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# Spousal Caregiver Narratives and Credible Authority: Uncertainty in Illness of Spousal Caregivers

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## Spousal Caregiver Narratives and Credible Authority: Uncertainty in Illness of Spousal Caregivers

### **Abstract**

This article is taken from a larger longitudinal study that used caregiver interviews, caregiver surveys, and caregiver statistical information of one community. The interviews were conducted with six spousal caregivers to examine the narratives produced by spouses actively caring for their partners with dementia. The spousal caregivers were interviewed multiple times over approximately 12 to 18 months. The author was the caregiver counselor and had worked in the community in social services for fifteen years. The narratives were analyzed using a phenomenological approach that allowed the development of descriptions of uncertainty and sharing caregiver narratives with a specialized audience. The duality of caregiver uncertainty based on making decisions for and about cognitively impaired care recipients is evident in diagnosis, safety, end-of-life decisions, and the caregivers' health. The choice of professional listeners as the audience when talking about uncertainty in illness relates to the importance of credible authority in reducing caregiver uncertainty.

### **Keywords**

Uncertainty, Credible Authority, Caregivers, Dementia, Narratives

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## **Spousal Caregiver Narratives and Credible Authority: Uncertainty in Illness of Spousal Caregivers**

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As the American population ages, so does the awareness of chronic illnesses that predominantly affect older adults. Older adults are more likely to experience illnesses affecting their cognitive functioning, such as Alzheimer's disease and other forms of dementia. Currently it is estimated that 5.1 million Americans over 65 years old have Alzheimer's disease or dementia and are cared for by 11 million unpaid caregivers composed mostly of family members (Alzheimer's Association, 2010). The research over the last twenty years of family caregivers of people with dementia revealed an increased risk of emotional and physical well-being measured through levels of stress, depression, and medical problems (Bond, Clark, & Davies, 2003; Gaugler, Kane, Kane, & Newcomer, 2005; Sanders, 2005). Caregivers of people with dementia face another level of stress created by being surrogate decision-makers for care recipients who can no longer contribute to deciding their own physical care.

### **Caregiver Uncertainty in Illness**

Uncertainty in illness is created through the many unknowns of dealing with disease, treatment, and the medical community (Mishel, 1988, 1990). Uncertainty was documented among many groups of people dealing with chronic illnesses such as AIDS (Brashers et al., 1999; Brashers et al., 2000; Brashers, Neidig, Reynolds, & Haas, 1998; Folkman, 2001), end-stage renal disease (Hines, Babrow, Badzek, & Moss, 2001), cancer (Ford, Babrow, & Stohl, 1996) and other chronic illnesses requiring nursing home care (Singer, Martin, & Kelner, 1999). The patients' appraisal of the uncertainty and adaptive communication helped them manage the uncertainty produced by the health problems

and subsequent treatments (Babrow, Kasch, & Ford, 1998; Brashers & Babrow, 1996; Hines, Babrow, Badzek, & Moss, 1997; Hines, Moss, & Badzek, 1997; Mishel, 1988, 1990; Mishel & Braden, 1998). According to Mishel (1988, 1990), the patient's confidence in the source of information is considered credible authority. The health care providers' knowledge is one piece of the patients' confidence level in the information they provide. In a study of people living with HIV, Brashers, Hsieh, Neidig, and Reynolds (2006) found that the participants considered the health professionals' knowledge of the disease and their communication skills as qualities of credible authority. Simply having knowledge is not enough to create relational confidence in the information; the health care providers must be able to establish professional credibility through effective and appropriate communication.

Caregivers face the uncertainty described in Mishel's (1988) model and the uncertainty is complicated by the need to make substituted judgments for their care recipients who are cognitively impaired. When deciding on behalf of someone else, intimate and complicated health care choices are a difficult task. Studies indicate care recipients prefer their family make decisions about health problems (Hines et al., 1999; Moore & Sherman, 1999; Moore, Sparr, Sherman, & Avery, 2003), but this is not as simple a resolution as it sounds. The preference does not then equate to caregivers having confidence in their decision-making capacity (Hines et al., 2000) or that caregivers' substituted judgments coincide with older adults' choices (Hummert & Morgan, 2001; Sanesone & Phillips, 1995). Often an individual does not address their health care choices until an illness occurs. If people have difficulty making decisions for themselves, it is immensely more complicated to make decisions for a care recipient.

Although numerous researchers have studied the use of formal advance directives (end-of-life decisions) and the caregiver role (Hines et al., 1999; Mutran, Danis, Bratton, Sudha, & Hanson, 1997; Rosenfeld, Wenger, & Kagawa-Singer, 2000; Sanesone & Phillips, 1995), there are many incremental changes, such as functional impairments and changing emotional roles that require caregiver decisions not specifically covered by advance directives (Hooker, Frazier, & Monahan, 1994; McCarty 1996; Vernooij-Danssen, Persoon, & Felling, 1998). Cultural concerns (Carrese & Rhodes, 1995; Germino et al., 1998; Hopp & Duffy, 2000), the caregiver's health status (Sanders, 2005), physical intimacy (Baikie, 2002; Svetlik, Dooley, Weiner, Williamson, & Walters, 2005), choosing nursing home care (Nolan & Dellasega, 2000), and managing social and financial responsibilities (Jansson, Nordberg, & Grafstrom, 2001; Perry, 2002) can all create caregiver uncertainty. The question is then how important is the credible authority to the caregiver of a person with dementia. The knowledge and communication skills of the professional listener may be essential to the caregiver's feelings of social support. Also, the acceptance of the caregiver's narrative by a representative of the health care services adds a level of emotional support not available from informal social support given by family and friends.

