

**Information use environments of African-American dementia caregivers over the course of
cognitive-behavioral therapy for depression**

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Abstract

Caregivers of older adults with dementia face significant challenges associated with their care recipients' condition and with their own mental and physical well-being. Qualitative research data were collected via interviews with caregivers who participated in the African-American Alzheimer's Caregiver Training and Support (ACTS) research project. Analysis of these data with a focus on information use indicated that participating caregivers' information use environments were shaped by key individuals, settings, and information sources. These included the ACTS counselors, ACTS intervention guidebook, fellow caregivers, use of a personal calendar/datebook, and the identification of key problems and development of goals to help ameliorate those problems. CBT groups fostered sharing, synthesizing, and validating information about dementia caregiving and dementia care resources; the ACTS CBT guidebook served as an important physical touchstone of reliable and portable information. Understanding the specific needs, behaviors, and constraints of African-American caregivers is important to the future development of information components of tailored, depression-reduction interventions.

1. Introduction

Epidemiological studies estimate that 5.4 million adults in the United States have some form of progressive dementia (Alzheimer's Association, 2011). The number is expected to more than double by 2050 as the proportion of adults who survive to their late 80s and 90s increases (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). Symptoms of Alzheimer's disease and related dementias include progressive memory loss, decline in ability to perform daily routine activities, and disorientation. Dementia worldwide is distributed unevenly among racial and ethnic groups. In the U.S., the incidence, prevalence, and cumulative risk rates of Alzheimer's and related dementias are substantially higher in African-Americans than in non-Hispanic Whites (Alzheimer's Association, 2011; Miles, Froehlich, Borgardus, & Inouye, 2001). Most adults with dementia (80%) receive care and support from family members at home (Alzheimer's Association, 2011). These caregivers (CGs) face challenges in assisting care recipients (CRs) with dementia, such as monitoring hygiene activities, issuing frequent reminders, and dealing with agitation and aggressive behavior. CGs 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 (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).

CGs of older adults with dementia use various strategies and rely on different types of resources to help with their caregiving. Increased understanding of how CGs use information to manage their caregiving demands, and which people, settings, and sources shape their information use, has the potential to improve the design of CG-related information sources and services. This study used qualitative interview data from the African-American Alzheimer's Caregiver Training and Support (ACTS) research project (Glueckauf et al., 2012) to develop this understanding. The primary purpose of the ACTS randomized clinical trial was to compare the effects of telephone-based versus in-person cognitive-behavioral therapy (CBT) on changes in depression and health

status for African-American CGs with depression. The research included a pilot and a main phase, and quantitative and qualitative data collection and analyses. The qualitative and quantitative results of the pilot are reported by Glueckauf, et al. (2012). The analysis of the overall findings from the main phase of the study is in progress.

The purpose of this paper is to facilitate understanding of the information problems, settings, and uses of dementia CGs. This can help health care and information professionals designing CG-support interventions to shape the information sources within the interventions to most closely match how CGs use information when solving challenging caregiving problems. It can also help inform how interventions can be designed to match the availability of people and information with CGs' problem-solving needs. Although the ACTS project focuses on low-tech systems and resources, such as counseling groups, meetings by telephone, and paper information materials, the overall findings may be used to inform the design of health information systems by highlighting the aspects most and least tractable to high-tech development. Finally, although ACTS focused on dementia CGs, many of the challenges faced by this group are similar to those faced by CGs of persons with other severe neurological disabilities and may have implications for information provision and information system design for other CG populations (see Forducey, Glueckauf, Bergquist, Maheu, & Yutsis, 2012).

2. Problem Statement and Research Questions

Dementia CGs engage in various information behaviors within complex information use environments (defined below), but most existing research on CGs and information focuses on the more narrowly-construed information *needs* (e.g., Conley & Burman, 2011; Hirakawa, Kuzuya, Enoki, & Uemura, 2011; Thompsell & Lovestone, 2002; Wackerbarth & Johnson, 2002; Wald, Fahy, Walker, & Livingston, 2003). Information behaviors within information use environments (IUEs) include a broader spectrum of activities than needs, such as acquisition, management, search, scanning, and avoidance, and take into account changes over time in information activities and sources. The information is varied and abundant (although the abundance does not always

match the CGs' problems), and includes information about the characteristics of dementia, the CGs' roles, demands and rewards, dementia care options, and end-of-life planning for their CRs and for themselves. This information exists in varied media and formats, resides in many information sources (formal and informal), and is sometimes accessed through types of support not generally considered channels for legitimate information (e.g., informal interpersonal support), but which nonetheless act as information sources.

