say something that might help me and maybe I can say something that might help her you know? So, I think we're, I think we're trying to get to the same point, the same goal. And it's helpful, talking the way we do you know. What she has to say, I'll listen, what I have to say, she'll listen... (CG61).

Overall, caregivers felt sharing with others during the group sessions contributed greatly to the sense of unity and connectedness during group sessions. However, some caregivers noted their time being limited because group sessions required everyone to participate. CG76 explained "...in group sessions, you know everybody's voice needs to be heard in the group session and we learn from each other but when it's one on one we get to share more and share more direct questions and, so it helps me clarify my mind and my thought processes what I should be doing with whatever I'm doing" (CG76).

Another caregiver explained how sharing with others during the group session can be difficult if not all of the other caregivers are willing to cooperate.

Yeah, it's like three of us in the group, and I feel like two of us, again I don't want to put nobody down, but I feel like two of us are really interested in trying to learn how to care for ourselves and also, caregiver but the third person seemed to uh have all the

answers...Not that I really have a problem with that, but if I'm in a class, and this is just my belief ma'am. If I'm in a class I shouldn't try to act like I know more than the teacher, I don't need to be there if that happens (CG60).

It also was difficult to share when group members (the caregivers) had care recipients in later stages of dementia. One caregiver explained how her less disabled care recipient affected her ability to share during the group sessions.

Come in with an open mind, um and just come in wherever you fit in at like I did. Other people who have patients or loved ones, their loved ones was a little advanced than my husband, so I didn't need, I didn't quite understand what they were going through because I hadn't experienced what they were going through, you follow what I'm saying? The sessions with them was just information for me, yes, it's going to be helpful when he gets to that point, but to me I didn't really need to hear all that. That's the way I felt (CG56).

In summary, sharing with others provided several caregivers an opportunity to feel understood and to both share and receive knowledge. Although a few caregivers felt their time with the facilitator was limited due to the group settings, the majority reported benefitting from the experience.

Developing Caregiver Relationships through Spirituality. Several caregivers noted their common faith tradition fostered a strong alliance among their peers during the group sessions. One caregiver described how he held his group members to a higher standard of trustworthiness because of their shared spiritual beliefs.

You feel like you're talking to people that you can get an honest response and feedback from. Not just people who are going to give by the book answers or status-quo answers,

you get that honestly because you're dealing with people that should have a godly mindset (CG12).

Incorporating spirituality into the group sessions not only facilitated a higher level of open communication, but also for a sense of unity among the caregivers. When asked how the addition of the spiritual component helped shape caregiver interactions, CG29 observed how the level of comfort which other caregivers expressed toward spirituality brought about "a commonness between us because we all seem to believe and have faith, and I think that just helps bring us closer" (CG29).

This sense of unity from a common faith tradition was expressed by several caregivers. CG61 described the sense of unity she felt among her fellow caregivers as being "on the same page," emphasizing that "some people may not BELIEVE, you know, in the spiritual aspects, so that's a blessing, the three of us all on the same page, as far as spiritual wise. Glad of that" [CG11]. Another caregiver emphasized how being "on the same page" was necessary in order for bonding to occur among the caregivers.

We need God to help us, and we need people to help us along the way, so if we have that spiritual outlook and somebody who could be on the same page that we are on, we're going to be stronger and wiser, and helpful, more loving and kind. But if they are not on the same page as you spiritually, it's just a battle; it's a warfare. If we are on the same page spiritually, if you're with somebody that can understand it, that's how you become stronger by bonding together, you know (CG58)?

Although appreciation of strong spiritual alliance was commonly expressed, two caregivers expressed concern about the involvement of caregivers who may not hold similar faith traditions. CG56 and CG50 had reservations about the involvement of individuals who may not

“be on the same page” spiritually. When asked if there should be more, less or different spiritual activities, CG56 was concerned about how his spirituality could potentially affect someone who believed differently.

“Yeah well umm, one thing about that is that some people don't want the spirituality part forced on them. I think we should not, I'm just going to be my own individual self and if I want to say Thank You Lord Jesus then I think I'll be allowed to do so and I want to be allowed to do this, you know, without offending anybody” (CG56).

CG50 also expressed concern for how spirituality would affect group sessions if caregivers were not “on the same page.” CG50 stated, “I try not to rub my beliefs on nobody per se, I wouldn't want uh to get the idea that I'm a spiritual person and the class gotta talk spiritual because of me” (CG50).

In summary, incorporating spirituality into the group sessions appeared to act as a strong bonding agent across caregivers. Concerns of whether including spirituality potentially may offend group members were noted, but they did not seem to impact the quality of interactions among the caregivers.

