2018

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This is an accepted manuscript of Qualitative Health Research. The publisher's version of record is available at https://doi.org/10.1177/1049732317743238.
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Funding Acknowledgements

This project was funded by a grant from the Byrd Alzheimer’s Institute to Dr. Robert Glueckauf (AR-2007-05).

Acknowledgements

We acknowledge with gratitude the assistance of Dr. Patricia Chipi, Dr. W. Shuford Davis, Dr. Lance Tegen, and Stephanie Williams in conducting the research.
Abstract

This article presents themes emerging from semi-structured interviews with dementia family caregivers in rural communities who participated in an integrative, cognitive-behavioral and spiritual counseling intervention, and with faith community nurses (FCNs) who delivered the intervention. The primary objectives of the counseling intervention were to ameliorate dementia caregivers’ depressive affect and the severity of their self-identified caregiving and self-care problems. The qualitative portion of the study was intended to elicit caregivers’ and FCNs’ perceptions of the benefits and drawbacks of the intervention. We conducted interviews with seven FCN/caregiver pairs four times during the six-month counseling process, totaling 56 interviews. Themes emerging from the interviews included caregivers’ perception of burden and care partners’ problem behavior; formation of therapeutic alliance between FCNs and caregivers; problem-solving skills, tools, and resources; caregivers’ use of problem-solving strategies; spirituality in caregiving and counseling processes; FCNs’ prior professional experience; and caregiver and FCN time constraints.
Introduction

Eighty percent of adults with dementia receive care in the home from family caregivers, who face challenges that put them at increased risk for depression and compromised physical health (Alzheimer’s Association, 2017; Ory, Yee, Tennstedt, & Schulz, 2000; Ostojic, Vidovic, Bacekovic, Brecic, & Jukic, 2014). Cognitive-behavioral intervention (CBI) has been shown to improve caregiving skills, self-efficacy, depression, and health status in dementia caregivers, but access to such services has been hindered by geographical, financial, and socio-cultural barriers (Brenes, Danhauer, Lyles, Hogan, & Miller, 2015; Glueckauf, et al., 2005; Glueckauf et al., 2009). Over the past decade faith community nurses (FCNs), licensed RNs with a sub-specialty in faith-based service provision, have assumed an increasingly large role in delivering CBI to family caregivers, with the potential benefit of aligning such interventions to caregivers’ spiritual beliefs. FCNs’ community ties, commitment to reducing gaps in health care shortage areas, volunteer service, and spiritual orientation make a compelling case for their involvement in CBI for dementia caregivers (McGinnis & Zoske, 2008; O’Brien, 2018; Rydholm et al., 2008; Ziebarth, 2014).

The primary purpose of the overall faith community nurse study was to evaluate the effectiveness of an FCN-delivered cognitive-behavioral and spiritual counseling (CBSC) intervention on changes in depression and the severity of caregivers’ identified caregiving problems and self-care problems. This article reports exclusively the qualitative portion of the study, relating key descriptive findings that include caregivers’ perception of burden and care partners’ problem behavior; formation of therapeutic alliance between FCNs and caregivers; problem-solving skills, tools, and resources; caregivers’ use of problem-solving strategies; spirituality in caregiving and counseling processes; FCNs’ prior professional experience; and
caregiver and FCN time constraints. The article concludes with implications for caregiver interventions that include spiritual components.

**Background**

**Dementia Caregiving**

Epidemiological studies have estimated 5.5 million adults in the United States have Alzheimer’s dementia, and this figure is expected to reach 13.8 million by mid-century (Alzheimer’s Association, 2017). Worldwide, approximately 47 million people have dementia, with almost 10 million new cases annually estimated by the World Health Organization (2017); Alzheimer’s Disease International (2013) projects 115 million people worldwide diagnosed with dementia by 2050. Symptoms of progressive dementia include increasing memory loss, decline in ability to perform daily routine activities, and disorientation related to time, place, and person. As the illness progresses over time, those with dementia become increasingly dependent on others, especially family members, for assistance in activities of daily living. There is global acknowledgement of a need for integrated, coordinated care for people living with dementia (Alzheimer’s Disease International, 2016),

In the United States, more than 15 million people provide unpaid care for someone with Alzheimer’s or other dementias, and this care is often provided by family members in the home (Alzheimer’s Association, 2017). Family caregivers face various challenges in providing assistance to older adults with progressive dementia, such as monitoring hygiene activities, managing complex medication regimens, and dealing with agitation and aggressive behavior. Caregivers who perform such intensive home care activities often experience significant psychological distress, sleep fragmentation, reductions in social activities, and disrupted family relationships, leaving them at substantial risk for mental health problems, especially depressive
disorders (Joling, et al., 2015; McCurry, Logsdon, Teri, & Vitiello, 2007; Schulz, Visintainer, & Williamson, 1990; Svendsboe, et al., 2016) and compromised physical health (Gilhooly, et al., 2016; Vitaliano, Schulz, Kiecolt-Glaser, & Grant, 1997).

Evidence from meta-analytic studies has found CBI effective in enhancing coping skills and reducing depressive affect in dementia caregivers (Belle et al., 2006; Coon & Evans, 2009; Dickinson, Dow, Gibson, Hayes, Robalino, & Robinson, 2017; Schulz et al., 2003; Sorensen, Pinquart, & Duberstein, 2002), and individual empirical studies have also demonstrated such effectiveness (Gallagher-Thompson et al., 2003; Gaugler, Roth, Haley, & Mittelman, 2008). CBI has been shown to help dementia caregivers cope with pre-death grief (Meichsner, Schinköthe, & Wilz, 2016; Meichsner & Wilz, 2016) and overall to improve their self-efficacy (Tang & Chan, 2016). Although CBI has shown promise in reducing depression, a substantial gap exists between caregiver mental health needs and available services (Glueckauf et al., 2005). Translation of CBI programs to the community has been thwarted by geographic, financial, and socio-cultural barriers. These interventions typically have been performed at health science centers in major metropolitan areas for urban dementia caregivers (Schulz et al., 2003). Dementia caregivers find it difficult to attend any form of group intervention, even locally, due to high costs of and logistical problems in obtaining respite care and transportation (Scott et al., 2016). Socio-cultural barriers are also a significant obstacle in translating CBI-based treatment (Wells et al., 2017). Individuals tend to be somewhat mistrustful of providers and interventions originating outside their locale, and this is particularly the case when the provider and/or the treatment approach appear to conflict with their family and religious values (e.g., Glueckauf et al., 2012; Glueckauf et al., 2005; Glueckauf & Lustria, 2008).
Religion, Spirituality, and Religious Coping

To better understand the coping process of distressed dementia caregivers, researchers have investigated the relationships among spirituality, religion, and caregiving support. Spirituality and religion are distinct ideas operationalized in different ways. Spirituality generally refers to individuals and their relationship with sacred, transcendent, and meaningful entities beyond themselves; religion incorporates a shared set of beliefs and practices that are developed within a community and provide structure in guiding formal worship practices (Stuckey, 2001, p. 70; Sun & Hodge, 2014, p. 3).