The purpose of this study is to help continue to push the focus of health information research toward information behaviors and the environments in which they occur, and to contribute to the ongoing research of information behaviors of CGs, helping to further integrate research approaches from health care and information science.

The general problem area explored in this study is the improvement of services to African-American CGs through an understanding of how they use information to manage their caregiving activities and to solve caregiving-related problems, and what people, settings, and sources shape that information use.

The research questions to be addressed in this analysis are:

1. (a) How do African-American dementia CGs who have participated in CBT use the information around them to help them manage their caregiving activities; (b) How do African-American dementia CGs who have participated in CBT use the information around them to help them solve problems associated with their caregiving responsibilities?
2. What people, settings, and information sources shape this information use?

3. Background

3.1. Caregivers and information behavior

The shift from thinking about information *needs* (narrower approach) to information *behaviors* (broader approach) in the CG literature is limited (Dervin, 2005; Ginman, 2000). Existing approaches to the study of information and CGs often focus on CGs' information *needs*. Such approaches tend to focus on filling a gap in knowledge, whether or not that gap is perceived

and/or acknowledged by the CG, or they reflect a tacit agenda of others for influencing CG action (e.g., if health care providers believe CGs need information about community-based dementia care). 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 materials used to provide information (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). Although limited in scope and number, previous studies have analyzed the potential usefulness of applying information behavior theories and models in assisting CGs (e.g., Harland & Bath, 2008; Ormandy, 2010).

3.2. Information use environments

In exploring the information behavior of individuals, it is important to understand the factors around them that influence their information behaviors directly or indirectly; that is, individual information behaviors and the information environments in which they occur. The concept of "information seeking in context" has been central to information behavior research since the first ISIC conference in 1996 (ISIC, 2012). Many theories and conceptual frameworks have been developed to take these factors into consideration (Fisher, Erdelez, & McKechnie, 2005). Examples include 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). IUEs are appropriate for the current study because they require a focus on problems and their resolutions, matching closely the experiences of the ACTS CGs.

The framework offered by Taylor's IUEs "looks at the user and the uses of information and the contexts within which those users make choices about what information is useful to them

at particular times" (Taylor, 1991, p. 218). It "account[s] for... the social context within which information is generated, sought for, acquired, evaluated, organized, disseminated, and used" (Rosenbaum, 1996, p. 152). IUE's basic analytical framework includes four components: people, setting, problems, and problem resolutions (Taylor, 1991). The focus on problem resolutions makes it appropriate for this study of African-American family CGs, all of whom received problem-solving training during the course of CBT. IUE has been applied across various contexts over the last two decades, and of relevance to this study, it has been used as a framework for studying health information behaviors (e.g., Fortier, Dufour, & Bergeron, 2010; MacIntosh-Murray & Choo, 2005; Turner & Allen, 2010) and has been shown to work well with a grounded data analytic approach similar to that used here (Mutsheva, 2010).

When people seek information about health (and other) activities and events, several factors influence their information behaviors. These factors have been identified and elaborated within Taylor's IUE framework of people, situations, and problems (see also Agada, 1999; Hersberger, Murray, & Sokoloff, 2006; Olatokun & Ajagbe, 2010; Rieh, 2004; Rosenbaum, 1996). People factors include the roles of the individual, such as those they perform at work, in the family, and in the community (e.g., Wicks, 1999). Culture and ethnicity influence information behaviors, shaping access to interpersonal networks of information such as affiliations with religious congregations (Jeong, 2004), and in certain circumstances constraining the use of health information (Yi, Stvilia, & Mon, 2012). The age of individuals affects their approach and access to information (Asla, Williamson, & Mills, 2006), as does gender (Harris, 2009). Situation factors include the living environment of the person, such as residence in a rural or urban location, (Mooko, 2005; Shin, 2009; Veinot & Harris, 2011; Wathen & Harris, 2007) and socioeconomic status (Spink & Cole, 2001). When health is the focus, the type of medical condition and associated symptoms are pertinent situational factors shaping information behavior (Henwood, Harris, & Spoel, 2011; Johnson, Andrews, & Allard, 2001). The elderly, African-American

dementia CGs participating in the ACTS study lived in IUEs that were influenced by each of these factors.