Caregivers' Appraisals of the Consequences of Group Skills Training

Group skills training sessions were delivered by facilitators guided by the ACTS 2 Skills-Building Guidebook for Dementia Caregivers (2014) which covered the following group skills: Basics of Memory Disorders, Relaxation Techniques, Effective Thinking, Increasing Emotional Well Being, Assertive Responding, and Challenging Situations (Glueckauf et al, 2014). Group sessions focused on a specific skill aimed at enhancing the caregiver's quality of life and caregiving abilities. Key features of the consequences of group skills training were highlighted in caregivers' responses to semi-structured interviews following group sessions 2 and 5 of the Pilot

Study and after group session 4 of the RCT. Three primary sub-themes emerged from the analysis of the data: Consequences of Relaxation and Stress Reduction Training, Consequences of Effective Thinking training, and Consequences of Assertiveness Training

Consequences of Relaxation and Stress Reduction Training. Group session 2 of the ACTS 2 Skills-Building Guidebook for Dementia Caregivers (2014), “Relaxation Techniques Skills Building Session 2,” focused on “how relaxation helps your thoughts, feelings, and actions under stress” (Glueckauf et al., p. 10). This goal coincided with the needs of several caregivers, as many expressed feeling stressed as a result of daily caregiving activities. They perceived the relaxation techniques covered in group session 2 beneficial and informative. One caregiver noted how the ACTS 2 group session influenced her desire to relax while caregiving.

Being able to relax is um, was stressed, and so that is something that you know I have now that I've conversed with the other ladies about it, is helping me to realize all the more that it's so important to be able to do it. And uh just to kinda not get yourself too stressed out or too worked up in order to be able to go on, you gotta find some kinda way to take a step back from it (CG29).

When asked how much the relaxation session affected their caregiving routines, CG 12 stated “OH I think it was very important in the sense that because caregiving can be such a stressful situation to be in, learning and understanding how to utilize techniques to help you relax and to help you decompress I think are ESSENTIAL to EFFECTIVE caregiving” (CG12). CG12 also described how learning how to relax during stressful situations had been beneficial as a caregiver.

...with the stress, sometimes I get stressed out with my mother because she repeats the same things, she asks me the same things, and you know AND now I know how to calm

myself down to handle her when she start asking me the same things and stuff like that so you know that that helps a LOT, you know (CG12)?

Another caregiver discussed the effects of relaxation training on her daily life.

...You gotta take time and have some time to do things for yourself. That's just the bottom line. Because you know you can't spread yourself too thin, which we do anyway, but you need that time to [be] alone, or relaxing, uh meditating, you know we uh and this was a good session to learn how to do that. You know. That would help us a lot. I know it helped me, helped me improve my memory, uh my moods will probably be better, [laughter], I'll probably think a little faster and clearer, and uh it says that it improves your general health if you take time to learn to relax and do it. You know you won't be so anxious all the time you know (CG61).

In summary, the relaxation group training skills derived from session 2 of the ACTS 2 Skills-Building Guidebook for Dementia Caregivers (2014), were reported as beneficial for its use across several areas of the caregiver's lives including but not limited to, self-care and caring for loved ones.

Consequences of Effective Thinking Training. Group session 3 of the ACTS 2 Skills-Building Guidebook for Dementia Caregivers (2014) entitled "Effective Thinking Skills Building Session 3", focused on learning to "recognize different patterns of thinking and how they impact the way you feel and respond to your loved one with dementia" (Glueckauf et al., p. 16). Several caregivers addressed the benefits effective thinking had on their caregiving activities. Both CG 61 and CG 12 explained how learning to think effectively about "me time" impacted the quality of their caregiving.

...I've learned that you have to take some time for yourself you know even if you have to call for help- call for help, if need be. It's not bad if you need to call for help sometimes. Take your husband to the doctor or wherever he needs to go, and you just sit back and mediate and talk to God and do what little things need to be done for yourself, and that's not a bad thing. Because, a lot of times, you uh- you used to uh feel kinda guilty if you take off and say you're going to leave him here while you run some place and do this and go to the hairdresser, uh get your nails done, or something whatever you know do for yourself sometimes. You might feel guilty, but no you shouldn't feel that way 'cause there's times you NEED to get away for a few minutes, take a break, take a break for yourself... (CG61).

I think it has in a positive way I think it's helped me just come to terms with the fact that I can't be there for her all the time it's not my job. I have her in a community that offers me more care and I put her there with the intention of being able to free up my life and get back to my normal and I think the session has allowed me to better accept the decision that I made, regardless of the opposition I may get from family and friends, the sessions have confirmed that the path that I'm going down is the RIGHT path (CG12).

In summary, the findings reported by the majority of caregivers, suggests that the group skills training from group session 3 of the ACTS 2 Skills-Building Guidebook for Dementia Caregivers (2014) positively impacted their caregiving abilities by implementing correct thinking patterns for issues such as the care-recipient, and one's self.