Prior research has indicated dementia caregivers use religious coping to help them manage caregiving stressors, but the specific effects of such coping strategies on depression and caregiving burden have varied considerably (Heo, 2014; Rabinowitz, Hartlaub, Saenz, Thompson, & Gallagher-Thompson, 2010; Rathier, Davis, Papandonatos, Grover, & Tremont, 2015; Stolley, Buckwalter, & Koenig, 1999). Spirituality alone has shown inconsistent results with various health-related outcomes among dementia caregivers, with different research studies demonstrating positive associations, negative associations, and no associations between spirituality and caregiver well-being (Hebert, Dang, & Schulz, 2007; Hebert, Weinstein, Martire, & Schulz, 2006; Rathier, Davis, Papandonatos, Grover, & Tremont, 2015; Wilks & Vonk, 2008). The related concepts of spirituality and self-efficacy have been explored among dementia caregivers to determine their relationship to caregiver well-being, again with varying results, with mediating and moderating effects on depression, anxiety, and anger covarying inconsistently with caregivers’ spirituality and religiosity (López, Romero-Moreno, Márquez-González, & Losada, 2012; Márquez-González, López, Romero-Moreno, & Losada, 2012).
The present study incorporated spirituality into the framework of CBI, emphasizing development and implementation of problem-solving strategies. Spurlock (2005, p. 154) stressed the need for “culturally relevant caregiver intervention strategies and programs that incorporate spirituality as a core component,” a need echoed by Sun and Hodge (2014, p. 20). Ennis and Kazer (2013, p. 110), in their review of spiritual nursing interventions for dementia, and Heo (2014, p. 380), in her study of religious coping among dementia caregivers, also emphasized the need for faith-based programs to support dementia caregivers. When nurses are involved in caregiver support, the nurse’s understanding of the caregiver’s spiritual situation is key to supporting their caregiving efforts (Levine, 2011, p. 50). To this end, the current study evaluated the effectiveness of using FCNs to facilitate a cognitive-behavioral spiritual counseling intervention delivered to rural dementia caregivers.

Faith Community Nursing

Professional volunteer groups, including FCNs, have begun to assume a greater role in delivering skills-building and support interventions to family caregivers of older adults with chronic illnesses (Glueckauf, et al., 2009; McGinnis & Zoske, 2008; Ziebarth, 2014). The American Nursing Association (ANA) has recognized faith community nursing as a specialty area of practice with published scope and standards of practice (ANA/HMA, 2012). Faith community nursing is a national endeavor involving more than 12,000 nurses across the country (King & Pappas-Rogich, 2011) and holds promise as a community-based practice that may contribute to the reduction of health care costs (Rydholm et al., 2008; Yeaworth & Sailors, 2014) and promote health and disease prevention (Dyess, Chase, & Newlin, 2010; Ziebarth, 2016).

Nursing practice that includes spiritual care should include a focus on cues coming from the client or patient about the desirability of spiritual practices, and responsive reflexivity to the
reactions of nurses and clients to a spiritual encounter (Burkhart & Hogan, 2008). The development of “caring relationships” between nurses and clients in spiritual nursing is necessary for the desired outcome of “spiritual comfort and well-being” (Carr, 2008, p. 690). The spiritual connection between nurses and clients should be developed in a cyclical, iterative, way that accommodates the background perspectives of both (Hood, Olson, & Allen, 2007).

A major advantage of using FCNs as facilitators for skills-building and educational interventions is that family caregivers perceive FCNs as skilled professionals who share their spiritual beliefs and values. FCNs typically deliver education and spiritual support interventions to family caregivers in the home setting, reducing access difficulties commonly faced by dementia caregivers (McGinnis & Zoske, 2008). FCNs’ strong ties to the community, their commitment to bridging the health care access gap, their spiritual orientation, and the low cost of their volunteer services make collaboration with this professional group in delivering cognitive-behavioral intervention to dementia caregivers a compelling option.

**Faith Community Nurse Study**

The purpose of the overarching FCN study (which included parallel quantitative and qualitative components) was to evaluate the effect of the cognitive behavioral spiritual counseling intervention on changes in depression and problem improvement in distressed rural dementia caregivers. The quantitative measures included the Caregiver Self-Efficacy Scale (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002), Caregiver Appraisal Inventory Burden Scale (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989), Center for Epidemiologic Studies Depression Scale (Radloff, 1977), Problem Severity Scale (Glueckauf, 2000), Interpersonal Support Evaluation List (ISEL; Cohen, Merielstein, Kamarck, & Hoberman, 1985; Schulz & Williamson, 1991) and the religious coping scale of Brief
Multidimensional Measure of Religiosity and Spirituality (Fetzer Institute & National Institute on Aging Working Group, 1999). The initial findings of the preliminary quantitative analysis, which is still in process, indicated significant improvement in caregivers’ self-efficacy, appraisals of subjective burden, depression, and problem improvement were obtained from pre- to post-counseling. No significant changes were indicated on measures of social support and religious coping.

This article reports the analysis of the qualitative component of the FCN study, and all subsequent mentions of “the study” refer exclusively to the qualitative component. The purpose of this component is to amplify our understanding of FCNs’ and caregivers’ acceptance of, and experiences in, integrating evidence-based, problem-solving interventions with spiritual counseling. The qualitative questions probed FCNs’ and caregivers’ descriptions of the overall project, their experiences in specific counseling sessions, the relationships within the FCN and caregiver pairs, the spiritual/religious practices they used during the counseling, and their perceptions of the efficacy of the intervention. The study was reviewed and approved by the Florida State University Human Subjects Committee.

**Specific Aims**

The specific aims guiding the design of the qualitative portion of the study were:

1. Increase understanding of FCNs’ perceptions of the benefits and drawbacks of problem-solving counseling, and of how problem solving was incorporated with the spiritual counseling process.

2. Identify FCNs’ perceptions of facilitators of, and barriers to, caregiver problem improvement in the counseling process.
3. Explore FCNs’ perceptions of the benefits and limitations of this counseling intervention.

4. Explore caregivers’ beliefs about, perceptions of, and experiences with the problem-solving counseling sessions.

5. Increase understanding of the caregivers’ perceptions of the effects of the counseling.

6. Explore caregivers’ perceptions of, and experiences with, their spiritual relationships with their FCNs and their care partners.

**Methods**

**Participants**

Caregivers were recruited for the study through outpatient neurology clinics at two large health facilities in the Southeastern United States. Caregivers 18 years of age or older were eligible to be included in the study if they provided at least six hours of care per week for a spouse, parent, or relative who was 60 years or older and had dementia, and if they scored a minimum of 10 on the Patient Health Questionnaire–9 (PHQ–9; Kroenke, Spitzer, & Williams, 2001). FCNs were solicited by nurse managers/coordinators of the FCN programs at the health facilities and were registered nurses (RNs) already engaged in faith community nursing endeavors. Caregivers and FCNs were assigned to each other based on geographic proximity. FCNs each received an honorarium (not a payment for services) of $75 for serving as facilitators. Caregivers each received $72.50 for their participation in the study.

The cognitive behavioral spiritual counseling intervention comprised twelve one-hour sessions delivered biweekly in caregivers’ homes over a period of six months. The counseling focused on the identified problems of dementia caregivers, and the most frequently used CBT
elements of the treatment program were relaxation training, reframing ineffective thinking, increasing assertiveness, and building in pleasant daily events. Spiritual counseling focused on the use of religious coping strategies, such as prayer, meditation, positive affirmation, and communal support.

