

2-2002

## Contradictions of Interaction for Wives of Elderly Husbands with Adult Dementia

Leslie A. Baxter

*University of Iowa*, [leslie-baxter@uiowa.edu](mailto:leslie-baxter@uiowa.edu)

Dawn O. Braithwaite

*University of Nebraska–Lincoln*, [dbraithwaite1@unl.edu](mailto:dbraithwaite1@unl.edu)

Tamara D. Golish

*Pennsylvania State University*, [tdg3@psu.edu](mailto:tdg3@psu.edu)

Loreen N. Olson

*Cleveland State University*, [lnolson@uncg.edu](mailto:lnolson@uncg.edu)

Follow this and additional works at: <http://digitalcommons.unl.edu/commstudiespapers>



Part of the [Critical and Cultural Studies Commons](#), [Gender, Race, Sexuality, and Ethnicity in Communication Commons](#), and the [Other Communication Commons](#)

---

Baxter, Leslie A.; Braithwaite, Dawn O.; Golish, Tamara D.; and Olson, Loreen N., "Contradictions of Interaction for Wives of Elderly Husbands with Adult Dementia" (2002). *Papers in Communication Studies*. 99.

<http://digitalcommons.unl.edu/commstudiespapers/99>

This Article is brought to you for free and open access by the Communication Studies, Department of at DigitalCommons@University of Nebraska - Lincoln. It has been accepted for inclusion in Papers in Communication Studies by an authorized administrator of DigitalCommons@University of Nebraska - Lincoln.



Published in *Journal of Applied Communication Research* 30:1 (February 2002), pp. 1–26; doi: 10.1080/00909880216576

Copyright © 2002 National Communication Association; published by Routledge/Taylor and Francis. Used by permission.

Submitted September 29, 2000; accepted January 16, 2001; published online January 10, 2011.

## Contradictions of Interaction for Wives of Elderly Husbands with Adult Dementia

Leslie A. Baxter, Dawn O. Braithwaite, Tamara D. Golish,  
and Loreen N. Olson

*Corresponding author* – Dawn O. Braithwaite, Department of Communication Studies, 424 Oldfather Hall, University of Nebraska–Lincoln, Lincoln, NE 68588-0329, phone 402-472-2239, email [dbraithwaite@unl.edu](mailto:dbraithwaite@unl.edu)

### Abstract

The researchers used a dialectical framework to examine interviews with wives whose elderly husbands experienced adult dementia from Alzheimer’s disease and related disorders (ADRD), centering on how wives coped communicatively with their husbands’ illness. These “married widows” experienced a primary contradiction between their husbands’ physical presence and cognitive/emotional absence. Interwoven with the presence-absence contradiction were three additional contradictions: certainty-uncertainty, openness-closedness, and past-present. Results describe the ways these wives communicatively negotiated the web of contradictions as they interacted in the present with husbands they once knew. Applications for practitioners and caregivers working with ADRD patients and their wives, including formal and informal support, understanding, and managing contradictions, and ways to more effectively interpret ADRD patients’ communication, are discussed.

**Keywords:** Alzheimer’s disease, married widowhood, dialectics, contradiction

Most, if not all, theories and definitions of communication are predicated upon the presence of consciousness and ability to communicate on the part of interactants. For example, Bochner (1989) defined interpersonal communication as “at least two communicators; intentionally orienting toward each other; as both subject and object; whose actions embody each other’s perspectives both toward self and toward other” (p. 336). Similarly, Wood (1999) defined interpersonal communication as “a selective, systemic, unique, and ongoing

process of interaction between individuals who reflect and build personal knowledge of one another and create shared meanings" (p. 24). However, what happens to the communication process when the assumption of dual consciousness is challenged? In particular, what happens when one interactional partner is physically present but cognitively and emotionally absent due to an impairment? To date, communication scholars have done little to account for how interactants attempt to communicate and maintain relationships when one of the partners is cognitively/emotionally impaired. The current study focused on one specific subgroup within the population faced with this particular challenge—wives whose elderly husbands experience adult dementia from Alzheimer's disease and related disorders (hereafter referred to as ADRD). In relationships where one spouse suffers from ADRD, the cognitively functional spouse must learn to deal with a partner who is physically present but cognitively/emotionally absent, or, one who is "lost but not gone" (Morgan & March, 1992, p. 566). "Married widowhood," a term first coined by Rollins, Waterman, and Esmay (1985), aptly fits the presence-absence experience faced by these spouses. Yet, scholars know little about how these spouses relationally manage the presence-absence contradiction that epitomizes their married widowhood experience.

This study represents an important undertaking for applied communication researchers and has value for members of the social network who are interacting with a loved one with ADRD or other forms of serious communication-related disorders. They need help in understanding the communication abilities of the person with ADRD, as well as assistance in negotiating the relational struggles associated with one who is present and absent. This knowledge is also important for professionals working with these patients and their relations. This is especially true for professionals working in nursing homes. Nussbaum, Pecchioni, Robinson, and Thompson (2000) explain that the relationship between nursing home staff and family members has the potential to be cooperative or quite negative. Very little research and training exist that will help nursing home staff understand and contribute positively to the experience of the spouse who is coping with this state of married widowhood. Therefore, using dialectics (Montgomery & Baxter, 1998) as our theoretical foundation, the purpose of our study was to examine how women who have spouses with ADRD communicatively manage their partners' presence-yet-absence. As such, the findings from this study can hopefully help spouses of patients with ADRD, family members, and practitioners manage the tensions that often accompany ADRD. In the sections that follow, we first review the nature of ADRD and how the incremental cognitive deterioration affects the communication patterns of ADRD patients. Secondly, we more thoroughly explore the research on married widowhood and how it sheds light on the dilemma of presence-absence faced by spouses with partners who are suffering from ADRD. Finally, we review selected tenets of dialectical theory and how they inform our study.

### **Adult Dementia from Alzheimer's Disease and Related Disorders**

Currently, one out of 10 persons over age 65 and approximately one half of those over age 85 have been diagnosed with ADRD (Facts, 2000), totaling nearly 4 million Americans (Alzheimer's Disease, 2000; Early Alzheimer's, 1996; 1999 Progress Report, 2000). These numbers are significant when one considers the ever-increasing life expectancies in the

United States and the aging Baby Boomer population. Since the early 1900s, life expectancies have increased substantially (Ellis, 1996; 1999 Progress Report, 2000; Reisberg, 1983b). According to the Administration on Aging, in 1900, 4.1% of the population was 65 and over; in 1990, that percentage grew to 12.5% and is estimated to exceed 20% by the year 2030 (Older Population, 1999). As life expectancies continue to increase, so will the number of people affected by age-related diseases, including ADRD (1999 Progress Report, 2000). The magnitude of these numbers prompted the National Institute on Aging and National Institutes of Health to assert that ADRD deserves urgent research priority (1999 Progress Report, 2000).

Called "the disease of the century" (Reisberg, 1983a, p. xvii), Alzheimer's disease is the most common cause of dementia among individuals age 65 and older (1999 Progress Report, 2000; Van Hoesen, 1990). According to the National Institute on Aging (1999 Progress Report), Alzheimer's disease is "an irreversible, progressive brain disorder that occurs gradually and results in memory loss, behavior and personality changes, and a decline in thinking abilities. The losses are related to the death of brain cells and the breakdown of the connections between them" (p. 4).

Alzheimer's disease advances in three general stages: early ("forgetfulness phase"), later ("confusional stage"), and final ("dementia phase") (Alzheimer's Disease, 2000; Early Alzheimer's, 1996; 1999 Progress Report, 2000; Reisberg, 1983b). Throughout these stages, the patient with Alzheimer's disease experiences a gradual loss of short-term memory (Early Alzheimer's, 1996; 1999 Progress Report, 2000) and incremental cognitive absence. More specifically, the *forgetfulness phase* is characterized by a loss of recent memory, mild changes in behavior and personality, and faulty judgment (Alzheimer's Disease, 2000; Early Alzheimer's, 1996; 1999 Progress Report, 2000). The persons also experience subtle cognitive and linguistic changes, including "agnosia," the inability to recall once familiar names and objects and "aphasia," the inability to comprehend abstract language such as metaphors (Alzheimer's Disease, 2000; Early Alzheimer's, 1996; 1999 Progress Report, 2000; Orange, Van Gennep, Miller, & Johnson, 1998; Pollen, 1993; Reisberg, 1983b; Van Hoesen, 1990).

In the later, or *confusional*, stage the cognitive deficits increase and become more pronounced (Reisberg, 1983b). Persons can no longer function professionally or socially, and they develop "apraxia," or the inability to complete basic, previously learned tasks (i.e., washing their hands, brushing their teeth, combing their hair, using a pencil, shutting off the stove, closing windows, or locking doors) (Alzheimer's Disease, 2000; Early Alzheimer's, 1996; 1999 Progress Report, 2000; Pollen, 1993; Reisberg, 1983b). They also experience more dramatic mood and personality changes (Early Alzheimer's, 1996) and a flattening of affect (Reisberg, 1983b). Linguistically and communicatively, persons in the later stages of Alzheimer's disease use fewer nouns and verbs and have difficulty comprehending what they read and understanding everyday conversation (Orange et al., 1998). They also begin an abnormal repetition speech pattern called "echolalia" which is used to gage the progressively deteriorating nature of the disease (Ramanathan, 1995).