Consequences of Assertiveness Training. Group session 5 of the ACTS 2 Skills-Building Guidebook for Dementia Caregivers (2014) entitled "Assertive Responding Skills Building Session 5" focused on how to "act in loving interest of yourself and your loved ones

with dementia, stand up for what you believe is right and needed without undue anxiety, and express feelings and emotions in a more comfortable and sensitive manner” (Glueckauf et al., p. 30). Several caregivers addressed the benefits of assertiveness training on their caregiving and their personal lives. CG 12 addressed how learning to speak assertively with their care recipient impacted the quality of her caregiving experience.

I mean I'm good with the business piece [laughs], I'm good with the business piece uhm and and and I think I'm fairly good in in the personal piece AS WELL but it's one thing when you're dealing with, uhm, a personal interaction where the person has the same faculty and capacity that you do or similar faculty and capacity as you but then it's another thing when you're having to communicate with someone whose faculty and their capacities are impaired...So that made a HUGE difference uhm for ME in just in just really understanding, uhm, especially being new to this to this, period of her life [Laughs] that made a huge difference with ME in understanding how my communication with her uhm affects the different outcomes and the different reactions that I could get from her (CG12).

When asked how important this session was to caregivers' goals, CG 16 and CG 61 both felt learning assertiveness techniques were highly consistent with their caregiving goals.

...now I can know how I can deal with people with my voice, with my eye contact, do what I'm, you know, do what I am taught, and I have to think about I'm what I am getting ready to say. It was very good, I think it was very good (CG16).

...Very. Very important. Because uh, like I said, learning to be assertive person, which I would like to be, to be assertive person, it uh helped me to attain my goals that I need to [recording pauses] and not be frustrated- just be calm and pray you know, that's one of

the main things I feel Like I need to continue run this race- it's like a race you're running with uh being a caregiver. You really have to talk to God a lot and uh [recording pauses] it's given me courage and [recording pauses] I can do all things through Christ who strengthens me. That's going to be my motto now. (CG61)

In summary, group-based assertiveness training was reported as beneficial to the caregivers. Many caregivers reported being able to use assertiveness training not only when speaking to their loved one with dementia, but also when asking friends and family to assist in caregiving activities. Several caregivers noted assertiveness training helped them achieve their personal caregiving goals.

Caregivers' Perception of the Effectiveness of Facilitators

Lay pastoral care volunteers, known to the caregivers as facilitators, were responsible for leading all ACTS 2 sessions. Facilitators were responsible for creating an environment of trust and open communication in the course of disseminating information about key caregiving skills. Caregiver's perceptions of their facilitator's capacity to manage the above effectively were obtained from semi-structured interviews. Key components of the facilitators' effectiveness during the ACTS 2 telephone-based group sessions were identified following group sessions 2 and 5 of the pilot study and group session 4 of the RCT. Two primary sub-themes emerged from the qualitative analysis: Effectiveness in Uniting the Group and Effectiveness in Guiding Topics for Discussion.

Effectiveness in Uniting the Group. Facilitators were encouraged to foster an atmosphere of trust and openness in which caregivers felt comfortable discussing personal matters pertaining to caregiving. Almost all caregivers reported feeling “very connected “to their

facilitators. One caregiver reported that by reviewing conversations from previous sessions, the facilitator created a “family” atmosphere during the group sessions.

[The Facilitator] is very knowledgeable. She listens she gives ideas and I think she tries to get to know each one of us individually, so when she's talking to us she tries to relate. And she kinda remembers what we say from the last session and she brings it into forward. So, it really makes it like a family affair. So that helps (CG56).

Another caregiver reported her facilitator promoted feelings of unity among the other caregivers in the group.

I think we're connected, or I think number 1 she has a way of asking you know she'll call a name and ask that person their opinion or relate to their situation so we're good you know we don't know each other that well but we're getting to know each other better... I think it's a good group that's mellowing quite well (CG50).

Another caregiver observed how the facilitator was directly responsible for encouraging interaction among the caregivers.

...the information that she presented and the techniques that she had us to to utilize uhm... [long pause] and the fact that we interact I mean she encourages interaction, she asked open ended questions which encourages interaction with all of us so... she would comment whenever, she would ask a question and based on the responses that were given she would comment on those responses or she would talk about some of her own experiences and somethings that she may do that may be similar or somethings that she may have done to encourage other group members or something like that (CG12).

Caregivers 61 and 16 also reported their facilitator disclosed her own caregiving experiences and shared in the laughter and enjoyment of group exchanges. CG 61 noted how having a facilitator who shared in the caregiving experience, functioned to assist them in connecting as a group.

Yeah, we got a good instructor. [coughs] She's so down-to-earth and uh [clears throat] she acts like we've been knowing each other- uh she, and the other caregiver, and myself- we act like we've been knowing each other a long long time you know when we get- get together you know. [chuckles]. Yeah, we uh have a little fun times sometimes you know. Like I said, she tells us her experiences with her mom and uh [recording pauses] I do likewise with my husband. [laughs] Sometimes we all be laughing at the same time at what's going on... (CG61).