4. Methods

This study used qualitative interview data to answer the research questions stated above. The ACTS CGs were located in Tallahassee and Jacksonville, Florida. They were recruited for ACTS using the rosters of the Tallahassee Memorial Healthcare Memory Disorder Clinic and the Mayo Clinic Jacksonville Memory Disorder Clinic, local Alzheimer's caregiver organizations, local newspapers, and self-referrals. Prospective participants were screened using criteria that included measurement of CG depression and assessments of the conditions of their CRs (Glueckauf et al, 2012). Eligible participants were assigned randomly to the telephone or in-person condition. The CGs were randomly assigned to African-American masters-level counselors trained in CBT and proceeded through the intervention program:

The intervention program consisted of a total of 12, one-hour, weekly sessions, 7 group and 5 individual CG goal-setting and implementation sessions. The small group format was used to encourage discussion and clarification about the rationale for and application of fundamental, cognitive-behavioral skills (e.g., assertiveness and effective thinking), as well as to enhance social support among participants. Individual sessions concentrated on the development of problem-solving skills, beginning with the identification of key caregiving problems and the performance of focused problem histories, followed by goal setting, rehearsal of goal-related behaviors, goal implementation and monitoring change over time. (Glueckauf et al., 2012, p. 130)

ACTS also included a qualitative component. Interview data were collected during the pilot phase and the first part of the main study. Of the CGs from the pilot, 11 were solicited for interviews and 10 responded (1 male, 9 female, a typical distribution for ACTS and for African-American CGs in general; extensive demographics are reported by Glueckauf et al., 2012). The study design called for only limited qualitative data collection beyond the pilot phase, but six CGs

(all women) in the first part of the main study were solicited for interviews in order to collect further qualitative data from the telephone (three CGs) and in-person (three CGs) conditions. The CGs were primarily older African-Americans, and their internet use was limited, a trend reinforced by incidental comments in some of the interviews; see <http://pewinternet.org> for most current statistics on internet access and use.

The qualitative design called for CGs to be interviewed after a group session and an individual session. Of the 16 CGs interviewed (10 pilot, six main study), 12 were interviewed twice (eight pilot, four main study) and four were interviewed once (two pilot, two main study), for a total of 28 interviews. Two of the four groups of CGs were located in Jacksonville, FL, approximately 180 miles from the researchers. To ensure consistency in the interview context, all 16 CGs were interviewed via telephone. The interviews ranged from 10 minutes to 50 minutes, with 15 of them less than 30 minutes. The interviews were audio-recorded and imported into NVivo 8(TM) software for qualitative analysis.

The qualitative component of the ACTS research was designed to provide an understanding of the CGs' counseling experiences in their words. The interview instruments were created to inquire about the CGs' experiences in the counseling sessions and their perceptions of the usefulness of the counseling and other aspects of the ACTS project. Each interview included questions to elicit the CG's description of the counseling session; thoughts about the counseling session's content, topic, activities, and usefulness; feelings about the counselor; experiences using the participant intervention guidebook; opinion of the effect of the session on his/her daily experiences; and opinion of the overall effect of the counseling experience. 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 CRs.

The initial examination of the qualitative data suggested that further analysis focusing on information behaviors could inform the improvement of information services to African-American

CGs through increased knowledge of how such CGs use information to manage their caregiving activities and solve problems. To conduct this analysis, two researchers re-examined the 28 interview transcripts and engaged in an additional coding of their content with a focus on expanding and refining existing open codes reflecting information behaviors and adding codes suggested by sensitizing concepts (Strauss & Corbin, 1998, pp. 48-52) such as information use, information exchange, and information avoidance. The IUE framework of users, settings, problems, and problem resolutions was used to structure the codes and to provide insight into the experiences of CGs throughout the CBT process. Using the IUE framework served two purposes: (a) it helped shift the focus of the analysis to information use and (b) it provided a structure for understanding and relating otherwise disparate instances of people, settings, and sources that helped the CGs solve problems.

5. Findings

The presentation of findings follows the structure of the IUE framework: people, settings, and problems and their resolutions. Quoted statements from interviews show how CGs talked about their experiences. Quotes were selected because they exemplified sentiments expressed by multiple CGs; they were intentionally chosen for their ordinariness rather than their uniqueness. Some quotes contain the mark [...], which means that identifying details were removed to protect the anonymity of the CG or were replaced in the quote to protect anonymity while preserving meaning, or that disfluent utterances were removed to improve readability.

5.1. Sets of people

The *a priori* set of people for this analysis is the 16 African-American dementia CGs interviewed. In age, gender, and location, they closely represented the 120 CGs who completed all phases of the ACTS project. Others, such as CRs and the project counselors, whose activities shaped the IUEs of the CGs, also appear *a priori* based on the project design. Other sets of people can be determined from the interview data and consist of family members; religious community;

and health care professionals including doctors, nurses, and various staff members at doctors' offices, hospitals, and health care facilities.