Eventually, persons with ADRD lose all reasoning, functioning, and communicating abilities, resulting in the complete dependence on others for their care (Alzheimer's Disease, 2000; Reisberg, 1983b). In the final *dementia stage* of the disease, people with ADRD

are no longer able to feed, bathe, or dress themselves, identify people, places, or objects, or maintain continence and the ability to ambulate (Reisberg, 1983b). Reisberg (1983b) summarizes the cognitive absence experienced in this stage, "all memories (recent and remote) and cognitive capacities gradually disappear. Patients forget the name of the spouses upon whom they are entirely dependent for survival and, subsequently, cannot even recognize their own names. In short, all identity is lost" (p. 8). As a result, the person in final stages of ADRD will eventually require 24-hour care (Understanding, 2000). Often, as the deterioration continues, the burdens of caregiving overwhelm the caregiver (typically the spouse) and placement in a nursing home becomes necessary (Morgan & March, 1992; 1999 Progress Report, 2000).

There is much that communication scholars can do to contribute to the overall understanding of ADRD and its effects on family functioning (Ellis, 1996). According to Ellis (1996), problems associated with ADRD are both communication *and* cognitively oriented. However, much of the extant communication literature on ADRD has focused on the cognitive perspective of language deterioration or the discourse features of persons with ADRD (e.g., Ellis, 1996; Kemper, Lyons, & Anagnopoulos, 1995; Knuf, 2000; Orange et al., 1998; Ramanathan, 1995; Rivers, 1990). More specifically, various researchers (e.g., Ellis, 1996; Knuf, 2000) have focused on the linguistic features of ADRD speech and noted that as the disease progresses, the language of persons with ADRD becomes vocabulary driven and simpler in grammatical structure. Eventually, ADRD discourse is characterized by "empty," or uninformative, speech (Ellis, 1996; Kemper et al., 1995). Nevertheless, according to Ramanathan (1995), certain segments of ADRD patients' lives became frozen in their memory. While ADRD patients' speech becomes more "text-based" and less "meaning-based" over time, they are able to recall certain memories that are part of their earlier schema. These "frozen memories" allow ADRD patients to make sense of their lives (Ramanathan, 1995).

Some research has focused on the interaction patterns of persons with ADRD. For instance, Rivers (1990) compared how memory-impaired and able-minded interactants managed to stay focused on the conversation at hand. Analyzing the conversations of five female elderly persons with familiar others, she found that individuals with ADRD could not manage the focus of attention and, as a result, the conversations broke down. A study conducted by Orange and colleagues (1998) found similar results. They conducted a longitudinal study of 15 spousal dyads, some with ADRD and some able-minded older adults serving as a control group. These researchers found that over time, the individuals with ADRD and their spouses were less able to resolve communication breakdowns than were the control dyads. These two studies demonstrate how the increased cognitive impairment of the person with ADRD makes interaction increasingly problematic.

Limited attention has been given to the interaction between persons with ADRD and their partners. However, a study conducted by Kemper and colleagues (1995) focused on how cognitively functional spouses collaborated with their ADRD partners in telling joint narratives. These researchers found that the able-minded spouses used a cooperative strategy when constructing joint narratives, filling in the missing parts prompted by the person with ADRD. Not only did these spouses supply the missing information, they also provided contextual cues so that their partners could retrieve the missing information. This

helped those with ADRD add to the story, making the joint narratives longer and more elaborate than the ones the partners with ADRD were able to tell alone. Interactionally, the spouses were particularly adept at adjusting their speech to their partners with ADRD, indicating a heavy reliance on the relational level of messages. By emphasizing the relational message, the spouses helped their partners with ADRD maintain a communication presence. It is important to note, however, that while the Kemper et al. (1995) study underscores the importance of “interpersonal interactions within socially structured contexts” (p. 215), their findings do need to be tempered by the cross-sectional design of the study. Orange et al. (1998), for instance, found in their longitudinal study that the spouses were less able to resolve communication breakdowns as their spouses with ADRD deteriorated, demonstrating once again the ever-increasing cognitive/emotional absence characteristic of ADRD.

With the two exceptions just noted (i.e., Kemper et al., 1995; Orange et al., 1998), there has been little research that has focused on how relational partners continue to attempt communication with cognitively impaired spouses who are increasingly absent cognitively and emotionally. According to Ade-Ridder and Kaplan (1993), the “loss of functional capacity of one partner has reciprocal emotional effects on both partners” (p. 15). Throughout the entire deterioration process, the cognitively functional spouse must begin to reorganize the marital relationship around the dependency of the spouse with ADRD (Morgan & March, 1992). It is an excruciating process for all involved. As Pollen (1993) describes:

A disease such as Alzheimer’s is an especially cruel affliction, devastating alike to its victims and their families. The families are rendered almost helpless to respond to the inexorable downhill course of their loved ones, who eventually lose their ability to preserve those meaningful human contacts that had bound them together. (p. 75)

Unfortunately, millions of family members and spouses are faced with the challenge to confront the pain and continue the relationship despite the devastating effects of ADRD. The spouses, in particular, must learn how to make sense of their partners’ ever-increasing absence of consciousness in light of the ever-decreasing moments of lucidity or cognitive/emotional presence. Researchers have helped us understand much about the cognitive and linguistic deterioration of ADRD, but few have focused on the way in which spouses communicatively navigate the presence-yet-absence of their partners. In an attempt to help further explain the dynamics of the presence-absence contradiction experienced by spouses of persons with ADRD, the research on married widowhood is discussed next.

### **Married Widowhood**

Rollins, Waterman, and Esmay (1985) first identified the phenomenon of married widowhood during their professional work with individuals whose spouses were in a nursing home. From their research, we have learned that non-institutionalized spouses feel “much of the same psychological, physiological, and sociological guilt reaction to loss that widows and widowers experience after a spouse dies. However, the responsibilities of the

marriage relationship continue" (Rollins et al., 1985, p. 68). As the term implies, married widows' lives are fraught with contradictions. On one hand, they are still married and therefore part of a couple; while, on the other, they are alone and disengaging as they pre-grieve the loss of their partners. Moreover, the responsibilities of marriage for the well spouse can actually increase as they assume new roles and tasks that had been previously handled by the institutionalized spouse (Ade-Ridder & Kaplan, 1993; Braithwaite, 2002; Kaplan & Ade-Ridder, 1991; Rollins et al., 1985). Yet, in assuming these new roles and mastering new tasks, they simultaneously begin a life of independence from their spouses (Rollins et al., 1985). However, there is only so much pre-grieving they can do and independence they can establish, for their partners are still with them. In fact, Morgan and March (1992) found that widows and caregivers of institutionalized spouses with ADRD responded quite differently. Widows were faced with replacing a couple-based way of life and, instead, creating an individual-based one. In contrast, the caregivers were faced with "transforming" instead of replacing their couple-based way of life, which involved "both an increasing workload and the progressive loss of meaningful interaction with the spouse" (Morgan & March, 1992, p. 575). In general, while widowhood is a difficult time, there are more established norms and roles for how widows and their support networks manage the grief process (Morgan, Carder, & Neal, 1997). In contrast, married widowhood is characterized by much less certainty and the norms for interaction and grieving are less clearly defined. In essence, these caregivers and others like them "find themselves dangling in the grief experience" (Rollins et al., 1985, p. 70). They are suspended between opposite relational identities—married *and* widowed.

The question becomes, how do the caregivers deal with their status of married widowhood? A few studies have examined how women, after their spouses moved to nursing homes, reestablished equilibrium (Kaplan & Ade-Ridder, 1991) and (re)defined their sense of couplehood (Braithwaite, 2002; Kaplan, Ade-Ridder, Hennon, Brubaker, & Brubaker, 1995). These studies give us insight into how spouses vary in the negotiation of their situated identity of married widowhood. However, as discussed above, we do not understand very much about the interactional experiences between these spouses and their ADRD partners.

### **The Dialectics of Communication between Spouses and Their ADRD Partners**

As Baxter and Montgomery (1998) indicate, dialectical theory is not a single, unitary theory; rather, it is a family of theories organized around certain shared assumptions or principles. Central to these assumptions is the concept of contradiction. A contradiction refers to a unity of opposites; that is, two phenomena are opposites at the same time that they are united. Although the married widowhood literature is not framed theoretically from a dialectical perspective, it nonetheless paints a portrait of the contradictory experience that is central to the relationship in which one partner has ADRD. The spouse with ADRD is still physically present, yet consciousness is increasingly absent. The partners, thus, are still married despite the widowhood felt by their spouses' cognitive and emotional absence.