CG 61 also remarked her relationship with the other caregivers as one of laughter and fun as a result of the facilitator by stating, “Well I have very good rapport, I do with them, because you know we can talk and we laugh, and we tell different kinds of stories and stuff and I think [the facilitator] is very very helpful. You know she is very helpful and the lady that's on there, she interacts with me too. So I think we just get along perfect. I don't have no complaints” (CG16).

In summary, almost all of the caregivers reported their facilitator as effectiveness in the uniting the group sessions. Several caregivers reported tactics employed by the facilitator in order to unite the group which included asking open-ended questions and sharing personal caregiving stories. What resulted was not only a sense of connectedness among the facilitators but also a “family”, according to some.

Effectiveness in Guiding Topics for Discussion. In addition to encouraging comradery and openness among caregivers, facilitators were responsible for guiding group discussion. When asked how effective facilitators were in organizing the group sessions, almost

every caregiver answered, “very effective”. Several caregivers appreciated the group process skills of their facilitator. One caregiver addressed how a group session was led by the facilitator.

...We follow her you know in the book you know, like what she's talking about. And you know just where she's at and you know you don't get lost and and um she's she's very good. She's very good. You know I like the way she does the, these sessions. They're good. And then she will ask you questions, do you have any questions? Do you have anything to say? Any comments? And you know that's good. I like that (CG61).

CG 58 felt that the facilitator’s knowledge and training was effective in providing answers and talking points when caregivers were unsure of what to discuss.

...our facilitator is really good, when she goes and explains thing to us we take it back and use it so she it is good at that, and she is good at guiding the caregivers into discussions even more you know, to go even further if we don’t have enough information or feel like it’s not too clear, she helps us along with that (CG58).

CG50 commented on the facilitators’ effectiveness in reflecting and restructuring the thoughts of group participants stating, “...She’s sharp on listening to what we’re saying. And she takes it from there and helps us to relate back in some way what we really feel about a given situation” (CG50).

Multiple caregivers have reported benefitting in their relationship with both the other caregivers and their care recipients as a result of their facilitator’s effectiveness in guiding the topics discussed during the group sessions. In summary, most caregivers reported that their facilitator’s leading of the group session was highly effective. Additionally, through the implementation of shared resources such as the ACTS 2 Skills-Building Guidebook for Dementia

Caregivers (2014), the caregivers reported being able to follow along easily and comprehend the topics (Glueckauf et al).

Discussion

As a result of socio-cultural and economic barriers, African-American caregivers face substantial challenges in accessing mental health services. In an effort to overcome these shortcomings, ACTS 2 was created to facilitate the development of skills to cope with the stress and burden of caregiving and in turn, to reduce depression and enhance health status of African-American dementia caregivers. A qualitative study was performed to assess family caregivers' perceptions of the strengths and limitations of the ACTS 2 telephone-based group sessions. The foci of the qualitative analysis were perceived quality of interactions among their peers, caregivers' appraisals of the consequences of group skills training, and their perceptions of effectiveness of group facilitators.

Quality of Interaction among Peers

Caregivers perceived the quality of their interactions was better when they had more opportunity to share with one another. For many caregivers, participation in the ACTS 2 group sessions was the first time they felt completely understood as a result of sharing in caregiving activities. The reported sense of commonality derived from sharing similar caregiving experiences was considered both a coping mechanism and an opportunity to learn from others.

The sense of sharing common experience and goals fostered in group sessions was an intended outcome in the way the ACTS 2 program was designed, and this finding is one indicator that this group process objective was achieved. Note, however, two caregivers preferred having more direct attention from the facilitator but each for unique reasons. One caregiver did not appreciate one member in the group acting as "the teacher" and dominating the

conversation. This finding was unexpected as all facilitators are trained in managing individuals who dominate conversations prior to conducting group sessions. According to the Workshop Guidebook for ACTS 2 Facilitators (2014) facilitators are instructed to:

“Ensure that all caregivers have opportunities to participate: Be sure that everyone has a chance to share their thoughts and that no one dominates the conversation. Review of group rules at the beginning of the session will help to remind members of the need to have equal “air time”. (Glueckauf et al, p. 28).

This finding indicates a need for specialized training in reinforcing session guidelines precluding unwanted “advice giving” among caregiver participants. In addition, this issue can be further addressed in one-on-one discussions with facilitators’ consultants during the course of the caregiver training program.

Another group process problem was found in the variation of severity of the care recipients’ health conditions. One caregiver’s loved one with dementia was not as far advanced in the disease as the other care recipients. She felt the problems she faced were discrepant with those of her caregiver peers. Although the knowledge and experiences of caregivers with care recipients in the advance stages may be helpful to all participants, facilitators need to acknowledge such differences and encourage discussion addressing the concerns of those in earlier stages of the condition. Thus, the majority of caregivers benefitted from learning from one another and from feeling understood. Specialized facilitator training may serve to enhance the positive impact of the group sessions by taking into account the need for eschewing advice giving and attending to the needs and concerns of caregivers across various stages of dementia.

