"My greatest help comes from the Lord": Religion and the information behaviors of dementia caregivers

Michelle M. Kazmer*, Florida State University College of Communication & Information
Robert L. Glueckauf, Florida State University College of Medicine
Kathleen Burnett, Florida State University College of Communication & Information
Gabriel Schettini, Florida State University
Jinxuan Ma, Florida State University
Michelle Silva, Florida State University

*242A Louis Shores Building, 142 Collegiate Loop, Tallahassee, FL 32306-2100
mkazmer@fsu.edu

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Introduction

How do religious beliefs, practices and communities affect how caregivers of loved ones with dementia approach information seeking, information use, and information evaluation with respect to their caregiving activities? This paper is based on qualitative data collected via 84 interviews with dementia caregivers and counselors who were involved in two research projects designed primarily to evaluate the efficacy of cognitive-behavioral therapy (CBT) problem-solving interventions in improving depression and reducing stress among dementia caregivers. In one project the interventions were delivered by faith community nurses (FCNs); in the other, by
ministers with counseling experience/credentials (this project was called African-American Alzheimer's Caregiver Training and Support, or ACTS). Both studies included quantitative assessments of the efficacy of the interventions, but also incorporated significant qualitative components based on semi-structured interviews. During the interviews, which were conducted with the caregivers and counselors at several points during their counseling experiences, the researchers asked a variety of questions about the counseling experience, problem-solving, goal-setting, materials and training, and the care recipients. There were some questions explicitly about spirituality and caregiving, but caregivers also often talked about their religious beliefs in the context of their caregiving experiences even in response to questions that were not explicitly about religion. The interviews were transcribed and coded using open coding and categorization analysis methods; one project used NVIVO to support the initial coding, the other used Excel, but this combined analysis was completed using Excel. The theme of spirituality was expected to appear in the FCN study, but it also arose from the interviews with caregivers in the ACTS project, leading the researchers to further mine the interview data to answer the question posed at the beginning of this paragraph.

Background

Most information-oriented examinations of caregivers focus on information needs (e.g., Conley & Burman, 2011; Hirakawa, Kuzuya, Enoki, & Uemura, 2011; Thompsell & Lovestone, 2002; Wackerbarth & Johnson, 2002; Wald, Fahy, Walker, & Livingston, 2003). Some focus on information materials (e.g., van der Steen et al., 2011), while others focus on information providers or intermediaries (e.g., Abrahamson, Fisher, Turner, Durrance, & Turner, 2008). Such approaches tend to focus on filling a gap in knowledge, whether or not that gap is perceived or acknowledged by the caregiver, or they reflect a tacit agenda of others for influencing caregiver
action (for example, if health care providers believe that caregivers need to have information about out-of-home care). Studies of information needs and use are rare (Kazmer, Glueckauf, Ma, & Burnett, in press), and conceptualizations of information by caregivers in light of spirituality and religion seem to be absent.

However, a strong relationship between spirituality and medicine has been identified in the research literature, and in particular there is indicated a positive link between religious commitment and mental and physical health outcomes (Anandarajah & Hight, 2001). Various aspects of religiosity (e.g., "general religiousness, religious practices, and positive religious core beliefs") are shown to be predictive of more positive mental health status (Rosmarin, Krumrei, & Andersson, 2009, p. 54). When treating older patients, and in particular "oldest [...] clients, the widowed, elderly Blacks, older men from manual jobs, and older women," considerations of religion need to be taken seriously, go beyond denominational preference, and acknowledge that "the church" represents an important mental health resource (Holt & Dellman-Jenkins, 1992, p. 106; see also Brodsky, 2000).

While patients desire and may benefit from a closer connection between medical practice and spirituality, health care providers who "incorporate spirituality into medical practice" need to do so "without sacrificing scientific integrity" (Anandarajah & Hight, 2001, p. 84). For cognitive behavioral therapy (CBT) in particular (the type of intervention used in the ACTS and FCN studies), it is important that it is "practiced in a manner that respects, and perhaps even incorporates, patient religiousness" (Rosmarin, Krumrei, & Andersson, p. 61).