### **Caregiver Narratives and Professional Audiences**

Medical sociologists initially looked at the role of the patient within the medical system, but that research has expanded to explore the personal experiences of the patient interacting with the medical system. Talcott Parsons (1951) developed the most

prominent functionalist perspective in the “sick role”. This model was based on structuralism with the patient fitting into the medical system in a prescribed way. According to the theory, the patient must perform certain obligations as the sick person and in return is granted entitlements from the same system. So the patient must seek and comply with medical treatment and in turn the patient is excused from working or fulfilling other duties associated with adulthood, such as father, wife, or employee. This model did not incorporate the unique experiences of the patient’s interactions with the health care providers within the medical system. The patient role did not take into account the unique perspective of each patient, such as the patient’s social, emotional, and educational characteristics. All of these qualities affect the way the patient views the medical system and then interacts with it.

Charmaz (1999) and Charmaz and Olesen (1997) chronicled the theoretical movement from Parson’s functionalist definition of the sick role to later researchers who based their narrative research on symbolic interactionism and social constructionism. Charmaz (1999) viewed this theoretical shift as a move to the study of the personal experiences of patients: “In contrast to the sick role, the narrative turn toward storytelling shifts attention from objectivity to subjectivity, from acts and facts to thoughts and feelings, and from portrayals of prescribed roles to images of past, present, and future selves” (p. 211).

Uncertainty management in illness is another model that has been heavily influenced by the field of communication. Research has focused on the communication choices that people make to manage the many fears, doubts, and challenges that come with illness and disability (Babrow, Kasch, & Ford, 1998; Brashers & Babrow, 1996; Brashers et al., 2000). Once again an event that crosses the physical, psychological, and social boundaries of human experience is explored by observing the communication that occurs when people find themselves in these circumstances. Providing care to a person with dementia often requires the caregiver to manage medical information and make decisions on the care recipient’s behalf using the caregiver’s substituted judgment. This is one example of uncertainty management from the caregiver’s perspective.

In the discipline of communication, Fisher (1984) proposed the narrative paradigm. The heart of this perspective is that people are storytellers. Narratives contain commonly understood symbols of communication that evaluate and consolidate social stories. Fisher (1985, 1997) expanded on the narrative paradigm: narratives are more than stories shared between speakers and listeners. Narratives are the means by which reason is assigned and decisions are made in communities. Themes of caregiver narrative studies have included reframing lives, coping mechanisms, and reciprocity of social support (Aryes, 2000; Bennett & Vidal-Hall, 2000; Harris, 1998; Russell, 2001). These narratives become part of the community narrative of caregiving. When the researcher interviews a participant to obtain his or her story, the researcher becomes the audience (Luborsky, 1987).

The interaction between audience and narrator in illness narratives and life stories has been established (Bochner, 2001; Charmaz, 1999; Singer, 2004). The listener interacts with the storyteller and becomes a part of the story; therefore, who the audience is and what identity and role the listener plays is intricately tied to the construction of the narrative. Docherty and McColl (2003) defined the professional audience in relational

terms. The interaction between the social worker (the audience) and the patient as (the narrator):

This process of coexploring the familiar (i.e., the client's story, view of the problem, and meanings) and codeveloping the new (i.e., meanings, realities, and narratives), marks shift away from problem definition and a move toward new ways of making sense of behavior, feelings and events. (p. 22)

This same narrator/audience relationship has been noted between physicians and patients in the construction of illness narratives (Eggly, 2002), and it has been encouraged in therapeutic relationships with the chronically ill (Sollod, 2002). In contrast, the physicians' failures to acknowledge the patients' narratives have led to limited communication between patients and physicians (Beach, Easter, Good, & Pigeron, 2005; Waitzkin, Britt, & Williams, 1994). Narratives shared with support group members (Hsieh, 2004), life reviews shared with hospice workers (Price, 1995), even participant interviews shared with researchers (Bennett & Vidal-Hall, 2000; Miczo, 2003; Pennebaker & Keogh, 1999) have been told to audiences who acknowledge the importance of the illness and caregiver narratives. These professional listeners who represent Fisher's (1997) concept of a greater societal narrative incorporate qualities of Mishel's (1988) credible authority. Physicians, nurses, nursing home administrators, counselors, clergy, and social workers compose an official reference point for what is appropriate and acceptable in health care and caregiving because of their position of knowledge. These professionals are the gatekeepers to treatment and services and therefore create ideas of what it means to be a "good patient" or "compassionate caregiver."

### **My Social Service Experience with Caregivers**

During a home visit as a medical social worker to a client and her spouse, I realized that, during most of my social service career, I listened to stories from patients and their family members. This particular visit brought that into focus because, over the course of approximately ten years, I had met with this couple at least three times. The husband had suffered multiple strokes, which left him physically and cognitively disabled; subsequently he was diagnosed with Alzheimer's disease. His wife, Evelyn (pseudonym) had decided for various reasons to keep Edward (pseudonym), her husband, at home and use minimal formal support in caring for him. She was a full-time caregiver for about ten years and had experienced the slow, but inevitable decline of Edward.

Evelyn was telling me her story once again. Some of the story was familiar and some of the story was new. The story, however, was the focal point of this meeting. I was listening to the history of this couple and this spousal caregiver's journey over the last ten years. Listening to the story was the most important part of the visit to her. I already knew the probable outcome of this visit. Evelyn would and indeed did continue to care for her husband in their home. Although I suspected that no physical change would be made, I did not discount the necessity of my visit. The need to make meaning of loss and suffering was the reason Evelyn had asked to speak to the social worker. The piece of the

story that stands out in my memory was the Evelyn telling me about Edward's recent final decline into cognitive oblivion. Through the years, although Edward did not respond to other people, Evelyn always felt that he responded to her. Finally even that spark of recognition was gone. It was like a door closing in their relationship. She summed up the experience by saying, "I could be just another nurse's aide to him."