Feeling understood was paramount in order for caregivers to perceive the quality of interaction among their peers as positive, and it extended beyond sharing caregiving experiences

to religious beliefs and practices. According to Dupree et al. (2005), African-American adults were two times more likely than their non-Hispanic White counterparts to seek assistance from church ministries when they had mental health problems. Caregivers appeared to prefer the level of understanding fostered by a shared faith tradition, and seem to believe that it would be hampered without it. Additionally, several caregivers stated that having a group in which not all participants were spiritual potentially may lower the quality of interaction during group sessions.

Caregiver's Appraisal of the Consequences of Group Skills Training

Relaxation techniques, effective thinking and assertive responding were skills most frequently mentioned as beneficial according to results from the semi-structured interviews. One possible explanation for the predominance of these group skills may pertain to when the follow-up interviews were scheduled. Caregivers may have recalled the information from the session in which they most recently participated. However, this argument does not explain why group sessions 2, 3 and 5, were retained and group sessions 1 and 4 were not. A more plausible explanation could be group skills acquired in group sessions 2, 3 and 5 are those most applicable to their daily caregiving routines, while those in group sessions 1 and 4 were not as salient. However, this argument does not fully explain why group sessions 2, 3 and 5 were most frequently mentioned. Another explanation may be the critical incident technique which focused on the last session the caregivers experienced and then focused more broadly about the sessions in general (Appendix A page 36-40). However, the application of this technique fails to explain why the skills obtained during group session 4 went predominantly unmentioned, as the semi-structured interview immediately followed group session 4 of the randomized clinical trial.

Caregiver's Perception of the Effectiveness of Facilitators

Lay pastoral care facilitators led the group each week through the corresponding chapters of the ACTS 2 Skills-Building Guidebook for Dementia Caregivers (Glueckauf et al, 2014). Facilitators were charged with creating an environment of trust and open communication while disseminating information. Following the analysis of caregiver's perceptions of facilitator effectiveness obtained from semi-structured interviews, two primary sub-themes emerged: Effectiveness in Uniting the Group and Effectiveness in Guiding Topics Discussed.

Most caregivers reported feeling "very connected" to their facilitator. This sense of connection seemed to serve as an anchor by which facilitators were able to create unity among other caregivers. By asking open-ended questions and calling on caregivers' by name, facilitators were credited with creating a comfortable and open environment that often felt like family. One reason for this could be the shared commonalities between the facilitator and the caregivers. Chosen intentionally for their prior service in lay pastoral care, their cultural background as African Americans, and often their own experience as caregivers, facilitators appear to have filled the gap between the caregivers and need for culturally-sensitive dementia care consultation services. Facilitators were trained to encourage community among the other caregivers with the intention of offsetting some of the many daily burdens of caregiving including: lack of social support. Additionally, by creating unity among the caregivers, facilitators created the caregivers the opportunity to be truly understood by others.

Caregivers were also charged with disseminating information to the caregivers in a clear and concise manner. Most caregivers reported that facilitators were "very effective" in doing so. Many caregivers also reported enjoying facilitators' review of core skills discussed in ACTS 2 Skills-Building Guidebook and their queries for the need for further clarification and questions about the materials. These findings illustrate that that the training strategies found in the

Workshop Guidebook for ACTS 2 Facilitators (2014) which states “Keep the group focused, but stay flexible: if the conversation goes astray, simply restate the most recent question or topic” are being employed effectively in keeping the group on task and focused (Glueckauf et al, p. 28).

Limitations

The limitations of the qualitative analysis of the group-session experiences of ACTS 2 participants include small sample size, focus on group data, reliance on self-report, and limited observations across sessions. Although this study examined participants’ responses from both the Pilot and RCT, the sample size was small, thus limiting the reliability of the current study’s findings. Furthermore, limiting data collection solely to the group sessions provided only a limited view of the caregivers’ perceptions of the group sessions. Without analyzing data from the semi-structured interviews following individual sessions 9 and 11 of the Pilot Study and 9 of the Randomized Clinical Trial, caregivers’ perceptions of group processes following the individual sessions could not be assessed. Additional limitations to the analysis of group process were found in the exclusive use of self-report data. Limiting the data to self-report method was necessary due to ethical constraints (e.g., preserving the privacy of family interactions) and the challenges of conducting behavioral analysis of group processes (e.g., turn-taking, number of interruptions). The number of semi-structured interviews in this study was limited to three of six group sessions. During the Pilot study, 2 semi-structured interviews were administered following group sessions 2 and 5, and after session 4 in the RCT. The use of a limited number of session probes was predicated on the need to reduce response burden in the caregiver participants.

Further limitations of the analysis include the geographical location of the sample, and the preponderance Christian faith orientation. The responses of Southeastern sample of African American caregivers may not generalize to other portions of the country where religiosity may

be lower than that found in this region of the U.S. Next, the current sample consisted of caregivers who exclusively professed a Christian faith orientation. The findings may not be generalizable to caregiver groups with diverse faith traditions and/or those who do not profess a faith or who are wavering in their faith.

