Information Behavior of Rural Dementia Caregivers Over the Course of Counseling Interventions

Michelle M. Kazmer
Florida State University
mkazmer@fsu.edu

Robert L. Glueckauf
Florida State University
robert.glueckauf@med.fsu.edu

Jinxuan Ma
Florida State University
jm07@my.fsu.edu

Gabriel Schettini
Florida State University
gs04@my.fsu.edu

Michelle Silva
Florida State University
ms08r@my.fsu.edu

Abstract

This poster reports findings from an analysis of 81 qualitative interviews with rural dementia caregivers who participated in two research projects that evaluated cognitive behavioral therapy (CBT) problem-solving interventions designed to help them manage their caregiving and reduce depression. The research questions posed in this analysis are: (RQ1) How do rural dementia caregivers who have participated in a CBT program interact with the information around them and available to them? (RQ2) How do these caregivers manage, explicitly or tacitly, their information needs and uses? The analysis demonstrates similarities and differences in information behaviors and information environments across the caregivers; for example that physical information artifacts are important to different caregivers for varied reasons, and that religious communities fulfill multiple information-related roles. The findings demonstrate the importance of accounting for the unique constraints on older caregivers in designing interventions to improve and support their caregiving experiences. Creating links among people, such as connecting caregivers to similar others facing similar challenges, and providing them with a structure to allow them to focus on their goals, appear critical to the success of such interventions.

Keywords: dementia caregivers, information use environments, health information behavior, qualitative health research

Introduction

Most adults with dementia (80%) receive care from family members at home (Alzheimer's Association, 2011). These caregivers (CGs) often experience significant psychological distress, sleep fragmentation, reductions in social activities, and disrupted family relationships, leaving them at substantial risk for depressive disorders (Gallagher-Thompson et al., 2000; McCurry, Logsdon, Teri, & Vitiello, 2007) and compromised physical health (e.g., Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996; Vitaliano, Schulz, Kiecolt-Glaser, & Grant, 1997). Increased understanding of how CGs use information resources to manage their caregiving demands, and how context shapes their information use, can improve the design of CG-related information sources and services.

This study seeks to further this understanding by examining rural dementia caregivers who participated in two research projects that offered cognitive behavioral therapy (CBT) problem-solving interventions to help them manage their caregiving and reduce depression: 1) a study of faith community nurses (FCN) trained to conduct cognitive behavioral and spiritual counseling for rural dementia caregivers; and 2) a study called "African-American Alzheimer's Caregiver Training and Support" (ACTS), which provided skills training and support, by phone or in person, to African-American dementia caregivers with depression (Glueckauf et al., 2012).

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Background

Most information-oriented examinations of CGs 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). Another subset of literature indicates the importance of examining and supporting information use among the elderly, but without a focus on CGs (Niemelä, Huotari, & Kortelainen, 2012; Xie & Bugg, 2009). Information needs are part of a broader approach that studies information behavior, which includes other phenomena such as information seeking, retrieval, motivations, avoidance, incidental acquisition, serendipity, overload, evaluation, and management (see Dervin, 2005; Ginman, 2000).

Understanding information behavior requires that we "account for... the social context within which information is generated, sought for, acquired, evaluated, organized, disseminated, and used" (Rosenbaum, 1996, p. 152). Many frameworks have been developed to consider such context, including information fields (Johnson, 1997), information grounds (Pettigrew, 1999), information ecologies (Nardi & O'Day, 1999), information worlds (Burnett & Jaeger, 2008), and information use environments (Taylor, 1986, 1991). Such frameworks have been evaluated for their applicability to CGs (e.g., Harland & Bath, 2008; Ormandy, 2010). When people seek information about health (and other) activities and events, this context includes many factors such as individuals' roles (Wicks, 1999), culture and ethnicity (Jeong, 2004; Yi, Stvilia, & Mon, 2012), age (Asla, Williamson, & Mills, 2006), living environment (Mooko, 2005; Shin, 2009) and – for health-related information behavior – the type of medical condition and associated symptoms (Johnson, Andrews, & Allard, 2001).