While the presence-absence contradiction is probably central to the relationship of a spouse and his or her partner with ADRD, it is not likely to be the only contradiction that

is experienced. A second assumption of dialectical theory is totality (Baxter & Montgomery, 1998). The concept of totality involves two features. First, it refers to the knot of contradictions that co-exist in a relational system. Contradictions do not exist in isolation of one another; rather, they form an interdependent knot in which one contradiction is implicated with other contradictions in a weblike manner (Baxter & Montgomery, 1996; Brown, Werner, & Altman, 1998). A number of dialectical scholars have generated lists of contradictions that frequent a variety of relationship experiences. Werner and Baxter (1994), for example, have summarized extant dialectical research by suggesting three basic categories of contradictions: integration-separation, expression-nonexpression, and stability-change. However, we are mindful of the second feature of the totality concept, situatedness, which emphasizes the need to attend to the unique, indigenous contradictions that characterize specific situations. As Conville (1998) has observed, "indigenous dialectics, those home grown in a given unique relationship, serve to balance the temptation to treat existing dialectical systems as a 'one-size-fits-all' analytical recipe" (p. 29). Although the knot of contradictions that characterizes interaction between spouses and their partners with ADRD may resemble the conventional categories of contradictions identified in existing research, we do not wish to pre-judge that outcome, choosing instead to inductively identify the knot of contradictions that are indigenous to the specific constraints of a relational system in which one party has ADRD. Our first research question, grounded in the dialectical concepts of contradiction and totality, can be summarized thusly:

**RQ1:** What are the perceived contradictions that organize interaction between wives and their husbands with ADRD?

A third assumption of dialectical theory that is central to the current study is that of praxis (Baxter & Montgomery, 1998). Interactants both act and are acted upon; their actions in the present are enabled and constrained by prior actions and function to create the conditions to which they will respond in the future. In the context of contradiction, praxis focuses our attention on how contradictions are negotiated in the communicative practices of the interactants. Baxter and Montgomery (1996) have identified a number of general praxical actions available to relationship partners as they negotiate the contradictory experience of their relationships. However, mindful of the necessity of studying praxis *in situ* (Baxter & Montgomery, 1996), we seek to understand inductively the communication practices that characterize spousal interaction with their ADRD partners. Thus, our second research question becomes:

**RQ2:** What are the reported communication practices through which wives manage the contradictions of interaction with their husbands who have ADRD?

## **Method**

The data for this study were part of a larger research project on the experiences of community-based wives whose husbands moved into nursing homes (Braithwaite, 2002). In-depth,

face-to-face interviews were conducted with a convenience sample of 21 wives whose husbands currently resided in a nursing home or who lived there before their deaths. Women were chosen as interviewees largely because there are more of them within the population due to their longer lifespans (Aldous, 1994). For instance, in 1999, there were over 20 million women 65 years and older compared to approximately 14 million men (Administration on Aging, 2001). Thus, the current study is representative of this overall demographic trend in the population.

Interviewees were located by contacting social work and gerontological professionals in the area, posting flyers in nursing homes, writing newspaper articles about the project, and asking interviewees if they knew of anyone who qualified and who would be willing to participate. Locating willing participants proved to be a challenge; levels of marital self-disclosure are reportedly lower among the current elderly cohort (Brubaker, 1990; Mares & Fitzpatrick, 1995; Sillars & Zeitlow, 1993). An estimated four hours were spent locating each participant. Interviews were completed until recurring patterns and a point of analytic saturation was reached (Leininger, 1994).

### **Participants**

The mean age of the 21 women who participated in this study was 77 years. Twenty of the women were Caucasian and one was African American. At the time of the interviews, sixteen of the husbands were living and five were deceased. The length of time since their husbands' death ranged from two to three years at the time of the interview. Consequently, the surviving spouses' memories of their husbands were still quite vivid. The mean age of the husbands (at the time of the interview or at the time of their death) was 81 years. The couples were married for an average of 49 years and nineteen of them had children. All of the women lived in a large southwestern urban community, many of whom resided in retirement communities. The interviewees did not have any serious physical illness or dementia that affected their mental health and/or communication skills. The women were asked to describe their husbands' current health and communication abilities (or their condition the year before their death). All of the husbands suffered from Alzheimer's disease or other dementia-related disorders. Nineteen of the husbands were seriously ill and in the later stages of Alzheimer's disease, Parkinson's disease, or mental impairments resulting from a stroke. According to the wives, their husbands had very limited communication ability, with only two of the husbands being able to maintain a conversation. Even then, this ability was severely limited.

### **Interviewer Procedures**

The semi-structured interview guide consisted of a series of demographic questions followed by open-ended, retrospective, and hypothetical questions. The wives were asked to describe the frequency and length of the visits with their husbands in the nursing home and the types of activities they engaged in while they were there. They also discussed feelings of closeness, changes in their relationship over time, communication-related issues (e.g., interaction with their husbands, displays of affection, topics they would or would not

discuss, privacy issues), important rituals in their lives, their relationships and activities with family and friends, and transactions with the nursing home staff. These questions were broad enough (e.g., "How do you and your husband spend your time together when you visit him in the nursing home?") to allow the participants to describe their relationships with their husbands in their own way. Other questions, however, were germane to issues in the ADRD literature and the purpose of this study. For instance, research suggests that Alzheimer's patients slowly lose the ability to show affection, communicate meaningful information, and often become agitated when certain "trigger words" are used by their spouses and family members (Knuf, 2000; Reisberg, 1983b). Thus, questions regarding how the wives and their husbands communicated affection, maintained conversations, and regulated information revealed how wives communicatively managed various tensions or struggles associated with their husbands' deteriorating emotional and mental abilities.

The interviews, conducted by nine interviewers trained to the interview protocol, took place in a location that was convenient for the participants. In the majority of the cases, the interviews were completed in the participants' own homes. The interviewees were informed of the purpose of the study and were reminded that their participation was completely voluntary. The participants also gave permission to audiotape the interviews and were assured that their identity would be kept confidential. Therefore, pseudonyms are used in this study rather than the participants' or husbands' real names. The interviews lasted between 30 and 60 minutes.

### **Data Analysis**

The interviews yielded 218 single-spaced pages of transcribed data. A qualitative/interpretive method was used to identify patterns or themes that captured the participants' perspectives (Coffey & Atkinson, 1996; Creswell, 1998; Leininger, 1994; Strauss & Corbin, 1990). An interpretive approach enabled us to uncover the meaning these women gave to their experiences and how they made sense of the world around them (Creswell, 1998). The analysis also allowed us to understand how the participants' experiences were shaped by the unique context in which they occurred. We attempted to be responsive to the reality of the participant and were mindful of the whole narrative, while attending to the process of categorizing information (Creswell, 1998; Kvale, 1996).

To complete the interpretive process, treatment of the data consisted of four steps. First, all four researchers read the data set in its entirety before analyzing individual transcripts. Ideas about general themes that surfaced in the interviews were shared among the researchers. Second, the researchers re-read the transcripts, but with more specific attention to recurring dialectical themes in the data. The constant comparative method of data analysis (Strauss & Corbin, 1990) was used to identify emergent themes. More specifically, open and axial coding were used to identify categories, their properties, and the relationships among the categories and subcategories (Strauss & Corbin, 1990). Throughout the analysis process, the categories were continually compared and contrasted, accounting for new insights and discrepant cases (Creswell, 1998; Leininger, 1994). Third, the researchers shared their ideas about the categorization of the data and a rough outline of the categories and their properties was created. One of the researchers then went back to the data to refine

the categories. The descriptions and properties of the categories were delineated further and examples were taken from the data to illustrate each category. This process helped distinguish the categories and reduce ambiguity among them. Finally, two of the other researchers then took this refined category system and provided additional feedback to synthesize the findings. After the findings were written, the researchers compared them to the transcripts to ensure the accuracy of the findings and representation of the participants' voices.

## **Results**

As the women described their communication with their husbands, it became evident that the husbands' illness was enormously problematic for the wives, forcing them to redefine what it meant to have a marital relationship with their husbands. An underlying theme that surfaced in the wives' narratives was the tension of being motivated and/or obligated by the physical presence of their husbands, while simultaneously feeling as if their "true" or "real" husbands were mentally/emotionally absent. In an effort to communicatively manage this tug-of-war between the "presence" and the "absence" of their partners, three additional contradictions emerged that made their praxis choices problematic: certainty-uncertainty, openness-closedness, and past-present. Each contradiction will be described in turn, including the communication practices employed by the wives to manage each contradiction.

### **The Presence-Absence Contradiction**

Throughout the interviews, the participants talked about how they loved their spouses and were married to them, but felt as if the person they married was gone or slowly passing away. Physically, the husband was present, but mentally and emotionally, he was absent. The women often were torn because they felt motivated, and in some cases obligated, by the physical presence of their husbands. Most of the participants would visit their husbands three to four times a week, and ten of the wives visited their husbands at least once each day, often for several hours. However, they often would come away from the visit frustrated because their husbands did not know who they were or would respond in a manner somehow foreign to their "true" selves. The impact of the need to stay connected to one's spouse, while feeling a sense of loss of the spouse, was illustrated by one woman who explained:

He's . . . he's not . . . he's not my husband anymore. When you have Alzheimer's . . . he's just not the same person. And I feel very little closeness to him . . . married for 55 years, obviously I love him. But there's no closeness, no intimacy. Hasn't been for a long time because he just isn't the same person. . . . It's just hard. I try to remember interesting things to tell him and talk with him about, but you see, he doesn't know I'm his wife. He knows me but he doesn't know I'm his wife. He talks to me about his wife. (18:2-6)

As this respondent poignantly noted, she still loved her husband and was committed to him, but she was frustrated that it was not her "true" husband with whom she was speaking. The fact that he would talk to her about his wife illustrates the level of dementia that the husbands were reported to experience.