Before they started the ACTS CBT program, CGs and their CRs already shared an IUE. For the CGs, it was the addition of the ACTS counselor that catalyzed a change in their IUEs. Adding the counselor as a person also added the counseling sessions as a setting, as well as a new way of thinking about problems and how to resolve them (see Settings and Problem Resolutions below). The CGs were pleased with their counselors, whom they described as "attentive," "honest," and "helpful." Typical statements from the CGs indicate that the counselors helped co-construct an IUE that supported the open exchange of information. For example, "I was able to talk openly about issues and problems and [the counselor] was able to help us to actually talk about it, and not being the problem solver, but as facilitators do, help you to solve your own issues," or "I felt like I could talk about anything, shared information I wouldn't normally have shared with somebody I'd never met in person."

The other CGs who participated in the sessions were another important set of people who formed the IUE. The CGs became friends and offered one another emotional support, but also shared information in the form of helpful tips, personal caregiving experiences, and perceptions of the challenges and benefits of specific components of the CBT program.

5.2. Settings

The settings relevant for the CGs' IUE emerge also from the data and include their homes, the counseling sessions, and other locations where they implemented specific problem solutions (e.g., churches, beauty shops, community gatherings, or adult day care facilities).

The home setting takes on added importance as the dementia progresses, because CGs must spend more time performing basic hygiene, feeding, and bathing activities for their CRs. Being unable to leave home easily (or at all) exacerbated CGs' appraisals of distress and isolation and restricted their participation in health-promoting self-care activities. As one caregiver CG put it, "I need another environment. You know, I have to get out sometime."

The counseling mode—in-person or telephone—was intrinsic to the project design as a way of determining settings, but this distinction comes from the perspective of the researchers. The participants rarely spoke about the mode of delivery. The difference in how the CGs talked about group versus individual counseling settings was more evident. The CGs were interviewed after group and individual sessions and although the latter had substantial therapeutic benefits (see Problems and their Resolutions below), CGs tended to focus their responses on the group sessions. The CGs appreciated the information shared during these sessions. The information was functional for present-day problem solving and helped them learn what to expect during their ongoing caregiving. The role of the counselor in facilitating and synthesizing this information sharing was critical, as exemplified in the following quote:

She [the counselor] is not just going through the motions of doing her job. I think she actually cares that we get the benefit, from what the material says. And she makes it clear that if we have questions or things that she could help us with or, she doesn't try to, she doesn't interrupt you, to tell you something. She lets you talk. And she is just an excellent facilitator, you know. [...] She pulls things out of you, and, that you might not even know it were in you.

Other relevant settings associated with problem solutions were: religious settings (e.g., churches or prayer groups) where CGs drew strength and support from their faith in God and from their communities; self-care settings where CGs engaged in relaxation and wellness activities (e.g., the gym or beauty shop); and supportive or familiar settings with their families, friends, and communities. For example, one CG and her CR were long-term members of a recreational vehicle club. The familiarity of that setting was comforting to the CR, and the other members offered needed respite to the CG.

5.3. Problems and their resolutions

The CGs identified problems and mapped them to goals during individual counseling sessions. A fundamental strategy of this intervention was to encourage CGs to recognize ongoing

problems associated with their caregiving. Common themes of problems were categorized from CGs' self-reported day-to-day caregiving challenges.

One challenge CGs encountered was providing proper care for their family members with dementia. Their main tasks consisted of dealing with CRs' declining functioning in daily activities (such as bathing, toileting, taking medication, managing money), CRs' difficult behaviors, and CRs' worsening health. Other related issues mentioned by CGs included problems with CRs' losing or hiding medication, and symptoms of depression in their CRs, such as lethargy, poor mood, and weight loss. The characteristics of problems varied widely, including simple and complex, anticipated and unexpected, and solvable and unsolvable problems. Here are two representative descriptions of the multi-faceted, challenging situations faced by the CGs:

My life is kind of, it's been kind of, a lot's going on with my mom. She seems to be failing, and just dealing with her day-to-day. If her blood sugar keeps going up, when it's not supposed to, things like that. And I've been told I have to have a heart catheterization, and I've tried to figure out what I am going to do with my mom while I'm gone. And I have a teenager. I have a daughter that has lupus. She hasn't been feeling well this week. She has other problems too. She is feeling bad. And I cook for everybody. Everybody eats different things. Just trying to scramble with all these things. I have to sit down with the [ACTS guide]book to see 'what was I supposed to be doing right now?'

I am juggling, two of my aunts have the dementia. And my mom [eighty years old] is sick. Yeah, so I've got, and my sister, believe or not, both my mom and my sister had blood clots in the lung. I am juggling four people doing this session. [The caregiver is disabled and also takes care of her two teenage children.]