In the end, however, there is a dearth of literature addressing how spirituality and religion affect views of health information. Lustria et al. (2010, p. 2250) distinguish two related ideas that emerge from focus groups with African-American breast cancer survivors in rural North
Florida: (a) that God works with and through healthcare providers to heal; and (b) that God provides healing emotional support directly to individuals. Kazmer et al. (in press) identify the religious community and the church setting as important parts of the "information use environments" of caregivers that help them to solve caregiving problems and get support (see also Kazmer, Glueckauf, Ma, Schettini, & Silva, 2013). It is hoped that the current study will be able to expand on and deepen our understanding of these and related factors.

**Research Setting and Methods**

This study used qualitative interview data from two different projects to help to answer the question: How do religious beliefs, practices and communities affect how caregivers of loved ones with dementia approach information seeking, information use, and information evaluation with respect to their caregiving activities? Both research projects were designed to improve the opportunities and access to CBT for rural dementia caregivers by increasing the number and types of people available to deliver CBT and increasing the modes through which it can be offered. One set of interview data comes from a study of faith community nurses (FCNs) who were trained to conduct cognitive behavior and spiritual counseling for rural dementia caregivers. Involving FCNs increases the available number of people who can offer therapy and it also helps to meet the need for spirituality to be integrated into self-care (Lustria, et al., 2010). The second set of interview data comes from a study called "African-American Alzheimer's Caregiver Training and Support (ACTS)" that provided skills training and support, either by phone or in person, to African-American dementia caregivers with depression. ACTS incorporated telephone therapy to increase access for a variety of reasons (the technology is readily available, does not require transportation, and helps meet caregivers' needs for privacy and confidentiality) and the
quantitative portion of the project was used to demonstrate efficacy of the communication mode (Glueckauf et al., 2012).

In each study, qualitative data were collected via interviews with participants at various points throughout the process, i.e., after multiple counseling sessions over the course of the CBT intervention. In the FCN study, counseling sessions were all "individual," that is, between one FCN and one caregiver. The qualitative data collection was designed so that seven nurse/caregiver pairs would be interviewed (individually, not together; n=14) after counseling sessions 2, 5, 8, and 12, for a total of 56 (14x4) interviews. In the ACTS study, counseling sessions were a mix of group and individual sessions. Qualitative data were collected from caregivers only (not the counselors) during the pilot phase and during the first phase of the main study. The study design called for the caregivers to be interviewed after a group session and after an individual session. Of the 16 caregivers who were to be interviewed (10 pilot, 6 main study), 12 were interviewed twice (8 pilot, 4 main study), 4 were interviewed once (2 pilot, 2 main study), and one was not available. The ACTS qualitative data thus comprise 28 interviews. The total number of interviews analyzed is 84 (56+28).

Interview questions were not exactly the same across two the projects because the focus of each project was slightly different. Common themes were addressed, as all interview instruments guided interviewers to ask participants about their experiences with the counseling, with their counselors, and with the instructional materials provided in each project. All interviews asked participants about benefits, drawbacks, problems, and highlights of the counseling experience, and all interviews guided participants to talk about the goals and outcomes of the counseling and its effects on their self-care and care of their loved ones with dementia.
Grounded theory methods have been used in health settings since their inception (Glaser & Strauss, 1965; Glaser & Strauss, 1967). The process generally involves open coding, categorization, integrated coding, theoretical sampling, and axial coding. During the coding process, the constant comparative method is employed to compare the data with the existing codes, new (emergent) codes with existing codes, and new codes with the whole data corpus.

The initial examination of the data suggested that further analysis specifically directed toward religion, spirituality, and information behaviors was needed. To conduct this analysis, the interview transcripts were subject to an additional examination of their content with a focus on expanding and refining the existing open codes that reflected information behaviors and adding codes suggested by sensitizing concepts (Strauss & Corbin, 1998, pp. 48-52) such as information use, information exchange, information avoidance, and so forth, as well as religious and spiritual beliefs, religious practices, and religious social settings. Because of the large number of researchers collaborating on the coding, Excel software was used to support the coding because it was accessible to all researchers and the files are easy to share securely.

Once all the data were re-examined with a focus on the information behavior concepts, axial coding was employed to help categorize the codes and identify how codes connect together. Axial coding, in this approach, does not use the "coding paradigm" often associated with Strauss and Corbin's (1998, p. 128) version of grounded theory. The axial coding process is contentious in the literature because of the coding paradigm, which is viewed by some scholars as being overly restrictive, and prescriptive (see, e.g., Kendall, 1999), but axial coding does not require use of the coding paradigm. The term "axial" is used here because of the metaphors it allows the researcher to bring to the coding process. These metaphors 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.