Eight FCNs (all female) participated in the program and attended a 2.5-day training workshop prior to delivering the counseling. The training for the FCNs included instruction and practice in core counseling skills, spiritual self-care, spiritual assessment and intervention, and problem-solving counseling skills. FCNs were explicitly trained to approach the counseling in a way open to caregivers who were of different faiths and spiritual traditions, and to caregivers who do not engage in spiritual traditions and/or who identify as agnostic or atheist. FCNs received a manual for the intervention during their training workshop; at the request of the FCNs, the caregivers were not given a formal step-by-step guidebook, so that the FCNs could more actively guide and monitor the caregivers’ progress. The PI and an associate also provided supervision to the FCNs over the telephone prior to and following each of the twelve problem-solving sessions.

Seven of the FCNs and their caregivers were interviewed for the qualitative portion. Of these seven caregivers, six were female and one male, which mirrors the gender composition of the overall project.

**Qualitative Data Collection**

One researcher interviewed all of the FCNs, and one researcher interviewed all of the caregivers, allowing each researcher to establish rapport over time with the participants they interviewed and affording early insights into the data through continuous memoing. All interviews were conducted via telephone and were recorded. Interviewer and participant engaged
in an informed consent process at the beginning of each interview. Interviews were conducted in a deceleration pattern with increasing intervals between interviews: participants were interviewed after counseling sessions 2, 5, 8, and 12. This pattern allowed the researchers to collect more data early to establish an understanding of the phenomena under study, and to capture changes over time through the intervention (May, 1991, p. 189). Prior research with caregivers indicates that frequent interviewing increases participant burden and stress levels (Glueckauf et al., 2012). The pattern of interviews was designed to avoid additional stress as much as possible while still permitting the collection of sufficient data to address the specific aims. For the same reason, although it would likely have been methodologically desirable, participants were not asked to review and reflect on the findings.

The themes addressed in the interview schedules (Appendix) were designed to meet the specific aims and are of the descriptive/interpretive type (McIntosh & Morse, 2015). The FCN interviews all asked about FCNs’ in-session experiences, their perceptions of the adequacy of counselor training and bi-weekly consultations with project PIs, and perceptions of their spiritual relationship with their caregiver. The first interview with FCNs also included questions about the FCNs’ background (work and education) and their perceptions of the benefits and drawbacks of the integrative cognitive behavioral spiritual counseling process.

The caregiver interviews all asked about caregivers’ in-session experiences, their perceptions of the efficacy of the counseling, and their perceptions of their spiritual relationships with their FCN and with their care partner. The final interviews with FCNs and with caregivers added questions on overall perceptions and reflections of the counseling process.
To allow interviews to pursue emergent topics of interest, the interview schedules included sample probes. The interviewers were instructed and prepared to ask additional questions during the interview as appropriate to the purpose of the research (May, 1991, 192–3).

**Data Analysis**

All interview recordings were transcribed by members of the research team. Microsoft Excel was used to support the data coding and analysis process (Meyer & Avery, 2009). The researchers decided that the unit of coding would be each utterance pair between the interviewer and interviewee, so each question or prompt by the interviewer was coded together with the participant’s response.

The 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). Analytic memoing occurred throughout data collection, and memos were included with the interview data during coding. 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 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” (Kazmer, 2010, p. 763).

The coders used an inductive, iterative process of discussion and additional coding to resolve disagreements and ensure trustworthiness of the coding (Ahuvia, 2001) resulting in one consistent corpus of coded data rather than multiple sets of independently coded data (Bradley,
Curry, & Devers, 2007; Steinke, 2004). The researchers worked together using concept mapping techniques to create categories of the codes and associated data. Visualizing how the codes related to each other in multiple ways helped to keep the categories from becoming exclusive and monolithic, instead staying flexible, interpretive, and accommodating of varying relationships in the data (Knigge & Cope, 2004). An example of the coding process is summarized in Table 1.

Table 1. Analytic vignette based on “Caregiver’s relationship to God” in the context of the FCN cognitive-behavioral spiritual counseling intervention.

<table>
<thead>
<tr>
<th>Caregiver’s relationship to God</th>
<th>Is not orthogonal to;</th>
<th>Relationship to Care Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Connection is of high magnitude</td>
<td></td>
</tr>
<tr>
<td>Caregiver’s relationship to God</td>
<td>Is not orthogonal to;</td>
<td>Relationship with FCN</td>
</tr>
<tr>
<td></td>
<td>Connection is of low magnitude</td>
<td></td>
</tr>
<tr>
<td>Caregiver’s relationship to God</td>
<td>Has inverse</td>
<td>Atheism [intentional non-relationship with God]</td>
</tr>
<tr>
<td>Caregiver’s relationship to God</td>
<td>Has directionality</td>
<td>Close personal predominantly accepting relationship with God; Questioning relationship with God [agnosticism]</td>
</tr>
</tbody>
</table>
Findings

The research team prioritized capturing the experiences and perceptions of both FCNs and caregivers throughout the shared process of the cognitive behavioral spiritual counseling intervention, so the data were analyzed together and are presented together here. Quotes are identified by role: FCN or caregiver (CG). Identifying information has been redacted. The quotes provided were selected because they represent typical statements made by the caregivers and FCNs.

The findings have been organized in a way that “best fits the data” (Sandelowski, 2000, p. 339) and are not presented in a 1:1 match to the specific aims or to the data collection instrument, but reflect the thoughts and perceptions of the FCNs and caregivers in their words. The findings are organized temporally, from the caregivers’ caregiving situations through their experience in the counseling, and conceptually, beginning with themes primarily associated with the caregivers and moving through themes more closely associated with the FCNs.

Caregivers’ Perception of Burden and Experiences with Care Partners

The responsibility of being a caregiver with an individual with dementia is stressful. In this study, as with most family caregiving arrangements, the care partners with dementia were close loved ones, such as a spouse, parent, or sibling. The care partners went through dementia-related changes the caregivers could not control, leading the caregivers to feel helpless and overwhelmed. In addition to this emotional stress, the burden of providing daily care was physically trying. The caregivers felt they were the only ones who could provide quality care for their care partners. Feeling alone in the process, the caregivers were tired and overworked, and had difficulty caring for themselves. An FCN said of their caregiver: “We discussed ways that she can care for herself because she stays stressed trying to do everything. She doesn’t feel she
has time to take care of herself.” Another caregiver described her feeling that she “had to be home” because of her care partner’s physical care needs and specific dementia symptom of anxiety:

I had to be there at all times. And if I left home, like if I left to go to the gym for half an hour, he was too, too nervous - so nervous that something would happen to me, and I could not go out. He thought I would be kidnapped at all times.

Although the care partners were not explicitly included in this intervention, they were an important tacit part of the process, especially for the caregivers. As their dementia progressed, care partners’ symptoms of physical decline and the difficulties of their daily routines became more challenging. Challenges included care partners’ forgetfulness, hiding or misplacing things (including cash or checks), wandering, miscounting or losing medicine, accidentally falling, and lack of interaction with others. For example, one caregiver was concerned for her care partner’s safety because “right now my sister has a very short memory if anything at all, you know. She can’t really remember one minute to the next on some things.” Another care partner’s deteriorating condition was described by an FCN: “care partner is declining very rapidly and in probably a month care partner’s gone from verbal and continent to completely incontinent and nonverbal.” Because of these rapid changes, the FCNs needed to prioritize teaching the caregivers about the disease process, what to expect, and how to anticipate and deal with care partners’ degeneration.