Future Directions

Further research with a larger sample of participants is needed to assess the reliability of the current findings. Studies with African-American samples from different parts of the country are necessary to assess the generalizability of the findings. Additionally, a behavioral analysis of group processes is also necessary. It also will be essential to evaluate the effects of inclusion of caregivers from different faith tradition. Limited information is currently available on the impact of including persons from different faith traditions on the quality of peer interactions.

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Appendix A

ACTS2 Caregiver Qualitative Interviews (Pilot Study)

Sessions 2, 5

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01 December 2014

Informed Consent and Background Information about Telephone Interview Process

The participants have engaged in the informed consent process with the Dr. Shuford Davis. Prior to your reaching out to the CGs, Tomeka Norton has already spoken with each CG for other project purposes and has let them know who will be calling for the qualitative interviews. However, you will need to call each CG to make sure you have established a mutually-available time for each qualitative interview.

Interviewer Introduction

“My name is _____. I am part of the ACTS2 project at Florida State University. I am calling today to talk with you about the sessions that you have taken part in up to now. I want to assure you that the feedback you provide is confidential, and will be used by Florida State College of Medicine and its affiliates to evaluate and improve the ACTS2 skills-building materials. I realize your time is limited; if at any point you need to stop our conversation, let me know, and I will call back at a later point to complete our interview. Do you have any questions? Our call today is being recorded so we can most accurately refer to your responses later. Is that okay?”

Session 2 Protocol

Group session

1) Caregiver’s in-session experiences

- a) Please describe what occurred in your last session. (*If it helps to organize the caregiver’s thoughts, ask her/him to describe the session chronologically or topically.*)
 - i) PROBE IF NEEDED: What were some of the specific topics you discussed? What were some of the activities that you participated in?
 - ii) PROBE IF NEEDED: Please describe your experiences in the last session and the types of interactions you had with the facilitator and other caregivers (e.g., topics covered in the session, group discussion)
- b) Where were you when you participated in the session? Were there any distractions during the session? [IF YES: Please describe them. How could your facilitator or other members of the ACTS 2 team help to prevent or reduce these distractions? What things might you do to prevent or reduce them?]
- c) About how long was the last session? Was the session longer or shorter than you expected?
 - i) Please describe any parts of the session that you felt were too long.
 - ii) Were there any topics or activities that you felt needed more time?
 - iii) To what extent do you feel the time in the group session was spent efficiently?

- d) How connected did you feel with your facilitator during the last group session? How attentive do you feel your facilitator was during the session (e.g., how focused did they seem to be on the group's discussion)? How effective was your facilitator in organizing the activities of the group session (e.g., group discussion and group practice exercises)? Were there any topics you felt uncomfortable discussing with the facilitator?
- e) How connected did you feel with the other caregivers during the session? What was helpful about being in the session with other caregivers? What did you think was NOT helpful about being in the session with the other caregivers?
- f) What was most helpful to you in the last session? What was least helpful to you in the last session?
- g) Please describe how important this session was to your caregiving goals. To what extent did the session help you recognize and focus on your own needs? Can you give me an example, please?

2) CG's perception of the spiritual aspects of the sessions

- a) Were spiritually-related activities or discussion included in the last session?
 - i) Probe for specifics if needed: prayer, scripture reading, faith sharing, positive affirmations
- b) How did you feel about engaging in those spiritual activities with your group?
 - i) Would you like to have MORE, LESS, or DIFFERENT spiritual activities included in the sessions? Can you give me an example(s)?
- c) How has the spiritual component of the session influenced your daily caregiving activities?
 - i) How have the spiritual parts of the session influenced your experience with other caregivers and facilitators?
- d) Do you have any other feedback about this aspect (i.e., the use of spiritually-related activities) of your sessions?

3) CG's perception of ACTS 2's effects on daily caregiving activities

- a) What impact, if any, have the sessions so far had on your day-to-day life? How often do you use the skills or strategies discussed in your sessions? Probe for specifics if needed, e.g., relaxation exercises
- b) How have the sessions so far affected your ability to meet your own needs?
- c) What are your thoughts and feelings about the ACTS 2 caregiving guidebook? Can you tell me about how you are using it – before sessions, during sessions, outside of sessions?
- d) Is there anything else you'd like to share at this point about your experience with ACTS2?

Session 5 Protocol

Group Session

1) Caregiver's in-session experiences

- a) Please describe what occurred in your last session. (*If it helps to organize the caregiver's thoughts, ask her/him to describe the session chronologically or topically.*)
 - i) PROBE IF NEEDED: What were some of the specific topics you discussed? What were some of the activities that you participated in?