This event had been the reason for my visit. She had turned another page in her book of caregiving and was once again evaluating her options. The biggest decision facing many spousal caregivers is nursing home placement. I had recited the basic financial and institutional processes involved with nursing home placement. This was an obligatory duty, as many health and social service professionals through the years had given Evelyn this information. It was not the need for information that had caused her to ask me to her home again. It was my status as an empathetic and knowledgeable listener, a counselor. This led me to several questions: Why was telling the story important when facing uncertainty producing decisions? Why was listening to the story important?

While working as a medical social worker in this community, I also found myself caring for my mother-in-law who suffered from Alzheimer's disease as well as significant cardiac problems. My husband was his mother's healthcare power of attorney and he depended on me for information and resource recommendations. As we worked to provide his mother with a safe and comfortable living arrangement, we were constantly balancing her desire to maintain her independence with her diminishing cognitive capacities. We were required to make many decisions guided by the directions of her advance directives and previous discussions with her when she was still able to express her health care wishes. Eventually we were required to make the ultimate decision about life prolonging care, when the physician stated there were no longer any curative treatments available.

I included this personal information, because it has given me a different perspective of the caregiver's narrative. As caregiver to a person with dementia, as well as a professional counselor to caregivers, I have also told my story to professional "listeners" (i.e., counselors, social workers, nurses, physicians). My words had an odd familiarity when I related my caregiving narrative. I heard the emotions, the uncertainty, and the urgency to tell my experiences before in clients' stories, when I was the audience. These client messages are narratives, in which people dealing with illness, disability, and aging talked about their changing lives and the uncertainty they faced. I will further explain this concept in the Methods section.

## **Methods**

This article represents research taken from a larger study. Although there are many theoretical perspectives used to analyze narrative research, the selection for the interview portion of this study was based on the journey of the researcher to find a theoretical framework that fits the narratives heard over a career in social work. Initially in researching the area of end-of-life decision making, I found no satisfying fit. There were many attempts to understand the dynamics of this process, but the research focusing on the demographics of the participants or educational programs designed to assist in this process all had limited success at explaining this human event. Finally when looking at this subject, I was introduced to research from the field of communication.

Narratives are the constructs of people living in a social world. Fisher theorized that people are storytelling creatures who judge the truth of narratives through the fit of personal narratives into greater societal narratives (Fisher, 1984, 1985). Narratives therefore are interactions between the narrators and their family, friends, community, and the world at large. In this study, that meant how caregivers view caregiving in their community and how they managed uncertainty. From my previous experience in speaking with caregivers of patients in home care and hospice, their stories frequently included communication related to this area. The analysis focused on the communication about the uncertainty in caregiving, and the benefit from telling their stories to an educated and empathetic audience.

Phenomenology is a philosophy that allows the exploration of human interactions in order to extract the full meaning from the experience (Moran & Mooney, 2002; Moustakas, 1994). The objective of a study based on a phenomenological perspective has been to describe the meaning of complex and richly layered human interactions (Bailey, 1997; Moustakas, 1994). The researcher's goal has been to elucidate the underlying structures of the event, allowing the participants to be co-researchers in the mutual exploration of the narrated event (Moustakas, 1994). Researchers have used this method to interpret illness narratives in order to describe the emotional and physical interactions of patients with health care professionals (Ekman, Lundman, & Norberg, 1999; Monks, 2000). Butcher and Buckwalter (2002) also used a phenomenological interpretive analysis to explore one spouse's meaning of caregiving.

The narrative was the pathway for the researchers to find the caregiver's construction of what it meant to care for her husband who was suffering from Alzheimer's disease. This study was exploratory in targeting not only caregiver narratives, but also participants in one community who share the role of spouse. This form of analysis also allowed a description of uncertainty in illness through caregiver narratives. Although the research material was not the equivalent of the immersion of a researcher in ethnography, the descriptive nature of the analysis did allow for my professional history and my knowledge of the community to be included. This information placed the narratives into the context of the caregivers' social world and increased the description of the caregiving experience in the caregivers' own words. These are the two research questions addressed by the material in this article:

- RQ: What meaning do spousal caregivers of partners with dementia ascribe to the professional listener as an audience for their narratives?
- RQ: How do spousal caregivers experience the uncertainty created in caregiving for a person with dementia?

## **Procedures**

The research methods were approved by the Speech Communication on Use of Human Participants, University of Illinois at Urbana-Champaign on May 15, 2003. The caregivers in this study were recruited from a caregiver program located within the senior services of the local county health department, where the researcher was also employed as the caregiver counselor. If the researcher was not the caregiver's first contact with the senior services department, the social service professional obtained permission for the



researcher to contact the participant. The researcher recruited participants who were spousal caregivers of older adults suffering from dementia. Although every caregiver's experience is unique, these specific characteristics allowed the research to focus on interpersonal communication between spouses and persons experiencing dementia. These experiences presented special challenges and offered opportunities for comparison. For example, the psychological and social pressures of placing a spouse in a nursing home presented similar issues of uncertainty management in the spousal caregivers.

I conducted two or three phenomenological interviews with five caregivers of older adults over a three-year period. Each caregiver was interviewed within approximately 12 months to explore meanings that spouses attach to the act of caregiving to their partners with dementia. A sixth spousal caregiver is also included with only one interview conducted. The contents were included because her narrative was consistent with the findings of the other interviews. The interviews were audio taped and transcribed for analysis. The number of interviews with each spouse is explained in his or her description later in this chapter.