The CGs' caregiving challenges were compounded by their emotional and self-care problems. Emotional problems included anxiety, boredom, frustration, sadness, feeling overwhelmed, denial, and guilt for seeking help. The CGs' lack of self-care—lack of personal

time, limited opportunities for socialization and recreation, no time for religious and spiritual activities, missing doctor's appointments, and poor self-health care—resulted in further emotional problems. CGs also identified specific stressors such as paying bills, leaving the CR alone or with alternative care attendants, lack of time for self-care and exercise, and headaches and insomnia. CGs described themselves variously as "tired," "stressed," "burned out," and "overwhelmed."

Another theme was CG communication problems. CGs openly discussed their own ineffective behaviors, negative actions, and aggressive response patterns when communicating with their CRs, family members, health providers, and colleagues or supervisors at work. One CG described this by saying "Sometimes, I can be very aggressive when I felt like I've done all I can do. I am not getting the help. I think my family members should jump in and help me." Another CG stated, "My doctor doesn't listen to my suggestions about providing care for my mom. I am getting frustrated with him." Still a third asserted, "It concerns me that I sometimes raise my voice at my husband [CR]."

CGs lacked access to resources they needed in taking care of their CRs, including essential information, education, assisted care, and finances for CRs' physical and psychosocial needs. CGs indicated they needed resources such as "access to CG support groups," "help in paying attendant care expenses," and "a plan to safeguard my mom's finances." CGs desired more information about medications for Alzheimer's, understanding how to manage their CRs' diets, and techniques for how to navigate the managed care system.

Finally, the CGs encountered problems in their daily lives apart from their caregiving activities. Problem types include those related to their work, financial situation, general life skills, and other daily stressors. CGs mentioned cooking meals, cleaning the house, managing financial debt, and working at jobs outside the home as examples.

5.3.1. Problem and goal identification as information production

Identifying and recording problems and goals are intrinsic to the ACTS CBT approach and are a form of information production. For the CGs, this involves creating a physical artifact,

and explicitly identifying an information gap to be used for more information seeking. CGs use their problem and goal statements to support them throughout the counseling process. As one CG put it, "The things I wrote down. I looked at what I wrote down. And kind of, ok, did I get this done? I haven't done that and the others. I did that often. That was good." Over the course of the intervention, CGs continued to create information resources to help them use the strategies learned during the sessions and from the ACTS guidebook. The following exemplar is from a CG who combined techniques from her workplace with strategies learned during the counseling sessions to create "job aids" to remind her how she might achieve her goal of a more harmonious week with her co-CG:

[I have] created a little job aid that I keep near my desk as a reminder. [...] One of my goals was: decrease the number of instances that I lose my temper with my co-caregiver to zero in one week. And so the activities and interventions that I got from the course were: be assertive instead of being passive aggressive by telling my co-caregiver how she makes me feel when she talks in a rude hostile tone. And then I had deployed a variety of interventions. These are job aid ones that I have created [...] to remind me: walk away when she begins to rant and raise her voice; take a deep breath and count to 10 before responding; focus on positive issues during our conversations; exhibit more patience; by remembering that she is a valuable member of my caregiver team.

During the process of problem resolution, CGs identified other sources of information they used, in addition to the sources they created by writing down their problems and goals. These included themselves, their calendars (day planners), the ACTS guidebook, the ACTS counselor, and other CGs in their counseling groups.

5.3.2. Self

The CGs learned they could be their own key sources of information by identifying their problems and goals and by seeking the information needed to meet those goals. Participants consistently expressed that they learned the importance of shifting their attention to themselves,

their self-care, and their goals for themselves, rather than focusing only on the care of their CRs and setting goals for how their CRs should act (or focusing on others seeking their care or attention; see Lustria, et al., 2010). The shift to a focus on self, for goal-setting and self-care, was a key component of the treatment approach, as indicated in the following quotes from three CGs:

I can set and track goals; I never thought about doing that before. Now I know how to manage my feelings when I'm stressed out; I can meet my own needs now.

I know now that in order to care for someone else, you've got to take care of yourself. And I know now I shouldn't be afraid to ask for help if I need help.

I learned I've got to take of me first, and everything else comes after that. Because if I don't take care of me, meet my needs, then I cannot help my husband.

The focus on the self is important because before the counseling, CGs were less likely to attend to the information coming from their 'selves' – their minds and bodies – and were exhausted and depressed. Coming to understand the self as a source of information required for problem resolution was vital.

While the self was a vital source of information, it was also an object of desired change, and several external sources were used to support such change: the personal calendar, ACTS guidebook, ACTS counselor, and other CGs.