- ii) **PROBE IF NEEDED:** Please describe your experiences and the types of interactions you had with the facilitator and other caregivers (e.g., topics covered in the session, group discussion).
- b) Where were you when you participated in the session? Were there any distractions during the session? [IF YES: Please describe them. How could your facilitator or other members of the ACTS 2 team help to prevent or reduce these distractions? What things might you do to prevent or reduce them?]
- c) About how long was the last session? Was the session longer or shorter than you expected?
 - i) Please describe any parts of the session that you felt were too long.
 - ii) Were there any topics or activities that you felt needed more time?
 - iii) To what extent do you feel the time in the group session was spent efficiently?
- d) How connected did you feel with your facilitator during the last session? How attentive do you feel your facilitator was during the session (e.g., how focused did they seem to be on the group's discussion)? How effective was your facilitator in organizing the activities of the session (e.g., group discussion and group practice exercises)? Were there any topics you felt uncomfortable discussing with the facilitator?
- e) What was most helpful to you in the last session? What was least helpful to you in the last session?
- f) Please describe how important this session was to your caregiving goals. To what extent did the session help you recognize and focus on your own needs? Can you give me an example(s), please?

2) CG's perception of the spiritual aspects of the sessions

- a) Were spiritually-related activities or discussion included in the last session?
 - i) Probe for specifics if needed: prayer, scripture reading, faith sharing, positive affirmations
- b) How did you feel about engaging in those spiritual activities with your group?
 - i) Would you like to have MORE, LESS, or DIFFERENT spiritual activities included in the sessions? Can you give me an example(s)?
- c) How has the spiritual component of the session influenced your daily caregiving activities?
 - i) How have the spiritual parts of the session influenced your experience with other caregivers and facilitators?
- d) Do you have any other feedback about this aspect (i.e., the use of spiritually-related activities) of your sessions?

3) CG's perception of ACTS 2 effects on daily caregiving activities

- a) What impact, if any, have the sessions so far had on your day-to-day life? How often do you use the skills or strategies discussed in your sessions? Probe for specifics if needed, e.g., relaxation exercises
- b) How have the sessions so far affected your ability to meet your own needs?
- c) What are your thoughts and feelings about the ACTS 2 caregiving guidebook? Can you tell me about how you are using it – before sessions, during sessions, outside of sessions?
- d) Is there anything else you'd like to share at this point about your experience with ACTS2?

ACTS2 Caregiver Qualitative Interviews (Main Study)**Sessions 4**

Drafted by Michelle M. Kazmer (mkazmer@fsu.edu), edited by Drs. Davis & Glueckauf, Elizabeth Ichite, & Eric Walker

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Informed Consent and Background Information about Telephone Interview Process

The participants have engaged in the informed consent process with the Dr. Shuford Davis. Prior to your reaching out to the CGs, Tomeka Norton has already spoken with each CG for other project purposes and has let them know who will be calling for the qualitative interviews. However, you will need to call each CG to make sure you have established a mutually-available time for each qualitative interview.

Interviewer Introduction

“My name is _____. I am part of the ACTS2 project at Florida State University. I am calling today to talk with you about the sessions that you have taken part in up to now. I want to assure you that the feedback you provide is confidential, and will be used by Florida State College of Medicine and its affiliates to evaluate and improve the ACTS2 skills-building materials. I realize your time is limited; if at any point you need to stop our conversation, let me know, and I will call back at a later point to complete our interview. Do you have any questions? Our call today is being recorded so we can most accurately refer to your responses later. Is that okay?”

Session 4 Protocol**Group session****1) Caregiver's in-session experiences**

- a. Please describe what occurred in your last session. (If it helps to organize the caregiver's thoughts, ask her/him to describe the session chronologically or topically.)
 - i. **PROBE IF NEEDED:** What were some of the specific topics you discussed? What were some of the activities that you participated in?
 - ii. **PROBE IF NEEDED:** Please describe your experiences in the last session and the types of interactions you had with the facilitator and other caregivers (e.g., topics covered in the session, group discussion)
- b. Where were you when you participated in the session? Were there any distractions during the session? [IF YES: Please describe them. How could your facilitator or other members of the ACTS 2 team help to prevent or reduce these distractions? What things might you do to prevent or reduce them?]
- c. About how long was the last session? Was the session longer or shorter than you expected?

- i. Please describe any parts of the session that you felt were too long
 - ii. Were there any topics or activities that you felt needed more time?
 - iii. To what extent do you feel the time in the group session was spent efficiently?
- d. How connected did you feel with your facilitator during the last group session? How attentive do you feel your facilitator was during the session (e.g., how focused did they seem to be on the group's discussion)? How effective was your facilitator in organizing the activities of the group session (e.g., group discussion and group practice exercises)? Were there any topics you felt uncomfortable discussing with the facilitator?
- e. How connected did you feel with the other caregivers during the session? What was helpful about being in the session with other caregivers? What did you think was NOT helpful about being in the session with the other caregivers?
- f. What was most helpful to you in the last session? What was least helpful to you in the last session?
- g. Please describe how important this session was to your caregiving and personal goals. To what extent did the session help you recognize and focus on your own needs? Can you give me an example, please?