Care partners’ disease progression also incurred negative changes in their personality and behaviors. Such changes were reported as their becoming progressively demanding, controlling, paranoid, and/or angry, or denying the occurring condition. For example, one care partner started making sexual jokes and comments in inappropriate settings, such as the doctor’s office; another
care partner emptied clothes closets at night; and a third care partner changed all the labels on her weekly medicine box.

**Formation of the Therapeutic Alliance between FCNs and Caregivers**

An essential component of the counseling was the connection established between each caregiver and FCN. Once this connection was made during early sessions, caregivers were willing to confide in and accept the help of their FCNs, which in turn allowed caregivers to improve their quality of life. As the caregivers opened up to their FCNs, the nurses began to understand their caregivers’ personalities and life challenges, which were then used to guide the counseling sessions. For some FCN-caregiver pairs, the connection was easy to establish. One caregiver said, “Right from the start we just hit it off and took off from there.” But establishing a connection was initially challenging for other pairs, as some caregivers were reluctant to receive help, did not feel comfortable letting a stranger into their lives, or did not understand exactly how the program could help them. An FCN described the early stages with her caregiver, saying, “[CG] was very reserved about having anybody come into her home, although, I think she was so far stretched and spent that she knew she needed some kind of help.” Another FCN described a similar process with her caregiver:

> The first couple of weeks it was like, this strange person is coming in, and [CG] is not sure what I’m doing, and I’m not sure what [CG] wants, but each week I feel more of a connection.

Caregivers started the counseling process with many common problems that could be more effectively addressed after the FCN/caregiver relationship was established. All caregivers were helped by their FCNs’ provision of accurate and accessible information about Alzheimer’s and related dementias. For example, one caregiver said, “[The counseling sessions] were
important because I had somebody to talk to and somebody that was familiar with the Alzheimer’s disease.” Another caregiver explained how receiving information helped: “The book [my FCN] gave me was a tremendous help in understanding how when my [care partner] would get into these moods, it wasn’t really her.”

After the connection between caregiver and FCN was established, the FCN could help the caregiver with the challenges they faced. Having access to a caring and knowledgeable listener provided relief to the caregivers. As one caregiver expressed, “It was just wonderful knowing that there was somebody out there that cared about what was happening, and was willing to listen and lend an ear and be helpful.” An empathetic listener was important, but not sufficient. The counseling was also crucial to caregivers because it taught them specific ways to deal with their challenges. An FCN described moving from establishing the relationship with the caregiver to working on the problem solving skills (in this case, the relaxation training):

In those first sessions I was mainly trying to set up a personal relationship with [CG] to gain her trust and also to enable her to talk through a lot of her problems in order to organize them a bit better in her mind. I was also, not trying to solve her problems, but trying to give her some basic relaxation techniques to use that might enable her to think a bit more clearly and more logically about her problems and their solutions.

With the help of the FCNs, caregivers who once felt hopeless and alone could see how changing their approach to a situation and asking for outside help could improve their lives. As one caregiver said, “I wasn’t sure that I could do it, but with [FCN]’s support and things that she’s taught me…. I feel very confident in it.”
Cognitive Behavioral Spiritual Counseling Tools: Skills and Resources

Most caregivers provided solo in-home care and experienced fatigue, exhaustion, insomnia, anxiety, depression, and other health ailments as a result of the demands of their daily care tasks and their lack of self-care. FCNs were trained to meet caregivers’ needs by informing them about the nature and progression of dementia and the necessary self-care skills from the skills module manual. The skills modules in the counseling helped caregivers to improve their capability to maintain their own physical and mental health. These major skill sets included communication, relaxation, goal setting, effective thinking, assertive responding, goal implementation, and outcome measurement. Many self-care and problem-solving skill sets were demonstrated with scenarios relevant to caregivers’ situations. With FCNs’ instruction and empowerment, caregivers could effectively implement the skills needed to manage the various physical, emotional, family, and financial stressors they encountered. Caregivers began asking family members, church members, volunteers, and out-patient nurses to care for their loved ones so they could have time to run errands or use relaxation techniques throughout the day. It was important for the FCNs to remind the caregivers that their health was essential and should not be pushed aside, because if they were happier and healthier, they could provide better care to their care partners. As one caregiver said, “I might not have been as aware of my own needs if [FCN] had not pointed out the importance.” Another caregiver stressed the connection between self-care and successful caregiving, saying that their FCN “made it quite clear that I needed to make sure that I took care of myself, in order that I could take care of my [care partner].”

In a post-session-twelve interview (near the end of the counseling process), one caregiver indicated that she continued to use the skills, which included taking time for self-care, learned during the counseling:
When I feel like things are starting to close in on me, I go back to what the FCN has said, and the FCN has given me meditations, and I just have to remember [...] that I have to take some time to myself, even if it’s just a few minutes.

In another post-session-twelve interview, an FCN confirmed that her caregiver continued to implement the relaxation and positive thinking skills in her daily practices of caregiving and working, saying: “We talked about [CG]’s basic skills and how [CG] was still using them. [CG] still is, and freely admitted that [CG] is still using the relaxation techniques and the positive thinking.”

The problem-solving skills and techniques were taught within a context of problem identification and teaching the caregivers to apply the appropriate problem-solving strategies to their specific situations. FCNs worked with the caregivers to assess the results of applying the strategies and to develop plans to cope with future challenges. One FCN described her work with her caregiver on the five skills modules: “We went through all five of them. I gave her the material, we talked about how best to utilize that, and we sort of referred to those as we went on in the sessions.”

Over the course of the counseling intervention, one care partner had to be moved to an assisted living facility (ALF). The FCN described, in this post-session-twelve interview excerpt, how she used the skills modules to help the caregiver through this transition:

For the last session in the module, it talked about transitioning and what you should cover. And I actually went back into the original books and used one of the appendices on how to deal with difficult things, and it was going into an ALF, it was going into leaving your home and into a facility. And how to deal with doing
that and the patient wanting to go home from there. I used the manual and the
skills list of the different modules throughout the 12 sessions.

An FCN explained how she selected skill modules tailored the caregiver’s current and
ongoing caregiving problems, and used materials from the FCN project manual to help ensure
the caregiver had a resource to use after the counseling was over:

I actually pulled out the manual and looked through it to find the different
sections that applied to what we had discussed and I started making copies for
some sections for [CG]. [CG] was very concerned about what would happen
when I would not be coming anymore, who she would talk to and how she would
handle it. We had gone through some skills that we had used to solve some things,
and I made copies of those sections so that she could use it like a little workbook
so she could remember what we had done.

Through the counseling sessions, FCNs often developed strong bonds with caregivers and
provided emotional support and a variety of resources to caregivers. These included information
about outside help or alternative care, available sources from the local community or
organizations, financial sources, and even the FCN’s personal help (Kazmer, Glueckauf, Ma, &
Burnett, 2013). When caregivers needed outside assistance and had limited access to it, it was
helpful for the FCNs to introduce the caregivers to available resources for home care help, such
as church respite programs, adult day cares, support groups, and alternatives to assisted living
facilities. A caregiver described the outside help as “some light at the end of the tunnel.”