Initial interviews began with a brief explanation of the purpose of the study. The participants were told that the study was designed to learn about caregiving from the point of view of people who are engaged in the real, everyday process of caring for a spouse. All of the participants agreed to participate in this study based on their desire to tell their stories and assist other caregivers. Each participant signed a consent form to participate in the study and no financial compensation was offered to the participants. The participants were asked a question that encouraged them to begin the story of caregiving from the point that was most meaningful to the individual caregiver. I used general questions such as: "Tell me about your caregiving experiences. What does being a caregiver mean to you? What has been happening in your life since you began taking care of your spouse?"

Subsequent questions were used to clarify points in the participant's story. The researcher interjected questions as necessary to clarify or expand points that appeared important to the caregiver. I asked about details that the caregiver assumed I already knew or clarified locations or time frames of events. I used the following questions to expand on the areas of interest in the study: "If I were to call you a spousal caregiver, how would you describe what that means to you? I have had many clients tell me that just talking to a person like me was helpful. How do you feel about sharing your story with me? Do you worry about managing and making decisions about your spouse's medical care and changes in condition?" The caregivers' narratives, however, contained uncertainty and importance of telling their stories with little explicit questioning.

The use of participant-directed interviews fits this method of research because it allows the narrator to express his or her knowing of the caregiving experience to be fully and individually expressed. Open-ended questions facilitated the storytelling process and informed the researcher about the meaning of spousal caregiving. This method of interviewing has been used to gain access to other illness experiences and life transitions (Anderson & Martin, 2003; Ekman et al., 1999; Gibbs & Franks, 2002; Luborsky, 1987). The researchers in these studies employed open-ended questions that invited the participants to tell their story. Follow-up questions were designed to encourage the participant to expand on the topics presented in the narratives.

The researcher's familiarity with the community provided a context in which to locate the narratives. As a medical social worker in this community, I am aware of the services available to caregivers. I am also aware of the different challenges faced by caregivers from a variety of socioeconomic groups in obtaining these services. Finally, I am aware of the community's general attitudes toward caregiving obligations and burdens. This is significant, because a narrative is created within a social and cultural environment that influences the experiences of the caregivers and the understanding of their audiences. This research provided an opportunity to study narratives constructed within a specific community that is very familiar to both the participants and the researcher.

## **Analysis**

The narratives were analyzed using basic steps of phenomenological method of analysis proposed by Giorgi (1979). The steps incorporated the researcher's full and deep exploration of the participant's expressed meaning of the caregiving experience followed by the researcher's analysis of the derived underlying structures or universal meanings of spousal caregiving including uncertainty, credible authority, and the professional listener as the preferred narrative audience.

1. I read the transcripts of each participant's interviews as they were completed to gain an overall sense of the meaning of caregiving for each participant.
2. I read the transcripts again looking for descriptions of caregiver uncertainty and audience relevance in the narratives; these descriptive words and phrases constituted meaning units.
3. The units were compared and contrasted to find consistent and substantial concepts related to uncertainty and audience relevance in the narratives.
4. Following reflection upon the meaning units in the narrators' language, I then developed written descriptions of themes within the caregiving categories based on my interpretation.
5. The caregiving themes were examined within the context of descriptions of community, state, and national caregivers from the relevant professional and academic literature to produce an overall structural description of spousal caregiving.

I have revealed my position as researcher and caregiver counselor in each participant's history. Disclosure was important, because it clearly positions me within the narratives. Other narrative studies have acknowledged the position of the researcher as a sympathetic or friendly audience (Harden, 2000; Irvine, 2000; Luborsky, 1987). The researcher as a sympathetic listener has been used to provide an insider perspective into the experiences of the participants (Anderson & Martin, 2003; Gibbs & Franks, 2002). This provided rapport between the researcher and the participants that encouraged the revelation of what is meaningful in the participants' experiences. It is then essential as researchers to recognize these possibilities and the effect the researcher has as the audience.

Beyond recognition of the researcher as the audience is the requirement for the researcher to engage in the epoche process in order to allow the participants to be heard by an interested and open audience. This includes the recognition that the participants are aware of my professional and academic role in listening to their stories of caregiving. It is not enough to simply acknowledge that the researcher plays a role in the creation of the participant's narrative. I wanted the participants to share caregiving from their perspective and in their words, ideas, and values. The researchers included the position of the researcher as the audience in the conclusions drawn from the narrative studies (Bochner, 2001; Charmaz & Olsen, 1997; Frank, 2000; Kelly & Dickinson, 1997). Haight and Miller, the co-authors (along with Hudley) of *Raise Up a Child* (2003) addressed one such issue in the introduction to Edith Hudley's story. The authors approached Hudley with the ethical concern of both co-authors being white, academic listeners and the written voices for a woman of color who had experienced very different cultural and socioeconomic opportunities. The book exists and gains credibility because the researchers addressed this issue, instead of dismissing the researcher's voice in the life story. Charmaz (2002) also recognized the relationship of the researcher to the participant in illness narratives and agreed that ethical concerns must be recognized. Ellingson (2005) supplied a critical analysis of her role as researcher and cancer patient as she presented her ethnographic study about a geriatric cancer team. Much like the previous researchers she shared her point of reference when entering the geriatric clinic not only as an observer of the professional team members, but as a former cancer patient.

As a former medical social worker, I acknowledge the educational and career interests that I bring to this subject. I also acknowledge that I have been a caregiver and that all of these experiences affect the research I choose and the analysis that I perform. Norum (2000) stated that "researchers are biased. We are biased by our experiences, our education, our knowledge, our own personal dogmas" (p. 319). In acknowledging who I am as a researcher, I accept the benefits of being an insider, as well as the potential bias of advocacy toward the participants I choose to study. I respect caregivers' emotional and physical strength in facing caregiving demands. Although this may influence my analysis, it also allows an insight that would not be available to an uninformed researcher.