Yet, these women would continue to include their husbands in activities, holidays, and conversations even though their husbands usually could not respond in a meaningful way. As one participant revealed, "Well, I still feel married, I don't know. I mean I try to have him a part of whatever celebrations we have, I mean, whether he understands it or not" (3:8).

It was painful for these participants to witness their husbands' increasing dementia. As one woman described her feelings of despair, "I think the worse he got, the more I loved him because I was so helpless and so was he. And I was losing him" (13:3). The same woman went on to tell of her husband's inability to show affection toward her:

Little by little by little. That ability. I used to be able to go in and stand him up and put his arm around me and then I'd hug him real tight and I'd say, "Daddy, hug me real tight just like I did," and for a while he was capable of doing that. And then towards the end the arms would just hang. He didn't even understand the simple "hug me." (13:7)

Another woman described how draining her visits were because her husband would become frightened or angry when "his mind was playing tricks on him" (11:6). There were many days when it took all of her energy just to visit her husband:

Sometimes I have thought it has been going on for so long, . . . ten years of this day by day by day. There were times I felt I couldn't keep my own sanity. . . . There have been times when I would get to the nursing home and shut the car door and start praying that I had enough strength to walk in there. (11:13)

As these excerpts illustrate, the women felt frustrated, despondent, and saddened in watching their husbands' mind deteriorate before their eyes. Yet, even in the face of such difficulty, the wives continued to visit their husbands and remained positive for their husbands' sake. The women often were torn between the physical presence of their husbands in the nursing home and the mental/emotional absence of the husbands' "true self." The wives' descriptions of the presence-absence contradiction capture the essence of "married widowhood"; the women felt that they were still married to their husbands, but at the same time widowed by their husbands' cognitive absence.

The wives employed a variety of communicative practices to manage their experience with the presence-absence of their husbands. Four in particular were salient in the interview transcripts: (a) Emphasizing Nonverbal Communication, (b) Increasing Interpretive Work, (c) Using Nursing Home Staff as Information Mediators, and (d) Limiting Contact with the Spouse. Each will be discussed in turn.

***Emphasizing Nonverbal Communication***

One of the most frequently reported coping strategies the women used was to give in to the mental/emotional absence of their husbands and focus instead on the physical presence of their spouses. For many of the interviewees this meant attending to the physical presence of their husbands through nonverbal communication and relationship level messages. In the absence of meaningful verbal communication, the wives often overcompensated by relying more extensively on acts such as handholding, hugs, kisses, and loving looks. As one woman noted, "Sometimes we just sit silent, we just sit there and hold hands" (4:8). Simply being with her husband and holding his hand was celebrating the fact that he was still alive. "I would take him outside and walk," another woman said. "There was never really any conversation. I would walk with him to be with him. Just be with him, you know" (7:4).

Doing things for their husbands, such as watching their favorite television shows, helping them eat their meals, and taking them out into the fresh air, helped the wives establish a connection with their spouses. For instance, one woman indicated that she would "hug him and do things like rub his shoulder . . . I knew he liked that and . . . Henry loved to have his hair combed and I would comb his hair. I would do everything I could think of" (7:9).

The wives also used their husbands' nonverbal communication as evidence that their husbands were emotionally present at some level. As one woman stated, "I always give him a hug when I go and I reach out to him with my lips and he answers me that way and I know that he knows me" (5:1). Another interviewee talked about how she would "take him out on the patio so he could see the pool. Uh, he was at a point of not being able to do much with me, like play cards. But, he seemed to want to be held and talked to" (13:1). Greater reliance on the kinesic behaviors of their partners provided the wives with deeper, relational level messages about the state of their relationships. That is, in the absence of verbal communication or content level messages, the women attended to their husbands' nonverbal cues, whether purposeful or not, to provide meaning and maintain an emotional connection. This gave the wives the perception that mutual awareness and understanding was taking place, even when the husbands' verbal communication belied such consciousness. Of course, there is no way to know whether the women were correct in their interpretations.

***Increasing Interpretive Work***

In the face of their husbands' cognitive/emotional absence, the wives worked harder to interpret their husbands' limited communication, inferring meaning on his behalf. The women had to renegotiate what it meant to communicate with their spouses. Many of the participants focused on interpreting idiosyncratic behaviors unique to their relationships, further relying on relationship level messages to provide meaningful communication. For instance, the wives often interpreted humorous remarks or behaviors, single words that captured a family story, or a special "look" from their husbands. One woman, for example, felt that she knew when her husband wanted a cigarette because "he had been a smoker and he wanted to get out in the open air space and he'd go like this [smoking gesture] to

tell me that he wanted a cigarette and of course, he couldn't have it" (10:1). Another interviewee demonstrated how she knew her husband was angry based on his eye movements: "I have learned those eye messages. I would say, 'Well, I don't like the way you're acting' . . . 'You're being very unkind to somebody'" (14:7). In many ways, the wives' self-perceived ability to interpret their husbands' abbreviated communication was a way for them to construct a cognitive/emotional presence for their spouses, even if temporarily.

As a result of the unique relationship between the wives and their husbands, they were immediately drawn to the relationship level messages inherent in their husbands' behavior. In many ways, the spouses' years together made this interpretative work easier and allowed them to remain connected. Yet, at the same time, it was the wives' ability to interpret these underlying cues that made the presence-absence tension much more difficult to manage. The wives would interpret their husbands' behavior as meaningful, but became frustrated when the nonverbal or idiosyncratic behaviors they thought were meaningful were potentially misinterpreted. That is, the spouses could not help but rely on relationship level messages, even though the behaviors may or may not have been purposeful or intentional. Nevertheless, the wives would perceive that these messages were real, regardless of whether intent was present or not.

The participants also engaged in perspective taking or communicated as if they were living through the eyes of their spouse. For instance, even though the husbands were often no longer cognizant of holidays and rituals, the wives continued to include their spouses in such celebrations because it is what they thought the husbands would have wanted. One participant talked about how she decorated her husband's room on the holidays even though there was a lack of response from him because "we felt that there was something way down inside him that he couldn't bring out, but that he recognized what was going on but couldn't show us" (7:6). This woman felt as if her husband knew, in some way, what was going on around him.

Taking the perspective of their husbands also meant treating them with respect. As a participant stated, "They are somebody; they're not a nobody just sitting in a wheelchair" (6:10). By doing things they thought their husbands would want, the wives allowed their husbands to live a life of dignity, grace, and honor, thereby preserving their husbands' presence, at least symbolically.

Another aspect of the wives' interpretive work involved "reframing" their husbands' behavior by bracketing the person from the disease. Some of the participants were able to get past their own anger about their husbands' condition by remembering that the behavior was not the person. They had to remind themselves that their husbands' actions were not his fault and that they were due to his dementia. As one woman expressed:

I think once you realize that there's no reversing this . . . I think initially there is anger. You feel anger. "Well why can't you do that, you've always been able to do that." But once you realize that they're not responsible, the anger goes away. It's just grief. (13:7)

Other participants went on to explain how the nursing home staff helped them realize that they had to separate the person from the disease: "They have taught me, the aides,

that that's not him and that . . . and so, he doesn't realize what he's doing. So, I don't get angry anymore." (14:7). By reframing their husbands' behavior, the wives were able to release their anger and maintain their emotional bond with their spouses. It also released the burden of responsibility from the wives when they could not communicate effectively with their husbands.

#### *Using the Nursing Home Staff as Information Mediators*

The participants also used the nursing home staff as information mediators, either relying on them for information about their husbands or asking them to help perform communicative work with them. Several women described how much they appreciated it when the staff would share stories about their husbands when they were unable to visit the nursing home: "They're always telling me the funny things he does," mentioned one participant. "He's always keeping them laughing, he's always smiling and that's my daily prayer that he'll be content" (15:6). When the staff relayed this kind of information, it helped the women remain close to their husbands. The nursing home staff also provided a sense of comfort to the wives as they could rest easier knowing their husbands' physical and emotional needs were being met. As another participant revealed:

He's getting the very best of care. All the aides, the nurses, the doctors, everyone, dietitians, everyone. . . . They are so caring and the fact that they are so good to John, [very emotional] I'm so grateful. I can't explain . . . I just thank God every day for my blessings. (6:10)

The nursing home staff also assisted the women with their relational work by providing activities and parties for their spouses. One of the participants, for instance, relayed a story about how thrilled she was that the nursing home staff had a St. Patrick's Day party for the patients because it was her husband's favorite holiday. In addition to helping the women interpret their husbands' behavior and needs, the staff helped relieve the wives' stress by taking over important celebrations and daily functions for them.

The staff also helped the participants relieve their guilt from wanting to spend more time with their husbands, but needing to maintain their own autonomy and freedom. For instance, an interviewee talked about the guilt she felt over wanting to be with her husband, but needing to go out with her friends. The staff helped her deal with this tension by telling her that "it's better if you only come every other day because he forgets two minutes after you leave and it's easier for you" (14:2). She went on to describe how she has learned to trust the staff to give her husband the best care. Thus, the nursing home staff helped the participants relinquish control over their husbands' lives, helping them to deal with their husbands' absence by giving wives permission to visit them less.