Time constraints, fear of or reluctance in asking for help, and limited access to available
resources held caregivers back from seeking outside help. FCNs persuaded caregivers to reassess
the value of self-care and to conquer their personal sense of guilt about accepting and reaching
for help from family members or outside communities. For example, an FCN taught her caregiver, who was depressed and tended to interact negatively with others, “to be more assertive and not accusatory or throwing guilt on people, but really telling people in her words what she needed help with.” Another FCN encouraged her caregiver to ask the caregiver’s son, who had been providing hands-off support by sending money and scheduling needed household repairs, to participate in more hands-on caregiving tasks, such as taking his father for lunch or for a haircut.

As care partners’ conditions deteriorated, caregivers often encountered increasing financial distress when seeking in-home help or alternative care. FCNs learned that caregivers might be unaware that they needed to take control of personal legal matters, and they worked with caregivers to develop the skills they needed to do so. For example, an FCN said that her caregiver changed from being scared to seek financial resources during session six or seven to independently and assertively “making appointments where she was filling out paperwork and making phone calls about Medicare and Medicaid and Social Security and financing” at session twelve.

**Role of Spirituality in Caregivers’ Relationships with their Care Partners**

The role spirituality played in caregivers’ reactions to care partners’ disease progression and their receiving care from others varied among participants, changed over time, and was influenced by the dementia progression. Many caregivers felt spirituality was inherent to their caregiving role. One caregiver viewed her faith as “a source of strength” in her caregiving role, and said she now felt God would want her to take better care of herself so that she could better care for her loved one.

When another caregiver was asked how spirituality had influenced the relationship with her care partner [husband], she said she considered spirituality as the “foundation and the basis”
of their relationship, but she could not engage in many spiritual activities, such as prayer and Bible reading, with her husband once his illness began. This caregiver also said “Yes, I think my religious stance definitely has an effect on how I relate to him. That’s been from the get go; we’ve been married for forty years.” Another caregiver expressed her thankfulness for her spirituality and that of her care partner, who is her sister:

We came from a very religious family and […] and [care partner] is a very religious person herself. And so I think that, especially now if I did not really have the strong faith and if we were not that close, I don’t know whether I could handle taking care of [her].

In another case, a caregiver stated that she and her care partner (her husband) were agnostic, and together had read and discussed many books about spirituality and religion. The caregiver continued to identify as agnostic throughout the interviews, but her husband seemed to be reaching out to God as he participated in prayer with hospice nurses. As the caregiver described:

[My husband] was agnostic too. I don’t know in the end if it’s true because he talked to the people in the nursing home there and, um, they said that he prayed so I don’t know. But he didn’t do it when I was there.

The findings thus far have focused on key themes emerging for the caregivers during the cognitive behavioral spiritual counseling process. The following sections focus on experiences that were more central to the FCNs: changes to their expectations of the counseling process, the impacts of FCNs’ prior professional experiences, and time constraints.
Changes in FCNs’ Expectations of the Spiritual Counseling Process

The decision to become an FCN was generally motivated by a desire to mix the vocation of nursing with spiritual aspirations. The formality of the FCN program in fostering this mix was an attractive feature, as one FCN explained:

A couple of the other nurses had gotten with me and said wouldn’t it be great if we could have some kind of nursing ministry. So then one of the nurses had found out about [X] and the faith community program there and got the rest of us referred to it and we went in and got our training, and that’s kind of how it got started. We wanted to do something more with our nursing.

In this project, in cases when the religious faith of the caregiver did not match that of the FCN, there was an adjustment to the FCN’s expectations of the faith-based nursing process. The FCN may have entered faith nursing with the expectation that they would be engaging in close spiritual relationships with the people they treated and counseled, that spiritual beliefs and religious practices would be in sync, and that they would be an intrinsic part of the counseling. When a mismatch occurred, the FCN and caregiver negotiated a mutually-acceptable solution driven by the preferences of the caregiver.

For example, one FCN was a religious person who took comfort in her spirituality, but was paired with a caregiver who was agnostic. The FCN described her reactions to this at two different points in the counseling process, which show that over time she adjusted her inclusion of religious behavior and her spiritual approach based on the caregiver’s agnosticism:

I think that’s a big thing, because for me, saying prayer is very comforting and I enjoy doing it. And I wanted to bring that into [CG]’s home but she didn’t really
welcome it. Working with a religious person, it would have been easier. Definitely. [post-session-2 interview]

It was a challenge because she was agnostic and she was going through the process where he was really getting sick. It gets worse, you know? How is all this happening and happening? So spiritually I had to be very open to her beliefs and be supportive and not bring upon my beliefs, you know. [post-session-8 interview]

A religious mismatch also happened for another FCN, who described her initial expectations: “I think it is very liberating where you can have this kind of setting where you are expecting to combine your faith with your healthcare.” But in practice this FCN’s faith did not match that of her caregiver’s; she characterized this aspect of the counseling as being “a little tough,” but they persisted and both FCN and caregiver experienced the counseling overall in a positive way.

In other cases there was religious and spiritual alignment from the beginning, and in such cases, the FCN’s experience tended toward a spiritual experience with the caregiver rather than a challenge to overcome. An FCN had this experience:

My upbringing as a Catholic, we don’t do a lot of overt prayer or things like that, and she was raised the same way. That was something we discussed initially: do you want to pray at the beginning of each session? Do you want to pray at the end? Do you want to pray at all? […] and really how it played out is she didn’t really go for the whole out loud prayer thing. Which was fine with me, but we do talk a lot about her relationship with God and her talking to Him and things like that.
Meeting a new person, you don’t know what their relationship is with their faith or what their relationship is with God, and through the sessions I’ve learned more and more what her relationship is with God. And unbeknownst to me at the beginning, she used to be a Catholic nun. So she has a pretty close relationship with God. You see it’s beneficial for me as well.

**Impact of FCNs’ Prior Professional Experience**

Another theme that emerged for FCNs was the impact of their prior professional nursing and/or counseling experience, and their own experiences in caregiving, on the cognitive behavioral spiritual counseling process. For some FCNs, this prior experience was closely related to dementia caregivers (e.g., counseling, hospice care, participating in caregiving within their families) but for others it was more remote (such as surgery).

FCNs used their prior work experience actively in the counseling and thought it helped them. For example, an FCN said, “I’ve been a hospice nurse in the past and everything. So my skills came back.” Another FCN explained: “Everything you do as a nurse plays in with what you do as a faith community nurse because you run into as many different situations as there are people on the planet.” Alternatively, volunteering to engage in FCN work was for some a way to gain new experiences and add a new dimension to their nursing work. One FCN described her workplace and the difference between it and the FCN context:

[At my job there are] the same nurses, the same doctors, and more or less the same patients—it is a revolving door. So I wanted to connect with other nurses. Of course I like the spiritual aspect, looking at the whole person. We’re entitled to talk about our faith, and use faith to get strength. At my job—we cannot do that.
In addition to the experiences the FCNs already had, the training for this project was an integral part of the FCNs’ experience of the counseling intervention. One FCN said the training “helped me to keep my boundaries so that I didn’t get over involved with [CG]. It also helped me look more professional and be a better resource.” Another FCN said she did not have much experience with the type of patient she encountered during this project, and that the inclusion of explicit training for the FCNs in the project helped her learn new things and remember relevant lessons from nursing school:

I didn’t have a whole lot of experience with elderly patients and caregivers of Alzheimer’s patients or even caring for Alzheimer’s patients. So the training kind of helped me understand a little more, what they might be going through. [...] We learn it in nursing school and that’s forever ago, and if you don’t use it you kind of lose it, and so it was a nice recap.