## **Participants**

As stated earlier, the caregivers in this study were recruited from a caregiver program located within the senior services of the local county health department, where I was also employed as the caregiver counselor. Based on the survey information and my experience as a caregiver counselor, I recruited six spousal caregivers, who were reflective of the caregivers in the community. The participants included four women (two White, ages 80 and 82; two African American, ages 58 and 80) and two men (both White, ages 88 and 70). All of the caregivers were married with adult children and like the majority of the community, ranged from middle to lower socioeconomic statuses. Only information provided during the course of the interviews is presented. Any information gained as a caregiver counselor was confidential and the participants were informed of this at the time of the interviews. The names and specific family details have been altered to protect the participants' privacy, but the substituted information is reflective of the participant's actual demographics.

## **Findings**

Mishel's (1988, 1990) model of uncertainty in illness is based on the patient's assessment and response to each health care situation. The caregiver is faced with the dual roles of interpreting what is happening to a care recipient who is unable to assess and/or describe the progress of the disease. This study found these four areas of uncertainty: diagnosis, care recipient safety, end-of-life care, and the caregivers' health status. The concept of credible authority from Mishel's (1988, 1990) model of uncertainty in illness was found to be transferable to the professional audience when caregivers were facing uncertainty. The caregivers preferred a professional listener who was well informed and expressed compassion. The connection of uncertainty in illness and credible authority was developed through the analysis process. My primary desire was to hear the caregivers' stories through their own words. From previous professional and personal experiences I recognized that caregiving creates many "What do I do next?" questions and that having an informed and compassionate listener was important to the caregiver when choosing with whom to share their narrative. Through multiple readings of the transcripts the connection between the "What's next?" question and the professional listener emerged.

### **Uncertainty in Diagnosis**

The beginning of chronic illnesses may start with minor symptoms or a significant traumatic event. In either circumstance the spousal caregiver faces uncertainty in observing the illness and in interacting with the medical community. The importance of the medical professional's expertise as the credible authority is significant. Bob Walker spoke about the first simple changes in Barbara Jean's physical condition:

So we thought it was arthritis and went to the arthritis specialist and he said no it was something else. It wasn't arthritis and he sent us to a neurologist and he right off told us it was Parkinson's disease.

Finding the correct specialist and having faith that the medical referral process will successfully provide the caregiver with credible information is related to reducing uncertainty in diagnosis. For Bob and Barbara Jean her Parkinson's disease diagnosis was soon complicated by another. Following the discovery of breast cancer, the Walkers moved to this community "and all the trauma of a new hospital, new doctors, radiation, you know all the rest of the stuff." As the observer of his wife's illness, he reported her symptoms to the medical community, and depended on them for analysis and advice. Once again the credible authority of the medical professionals in this new treatment process was a factor in the Bob Walker's uncertainty in treating his wife's illnesses.

Betty Harrison stated that her husband "was showing signs of disorders, not common to what he had been doing. And he was leaving the house early walking and coming back." A stranger who found her husband wandering several miles from their home recommended Betty take her spouse to the Veteran's hospital. The medical and social service professionals provided support and understanding when she told them of her husband's unusual behavior.

Irene Teller started her caregiving career with a similar unexpected first episode with her husband's illness. While the couple was eating out her husband became pale and unresponsive eventually fainting. By the time she and her friends were able to get him to the hospital he was recovering from the incident. The family physician ran numerous tests, but was unable to give a definitive diagnosis. A series of episodes led to the diagnosis of low blood pressure related to Parkinson's disease. Throughout this process of episodes, testing, and a series of specialists, Irene gathered information, evaluated the effectiveness of medications, and acted as a liaison with medical community treating her husband. Her husband was unaware of the significant changes in his health and in his spouse's role of reporter and health care advocate on his behalf. She valued her relationship with their long time physician who listened carefully to her reports and praised her ability to be her husband's "nurse" In all of these stories the caregivers' trust of the credible authority reduced uncertainty.

### **Care Recipient's Safety**

When the partner's cognitive decline results in behavior that is hazardous, the spousal caregiver is forced into the position of limiting the spouse's independence. Once again the caregiver must assess and respond to the uncertainty producing health situation which is occurring not to the caregiver, but the patient who does not perceive a change in his or her well-being. Alma Williams stated that even after her husband was diagnosed with Alzheimer's disease he was still able to do many of his usual activities:

So he started going downhill mentally, but not physically. So he was okay. He use to walk around and all. Play cards. He could cut the grass until about three years ago. He thought he was the best grass cutter in [the city's name]. The lawnmower had to go a certain way and come back a certain way or the grass wasn't right. [Alma laughs] But then last year, a couple of years ago he got where he'd be smoking and putting gas in the lawnmower and I was scared he was going to get blown up. He was very, very mean.

Although she laughed as she recounted this clash between the caregiver's concerns and the care recipient's behavior, the actual event was stressful as reflected in her last sentence, because her husband could not comprehend his wife's explanation of concern.

Bob Walker recounted an incident with his wife that reflects the same tension between caregiver and care recipient:

When it [the dementia] got progressively worse, one of the biggest battles we had is when I sold her car. Uh, I mean she got really mad at me. But I'd let her drive from church home and we was coming down Union and then on route 44 and uh she wouldn't stay in her lane and I was grabbing the wheel. Oh, and any time I ever would do that it would just make her furious.