**Findings**

The findings presented here are supported by quotes from the interviews with caregivers (CGs; the initials CR refer to "care recipient") and counselors. Identifying data have been removed. A theme that is seen throughout the analysis is that the primary relationship between analyzed factors is between caregiving and religious beliefs and practices; the tertiary relationship among caregiving, religion, and information generally has to be extracted via analysis rather than appearing in the raw data.

The ongoing practice of caregiving and the needs/behavior of CRs have an influence on some caregivers' religious practices; here a counselor explained that a CG has stopped attending church regularly because she is embarrassed by her CR's behavior in a church setting:

I don't get the feeling that she had a lot of close connection with people at her church. She's a Jehovah's Witness and she used to go to church until her mother started deteriorating and then she was too embarrassed to try to fight with that to take her to church. So she was pretty much socially isolated except for her immediate family.

[counselor response about CG]

The same CG referred to in the above quote indicates in her own interviews that having to stay at home with her CR means she cannot engage in one of the fundamental practices of her religion, which involves distributing information: "I'm supposed to, but not at the moment. Our main work is going out door to door, telling people about the blessings that are coming, and of course, you know, there's going to be change. God is going to clean out the Earth, take out all the
wicked people." For CGs whose religious practices could be done at home without sacrificing underlying beliefs of the church, caregiving was slightly less disruptive; CGs describe praying, reading the Bible, and saying the Rosary at home. One FCN points out that for Catholics although the physical church is vital ("as a Catholic we believe that the Eucharist, that Christ is physically present in the tabernacle at all times"), a fundamental piece of Catholicism (receiving the Eucharist) can be done away from a church building: "A big part of my ministry is visiting the sick as a parish nurse and perhaps taking Communion, taking the Eucharist to them either on a home visit if they're not able to make it to mass, or in a nursing home." This counselor was paired with a CG whose interviews are noteworthy for having almost no mentions of God, religion, or spirituality.

It is an old cliché that there are no atheists in foxholes, referring to an ostensible "human tendency" to turn to God for assistance or comfort in times of stress or danger. Aware of this cliché, we worked hard not to "see" it in the interviews, but similar thoughts emerged explicitly in the data. Here we see a caregiver identify the potential for this tendency in himself:

Well I don't think I have a relationship with God, at this point in my life. It's kind of between the crossroads to whether I believe or don't believe. I'm not gonna sit here and tell you that I'm an atheist, but …what's the word, agnostic? Well, that's just in my particular case. Let's put it this way, when talk about spirituality, if we go a year or so down the road, and my wife's condition deteriorated badly, I might need somebody to hold hands with and start praying. [CG]

Note in this case that the CG not only mentions the potential that he might turn to prayer, but that he might seek human companionship in doing so. Another CG identified as being
Agnostic and described her CR (her husband) as also Agnostic. In the following quote, she describes her surprise when she heard from a religious person who visited patients at the hospice where her CR had been cared for that he had prayed in the time before his death:

He was Agnostic too. I don't know what happened at the end there… because the hospice kept him and there was a group that came in and talked to him. And she came one day and… I said he is Agnostic and she said well I have been here before… I had left at around 3-4 o'clock… she had been there later on… and she said “I prayed with him and he told me that and he prayed with me and he knew his prayer” So maybe he had converted into, you know, I don't know about that because he didn't talk about it with me.

This example and the one above of the CG who stopped going to church and going out to share information about her religion with others both also demonstrate the close ties between religious practices and social connections.

In the caregiving role in particular, religious beliefs can also shape the CGs' understanding of their responsibility to their CRs. In this case, the CG and CR are a married couple, and the CG explains:

I think if, if God were not in my life - or I were not in His – I might be willing to put [CR] in a facility and just leave him, close the door and walk away. But I couldn't think of doing that. I believe that God will give me the strength to do what I need to do for [CR]. We are, you know, a married couple and have vowed to care for each other.

Another CG shows that it is not only the marriage vow before God that is important, but that her religious beliefs entail the need to take care of others, saying, "I just think that because
of our religious background and because we are sisters we just take it for granted that you have
to be there for each other.”