Sometimes, though, the training and counseling process taught the FCNs something they did not have the opportunity to learn in prior nursing experiences. An FCN shared:

The skill I learned the most was to listen. Teaching in the surgical field, I only have so much time to teach a patient what they need to know, and so I need to do teaching, and be the talker. Learning to listen is what I learned the most.

An FCN indicated that the psychosocial aspects of the project training helped her learn something new:

It’s not just medical information, a lot of what we deal with as a parish nurse is cognitive behavior therapy, and that’s why this program, the Alzheimer’s program is so helpful for me. I hadn’t had a lot of training in the psychosocial aspect of supporting.
Time as a Resource for FCNs and Caregivers

Time appeared as a factor in the interviews with the caregivers and FCNs, in part because it was the topic of several interview questions (asking about efficient use of time during the counseling sessions, for example), and in part because it was mentioned spontaneously by caregivers and FCNs as being a commodity that had to be acknowledged and managed, and as being closely associated with stress both short-term (not having enough time in the day to do things) and long-term (unpredictability and fleetingness of time with their care partners). The emphasis on time was also interjected into the counseling process because the caregivers were given a copy of The 36-Hour Day (Mace & Rabins, 2006), a book that includes practical advice for dementia caregivers.

The caregivers saw time as something they could “take” or “have”, and something that could be “given” to them by others: One caregiver said, “[He] gave me time then. I had several hours every evening for myself when I was sitting there reading. So, you know I had some time for myself for relaxation.” But not having time meant something had to be left undone. For many caregivers what was left undone was self-care, as an FCN said of their caregiver:

She doesn’t feel she has time to take care of herself. Um, working out maybe—so she feels tired. And also feels tired because she’s busy during the day and then she just relaxes after midnight so she doesn’t sleep ‘til 1:30. That’s another reason she’s tired: the lack of sleep and not working out, such as walking or swimming.

One caregiver was lacking time to rest, an additional important type of self-care, as her FCN said: “And she was like ‘I don’t have five minutes to relax anymore and when I do I’m sleeping.’ So we tried to modify some things, and that’s kind of where I’m getting with her. She has no rest time when she is home with [care partner].” Religious or spiritual activities that were
important to the well-being of the caregiver sometimes fell to the wayside because of a lack of time, as another caregiver described: “Meditation is something I try to do when I can and we usually get to church a little early and have a few minutes there, and sometimes when [care partner] is napping I am able to do that, but, usually I have other things I need to get done.”

Over the course of the counseling, caregivers experienced improvement in these aspects of organizing time to facilitate self-care. As a caregiver explained in a post-session eight interview:

They have made me more conscious of having to take care of myself for one thing. And in doing that, be sure to take meds and get the rest that I need and so on. I think I always knew it, but I was never really focused on it or practicing it maybe all the time.

Time limitations affected the FCNs as well. Caregivers realized that the FCNs had constraints on their time, sometimes similar to their own, and appreciated that they were being fit in to someone else’s busy schedule, as one caregiver reports: “I know she’s a very busy gal and she’s got two children of her own, and I think it’s just wonderful that she’s willing to spend this time with me and I really am thankful for it.”

The FCNs generally had other nursing jobs, so time spent on counseling for this project, and parish nursing in general, had to be carved out from other areas of their lives. On the other hand, because the FCN process lacked the constraints of paid jobs, the time spent on it could be more flexible and pleasurable to the FCNs. One FCN described it this way:

I don’t have to be rushed. As a faith community nurse you can take your time.

When you’re at a job and you get paid to see 12 patients in eight hours, your
interviews are really cut short. But when you’re doing the volunteer work it’s a pleasure.

Even given that welcome flexibility, the FCNs and caregivers usually preserved a consistent time structure for the counseling visits. For example, an FCN said, “I tried to stay always the same amount of time.” This predictability was welcome to the caregivers, whose lives were otherwise quite unpredictable. Within the consistent time structure, “efficient” use of the counseling time was characterized in different ways. For some FCN/caregiver pairs, efficient use meant being flexible with their time and letting the caregiver lead the discussion and topics. For other pairs, it meant following the FCNs’ counseling materials closely.

Discussion

Once the caregivers were paired with their FCNs, it took time for the caregivers to trust, accept, and understand their FCNs and the purpose and process of the cognitive behavioral spiritual counseling, a finding which resonates with the nurse/client relationship identified by Ziebarth (2014). Once the alliance between caregiver and FCN was established, each pair worked together to identify solutions to the difficulties the caregivers faced, a usual progression in cognitive behavioral problem solving (Dobson & Dobson, 2016). The FCNs’ offering of information resources up front helped the caregivers learn more about dementia and their care partners, and helped build the FCN/caregiver relationships, creating a foundation for problem-solving techniques and tools that came later in the 12-week intervention. While the focus on spirituality in this cognitive behavioral spiritual intervention is more structured than that described by Carr (2008), the need for relationship building is consistent (Barken & Lowndes, 2017). Establishing relationships between FCNs and caregivers entailed understanding their similarities and differences in religious beliefs and their expectations for spiritual practice within
the counseling, a finding which echoes and amplifies those of Burkhart and Hogan (2008) and Hood, Olson, and Allen (2007). When beliefs, expectations, or comfort with spiritual practices differed, caregiver and FCN explicitly and tacitly developed agreed-upon norms within their relationships that were interwoven into the counseling approach.

Caregivers and FCNs came to the intervention with assumptions about the religious commonality they would have in their counseling pairs, despite the explicit ecumenical approach of the training and counseling. For any such intervention, it is important to manage expectations about the level of spiritual diversity that will be encountered, and training and education for nurses who will participate in interventions that include a spiritual component is key (Carr, 2008). In some cases there may be none (by design or by accident), but important lessons learned from this project are that (a) even in cases where religious alignment seems exact, small differences in background, beliefs, and/or practices may emerge that need to be handled during the counseling; and (b) even in cases where religious conflict seems daunting (mis-matched proselytizing religions, for example), a good relationship and successful counseling outcomes are still possible. Introducing these potential issues during the initial training of FCNs (Ziebarth & Miller, 2010) and providing ongoing professional support for the counselors (as was provided by the PIs in this project) is key to helping them navigate this part of the counseling process.

The counseling sessions were positive for the caregivers and FCNs; while the caregivers were the primary beneficiaries of the intervention, the FCNs also felt as if they benefitted. Faith community nurses provided caregivers with support that helped them to initiate better care for themselves and for their loved ones with dementia. In return, the process of providing help, empathy, and support allowed the FCNs to grow spiritually and enabled them to be better nurses, similar to the way the nurses developed new understandings of connection and caring practice in
the earlier study by Hood, Olson, and Allen (2007). Engagement with the FCN role and the counseling process allowed them to interact with like-minded nurses, and in many cases to combine their professional and spiritual knowledge in ways they could not in their regular workplace but that they welcomed and valued (Funk, Peters, & Roger, 2017). It was beneficial for the counseling process to give the FCNs the freedom to guide the sessions how they saw fit, but it was important to implement a support system (in this case through the project PIs) that the FCNs could turn to for clarification, advice, or reassurance.