He was keenly aware of the loss of independence that taking away the vehicle represented. “But that was probably the hardest on her, because then she didn’t have her independence. She couldn’t go by herself, or do anything by herself.” In each example the caregiver assessed the progression of the illness and the risk to the spouse’s safety. This continues to be a more complicated model of uncertainty in illness than that experienced by a patient alone or with a caregiver for social support. Although both of these stories were told years after their occurrence the caregivers were seeking affirmation from another credible authority, the researcher, about their decisions to limit their spouses’ behaviors.

### **End-of-life decision making**

The uncertainty of end-of-life care was represented in different ways according to the care recipients’ severity of illness. Bob Walker, who lost his spouse during the course of the study, spoke specifically and adamantly about advance directives and choices at the time of imminent death. His actions at the time of her death were consistent with his previously stated intentions. In the first interview he declared, “There’s not going to be any tubes in Barbara Jean.” Because he had witnessed advance directives being ignored by health care providers when taking care of friends and relatives, he knew that his role as Barbara Jean’s advocate was more important than any legal documents. He stated, “So living wills are all right maybe, but you can’t trust some of those doctors might not do what it says so I figure I’m her living will.” Bob Walker stated that he had found a physician who shared his belief system and supported his desire to make Barbara Jean comfortable. The physician stated that he would do what was necessary and “leave the rest in God’s hands.” Bob chose a credible authority that understood his perspective of end-of-life care and stated that it would be honored.

Naomi Turner expressed similar concerns over the future loss of her husband’s ability to swallow. She also had witnessed other people with dementia entering the final stages of the disease:

I know that he might reach that place one day where he might not be able to swallow. Sometimes now he has a hard time swallowing sometime at night. But ah, when that day come I be able to handle it ’cause I have Jesus. Who knows one day what will come ’cause I don’t know whether he will have a tube feed or not.

She had not come to a point of resolution as had Bob Walker, but she was aware of the decisions that she might have to make in the future.

Although the other spousal caregivers had not come to this type of end-of-life decision at the time of their interviews, they had addressed the idea of nursing home placement for their spouse. Irene Teller commented on the constant tension between her ability to care for her husband the need for more assistance.

And each year he progresses a little more it seems like. I really had to fight the depression. I didn’t tell either one of my girls’ cause they kind of give me a talking to. “Mother you really need to put him in a home.” And I

just, I'm doing okay. I don't get everything done in my house like I want to.

Other caregivers still expressed uncertainty after their spouses had entered the nursing home. The caregivers frequently referenced talking with health care professionals to confirm their decisions. Paul Brown mentioned several conversations like the one below:

I asked one of the other ladies in charge of the nursing home about number three in command. I asked if I could talk to her and she said yes. So we went to her office. This was a different lady than I had spoken to previously. I asked her if I did the right thing and she told me that only God knows that, but in her opinion I did.

Making the decision to change the living arrangement of a spouse continues to produce uncertainty for the caregiver especially when the spouse questions the arrangement as in Alma Williams' case:

Yeah, every now and then he'll say well I want to know what I'm suppose to do. I know what's coming. So I'll say what do you mean? Well about being in this place. So well I say I can't take care of you that's the reason you got to be in here.

The spousal caregiver may also question the consequences of separation from the care recipient. Breaking up the couple's home creates difficulties as well as relieving responsibility. Betty Harrison expressed the burden of being alone: "It's very stressful. I'm by myself, he's by his self. But he's got people around him." Whether making decisions about heroic care or nursing home care each caregiver had to evaluate the progressive deterioration of their spouses. The duality of their decisions in these situations is evidenced by the consequences for both the caregivers and the care recipients. In each case the caregivers sought credible authorities to talk about their concerns. As the caregiver counselor I was included in Betty, Alma, and Paul's decisions about nursing home care. Paul also consulted with the nursing home administrative staff and his minister, people who he trusted and represented credible authority. Bob actively searched for a physician who he could rely on to follow Barbara Jean's advance directives, which was an issue of credible authority.

### **The spousal caregiver's health**

Finally, the spousal caregivers mentioned uncertainty because of their own health concerns. The caregivers were all aware that their health and well-being was tied to their spouses. For the three caregivers who were caring for their spouses at home, they recognized that if their own health failed their spouses would not remain at home. Both Bob Walker and Irene Teller stated that they did not expect their children to care for their spouses, if something were to happen to them. They both acknowledged that a nursing home would be the only level of appropriate care if they could no longer fulfill their role as primary caregiver. Naomi Turner continued to rely on her faith to give her strength and

avoid the thought of nursing home care for her husband. Although she is the youngest spousal caregiver in this study, she had several serious health conditions that ultimately could impair her caregiving ability.

For the other three caregivers whose spouses were currently in nursing homes, their health had been the major reason for making that choice. Alma Williams was advised by her physician that providing the twenty-four care needed to supervise her husband would be too overwhelming for a person of her age. Betty Harrison's family intervened to facilitate the placement of their father into a nursing home, because of concern for her health and their father's safety. Paul Brown's minister, however, summed up the ultimate uncertainty about caregivers' health:

I had several people, including the minister (Paul's minister) of the church; tell me, even before I put Leona in the nursing home, that if I wasn't careful he knew of several instances where the spouse did pass away before the person that was sick.

The caregivers' and care recipients' health and well-being are intertwined; therefore the uncertainty of illness is equally enmeshed between the spouses. In each case the spousal caregiver discussed their uncertainty with a person they considered a credible authority.