2) CG's perception of the spiritual aspects of the sessions

- a. Were spiritually-related activities or discussion included in the last session?
 - i. Probe for specifics if needed: prayer, scripture reading, faith sharing, positive affirmations
- b. How did you feel about engaging in those spiritual activities with your group?
 - i. Would you like to have MORE, LESS, or DIFFERENT spiritual activities included in the sessions? Can you give me an example(s)?
- c. How has the spiritual component of the session influenced your daily caregiving activities?

How have the spiritual parts of the session influenced your experience with other caregivers or your facilitator?

- d. Do you have any other feedback about the use of spiritually-related activities in your session?

3) CG's perception of ACTS2's effects on daily caregiving activities

- a. What impact, if any, have the sessions so far had on your day-to-day life? How often do you use the skills or strategies discussed in your sessions? Probe for specifics if needed, e.g., relaxation exercises
- b. How have the sessions so far affected your ability to meet your own needs?
- c. What impact have the facilitator's instructions or suggestions had on your daily caregiving activities?
- d. Are you providing care for anyone other than your loved one with dementia (e.g., are you a parent, do you have other care recipients)? If yes, are you using the skills or strategies from ACTS in your other caregiving situations?
- e. What are your thoughts and feelings about the ACTS 2 caregiving guidebook? Can you tell me about how you are using it – before sessions, during sessions, outside of sessions?

- f. Is there anything else you'd like to share at this point about your experience with ACTS2?

Appendix B

ACTS2 Coding manual for interview data

Drafted by Michelle M. Kazmer (mkazmer@fsu.edu), edited by Drs. Davis & Glueckauf, Elizabeth Ichite, & Eric Walker

10 October 2015

Coding procedures:

1. More than one code can be applied to an utterance.
2. If you had to think about anything, or you have an idea, type it out as a "memo"
3. If a concept appears in an utterance and it's not covered by an existing code, propose a new code and type a "memo"

Code: Caregiver resources and use

Includes guidebook and readings

Includes resources NOT part of ACTS2P explicitly (i.e., "outside" resources)

Includes NON-use of resources

Includes anything about the CG guidebook

Includes PCF use of it or suggestions for changes to it

if the utterance includes any mention of technology, add the Technology code

Code: PCF resources and use

Includes facilitator manual and readings

Includes resources that are not part of ACTS2P explicitly (i.e., "outside" resources) used by the PCF

Includes NON-use of resources

Includes caregiver statements about PCFs' use of resources

Includes anything about the PCF facilitator manual goes here

Does NOT include additional resources they suggest for the CG; use "Caregiver resources and use"

Does NOT include PCF use of or suggestions for CG guidebook; use "Caregiver resources and use"

If the utterance includes any mention of technology, add the Technology code

Code: Effects on CGs

Primarily this is used for effects of the training itself on the CGs

Includes effects on CGs of the caregiving process itself

Can occur in interviews with PCFs, if they talk about the effects on the CGs of the training

Will almost always co-occur with a benefits or problems code

If the utterance includes any mention of spirituality, also include the appropriate Spiritual Aspects code

Code: Effects on PCFs

Primarily this is used for effects of participation in ACTS2 as facilitators on the PCFs

Will almost always co-occur with a benefits or problems code
If the utterance includes any mention of spirituality, also include the appropriate Spiritual Aspects code

Code: Spiritual aspects CGs

Includes but is not limited to effects of the training; for example, may also include spiritual effects of the caregiving itself

Code: Spiritual aspects PCFs

Includes but it not limited to effects of being the trainer for the CGs; for example, may also include spiritual effects of other inputs such as the ACTS2 project leaders, church leaders, etc.

Code: Relationship between PCF and CG

Code: Relationship between/among CGs

Code: CR

Anything about dementia care recipient

Code: Family

Anything about a family member other than dementia care recipient

Code: Other people

Anything about people other than PCF, CGs in group, CR, or family

Code: In-session experiences

Includes assessments of time, efficacy, process

Code: Technology

Anything about the technology used for delivering the training: cell phone, the conference calling system

Anything about computers used for any reason (such as but not limited to PCFs entering data, PCFs or CGs using the internet or mobile networks for anything)

Code: Problems with training

Any problems or drawbacks associated with the intervention (e.g., timing, content, process, materials)

May be combined with another code (such as but not limited to resources, spiritual aspects)

Code: Benefits of training

Any benefits or upsides of the intervention
May be combined with another code

Code: Transitional disclosure

Use for utterances not relevant to project
Do NOT use for follow-up agreements to meaningful question/answer pairs.
Use for “hanging-up” conversations at the end of interviews, times when interviewer talks about him- or herself, if interviewee asks interviewer questions NOT about the project, etc. Use sparingly

Code: Interruptions

Use for interruptions during the interview itself.
May also include a code for who did the interrupting (CR, family, other people) if that is discernable
Do NOT use for discussions of interruptions during the training sessions; use “In-session experiences”