Within the family and social setting are not the only arenas where caregiving and religion
intersect; when CGs interact with the health care system, their spirituality is also an important
factor. For example, health care professionals can be so focused on instrumental assistance for
the CGs and CRs that they do not "hear" the CGs when they share the information that God is in
fact providing them with help:

Sometimes people are afraid to you know say, trust in the Lord or turn to God. I know, I
know occasionally I have gone to a Hospice care for the caregiver. I didn't even know
they had that, someone encouraged me to go. We go around and talk about our situation
and I was mentioning mine and they said well what do you do, what kind of assistance do
you get or help? I said my greatest help comes from the Lord. They said well where do
you get help, I said that's it. I say, 'Dear God, help me to remember that there isn't
anything that I can't get through today that you and I can't handle.' And that's how I start
my day. [CG]

As important as it is to incorporate spirituality into the relationship between CGs and
providers, forcing religious behavior or discussion is not useful. One CG/counselor pair was
comfortable knowing that they shared core religious beliefs but not having them as a prominent
part of their counseling sessions:

We do talk about God and about how, you know, she kind of, she does pray a lot about
thing and we talk about it but it's not really the first thing that we talk about when I come
in. It's like we talk for about thirty minutes and then as she's offering information, then she brings it up. So mostly I let her bring it up because I know she doesn't like to be pressured.

And another counselor, who had some religious differences with her CG, describes:

I wouldn't want to have to focus on witnessing and bringing them to Christianity. That wasn't the main goal of the study. It could be an opportunity to bring those things in and I'm more of a let them see how I am and how I live and what I say, but it's not appropriate to get in their face and say you have to believe in God.

On the other hand, this counselor also said it was "very liberating where you can have this kind of setting where you are expecting to combine your faith with your healthcare." Although the same counselor had just outlined a history of mild religious conflict between her and the CG she was counseling, that conflict seemed to be less important in a negative way. More important was the positive impact of being able to address religion directly in the counseling, probably strengthened by the counselor's understanding that the desired outcome of the counseling was not a religious one.

The theme of "help" which is used in the title of this paper echoes throughout the data: "I am a religious person and this is really making me more spiritual than before because I'm asking for more help than I used to, you know, when I pray. I certainly need God's help to go through this." [CG] "I'm always asking god for his help" [CG]; and "Well I think my relationship with God and my prayers, I'm always asking Him to help me through the day, help me not to get angry, help me control myself and I think that even though I might get impatient with her [CR] I
think the fact that I can control myself and understand her more is the fact that I am getting the help from God. I think God is watching over us. I think, I really don't think I could go through this without God."

**Conclusion**

The data from this analysis of the FCN and ACTS interviews – and findings from another population, breast-cancer survivors, reported by Lustria et al., 2010 – indicate that religion influences caregivers' approaches to health information seeking, evaluation, and use, although these effects are often intertwined with other factors. Some caregivers with religious beliefs seek health information through prayer or other requests for spiritual intervention. Their information use may be informed and shaped by their religious beliefs, but it is important to understand the approach that individuals are taking. For example, some caregivers view all information as being provided by God and requiring active application by the caregiver, while others view information as an additional channel that may contradict God's will and require carefully structured information avoidance.

Examining the information implications of the findings also demonstrates that the spiritual beliefs and religious practices of CGs affect their information environments. Dropping or decreasing participation in a religious community can narrow the array of available information resources as well as reducing social and spiritual support. A mis-match in religion between providers (physicians, hospice workers, counselors) and CGs can reduce the level of rapport in the relationships and perhaps decrease trust as a result. It can also increase the exchange of "functional" information as spiritual topics are purposely avoided although this shift is not exclusively positive, because it can result in the feeling that providers are ignoring the spiritual aspects of CGs' experiences and needs.
Religiosity can change during times of stress, near life's end, and/or during the progress of dementia, so it is important to continue to seek information from, and provide information to, CGs and dementia patients about and in response to such changes. Spiritual beliefs also inform CGs' expectations and sense of responsibility in caregiving. Finally, CGs experience receiving help as part of their spiritual beliefs and religious practices, which has implications for information provision to CGs in response to their perceived information needs. These findings have implications for the further study of health information and the influence of religion on its use among caregivers, an area so far under-researched in health information behavior.

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