### **The Professional Audience as Credible Authority**

Irene Teller confided in her daughters for assistance with medical treatments for her husband, but did not share her own health concerns about depression and declining physical strength. Instead she shared this information with me, as the researcher. She was already well aware of their opinion that her husband required more care than Irene could safely provide for him in their home. In similar comments Bob Walker was critical of the social support offered by one of his daughters. He perceived her suggestions about his and his wife's health care as interference, not support. He, however, expressed the importance of telling his story in great depth to the researcher. He also looked for a physician who shared his values concerning end-of-life care. Likewise, Paul Brown found mixed support and criticism from his children when making the decision to move his wife to a nursing facility. His need for social support in this health care crisis caused him to speak with several nursing home staff members who provided him a credible authority as an audience. He was still telling this story in the course of the interviews to a new audience (the researcher) who was another credible audience.

Each of the participants, either during or after the interview was completed, made some comment stating that just talking had been helpful. Some of the participants made comments about talking to me in my role as a counselor and as a researcher. In each example, their statements reflected the importance of being able to tell their story to an interested and compassionate individual. Bob Walker's statement was one example:

So it was [nice to talk with the researcher] and also it helps crystallize some things. When you talk about it, you know some things are there and if you ask me more questions some things might come out that I don't even know or realize. And that's why interviews like this I enjoy, because



if I try to explain something to somebody, I have to figure it out up here [points to head] before I can tell it to somebody. Sometimes the insights I had I didn't know I had.

He stated that he found that sharing his story helped him clarify his feelings about what he had learned and how he had grown. Other caregivers did not elaborate to the same extent but declared in simple ways that talking helped them when they were in uncertainty producing circumstances.

Alma Williams and Naomi Turner both referred to times in the past that talking with me as a counselor had been beneficial. Alma stated in both interviews that she felt I was trying to understand things from her point of view. She also stated that she felt I was being compassionate, "so I was talking to you at that time and you gave me a lot of encouraging words." She was referring to a time when she was deciding whether or not to place her husband in a nursing home. Naomi Turner was caring for her husband with no formal support services when we first met as client and counselor. In the interview, she referred to the informational and emotional support during our meetings:

She (the researcher) brought to my attention if I need more help I could get it. And finally I came to a point where I said, "Yes I do." And just knowing that I could get more help that was a big help to me, because I was doing it all by myself.

She asked me not to record our last visit, because she felt her husband's condition was something private between the two of them. Although she did not want our conversation recorded, she wanted me to stay and talk with her as she faced the uncertainty producing circumstances of end-of-life care.

Paul Brown expressed both current and past importance of talking with me as a counselor and now as a researcher:

I can count on you and I do rely on you. When you called me yesterday evening, I couldn't wait to have you come out and talk. Just talking to you means so much to me and it does most other people that have spouses in a nursing home. I have no one to talk to except like now, even the darn dog. I talk to myself like I told you. I just hope that there is no one around, but I do talk to the dog too.

He made this statement in the second interview, but in a briefer statement in the first interview he made a similar statement about the interviews. He said, "I am supposed to be helping you and you are helping me." In every case, the spousal caregivers placed some sense of satisfaction in being able to tell their story to someone who was informed and compassionate, i.e., a credible authority audience. The value of the narrative in counseling and research was voiced over the course of the interviews.

## **Discussion and Implications**

The findings in this study must be considered within the context of the community and the social networks of these participants. These participants shared generously with their time and emotional disclosure. They all expressed a desire to assist other caregivers by sharing their stories. This is an indication of the significance that their stories have to them and their belief that recounting them can help others. The interviews echo the voices of the many caregivers I have heard over the last fifteen years in social services.

### **Talking to the Right Audience**

This study began as a desire to acknowledge and explore the world of caregiving that I had observed as a medical social worker. My last position was in a new program especially designed for caregivers of older adults. This program emphasized the importance of counseling and education. Within the first three years of the program, over 200 caregivers were served through face-to-face interviews, support groups, and educational materials. A pattern emerged in the caregiver counseling sessions: caregivers wanted to tell their story, they wanted to talk about the challenges they faced, and they wanted to know that the person listening was a credible authority.

Several of the participants in this study mentioned my assistance in counseling them through the caregiver program. Others commented on the benefits of talking with me during the research project. Paul Brown and Alma Williams mentioned feeling understood or helped in both instances as participants and as clients. Communicating the stresses of caregiving to a person with inside knowledge, such as social services, physicians, and nursing homes, was found to be comforting to the spousal caregivers. Bob Walker spoke in depth about the benefit of crystallizing his own feelings by communicating them to someone else.

The freedom to talk about the spousal caregiver's needs and stresses with someone who is not a part of his or her inner circle of social support was demonstrated by Irene Teller's resistance to share her depression with her daughters. She stated that she did not want to share her depression with them, because they would insist that she place her husband in a nursing home. Similarly, Paul Brown found mixed support and condemnation from his children and looked for independent confirmation from sharing the story with credible authorities, including me. The spousal caregivers sought people who were informed. Spousal caregivers face a unique set of uncertainties when caring for husbands and wives with dementia. From diagnosis to their own health care needs these challenges were the content of these caregiver narratives. Their preferred audience when telling these stories can be defined as an informed and compassionate listener. This can be described as a credible authority in Mishel's (1988, 1990) model of uncertainty in illness.

In previous research about caregivers the focus has been on thematic concepts derived from analysis of the findings (Aryes, 2000; Bennett & Vidal-Hall, 2000; Harris, 1998; Russell, 2001). Basically this is comparing similarity in experiences; this study looks at the communication of the experience and compares the narrator and audience. These findings highlight the process regardless of the individual caregiving by looking at

how caregivers experienced uncertainty and managed it through communication with health care professionals who had credible authority. The emphasis then is not the type of uncertainty producing event, but that when faced with various caregiving challenges whether it is nursing home placement or end-of-life decision making the caregiver found help in talking with a professional listener.