#### *Limiting Contact with the Spouse*

There were a few cases in which wives would avoid facing the presence-absence contradiction by removing themselves emotionally and/or physically from contact with their spouses. One woman, for example, said that she skipped over holidays because they were too painful, downplaying them because they were meaningless to her husband: "Who

cares if I'm 78 or something you know, but I try . . . because so many people make themselves miserable over the holidays, I've tried to sort of skim over them. Maybe it's denial, maybe it's my escape or whatever" (2:7). As this woman demonstrated, some of the participants had to remove themselves physically in order to separate themselves emotionally. However, for other participants, the physical removal enhanced their feelings of guilt. As another interviewee explained, "I don't come in as often. It has bothered me a lot. I have had a terrible time with the guilt" (21:5).

Other participants used the time freed up by less frequent visitations with their spouses to increase their communication and activities with family and friends by, for example, going out with relatives/friends, attending church activities, exercising, or playing cards. One woman talked about how her closeness with her husband actually increased since he entered the nursing home because she had the ability to do things for herself. She explained, "I got a trainer, and he got my muscles firmer, and I got feeling better about myself. So that anger [toward her husband] went out. I just handled myself. And I took care of him and had no guilt feelings" (17:6). The women engaged in social activities to enhance their sense of self, counteracting the loneliness or other negative emotions they felt from the cognitive and emotional absence of their spouses.

Some participants, however, continued to feel guilty for not being able to include their spouses in such activities. One woman, for instance, noted that "you have more freedom, and I had one friend who started dating. Well, that's something I don't think I could do, and why not, I mean your husband can't take you dancing or places, but I feel like I wouldn't be fair to John" (1:10). Other participants also revealed that they joined bicycle clubs or played bridge with friends, but felt guilty for not spending more time with their husbands. However, as another wife suggested, participating in activities outside the nursing home was helping herself and her husband gain a sense of peace: "I found I wasn't doing anything but going to the nursing home and I didn't like that, so it was up to me to change so that I wouldn't blame him" (11:13).

The primary contradiction experienced by our participants was the presence-and-absence of the husband. Wives managed this contradiction by becoming increasingly reliant on nonverbal communication, by increasing their interpretive work, by using nursing home staff as information mediators, and by limiting contact with their spouses. However, the presence-absence contradiction is a complicated dialectical tension because of the fleeting moments of lucidity characteristic of the husbands' ADRD. This leads us to the second contradiction experienced by the wives—certainty-uncertainty.

### **Certainty-Uncertainty**

Even though the husbands' communicative abilities tended to be severely limited, there were fleeting moments of lucidity when the wives believed the husbands' "true self" had emerged. The participants clung to these moments of cognitive/emotional presence because it gave them hope of the person they married. A simple look, kiss, hug, or phrase provided fleeting evidence of the presence or certainty of their spouses' "real self." One woman described this feeling of experiencing her husband's cognitive/emotional presence:

I know that he knows who I am. . . . Occasionally he will say a few words and uh, a doctor, a neurologist, told me that this is a moment of lucidity in an Alzheimer's patient and he [husband] looked up and said, "There she is." I cried, I put my head on his shoulder and I cried. (5:1)

Another woman mentioned a similar sense of certainty of her husband's true self in the face of overwhelming uncertainty:

He was a very affectionate person. That's what is kind of hard. You know, he just sort of pushes me away. But I don't know if he hurts . . . his body hurts him or what. I don't know. He just . . . One day not too long ago, for some reason, he said, "Hold me." And I was so thrilled . . . I don't know what was wrong . . . what had happened . . . but "hold me." So I put my arms around him . . . and . . . excuse me [tears begin to stream down her face]. (14:7)

Such fleeting moments of lucidity often caught the wives by surprise, and they were bittersweet events. On the one hand, as these excerpts illustrate, the wives were overjoyed when they perceived that their husbands were cognitively/emotionally present. However, such moments were brief and could lead to the formation of false hopes, destined to be unfulfilled given the long-term prognosis for persons with ADRD. Wives could easily invest emotionally and over-interpret their husbands' actions, perceiving consciousness when, in fact, it was absent.

Uncertainty about their husbands' moment-to-moment lucidity made communication challenging for these wives. There were times when the women felt they were certain that they were communicating with their spouses' "real self." There were many instances, however, when they were clearly uncertain about the partners' behavior and whether or not communication with another consciousness was taking place. In a sense, just as the husbands' minds were "playing tricks on them," the wives were similarly confused over the authenticity of their husbands' behavior. They became highly frustrated because the fleeting moments of lucidity gave them evidence of the person they married, but these instances were overshadowed by dominant moments of uncertainty. For these wives, their frustration was realized when they attempted to interpret when their husbands' true self was present. This movement in and out of lucidity could take place within a single conversation, even within a single utterance. As one interviewee said about her husband, "I don't think he realizes that I don't come very often. He always says to me, 'Where were you yesterday?' . . . He starts to say three words and his mind goes blank and he can't finish where he started" (21:5). This false, but sometimes real, sense of hope challenged the wives' ability to remain connected to their husbands.

Thus, the participants' relationships with their spouses were struggles to identify what was "real" and what was not. Wives felt tugged between uncertainty and certainty about their spouses' cognitive/emotional presence. On any given day, the wives were often unsure how their husbands would respond to them. As one wife indicated, "I have to initiate any kind of affection here and then I don't even know if there will be a reaction or not" (1:9). Some of the women also noted that no matter how well they thought they were able

to interpret their husbands' behavior, they could not depend on their interpretations of lucidity:

When they can't communicate anymore by phone or verbally then it's difficult. And you just have to carry on kind of a one-sided conversation and you can't really depend on . . . if you say, "Did you have a good lunch today?" and they say "yes," they might have had a can of tomato soup. They might have had a glass of water. (13:9)

The back and forth movement between the certainty and uncertainty of their husbands' presence left them frustrated and apprehensive about their communication with them. The wives' communicative practices of coping with the certainty-uncertainty dialectic are integrally bound up with the third and fourth contradictions, to which we turn next.

### **Openness-Closedness**

One of the contradictions that emerged from the women's efforts to communicate with their husbands was the tension between openness and closedness. The wives wanted to refrain from disclosing certain information because of the anger, hurt, or sadness they thought it would provoke in their husbands. As one woman mentioned, talking about home was sometimes like "waving a red flag to a bull" (11:5). Many of the women perceived that their husbands would become upset when they talked about their homes. Another participant noted that she refrained from talking about home "because the word 'home' hurts. He's got the idea that he's in a peni . . . penitentiary serving a life sentence. . . . It's sort of his attitude" (11:6). On the other hand, many wives believed that what made their husbands happy was engaging in activities and the telling of stories that reminded them of their home or family. Thus, the wives wanted to disclose personal information to encourage and celebrate the presence of their "real" husbands, but were unsure how much information to reveal to them.

The participants attempted to decipher, often through trial and error, what information about their home life their husbands could and could not handle. As one participant explained:

I was very sensitive to what I could say to him and what I couldn't, and how I should treat him. And as he was there longer and longer, it was less and less that I could communicate with him. He wasn't able . . . he didn't get it. Or he got angry or something so I just knew what I could say or couldn't say to him. (17:3)

As this wife indicated, the issue of what to reveal and conceal was compounded by the fact that the women had to determine how much information their husbands understood. Another interviewee echoed this feeling as she tried to assess what to tell her husband about their house:

He doesn't understand some things. I just didn't want him to think that I made any changes. So I . . . I just talked like I still live as I did . . . I try to tell him about the family and things, but I don't know . . . Sometimes when I tell him something that is kind of . . . oh . . . stressful, he'll wince, you know . . . and seems like he understands . . . but I don't know. (14:1)

The punctuated "I don't know's" and the dysfluencies in the interviewee's sentences also reflect the uncertainty of the participant over not knowing what should be communicated to her spouse. This uncertainty about how to proceed with informational openness was a common theme in our interviews.

Some of the participants also noted the frustration of having to hide some of their feelings and emotions from their husbands. The wives wanted to show their husbands how much they missed them. However, to reveal their true feelings might be too stressful and hurtful for their spouses. For instance, an interviewee talked about how she perceived she had to hide her sadness from her husband:

All he can tell me is that he loves me, he misses me, and . . . it's hard for me not to take him home [she cries]. I have accepted it. I know I have . . . and I have to be brave about it and not let him know . . . how I feel. (6:7)

In the face of their uncertainty and frustration about how open to be, our participants generally opted for conservative coping strategies that displayed discretion more than candor. Two praxis strategies dominated our data: (a) Intentional Topic Avoidance and (b) Small Talk.

### *Intentional topic avoidance*

The participants coped communicatively by intentionally avoiding negative or conflict-inducing topics in order to protect their husbands, and secondarily themselves. Some of the participants used topic avoidance because they thought their husbands would not understand the information revealed and become stressed as a result of hearing it. The interviewees would avoid talking about their home life, social activities, finances, problems in the family, and friends who were ill because they perceived it would make their husbands angry, sad, or frustrated. For instance, as one woman revealed, "When he would ask about finances, I would just stuff it up. 'Oh, we're doing o.k.' Actually, I was looking at the road of poverty" (8:2). Another woman mentioned how she would monitor her discussions about what was happening with their children or friends because he would become resentful: "I realized that this is a no-no, that I shouldn't tell him that 'I'm going to a concert with Susan' (a friend) or something because I didn't want to upset him" (17:3).