5.3.3. *Calendar*

In a qualitative interview study, an indicator of the life context of participants comes during the interview scheduling process (Kazmer & Xie, 2008). While the CGs in this study were enthusiastic about the ACTS project and highly engaged in the interviews, the interview scheduling process underscored the busyness and unpredictability of the CGs' lives and their need for structured information sources to support their unpredictable lives. The interviewers learned to be prepared (temporally, mentally, and technically) to *conduct* the interview when calling to *schedule* an interview. CGs often said that the fact they had answered the phone meant they had a free minute, and they did not know when their next free minute would appear, so they should do

the interview immediately. If an interview was scheduled, it frequently happened that the CG had an unexpected schedule change, often due to the changing needs of their CR or other family members, so they were unavailable during the scheduled time. In other words, the calendar or day planner was a comforting source of information but not always an accurate representation of reality. The importance of the day planner/calendar became clear through these conversations. The participants were lost if they were caught without their calendar at hand, because they were using it to organize so many things in their busy lives, and because its physical presence helped remind them of their schedules overall.

5.3.4. ACTS guidebook

The need for the structured physical information artifact carried over from the calendar to the ACTS guidebook. Each CG received an ACTS intervention guidebook comprising seven major components: (a) overview of the characteristics of progressive dementia, (b) relaxation training, (c) effective thinking about the challenges of caregiving, (d) building in pleasant daily activities as a guard against emotional distress, (e) assertive (distinct from passive or aggressive) communication in caregiving situations and with family members, (f) developing problem-solving skills through personal goal setting, and (g) the importance of having a social support network and of continuing to maintain and refine problem-solving skills. The guidebooks were used during all counseling sessions, and CGs were encouraged to keep their guidebooks handy for future use.

CGs tracked their goals and recorded their progress in their guidebooks, which they used as a source of information and as personal validation of progress. One participant exemplified this: "The book made me aware on a day-to-day basis what I needed to do; I can continue to use the book to track and set goals." The guidebook helped the CGs clarify their expectations of themselves and of their CRs. It helped them to "understand some of the things that I go through, and better deal with them," and "helped me out a lot because I didn't actually know what to look out for or to expect." The guidebook was an effective information tool because the CGs found the contents to be understandable and easily readable. While it worked best in concert with the efforts

of the counselors to help the CGs make changes in their day-to-day lives, it was also a tool for revisiting concepts and tracking progress. CGs made or requested additional copies of the goal sheets to continue to track goals and strategies. They used the guidebook when talking with family members and health care professionals, using it as a reminder of what they had learned and as a reliable source of information to which they could refer during potentially contentious discussions.

Two participants shared some longer responses exemplifying CGs' ongoing uses of the guidebook:

It's just been an awesome tool, it's just like turning on the light. You knew all this stuff was here, you already had this information. But it was just like you were walking around in the dark. But now I have the lights on, and I'm opening the book and pulling the tools out, instead of digging the ground with my hands, I am using the tools. [...] Just reviewing the information, and obtaining the knowledge, just like you got your fingers there, but you don't never use them. You keep them balled up. Just open your hand, these fingers will help you do this, you can tap that button, if you open your hand. So it's like, open the book, review the book, go over the information. If you've already seen it or did it before, let's put it into action now.

Then to have the literature, and the resources, and that's another thing, too. You know, we always go back to, we are on target in terms of the workbook that was sent to us. We did that, I think, very much on time. All of our assignments have been done in a timely manner you know, led by [counselor]. I think for me the relaxation piece, and affirmation, the literature on being assertive. I should have mentioned that, too. Information on just finding out where you are, and especially when dealing with people in the medical profession.

5.3.5. *ACTS counselor*

Each CG had an ACTS guidebook, but it was the counselor who made the information in the guidebook come alive. Beyond their teaching the guidebook, three other aspects related to the

counselors are important to the IUE of the CGs: the counselor's ability to take in information; the counselor's ability to re-package information; and the counselor's voice (communication and information delivery medium).

The interview included questions about the CGs' perceptions of their connectedness to the counselors and the attentiveness of the counselors to the CGs' needs, questions generally answered with a focus on the counselors' ability and willingness to listen. It was important to the CGs that the counselors asked questions of them, seeking information from them actively and empathetically and listening to the answers.

Active listening by the counselors included taking information in and also repackaging it: CGs noted it was important that the counselor restated the CG's situation to help him or her understand it. As one CG described, "I think she [the counselor] is a good listener. She has a wonderful way of restating a situation." Active listening also involved remembering the needs the CGs expressed during the sessions and providing relevant information to them between sessions. The counselor was seen as a reliable source of information—especially for CGs who do not have ready access to the internet. One CG described her counselor this way:

Also, she [the counselor] asked us if we have questions or something we want her to research. And whatever it is, she always comes back with the information. She has even mailed me information, some things I expressed an interest in. That is helpful. It is nice to have somebody to share with. That can contact other people, that I wouldn't be able to access on my own, and resources that would be more difficult, because I am not really into computers.