Although the care partners were not directly part of the intervention, their disease trajectories shaped the caregivers’ counseling experiences, as also indicated by, for example, the caregivers who received a cognitive reappraisal reported by Cheng, Mak, Fung, Kwok, Lee, and Lam (2017). The needs of individual care partners must be accommodated in the counseling process without unduly taking the time of the counselors or detracting from the caregiver as the focus of the counseling. When caregivers consider their religious beliefs to be a key part of their caregiving practice and relationship with their care partners, the cognitive behavioral spiritual counseling approach helps by acknowledging and incorporating spirituality into the problem-solving techniques (Coats, Crist, Berger, Sternberg, & Rosenfeld, 2017).

An essential aspect of helping the caregivers was showing them that they were not alone (Stansletten, Bruvik, Espenhaug, & Drageset, 2016). Explaining to them what help was available and emphasizing the importance of self-care helped them to feel less overwhelmed. Caregivers could better understand and care for their loved one once they had become more knowledgeable about dementia and what to expect from an individual who has been diagnosed. Resources in the form of education, health care options, and coping techniques played a large role in the success of counseling.
Conclusions & Implications

The results of this analysis indicate that the combination of emotional support, outside resources, and education on dementia worked to help caregivers become more confident and healthy. Future research that expands the breadth of religious diversity among participants would help us better understand how spiritual approaches to counseling can still provide benefits to caregivers and FCNs even in pairings of people with diverse beliefs.

In future cognitive behavioral spiritual counseling programs it would be advantageous to continue to allow the counselors to have the freedom to adjust the counseling sessions based on the needs of the caregiver, as long as there is strong support for the FCNs such as was provided by the PIs in this project. Every caregiver is unique and what is beneficial for one may not help others, so allowing the FCNs to shape the intervention for individual caregivers is important for successful outcomes. In a sustainable model where FCNs gain experience guiding the counseling sessions and interacting with the caregivers, enlisting experienced FCNs to train new FCNs would allow for the continuation of successful counseling aiming to improve the lives of caregivers. It may also be beneficial for the caregivers of any future intervention programs to form partnerships with other caregivers (Glueckauf et al., 2012; Kazmer et al., 2013). In such partnerships, caregivers can encourage each other, share stories and advice, and gain a feeling of community. It is also essential for future interventions that the knowledge and resources provided during the counseling sessions are kept up-to-date to be as effective as possible.

Counselor selection and training should emphasize the best ways to interact with, connect, and support caregivers by implementing counselors’ healthcare and counseling experiences and skills, their motivation and passion, their empathy and understanding, their openness and honesty, and their faith or religion. The content of skills-building training and
information resource provision should be designed to help caregivers efficiently solve their current and potential problems. Spirituality can be used effectively to build a strong bond between caregivers and counselors and as an intrinsic part of the cognitive behavioral counseling approach to improve caregivers’ self-efficacy, depression, problem improvement, social support, and religious coping.
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Appendix: Interview Instruments

Faith Community Nurse, Post Session 2

1. Background Questions

a. Please describe your non-FCN and FCN-related professional experiences as a registered nurse or nurse practitioner.

b. Describe your major roles and job responsibilities in non-FCN employment settings. With what types of patients did you work?

c. Describe your major roles and job responsibilities in FCN employment settings. With what types of patients did you work?

d. What led you to become an FCN? When did you decide to become an FCN? How is faith community nursing different from regular nursing work?

e. How have your professional training and experiences as an RN influenced your work in faith community nursing?

f. Have you had previous experiences working with older adults with progressive dementia? With dementia family caregivers? [If yes, how do you feel these past dementia-related experiences may affect or influence your counseling with family caregivers?] [If no, what feelings or thoughts do you currently have about counseling dementia caregivers?]

2. FCN in-session experiences

a. Please describe what occurred in your last session.

b. Where did your session take place? Did you meet with the caregiver alone? [If no, please indicate who else was involved in the session or who was in the vicinity?] Were there any distractions during the counseling session? [If yes, please briefly describe them.]

c. How connected did you feel with your caregiver during the last counseling session? How attentive did you feel your caregiver was during the session? To what extent do you feel the time in counseling was spent efficiently? How did you feel about the outcomes of the last counseling session? How honest do you feel your caregiver was about her/his feelings during the counseling session?

3. FCN perceptions of the adequacy of counselor training and bi-weekly telephone and email consultations with Dr. Glueckauf or Davis.

a. Did you feel like you got a clear understanding of what your responsibilities are supposed to be?

b. Is the problem-solving counseling training you received at the intensive weekend workshop different from any other counselor training you’ve received in the past? [If yes, please describe the differences.] Were there specific skills you learned in the workshop that helped in your last counseling session? [If yes, please describe them.] Did you encounter any situations where additional training would have been helpful? [If yes, please describe them and the additional training experiences you needed.]

c. Did the training have an impact on your relationship with your caregiver? Can you provide a specific example where the training had a positive effect on that relationship and
explain how the training helped? Can you provide a specific example where the training had a negative effect or got in the way of your relationship with the caregiver and explain how?

d. How did you feel about the telephone consultation and/or e-mails you received from Dr. Glueckauf or Davis? Were you comfortable discussing your feelings and/or concerns during the telephone session? How did you feel about receiving group consultation over the phone? Were there specific skills you learned in your telephone consultation and/or e-mail with Dr. Glueckauf or Davis that helped in your last counseling session? [If yes, please describe them.] Did you encounter any situations where additional consultation would have been helpful? [If yes, please describe them and the additional training experiences you needed.]

e. How did you feel about the skills modules manual? Was it written in a clear and understandable way? Was there anything about the material you especially liked or disliked? How did you feel about the example situations that were used in the skills modules? Were they relevant to your counseling experience? Were they helpful in guiding the counseling process?

f. Did the sessions skills module help you in setting and implementing goals with your caregiver? [If yes, please describe.]

4. Faith Community Nurse perceptions of the benefits and drawbacks of the integrative CBSC counseling

a. How do you feel about combining your spiritual ministry and its practices with psychology-based, problem-solving counseling?

b. Does your FCN background influence the way you use the problem solving techniques? [If yes, how so?]

c. Describe how you feel/felt about starting a new relationship with a caregiver who was unknown to you. What specifically did you say or do to establish this new relationship?

d. How has your spiritual ministry evolved over the sessions with your caregiver? How similar or different is it to your ministry with a parishioner? Can you describe a particular instance where noted changes in your ministry with the caregiver, or similarities and differences in your ministry?

e. How would you respond if the caregiver expressed negative feelings about religious beliefs or practices?

f. If you were assigned a caregiver who was an atheist or agnostic, would that change your approach to the caregiver? In what ways would that change your approach?

**Faith Community Nurse Post-Session 5 and Post-Session 8**

1. FCN in-session experiences [same questions as FCN Post-Session 2, section 2]

2. FCN perceptions of the adequacy of counselor training and bi-weekly telephone and e-mail consultations with Dr. Glueckauf or Davis.

a. How confident did you feel about your counseling skills during the last session? Did you encounter any situations where additional training would have been helpful? [If yes, please describe them and the additional training experiences you needed.]
b. Were there specific skills you learned in your telephone consultations and/or e-mail with Dr. Glueckauf or Davis that helped in your last counseling session? [If yes, please describe them.]

c. Did the telephone consultation(s) and/or e-mail have an impact on your relationship with your caregiver? Were they any positive effects of the consultations on your relationship? Where there any negative effects of the consultations on your relationship (i.e., did the training get in the way of your relationship with the caregiver)?

d. Did you use the material in the skills modules booklet in your last session? [If yes, please describe.] Was there anything about the material you especially liked or disliked? Was the skills modules booklet helpful in guiding the counseling process? [If yes, please describe how the materials were helpful.] [If no, please describe what aspects of the skills modules materials were unhelpful or ineffective.] Please offer any suggestions for improving the skills modules materials.

e. Did the skills module help you in setting and implementing goals with your caregiver?

f. Which specific skills modules have you introduced to your caregiver since the beginning of the sessions? Describe the progress the caregiver has made applying each module to her/his goals in each session since the module was introduced.