Other interviewees used topic avoidance to protect their husbands from becoming stressed because of their inability to sustain a meaningful conversation. An interviewee describes the protective function that topic avoidance served: "You just really try to shield him from bad things that are happening . . . there's no need to tell him. He can't comprehend it anyway and if he makes a mistake in what he's telling me, I just accept it because there's no need to correct him. He can't help it" (6:5). Some of the women also mentioned

that they would avoid talking about particular topics because they were uncertain of their husbands' comprehension. For instance, one woman said, "I'll say I went to church, but I played bridge. . . . I don't tell him about when I go out to dinner or things like that" (14:1). She went on to tell of an incident in which she thought her husband might comprehend some of her conversations and did not want to take a chance of him misunderstanding her:

I just had this feeling that he understood and once, he almost sounded like he said something about a boyfriend or something you know . . . and I thought I didn't want him to think anything like that. So I just thought, "I don't want to say anything that will worry him or upset him." (14:1)

Topic avoidance not only protected the participants' husbands, but it also served a self-protective function. A few of the participants used avoidance to reduce their own guilt. For example, a couple of the interviewees indicated that they would avoid telling their husbands that they went out with friends or relatives because they would feel bad when their husbands could not go with them. "I have to remember if I am getting together with some friends for dinner that he knows," a participant stated. "I have avoided telling him that. I feel guilty the whole time" (4:9).

### *Small talk*

The participants also relied on small talk to cope with the dialectical tension between openness and closedness. The wives would engage in superficial talk about the weather, what was on television, the nursing home, or sports; topics that one would converse about with a stranger or an acquaintance. As numerous participants revealed, small talk was sometimes the only communication strategy they found possible: "Well, you really couldn't carry on a conversation except the weather. Um, I would say 'Isn't this a pretty day?' and he would kind of look and really wouldn't respond" (10:3). Their husbands became strangers, in many respects, and the wives responded accordingly, as another interviewee pointed out, "I can't carry on a normal conversation with him . . . it's sort of like talking to a five-year-old. I can entertain him with stories or what's going on" (18:2). Finally, one participant discussed how she used small talk out of her frustration with a lack of communication with her husband:

You come in and you talk at them . . . but as I say I try to talk about mundane things that go on. It isn't about something that has come up or that has happened. No, nothing really. It is like talking to a wall. You try to keep conversation going, but it is difficult. You really get no replies. You are just there for yourself. (21:5)

As this woman described, the wives often used small talk to maintain some semblance of connection, minimal though it was.

When wives were forthcoming with information to their husbands, the fourth contradiction became salient. Should they share information about the present, or should they limit conversations to topics linked somehow to the past? The fourth contradiction, past-

present, captures a basic tension between a need to live in the present and a need to sustain continuity with the past.

### **Past-Present**

The wives felt that all they had with their “true” spouses was the past. Yet, they were living with the day-to-day life of the present. Our participants mourned the loss of their husbands of the past. For example, one interviewee talked at length about how much she missed her husband’s sense of humor and witty personality: “He always made me feel like a queen. I felt like a queen. He was such a gentleman [she begins to cry]. And I miss that, you know? I really miss him” (14:3). Another woman shared a similar sentiment when she stated, “You know, I drive down the street and I see these couples in cars, and I think ‘Now why couldn’t that be us?’ You know? As it used to be” (14:6). While these women longed for the past they shared with their husbands, they also wanted or needed to live in the present. As one woman commented, “Everything has to be for the moment” (2:9). The participants sometimes had to force themselves not to become consumed by the past. As an interviewee explained:

Once your loved one enters a nursing home your life will never be the same again . . . and don’t try to make it the same, you can’t do it. You must accept it that way from day one, it’s all different, because if you try to make it like it was you’re just going to tear yourself to pieces and everybody else that’s around you. (11:4).

This woman went on to describe, however, how difficult it was to live for the moment when her spouse literally thought he was in the past: “He doesn’t realize that it can’t be the same again. . . . he still sees himself . . . If you asked him his age, oh he’d say . . . heaven knows he’d say he was about thirty or forty” (11:5). Another woman told a story about how one day when she was sitting in a well-lit area, her husband informed her that she “looked awful. You have really failed,” he said to his wife, thinking that she was still 41 years old (4:16). Thus, the ability to manage the presence-absence of one’s spouse is complicated by the fact that the wives and husbands themselves were often stuck in the past because that is where their husbands’ minds resided.

Although our participants felt a tension between the past and the present, they tended to privilege the past in their verbal communication with their husbands. As one wife explained, she would “remember things that were of joy to him. Like we always did a lot of dancing. And I used to take our picture and say ‘Remember when we were on this vacation, Daddy, or when you guys threw Jim in the pool?’ Try to talk about things that were some fun to him” (13:3). By invoking past-oriented topics, wives clung to the husbands they once knew, which was a very bittersweet experience.

### **Discussion**

In this study we used a dialectical framework to examine the relational experiences of wives whose husbands were experiencing ADRD and how they coped communicatively

with their husbands' illness. Clearly, this was a difficult time for these wives, as they managed their husbands' physical presence and concurrent mental absence. The experience of these wives epitomizes the liminal state of married widowhood and the dialectical nature of the concept (Braithwaite, 2002; Rollins et al., 1985). The husbands' limited mental and communicative abilities created a struggle for the wives because they desperately wanted to communicate with the husbands they once knew. In this sense, they felt widowed but did not have the opportunity to grieve and move on with their lives.

### **Theoretical Implications**

As the wives attempted to manage the presence and absence of their husbands, they became enmeshed in other competing forces, or what Cornforth (1968) refers to as a knot of contradictions. The narratives of these women provide a powerful illustration of totality, or the interdependence that exists among contradictions that Baxter and Montgomery described (1996, 1998). This study lends further credence to Montgomery and Baxter's (1998) contention that researchers must begin to shift their study of dialectics as simple binary oppositions, analyzing pairs of dialectical tensions in isolation, to a larger network of co-existing juxtapositions. In the present study, the presence-absence contradiction for the wives was interwoven with the dialectical tensions of certainty-uncertainty, openness-closedness, and past-present. For instance, the wives were often uncertain about when and if their husbands' true self would surface. However, there were times when they were confident of their husbands' cognitive/emotional presence. This uncertainty over their partners' presence and his ability to understand information became particularly salient when wives attempted to decipher what personal information to reveal or conceal. The wives' ability to manage the presence-absence of their husbands was intensified by their desire to preserve the relational past they shared for so many years, while continuing the relationship in the present. Analyzed together, such contradictions provide validation of the depth and complexity that underlies the communication between these couples (Brown et al., 1998; Montgomery & Baxter, 1998).

This study also provides further evidence of the need to study contradictions as interdependent entities that exist as part of the relational history and social milieu in which they are embedded (Baxter & Montgomery, 1996, 1998; Brown et al., 1998; Werner & Baxter, 1994). A second aspect of totality is the notion that contradictions are situated in temporal, spatial, and social contexts (Baxter & Montgomery, 1998). The wives' communication with their husbands was positioned within the context of ADRD, the nursing home, and their families. Cohen, Coppel, and Eisdorfer (1983) explain that ADRD affects one's whole family, changing "the entire family constellation" (p. 445). For example, many of the participants noted how their adult children also experienced the tension of wanting their "real" fathers, and feeling unsure how to communicate with who their fathers had become. The nursing home staff also influenced wives' ability to manage the presence-absence dialectic, often positively. When wives perceived their husbands were well cared for, they felt more comfortable in reducing the number or duration of visits to the nursing home. This allowed the wives to feel less guilty and to develop their own lives outside of the marriage. We

would suspect that, as wives successfully negotiate the presence-absence dialectic, relationships with the nursing home staff and family members are facilitated as well. These findings underscore the importance of grounding dialectical analyses in the social context in which they are experienced.

The results of the present study also highlight unique external tensions that, although beyond the scope of our data, do merit further research attention from applied communication scholars. For example, how do couples, and later community-dwelling spouses, negotiate their way through the ever-changing nature of a progressive disease like ADRD, while trying to maintain a sense of stability with and for their family and friends? What role(s) do family and friends play in the adjustment of married widows? How do family members and friends deal with seeing some wives become progressively more independent as the disease progresses? Understanding the tension between change and continuity for families affected by catastrophic illness is an important step in helping them live and function more successfully (Kuypers & Bengston, 1990).

Additional research is also needed to understand if and how those who are caring for spouses who are seriously ill or disabled maintain their social network while caring for their spouses with ADRD. At a time when the caregivers need the most help and support, they are pulled away from those networks because of the overwhelming demands of daily caregiving. Even when husbands move to a nursing home, our data indicate that most wives spend a great deal of time visiting and providing care for their husbands. Morgan and March (1992) reported that caregiving for a spouse with ADRD resulted in a mutual withdrawal between caregiver and their social networks, while widowhood resulted in an increased social network. For those in the married widowhood (pre-widowhood) phase of life, this experience is inherently dialectical. Caregivers may experience various contradictions, and the stress associated with them, as they attempt to balance the opposing needs from their partners and families, as well as their own needs for social interaction and beginning their life without their husbands. All of this occurs as the community-based spouses are themselves aging and often experiencing their own physical and emotional challenges.