CGs identified another beneficial repackaging behavior facilitated by the group counseling: counselors listened to the CGs in their groups, then synthesized their experiences to reveal common themes and problems that otherwise would have remained hidden in a plethora of personal details.

Another specific aspect that emerged from the data was the *voice* of the counselor. CGs consistently talked about the "soothing voice" of the counselors although the interview did not ask about voice. For example, one CG said of her counselor "She's got this calm, soothing voice, she's just perfect for the job." Words used by other CGs to describe their counselors' voices include "relaxing," "tranquilizing," and "therapeutic."

5.3.6. *Other caregivers*

CGs considered sharing problems, solutions, goals, and strategies within the group counseling context important for two reasons. The first was that "we were able to share situations and some solutions to our problems," and to hear "examples of different things that have helped them that I wasn't aware of." Another CG adds: "you really learn from others and their caregiving skills and techniques." The second reason was that hearing from other CGs whose CRs were at more advanced stages—or had different forms of dementia—reduced CGs' anxiety about the future by making it seem more understandable and predictable. Getting information about others' experiences helped them fill in "a big blank, because, now I know more, pretty much what to look for with my [CR], now I know what to do, I have resources and everything, so it's not just a big blank for me now." Similarly, the counseling groups (the combination of the guidebook, the counselor's feedback, their own assessments, and their fellow CGs) served as informal gauges by which participants checked their progress. One CG illustrates this idea:

It has kind of opened up another level for me. Because, I am talking with people who are doing the same things that I do. You know, they are caring for their loved ones. And pretty much single-handedly, you know, for the most part, at least 80% of the day. They are in charge of what happens to their loved ones. And, um, kind of seeing that you are not alone in this, our charge. And with me, it's my pleasure to be the person in this situation with my mother. And, basically, it's that, you know, other people have gone through these times, and that they have done well. And that they've passed on some things you can benefit from. And then likewise, you can do the same thing for them.

6. Discussion

The IUE of the CGs in the ACTS project was somewhat constrained by the unique features of the project, but several features of the people, settings, problems, and problem resolutions may have broader implications. A strength of the ACTS project was the capacity to bring together CGs in groups to share their experiences in a structured way that was (a) dedicated to enhancing caregiving problem-solving skills, (b) facilitated by a knowledgeable counselor, and (c) supported by a carefully-constructed guidebook. The skills-building component of the groups provided the foundation for facilitating CGs' attainment of their goals during individual sessions with their counselors, and created a link among group members in addition to validation and useful tips from peers. Facilitation by a knowledgeable counselor kept the group on track and helped to synthesize information for them.

The ACTS guidebook was important to the CGs as an information source and physical artifact. The CGs found the guidebook understandable and accessible, but the content of the guidebook alone was insufficient to motivate behavior change. Its impact was potentiated by the counselor providing functional explanations using concrete, daily caregiving examples, and by delivering the content in a "soothing voice." The packaging and delivery of the information, in print in the guidebook and in voice from the counselor, were key elements of the behavior change process. Beyond that, the guidebook served as a way to support interpersonal information seeking and sharing: when CGs needed to exchange information with others such as family members or health care providers they used the guidebook as a physical point of shared focus and a source of authority.

The IUE of the counseling group was critical to the CGs in meeting their goals, but the groups – and the counseling – ended after 12 sessions when access to, and interaction with, some key parts of the counseling IUE also ended. CGs no longer met in a structured way with their counselors and fellow group members. Although they could keep their ACTS guidebooks, CGs needed an effective way to facilitate their transition from structured, shared group activities to the

next phase of their caregiving and goal management (Glueckauf et al., 2012; Strauss, 1984). One aspect of this transition was to provide emotional support as they refocused themselves to maintaining their gains, or to facilitate getting involved in different support groups. Another was to provide basic support for keeping in touch with each other and their counselors. This kind of basic information exchange – such as facilitating ongoing contact among CGs, or providing additional copies of the goal sheets from the ACTS guidebook – was often overlooked, but its importance cannot be over-emphasized (Kazmer, 2007; Veinot, 2010). The CGs expressed their interest in staying in touch, saying, "we kind of developed a friendship and at some point in time the three of us are going to meet and have lunch ... we exchanged phone numbers and addresses so that we could maintain communication," or "we all agreed that we will keep in contact with each other." Some such contact naturally falls away over time, but ongoing functional support can keep useful friendship ties alive.