3. FCN perception of Spiritual Relationship

a. How do you feel about your spiritual ministry with your caregiver?

b. Can you describe any changes in your spiritual ministry with your caregiver in the last session?

c. Please describe specific counseling interactions in which spiritual intervention with your caregiver played a significant role.

d. Were there any negative reactions from the caregiver to spiritual interventions? [If yes, what were they and how did you respond?]

Faith Community Nurse Post-Session 12

1. FCN in-session experiences [same as FCN Post-Session 2, section 2]

2. FCN perceptions of the adequacy of counselor training and bi-weekly telephone and e-mail consultations with Dr. Glueckauf or Davis [same as FCN Post-Session 5 & 8, section 2]

3. FCN perception of spiritual relationship [same as FCN Post-Session 5 & 8, section 3]

4. Overall Evaluation

a. How do you feel about the caregiver counseling you have done over the past six months? What contributions do you feel you have made to the well-being of your caregiver? Do you have any concerns about the counseling experience? [If yes, please describe them.]

b. Would you recommend this problem-solving training program to other parish nurses? [If yes, what advice would you give them?] [If no, please describe what aspects of the training were unhelpful or ineffective.] Please offer any suggestions for improving the counselor training program.
c. To what extent did the counseling meet your needs? Please describe what you got out of the program that met your needs. [If your needs were only partially met, please describe what these needs were and what needed to be done to help you.]
d. If the opportunity were to arise in the future, how would you feel about participating in another counseling research program?
e. Do you think you will use the counseling skills you have learned in other situations in the future? [If yes, please describe how you plan to use them.]
f. Do you have any additional comments?

Caregiver Post-Session 2

1. Caregiver’s in-session experiences

   a. Where did your session take place? Did you meet with the FCN alone? [If no, please indicate who else was involved in the session or who was in the vicinity?] Were there any distractions during the session? [If yes, please briefly describe them.]
   b. Please describe what occurred in your last session. What were some of the specific topics you discussed? What were some of the activities in which you and your FCN engaged? [May also ask caregiver to describe his/her experiences and the types of interactions s/he had with the FCN, e.g., prayer, scripture reading, or heart-to-heart discussion.]
   c. About how long was the last session? Was the session longer or shorter than you anticipated? Please describe the parts of the session that you felt were too long. Were there any topics or activities that you felt needed more time? To what extent do you feel the time in counseling was worthwhile?
   d. How connected did you feel with your FCN during the last session? How attentive do you feel your FCN was during the session? How did you feel about the outcomes of the last session? What was most helpful to you in the last session? What was least helpful to you in the last session? How honest do you feel you were able to be with the FCN? Were there any topics you felt uncomfortable discussing with the FCN? Please explain.
   e. Please describe how important this session was to your care giving goals. To what extent did the counseling experience help you to recognize and focus on your own needs? If the session was helpful, please give specific examples on how it has worked for you. Also, please describe any drawbacks or difficulties you experienced in your last session?

2. Caregiver perception of efficacy

   a. What impact, if any, have the sessions to date had on your day-to-day experience? How often do you make use of the strategies discussed in your sessions?
   b. Have the sessions to date impacted your ability to meet your own needs? [If so, how?]

3. Caregiver spiritual reflection

   a. How do feel about your spiritual relationship with your FCN?
   b. Have you noticed any changes in your spiritual relationship with your FCN since session one [two/five/eight]? [If yes, please describe these changes.]
   c. If pertinent, please describe specific counseling interactions in which spirituality or your spiritual relationship with your FCN played a significant role.
d. Have there been any changes in the way you incorporate your spirituality into the care of your loved one? Have there been any changes in which you apply your spiritual beliefs in your own self care?

4. Caregiver Spiritual Relationship with Care Partner

a. Do you consider yourself a spiritual or religious person? How would you describe your own spirituality?

b. If the person identifies him/herself as a spiritual or religious person, ask (c through i):

c. What kinds of religious or spiritual activities (e.g., prayer, bible reading, meditation, listening/viewing religious programs) do you participate in during the day/week?

d. Are you a member of an organized religious or spiritual group(s) (e.g., church or Bible study)? If so, please briefly describe your group(s) and the activities you carry out with them. How would you describe your relationship with the members of your religious or spiritual group? Do you feel supported by the members of this group? If so, in what ways do you feel supported?

e. I understand that this may be a difficult question to answer, however, how would you describe your relationship with God (or other supreme being)? How do you benefit from this relationship?

f. How does your spirituality influence your relationship with your care partner [use care partner’s name]?

g. Do your private spiritual or religious activities (as described earlier) affect how you view your care partner since the onset of the disease? If yes, please explain. Do these activities affect how you interact with your care partner?

h. Does participation in your religious group activities have an impact or influence how you feel about your care partner? If yes, please explain. Does participation in these activities affect how you interact with your care partner?

i. How does your relationship with God (or other supreme being) influence how you view your care partner? Has this relationship affected the ways in which you approach your duties as a caregiver? Has your relationship with God influenced how you interact with your care partner? Please explain.

Caregiver Post-Session 5 and Post-Session 8

1. Caregiver in-session experiences [same questions as Caregiver Post-Session 2, section 1]

2. Caregiver perception of efficacy [same questions as Caregiver Post-Session 2, section 2]

3. Caregiver spiritual reflection [same questions as Caregiver Post-Session 2, section 3]

4. Caregiver Spiritual Relationship with Care Partner

a. How do you feel about discussing your spiritual beliefs with your FCN? Has your opinion changed since session two [five/eight]?

b. Have the religious or spiritual activities you participate in changed since session two [five/eight]? Has your perception of the care partner changed as a result of this? Have these changes in your spiritual activities affected your interaction with the care partner?
c. Have your organized religious activities changed at all since session two [five/eight]? If so, has this changed how you view your care partner? How have the ways in which you interact with the care partner changed as a result of this?

d. Has the way in which you view your relationship with God changed since session two [five/eight]? If so, what impact (if any) has this had on your relationship with your care partner? Has this changed the way you view the care partner?

Caregiver Post-Session 12

1. Caregiver in-session experiences [same questions as Caregiver Post-Session 2, section 1]

2. Caregiver perception of efficacy [same questions as Caregiver Post-Session 2, section 2]

3. Caregiver spiritual reflection [same questions as Caregiver Post-Session 2, section 3]

4. Caregiver spiritual relationship with Care Partner [same questions as Caregiver Post-Session 5/8, section 4]

5. Caregiver overall evaluation

   a. How do you feel about the spiritual support and problem solving training over the past six months? Do you feel there has been any change in the way in which you approach your self-care? If yes, please explain. Do you have any reservations about the counseling experience? If yes, please describe them.

   b. To what extent did the training meet your needs? Please describe what you got out of the training that met your needs. If your needs were only partially met, please describe what these needs were and what needed to be done to help you.

   c. Do you have any additional comments?