In addition to gaining a deeper understanding of the contradictions of interactions for wives of husbands with ADRD, our analysis revealed that the women employed several praxis strategies when faced with such tensions. As Baxter and Montgomery (1996) note, praxis refers to the notion that "people are at once actors and objects of their own actions" (p. 13). That is, people make conscious, proactive choices about how they communicate with others. People's communicative choices, however, are simultaneously a product of their previous actions and experiences. As numerous participants in the present study indicated, the way they communicated with their husbands with ADRD and their ability to predict their husbands' reaction to messages, was based upon previous experience interacting with their husbands over the years. For example, many of the wives intentionally avoided talking about their home life because they believed it would make their husbands angry or sad. Similar to previous research, topic avoidance served a self and relationship protection function for these wives (Afifi & Guerrero, 1998; Guerrero & Afifi, 1995). Further, the participants also realized that engaging in small talk was a way to maintain the feeling of a relationship in the cognitive absence of their spouses.

The wives' relational history with their husbands also helped them maintain an emotional connection with their husbands and made their interpretive work easier. The women were able to identify their husbands' favorite activities, television shows, sense of humor, and gestures because of their time spent together in the past. This finding coincides with extant literature on communication patterns of older, long-term couples, which reveals that long-lasting, later-life relationships are often characterized by a conjoined reality in which the couples' individual perspectives and behaviors become integrated (Dickson, 1995; Nussbaum et al., 2000; Sillars & Zietlow, 1993).

In addition to contributing to our understanding of dialectical theory, the findings of the present study complicate some of our basic assumptions about interpersonal communication, making a contribution to how we understand communication in our personal relationships. Most, if not all, of our definitions and theories of interpersonal communication are contingent upon mutual awareness or dual consciousness of the interactants (e.g., Bochner, 1989; Burke, 1950; Cappella, 1987; Wood, 1999). An underlying assumption of these theories and definitions is that for communication to occur, collaboration, meaning-generation, and awareness of the communication must be present *between* the interactants (Knuf, 1999). The results of the present study question our understanding of the communication process when an interactional partner is physically present but cognitively absent. Collaborative meaning generation was less important than the wives' *perceptions* of communication and how they assigned meaning to their interactions. The wives often engaged in perspective taking, which allowed them to generate meaning and remain emotionally and relationally connected to their spouses. The perspective taking process commonly involved relying on nonverbal communication, interpreting the relational level of messages, and participating in shared activities. It was the women's perceptions and sense-making of their spouses' communication and behaviors that allowed the wives to create mutual understanding and (re)define their marital relationships.

### **Implications for Practice**

In addition to the theoretical implications coming from this study, our results offer salient applications for practitioners and caregivers of ADRD patients and their spouses. By "translating our scholarship into practice" (Petronio, 1999), health care providers, ADRD support groups, and family members can help community dwelling spouses manage their relationships with their spouses with ADRD and deal with their status as married widows. For example, support groups for community dwelling wives can provide a way to share the lived experiences with other spouses in similar situations. Structuring counseling or support group sessions around discussions of these tensions could prove therapeutic for the spouses and family members as well as they come to grips with changes in their marriages and their own lives. The results of our study reveal a complex dance as spouses manage the various dialectical tensions. Gaining insight into the complex nature of these contradictions and learning how other families manage these tensions could be beneficial to the spouse and her family. The widespread nature of peer support groups and the usefulness of these groups have been well documented in the literatures (e.g., Boreman, Brock, Hess, & Pasquale, 1982; Query & James, 1989). While we did not ask the women if they

participated in support groups, we did ask them to describe interactions in their networks and the topic of support groups was rarely raised. Our suspicion is that participation in support groups was quite low, if not nonexistent. This may be due to a number of factors, including lack of awareness of these groups, transportation, time constraints (these women spent a great deal of time visiting their husbands), and privacy concerns, as discussed earlier. Nursing home and mental health professionals should have referral information to Alzheimer's or other peer support groups available for these women.

There are also numerous helpful suggestions that practitioners and nursing home staff can offer to spouses who are experiencing the tensions associated with their partners' decreasing mental abilities. As our results indicated, the nursing home staff affected wives' abilities to manage the stresses related to caregiving and to negotiate their married widowhood identities. When wives felt their husbands were well cared for, they felt more comfortable reducing the frequency of their visits and working on developing their own lives outside of the nursing home environment, which would help them cope with eventual widowhood. Staff members, mental health professionals, and family members can help spouses manage concern or guilt associated with less frequent visitations by reassuring them that such a strategy helps them remain positive for their partners. This can benefit the relationship between the spouse and nursing home staff as well, as it is easier for them to do their job when the spouse is comfortable with her husband's care (Schmidt, 1987).

Finally, the results of the present study suggest several useful communication strategies for spouses and family members of an ADRD patient. The praxis strategies we identified could be used to help other wives know what to expect and to learn how to manage the contradictions. It is likely that individuals with spouses or family members with ADRD may be unsure how to navigate the challenges ADRD brings to their families and relational functioning. The strategies revealed in this study could become navigation tools to assist others.

Additionally, physicians and nursing home professionals can also help spouses and family members by educating them about ADRD and the changing nature of ADRD patients' communicative abilities. Medical staff, for instance, could help caregivers use their relational histories and context-based information to their advantage. As the findings of the current study illustrate, the wives had unique insight into the relational level messages inherent in their husbands' communication and were able to interpret meaning on their behalf. These relationship level messages, however, could be refined further with additional help of staff trained in the linguistic patterns of ADRD patients. Caregivers can learn how to keep the topic of conversation specific and unambiguous, actively cue the awareness of their impaired partner, use clear and repeated references to time, space, and context, and uncover important conversational cues (Knuf, 2000). Thus, caregivers could be shown how to become interpretive listeners and use their relational history to decipher their spouses' communication.

In light of the theoretical and practical contributions of this study, we do recognize several limitations and directions for future researchers. First, in the current study, we focused primarily on partners who were in the latter stages of ADRD. Additional research is necessary to understand the progressive communication and relational changes in different stages of the illnesses, beginning as the husband and wife are living in the community. The

presence-absence dialectic may be even more salient given the progressive nature of ADRD as a person's cognitive presence and communicative abilities decline over time (Orange et al., 1998; Ramanathan, 1995). Second, researchers should examine how these contradictions are experienced when a spouse has a sudden onset of serious illness or disability, for example, a serious stroke that leaves communication abilities significantly impaired. We suspect that the contradictions and praxis strategies used to cope with them would be experienced and enacted differently. Third, there is also a need to try to understand how diseases associated with ADRD affect communication and relational functioning from the perspective of the person with ADRD. The voices of people who have ADRD are absent in the extant literature and largely in the present study as well. Other than the linguistic analysis of their speech patterns, we know very little about how persons with ADRD renegotiate their relational lives when faced with the impending eventuality of cognitive absence due to progressive disease. Finally, researchers have noted different ways community-dwelling wives experience married widowhood (Braithwaite, 2002; Kaplan et al., 1995) and that there are different types of long-term marriages (Dickson, 1995; Noller & Fitzpatrick, 1993). We need to know more about how individuals within different types of marriages and married widowhood experiences negotiate their way through married widowhood.

As the human lifespan increases and medical technology advances, so does our need to understand and communicate with those who may not be able to respond in ways we have grown to expect. This study challenges current assumptions about communication, co-construction of meaning, and relating. Moreover, it helps us understand how relational partners must renegotiate their relationships, relational identities, and communication over the lifespan. Finally, the present study informs our understanding of the difficult and painful nature of ADRD, and how the cognitively functional spouse, in particular, manages the state of married widowhood. All of these issues present challenges to the way we understand and study communication in personal relationships and presents needs and opportunities for scholars and practitioners.

**Acknowledgments** – Leslie A. Baxter is an F. Wendell Miller Distinguished Professor of Communication Studies at the University of Iowa, Iowa City, IA 52245. Dawn O. Braithwaite is a Professor in the Department of Communication Studies at the University of Nebraska–Lincoln. Tamara D. Golish is an Assistant Professor of Speech Communication at The Pennsylvania State University. Loreen N. Olson is an Assistant Professor of Communication at Cleveland State University. The authors gratefully acknowledge the assistance of Kathy McElvain, K. T. Baldwin, Ruth DeCosse, Melinda Felice, Judith Guarino, Joy Jordan, Sue Pisano, Dan Reilly, Minnie Torres, and Judy Watkins.

## References

- Ade-Ridder, L., & Kaplan, L. (1993). Marriage, spousal caregiving, and a husband's move to a nursing home: A changing role for the wife? *Journal of Gerontological Nursing*, 19, 13–23.
- Administration on Aging (2001). *The older population* [On-line]. Available: <http://www.aoa.gov/aoa/STATS/profile/default.html>.
- Afifi, W. A., & Guerrero, L. (1998). Some things are better left unsaid II: Topic avoidance in friendships. *Communication Quarterly*, 46, 231–249.