7. Limitations

Because this project focused on the IUE of the counseling experience, additional sources of information used to facilitate problem resolution were not foregrounded in the data and only appear if the participants mentioned them incidentally. The findings that are not specific to the circumstances of the ACTS project may be applicable to other CGs, but are not intended to be generalizable to any population at large. The data used for this study were subjected to a secondary analysis focusing on information behaviors, but further interviews to resolve uncertainties or pursue promising leads in the data were not conducted. The analysis of the data implies that more follow-up questions are needed about: long-term use (or non-use) of the ACTS guidebook in the absence of the counselor, post-intervention; and how the learned behaviors from the intervention (e.g., seeking information from other CGs, using one's self as an information source, setting goals) shape information use over time or in other settings. In addition, further interviews could have allowed for open-ended or critical incident questions focused specifically on

information use, which would almost certainly have added people, sources, and behaviors that were not revealed through this analysis.

8. Conclusions and Implications

The results of this analysis, using the IUE framework to probe the people, settings, and problems of African–American ACTS participants, revealed several aspects of this IUE that are important to consider when working with similar groups. It has shed light on the experiences of CGs and may help inform the design of health information technology systems (such as computer databases). The findings also help frame interpersonal healthcare interactions and interventions by suggesting the design of low-technology information materials, where appropriate, and by helping us understand how to accommodate changes in information behavior over time. It also has a few possible implications for the IUE framework.

Taylor (1991) stressed that the IUE model as described was limited and narrowly scoped to make its explication manageable, and that further research was needed focusing on non-professional information users. The findings from this study highlight two amplifications of the IUE approach. First, IUE considers "the kinds and structures of problems deemed important and typical by this set of people" (p. 221) but the ACTS CGs are not always in the position to determine which problems are important or to exert influence on the shape of those problems. Thus including consideration of power and agency in the problem determination stage of IUE is important. IUE also places importance on the solutions or resolutions to problems (p. 221) but the CGs in this study often wrestle with problems that cannot be resolved. The possibilities of re-framing the problem so that the re-framed problem is resolvable, or of developing mechanisms to support satisficing, in the absence of re-framing, need to be considered in the latter stages of IUE.

Exploring this study's implications for information provision indicates that physical artifacts of information are not always to be eliminated, even when it is technologically possible to deliver all information electronically. Something tangible to hold, that is not technologically daunting, can be a valuable source of comfort and support. A physical artifact that acts as a formal

information source can serve as a vital support for interpersonal information exchanges. It is important not to think about formal and interpersonal information exchanges as being mutually exclusive. As the CGs in this study indicated, they use the formal information source of the guidebook to guide their interpersonal information exchanges. The guidebook can be used as a source of information to share with family members or other CGs, but it can also lend authority when conflicts emerge between the CG and others.

It is important to understand and test how information materials associated with an activity or intervention will be used. This study implied some specific changes to the ACTS guidebook. The guidebook should be easy to carry to support the CGs' use of it. Additional paper copies of often-needed or often-reused parts of the materials, such as the goal-setting worksheets or the instruction sheet for the relaxation techniques taught during the counseling sessions, should be provided. These changes might seem small to the point of extreme triviality to information professionals, but to the CGs they are significant and meaningful. The larger implication is to encourage the use of participatory design techniques, even for low-tech interventions, and to test the use of materials and be attuned to the need for even small changes, never belittling as unimportant factors that are significant to the targeted users.

Sharing information among others who encounter similar difficulties is important to CGs. Their feelings of isolation are often compounded by increasing care demands in the home setting, particularly as their CRs' dementia progresses, and may be exacerbated by social norms (e.g., cultural and familial) that discourage over-sharing or complaining about caregiving burdens. These types of information exchange, however, are identified as some of the most important by the CGs in this study. Providing a structured environment where information can be shared and synthesized is key to helping them manage their perceived burden and anxiety about the future.

This study indicated that the counseling session settings are not defined by medium (such as the difference between in-person and telephone groups) but by people and activities, a finding that echoes existing conceptual frameworks such as social worlds (Strauss, 1978). The IUE

described in this paper is not reflective of the whole-life IUE of the CGs, but of the IUE relevant to the ACTS experience, and as a result provides a specific understanding of information use during and related to therapeutic intervention. 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 to create a viable IUE rather than what seems interesting in terms of technology, or rich in terms of interaction (see Forducey, et al., 2012). A low-tech intervention, such as telephone-based CBT, is likely to be an optimal fit for the needs of many older dementia CGs. Including the right people (e.g., 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. At the same time, as technologies such as smartphones begin to achieve critical mass for all population groups (see <http://pewinternet.org> for most current statistics on internet access and use) the lessons learned from this low-tech intervention can still be applied: continued access to information from various formal and informal sources, whose synthesis is guided by a knowledgeable person, is important but must be constantly tested in the real-life experiences of the target users.

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