Mishel's (1988, 1990) model of uncertainty concentrated the importance of credible authority on the knowledge and trust that the patient has in health professionals especially in diagnosis. Brashers, Hsieh, Neidig, and Reynolds (2006) expanded this perception to emphasize credible authority includes the professional's communication skills. Credible authority to caregivers specifically looks at the health professional's role as the audience and what that represents to the caregivers. To the caregivers in this study credible authority is not just the professional listener's skill at listening, but the professional listener's position of a greater societal audience representing caregiving in this community.

### **Implications for Health and Social Service Professionals**

The primary limitations of this study rest in its exploratory nature. There were a limited number of participants. The participants level of involvement both in number of interviews and length of time in the study varied. This factor was somewhat modified by my previous relationship with a number of the caregivers through the county health department caregiver support program. This previous knowledge allowed me to see an interesting circumstance for future research. These participants had all been caregivers for at least five years and having interacted with some of them during previous stressful circumstances, I realized that their narratives at each point in their caregiving career were unique to that time. In order to hear the progression of the caregiver narratives, the researcher needs to be present throughout these transitions.

This leads to the first recommendation for future research in caregiver narratives. Research associated with an early diagnostic clinic or practice would allow the recruitment of caregivers early in their caregiving careers. Following caregivers from this point throughout the care recipients' illness would allow a deeper analysis of changes in the caregiver narratives, i.e., uncertainty in the care recipients' illnesses. A longitudinal study structured to capture caregiver narratives through the end of the care recipient's life would yield findings of greater depth.

The description of these findings can provide a starting place for further research into the areas of identity, social support, and uncertainty in the illness. The unique position of caring for someone who can no longer communicate identity, collect information, or formulate judgments about illness deserves investigation with the growing number of older adults in the nation's population. Spousal caregivers are not the only caregivers experiencing these dilemmas, but they are often the first line of defense when caring for a spouse with dementia. The communication of caregiving stresses and successes is a primary coping method for spousal caregivers of partners' with dementia. The spousal caregiver also found it helpful when faced with the uncertainty of illness to share these difficult decisions. Communication about these many issues helped the spousal caregivers cope with caregiving.

Expanding from spousal caregivers similar methods could be employed to capture the unique concerns of other caregivers, such as sons, daughters, unmarried partners, gay and lesbian partners, and friends. The expectations of these roles may include some of same concerns as spousal caregivers, but they may also have unique differences.

Health care and social services professionals interact with care recipients and caregivers in providing management of chronic illnesses. Due to the progressive deterioration of the care recipients' ability to understand and communicate their medical concerns, caregivers are relied upon to speak for the care recipient. Physicians, psychiatrist-geriatricians, nurses, social workers, and other health and social service providers who assist the care recipients need to listen to the caregivers as well (Farran, Loukissa, Perraud, & Paun, 2004; Sanders, 2005; Salfi, Ploeg, & Black, 2005; Schulz & Martire, 2004; Teel & Leenerts, 2005; Vitaliano, Katon, & Unutzer, 2005).

In formulating best practices for medical and social service providers, the role of uncertainty in illness needs to be considered from the spousal caregiver's perspective. First the difficulty of experiencing diagnosis and symptoms that are changing not only the partner's physical abilities, but his or her cognitive functioning produces uncertainty. The first signs of dementia are often undetectable to the patient, but evident to the caregiver. Next, the safety concerns that limit the care recipient's independence are often met with resistance by the care recipient who is unable to assess the changes taking place. Finally, major change of life decisions like nursing home placement and end-of-life care are filled with uncertainty for spouses and occur throughout the course of the illness. Spousal caregivers will seek support in their decisions from health care and social service providers as credible authorities. Professional caregivers must realize the process that the spousal caregiver is going through to make decisions and assist them in reducing the uncertainty.

Services for caregivers then need to maximize the supportive nature of health and social service providers to reduce levels of uncertainty. The Area Agency on Aging that served the community in this study chose to use new funds made available for caregivers by developing a program based on individual counseling, support groups, and education. The program also had some respite care services built into the structure, but the majority of program's resources were directed at psychosocial support of the caregivers. Sörensen, Pinquart, and Duberstein (2002) conducted a meta-analysis of caregiver interventions that support the effectiveness of psychoeducational and psychotherapeutic interventions. Caregiver uncertainty was reduced in a study that used structured intervention to caregivers during the transfer of their care recipients from intensive care to a regular medical floor in the hospital (Mitchell & Courtney, 2004). Mittelman, Roth, Coon, and Haley (2004) found that counseling and support groups decreased depressive symptoms in spousal caregivers of persons with Alzheimer's disease. These studies along with other literature reviews supported the positive responses of caregivers to a variety of interventions (Schulz & Martire, 2004, Schulz et al., 2002).

The research then supported the types of interventions that the participants in this study had received through the Area Agency on Aging by way of administration at the county health department. I held the position of caregiver counselor from the inception of the program through the beginning of its third year. The component of the program that was most requested and which consumed most of my time was individual counseling. As I incorporated principles of uncertainty management into my counseling methods, the

caregivers responded positively. As I review my counseling skills in light of the findings in this study and other research, the awareness of the stress created by uncertainty and the realization that caregivers may choose different methods coping with uncertainty changed my counseling goals. My original goal was to solve the caregivers' problems, but my realized goal was support the caregivers' process of coping with uncertainty.

I am certain that the narratives in this study were linked to my ability to be a supportive audience. That was the unique quality that my social work history brought to this study. It is a tribute to all of the caregivers who have shared their joy and their sadness with me over the last fifteen years. By listening I have learned and hopefully have shared that knowledge with other caregivers. Most importantly I have learned that listening is a critical part of assisting caregivers. Listening needs to be included in every service designed to support caregivers.

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### Author Note

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