- Aldous, J. (1994). Someone to watch over me: Family responsibilities and their realization across family life. In E. Kahanam, D. E. Biegel, & M. L. Wykle (Eds.), *Family caregiving across the lifespan* (pp. 42–68). Thousand Oaks, CA: Sage.
- Alzheimer's disease—Administration on aging fact sheet (2000, May 4). *Administration on Aging* [On-line]. Available: <http://www.aoa.dhhs.gov/factsheets/alz.html>.
- Baxter, L. A., & Montgomery, B. M. (1996). *Relating: Dialogues & dialectics*. New York: Guilford.
- Baxter, L. A., & Montgomery, B. M. (1998). A guide to dialectical approaches to studying personal relationships. In B. M. Montgomery & L. A. Baxter (Eds.), *Dialectical approaches to studying personal relationships* (pp. 1–16). Mahwah, NJ: Erlbaum.
- Bochner, A. P. (1989). Interpersonal communication. In E. Barnouw, G. Gerbner, W. Schramm, T. L. Worth, & L. Gross (Eds.), *International encyclopedia of communications* (pp. 336–340). New York: Oxford University Press.
- Boreman, L. D., Brock, L. E., Hess, R., & Pasquale, F. L. (1982). *Helping people to help themselves: Self-help and prevention*. New York: Haworth Press.
- Braithwaite, D. O. (2002). "Married widowhood": Maintaining couplehood when one spouse is living in a nursing home. *Southern Communication Journal*, 67, 160–190.
- Brown, B. B., Werner, C. M., & Altman, I. (1998). Choice points for dialecticians: A dialectical transactional perspective on close relationships. In B. M. Montgomery & L. A. Baxter (Eds.), *Dialectical approaches to studying personal relationships* (pp. 137–154). Mahwah, NJ: Erlbaum.
- Brubaker, T. H. (1990). An overview of family relationships in later life. In T. H. Brubaker (Ed.), *Family relationships in later life* (2nd ed., pp. 13–26). Newbury Park, CA: Sage.
- Burke, K. (1950). *A rhetoric of motives*. Englewood Cliffs, NJ: Prentice-Hall.
- Cappella, J. N. (1987). Interpersonal communication: Definitions and fundamental questions. In C. R. Berger & S. H. Chaffee (Eds.), *Handbook of communication science* (pp. 184–238). Newbury Park, CA: Sage.
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA: Sage.
- Cohen, D., Coppel, D., & Eisdorfer, C. (1983). Management of the family. In B. Reisberg (Ed.), *Alzheimer's disease: The standard reference* (pp. 445–448). New York: The Free Press.
- Conville, R. L. (1998). Telling stories: Dialectics of relational transition. In B. M. Montgomery & L. A. Baxter (Eds.), *Dialectical approaches to studying personal relationships* (pp. 17–40). Mahwah, NJ: Erlbaum.
- Cornforth, M. (1968). *Materialism and the dialectical method*. New York: International Publishers.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Dickson, F. C. (1995). The best is yet to be: Research on long-lasting marriages. In J. T. Wood & S. Duck (Eds.), *Under-studied relationships: Off the beaten track* (pp. 22–50). Thousand Oaks, CA: Sage.
- Early Alzheimer's disease patient and family guide. Consumer guide number 19. AHCPR No. 960704 (1996, October). *Healthfinder* [On-line]. Available: <http://text.nlm.nih.gov/tempfiles/is/temp-BRpG39757.html?t5961251390>.
- Ellis, D. G. (1996). Coherence patterns in Alzheimer's disease. *Communication Research*, 23, 472–495.
- Facts about Alzheimer's Disease (2000, February 28). *Virtual hospital: The apprentice's assistant*. Iowa Geriatric Education Center and University of Iowa Hospitals & Clinics [On-line]. Available: <http://www.vh.org/Patients/IHB/GeriatricEducation/Facts.html>.

- Guerrero, L., & Afifi, W. A. (1995). Some things are better left unsaid: Topic avoidance in family relationships. *Communication Quarterly*, 43, 276–297.
- Kaplan, L., & Ade-Ridder, L. (1991). Impact on the marriage when one spouse moves to a nursing home. *Journal of Women & Aging*, 3, 81–101.
- Kaplan, L., Ade-Ridder, L., Hennon, C. B., Brubaker, E., & Brubaker, T. (1995). Preliminary typology of couplehood for community-dwelling wives: “I” versus “we.” *International Aging and Human Development*, 40, 317–337.
- Kemper, S., Lyons, K., & Anagnopoulos, C. (1995). Joint storytelling by patients with Alzheimer’s disease and their spouses. *Discourse Processes*, 20, 205–217.
- Knuf, J. (2000). The margins of communication: Coping with adult dementia. In D. O. Braithwaite & T. L. Thompson (Eds.), *Handbook of communication and people with disabilities: Research and application* (pp. 485–506). Mahwah, NJ: Erlbaum.
- Kuypers, J., & Bengston, V. L. (1990). Toward understanding health in older families impacted by catastrophic illness. In T. H. Brubaker (Ed.), *Family relationships in later life* (2nd ed., pp. 245–266). Thousand Oaks, CA: Sage.
- Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Leininger, M. (1994). Evaluation criteria and critique of qualitative research studies. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 95–115). Thousand Oaks, CA: Sage.
- Mares, L., & Fitzpatrick, M. A. (1995). The aging couple. In J. F. Nussbaum & J. Coupland (Eds.), *Handbook of communication and aging research* (pp. 185–205). Mahwah, NJ: Erlbaum.
- Montgomery, B. M., & Baxter, L. A. (Eds.) (1998). *Dialectical approaches to studying personal relationships* (pp. 17–40). Mahwah, NJ: Erlbaum.
- Morgan, D., Carder, P., & Neal, M. (1997). Are some relationships more useful than others? The value of similar others in the networks of recent widows. *Journal of Social and Personal Relationships*, 14, 745–759.
- Morgan, D. L., & March, S. J. (1992). The impact of life events on networks of personal relationships: A comparison of widowhood and caring for a spouse with Alzheimer’s disease. *Journal of Social and Personal Relationships*, 9, 563–584.
- 1999 progress report on Alzheimer’s disease. (2000, June 17). *National Institute on Aging and the National Institutes of Health* [On-line]. Available: <http://www.alzheimers.org/pubs/pr99.htm>.
- Noller, P., & Fitzpatrick, M. A. (1993). *Communication in family relationships*. Englewood Cliffs, NJ: Prentice Hall.
- Nussbaum, J. F., Pecchioni, L. L., Robinson, J. D., & Thompson, T. L. (2000). *Communication and aging* (2nd ed.). Mahwah, NJ: Erlbaum.
- Older population by age: 1900 to 2050 (1999, October 1). *Administration on Aging* [On-line]. Available: <http://www.aoa.gov/aoa/stats/AgePop2050.html>.
- Orange, J. B., Van Gennep, K. M., Miller, L., & Johnson, A. M. (1998). Resolution of communication breakdown in dementia of the Alzheimer’s type: A longitudinal study. *Journal of Applied Communication Research*, 26, 120–138.
- Petronio, S. (1999). ‘Translating scholarship into practice’: An alternative metaphor. *Journal of Applied Communication Research*, 27, 87–91.
- Pollen, D. A. (1993). *Hannah’s heirs: The quest for the genetic origins of Alzheimer’s disease*. New York, NY: Oxford University Press.

- Query, J. L., & James, A. C. (1989). The relationship between interpersonal communication competence and social support among elderly support groups in retirement communities. *Health Communication, 1*, 165–184.
- Ramanathan, V. (1995). Schematic understanding: Evidence from Alzheimer's discourse. *Communication Theory, 5*, 224–247.
- Reisberg, B. (1983a). Preface. In B. Reisberg (Ed.), *Alzheimer's disease: The standard reference* (pp. xvii–xix). New York: The Free Press.
- Reisberg, B. (1983b). An overview of current concepts of Alzheimer's disease, senile dementia, and age-associated cognitive decline. In B. Reisberg (Ed.), *Alzheimer's disease: The standard reference* (pp. 23–28). New York: The Free Press.
- Rivers, M. J. (1990). What are we talking about? A comparative analysis of the focus management capabilities of memory impaired and able-minded interactants. *Journal of Applied Communication Research, 18*, 76–92.
- Rollins, D., Waterman, D., & Esmay, D. (1985). Married widowhood. *Activities, adaptation, and aging, 7*, 67–71.
- Schmidt, M. G. (1987). The patient's partner: The spouse in residential care. *Health and Social Work, 12*, 206–212.
- Sillars, A., & Zietlow, P. H. (1993). Investigations of marital communication and lifespan development. In N. Coupland, & J. F. Nussbaum (Eds.), *Discourse and lifespan identity* (pp. 237–261). Newbury Park, CA: Sage.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Understanding and coping with problem behaviors related to memory loss (2000, February 28). *Virtual hospital: The apprentice's assistant*. Iowa Geriatric Education Center and University of Iowa Hospitals & Clinics [On-line]. Available: <http://www.vh.org/Patients/IHB/GeriatricEducation/LearningGuide.html>.
- Van Hoesen, G. W. (1990). The dissection by Alzheimer's disease of cortical and limbic neural systems relevant to memory. In J. L. McGaugh, N. M. Weinberger, & G. Lynch (Eds.), *Brain organization and memory: Cells, systems, and circuits* (pp. 234–261). New York: Oxford University Press.
- Werner, C., & Baxter, L. A. (1994). Temporal qualities of relationships: Organismic, transactional and dialectical views. In M. L. Knapp & G. R. Miller (Eds.), *Handbook of interpersonal communication* (2nd ed., pp. 323–379). Newbury Park, CA: Sage.
- Wood, J. T. (1999). *Interpersonal communication: Everyday encounters* (2nd ed.). Belmont, CA: Wadsworth.