As part of an overall research agenda focused on the information behaviors of dementia caregivers, this poster addresses two specific research questions: (RQ1) How do rural dementia caregivers who have participated in a cognitive behavioral therapy program interact with the information around them and available to them? and (RQ2) How do these caregivers manage, explicitly or tacitly, their information needs and uses?

Methods

The FCN and ACTS projects were designed as quantitative trials of the CBT interventions, but each included a qualitative portion. Qualitative data were collected via interviews with participants, totaling 81 interviews across both projects. All interviews were transcribed. The preliminary "open" coding – coding that emerges from the content of the interviews rather than from a pre-existing code list (Charmaz, 2006; Strauss & Corbin, 1998) – suggested that further qualitative analysis of these data, directed toward information behaviors, was needed. All 81 interview transcripts were subsequently coded with a focus on expanding and refining the existing open codes that reflect 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. NVIVO8 qualitative analysis software was used as a platform to support this analytic work.

Findings

The findings to be presented in this poster represent the primary similarities and differences across the CGs in both projects. All the CGs engaged in problem identification and goal setting. They worked with their counselors to record the problems they faced and to develop goals they could achieve to help ameliorate the effects of those problems. Their "selves" became primary information sources because they were responsible for identifying their problems and for creating a physical information artifact to record those problems and associated goals. The CGs learned to turn to themselves for verification of their progress: Is what I am doing helping me achieve my goals? Have I completed the tasks I need to complete to help me achieve my goals? Now that I have completed my goals, for what (new) problems do I need to set new goals?

Common among CGs was the role of the counselor as an information intermediary facilitating open information exchange among counselors and CGs. The counselors interpreted printed instructions or rote problem-solving steps, making them understandable and actionable. CGs relied on the counselors for accurate and timely information in various areas including legal, mental health, physical health, lifestyle, and so forth.

CGs' religious communities and spiritual beliefs and practices also shaped their information environments. ACTS and FCN CGs involved in religious communities rely on them for information and social support. Among the large majority of CGs in both studies who held strong religious beliefs (primarily Christian), those beliefs influenced their information behaviors such as their willingness to seek information, tendency to believe or disbelieve certain types of information, and how they dealt with health care professionals as people who had information and were empowered to act on it (see also Lustria et al., 2010).

Major differences in information behavior are driven by intrinsic differences in the two projects. ACTS includes a guidebook for CG participants that takes on high importance in CGs' lives: they use it as a reference, as a source of authority in dealing with family members or healthcare providers, and as a physical reminder of their goals. The FCN study included no such guidebook; occasionally the FCNs gave printed materials to their CGs, but it was not an intrinsic part of the intervention.

Another difference was that the ACTS project included group and individual counseling sessions while FCN only included individual sessions. The groups of ACTS CGs were an important source of information to each other; they exchanged alternative problem solving techniques and shared information among CGs whose care recipients were at different stages of dementia, which the CGs indicated was important in reducing their anxiety and fear. The CGs in FCN often sought other groups of CGs (such as church groups) to provide this type of support. When they did so, they were outside the structured problem-solving environment offered by the CBT intervention and some groups devolved into shared suffering rather than focused problem solving.

Conclusion

The findings in this project remind us that it is important to focus on CGs' information behaviors in context and identify their information needs in light of their problems and goals. The CGs information behaviors are shaped by economic, cultural, and social factors including religion, cultural factors associated with race and region, access to the internet and other information sources. When considering an activity or intervention, it is important to consider the constraints on the target users and do what will work best for them rather than what seems interesting in terms of technology, or rich in terms of interaction (see Forducey, et al., 2012). Including the right people (e.g., similar others facing similar challenges) and providing the CGs with a structure to allow them to focus on their goals appear critical to the success of such interventions.

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